

REPORT OF THE JOINT STROKE STRATEGY WORKING GROUP

June, 2000

Executive Summary

Stroke costs the Ontario economy almost a billion dollars a year and is a leading cause of death and adult neurological disability. Currently, at least 90,000 Ontarians are living with the effects of stroke, such as motor, sensory, cognitive or communication deficits. Stroke is believed to be one of the leading causes of transfer of the elderly to long-term care. As the population of Ontario ages, the number of strokes is expected to increase.

Stroke poses a number of challenges to not only the health care system but to the citizens of Ontario. In the past, it was assumed that little could be done to prevent or treat stroke. As a result, strokes were not generally treated as medical emergencies requiring urgent care, resources for expert stroke rehabilitation – particularly home-based rehabilitation – were limited, and minimal attention was paid to stroke prevention.

With the advent of new knowledge and therapies, there is the potential to dramatically improve stroke care in Ontario. There is now good scientific evidence that strokes can be prevented and acute care and rehabilitation appreciably enhanced. Such developments could significantly reduce the future human and economic burden of stroke. Those who are at risk of stroke -- or who have had a stroke -- and their families will benefit significantly from the developments being proposed in stroke care in Ontario.

To begin, we now know that stroke is highly preventable. The number of Ontarians at risk of stroke can be significantly reduced through lifestyle modifications such as smoking cessation and the promotion of increased physical activity and good nutrition. Among individuals at high risk, the number of strokes can be cut in half by such interventions as blood pressure lowering medications, antiplatelet or anticoagulant drugs (“blood thinners”) or surgery (carotid endarterectomy).

More recently, developments have shown that – contrary to what we thought in the past – stroke can be effectively treated. Using evidence-based stroke protocols and interdisciplinary stroke teams can significantly reduce stroke mortality, morbidity, hospital costs and the need for long-term care. This approach (called “organized stroke care”) does not depend upon large investments in new technologies but rather reorganization of existing resources. An even more exciting discovery has been that, under the right circumstances, the thrombolytic drug used to stop heart attacks (t-PA) can also stop “brain attacks” (strokes). And this is only the beginning. Other drugs for stroke (such as “neuroprotectives”) are in development.

Of particular note should be two innovative and ground-breaking initiatives that are currently underway in Ontario. The Coordinated Stroke Strategy and the Canadian Stroke Network represent valuable opportunities for Ontario to build on the most advanced work in Canada on stroke care. This will allow Ontario to make more rapid progress in the development of organized stroke care and stroke research.

If we take advantage of these many new developments, we could improve the quality of life for Ontarians and avoid a significant proportion of future stroke costs and burden. To do so, we must organize stroke care across the entire continuum (i.e. from prevention, to acute care, rehabilitation and secondary prevention) on a province-wide basis.

A comprehensive, integrated, evidence-based province-wide stroke strategy would also make Ontario a world leader in stroke prevention, care, rehabilitation and research.

After careful consideration and review of both current stroke practices in Ontario and the international literature, the Joint Stroke Strategy Working Group came to a number of recommendations as to how stroke care can be improved. These recommendations are:

Stroke Prevention

- 1: The Ministry of Health and Long-term Care should support health promotion efforts that contribute to the primary prevention of stroke.
- 2: Stroke Prevention Clinics should be developed to improve secondary stroke prevention and to provide support to ongoing prevention efforts in the primary care, acute care and rehabilitation sectors.
- 3: Stroke prevention by primary care providers should be supported.
- 4: Drugs needed for “best practices” in stroke prevention should be provided on the Ontario Drug Benefit program.

Emergency/Acute Care

- 5: As part of an integrated stroke plan for Ontario, stroke should be designated a priority of the Ministry of Health and Long-term Care.
- 6: A system of Regional and District Stroke Centres and protocols should be established linking all acute care hospitals in Ontario.

- 7: To further the development of “telestroke”, the Ministry of Health and Long-term Care should move to address the legal and funding implications of using telecommunication linkages for remote diagnosis.
- 8: To support organized acute care of stroke and implementation of thrombolytic therapy for ischemic stroke, public education should be conducted on the warning signs of stroke.

Rehabilitation

- 9: The Ministry of Health and Long-term Care and the Heart and Stroke Foundation of Ontario should promote the development of regional stroke rehabilitation systems.

Measuring and Monitoring

- 10: An information system should be developed to further data collection and monitoring across the continuum of stroke care.

Human Resources

- 11: The Ministry of Health and Long-term Care should study future needs for human resources in stroke.
- 12: A committee responsible for stroke training should be established to administer a provincial stroke training fund.

Implementation and Development

- 13: To advance the evidence base for specific issues in stroke care, the Ministry of Health and Long-term Care should support a number of pilot projects (e.g. on “telestroke” and stroke rehabilitation).
- 14: To ensure that all recommendations are realized in an orderly manner, an implementation structure should be developed to oversee a phased development of organized stroke care. The implementation structure should consist of a Stroke Implementation Steering Committee, Work Groups, Ministry of Health and Long-Term Care regional offices and a Forum of Regional Stroke Centres, with Ministry Management Team support. The phased implementation should cover a three-year period.
- 15: A coordinated and intensified approach to funding stroke research should be developed.

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1. GENERAL FINDINGS

1.1 Stroke is a devastating disease which is costly to individuals and society.

A stroke is a sudden loss of brain function caused by the interruption of the flow of blood to the brain (an *ischemic* stroke) or the rupture of blood vessels in the brain (a *hemorrhagic* stroke). Depending upon which parts and how much of the brain is damaged, the effects of a stroke can include motor deficits (e.g. paralysis on one side), communication deficits (inability to speak, write, read and/or understand speech), sensory or perceptual deficits, cognitive disorders, difficulty swallowing, emotional disorders, dizziness, unsteadiness, or slurred speech. Even small strokes markedly increase the risk of dementia (senility).

At the current time, there is no registry that can tell us the exact number of strokes in Ontario. Hospital records suggest that in 1997 there may have been 14,937 strokes, a conservative estimate that does not include transient ischemic attacks (temporary “mini-strokes”) or strokes which did not result in hospitalization. In the same year, there were 6,152 deaths due to all cerebrovascular disease in Ontario, of which 4,955 (81%) were the result of stroke.

The economic cost of stroke to the Ontario economy is estimated to be about \$857 million a year, ranging from a low of \$719 million to a high of \$964 million. Although the majority of stroke survivors return to the community, up to 87% are left with some form of restriction in the activities of everyday life. Data from the Framingham Study found that 16% of stroke survivors are subsequently institutionalized, 31% require assistance with the activities of everyday life, 20% need help walking and 71% are vocationally impaired. Results from the National Population Health Survey suggest that up to 88,000 community-based Ontarians are living with the effects of stroke. In addition, Statistics Canada estimates that 22% of institutionalized adults 65 years of age or older have had a stroke.

1.2 The number of strokes will increase in the future.

The rate of stroke increases dramatically with age (e.g. the risk of stroke doubles every decade after age 55). As the population of Ontario ages, improvements in stroke prevention and care will not be able to keep pace with the increasing size of our elderly population. Using hospital data, scientists at the Institute for Clinical Evaluative Sciences (ICES) calculate that the number of stroke in Ontario will increase 9% over the next ten years (i.e. from the year 2000 to 2010). Previous estimates from the Heart and Stroke Foundation and the Laboratory Centre for Disease Control, Health Canada, using different methods and definitions have projected more dramatic increases in the number of stroke deaths and/or hospitalizations (e.g. up to 30% over fifteen years).

Canada has one of the largest “baby boom” cohorts in the world. By 2010, the “front wave” of the baby boom cohort will just be reaching age 65. Is it critical that planning start now in order to avoid – or at least try to influence – future escalations in:

- ◆ The numbers of strokes that occur;
- ◆ Shortages in health care providers with stroke expertise;
- ◆ The proportion of health, medical and long-term costs associated with stroke.

1.3 Implementation of “best practices” in stroke prevention could substantially reduce the number of strokes in Ontario.

Analysis of the research literature suggests that the number of strokes could be reduced by up to 50% if best practices in stroke prevention were implemented. Scientists at the Institute for Clinical Evaluative Sciences estimate that even if prevention had only a 25% effectiveness, over five years 7,100 deaths could be avoided. Cost avoidance of even this modest level of effectiveness would be \$503 million (discounted cost at 3% per annum being \$471 million). It should be noted that these results are independent of any other intervention (e.g. of changes in acute/emergency care).

Reducing the number of strokes is critical given Ontario’s aging “baby boom” generation. However, stroke prevention currently is not integrated into chronic disease prevention programs or practices and is not available in all parts of the province and for all populations who could benefit. Current stroke prevention tends to be fragmented, inefficient and sporadic.

Practices that could significantly improve stroke prevention and reduce the number of future strokes include:

- ◆ Coordinated and systematic planning for all provincial risk factor strategies, ensuring that cardiovascular disease programs are unified and integrated;
- ◆ Stroke risk factor awareness integrated into other chronic disease prevention programs, such as Heart Health and diabetes;
- ◆ Complete development of the Active Ontario-Physical Activity Strategy and the Nutrition Strategy;
- ◆ Recognition of the Comprehensive Tobacco Strategy as critical to stroke prevention;
- ◆ Development of a high blood pressure prevention component, integrated with existing health promotion programming;

- ◆ Development and implementation of a population health approach to reducing excessive alcohol consumption.

1.4 If acute stroke care in Ontario was organized, stroke mortality and morbidity could be reduced and patient outcomes improved.

International research has demonstrated that stroke outcomes can be improved and stroke mortality and morbidity reduced if acute care is organized (i.e. stroke protocols and teams ensure that acute care resources are used efficiently and effectively). Organized stroke care is not only beneficial in itself but is essential if Ontario is to derive optimal benefit from new stroke therapies. The thrombolytic drug t-PA, for example, can literally stop a stroke in progress but only if given by clinicians with stroke expertise to appropriate patients within a specified amount of time. New drugs (“neuroprotectives”) are in development that may be able to protect the brain against permanent damage. Organized stroke care is essential if these new therapies are to be used effectively on an equitable, province-wide basis.

Elements of organized stroke care include:

- ◆ Development and implementation of evidence-based stroke protocols and clinical guidelines, including triage and transport protocols
- ◆ Development of interdisciplinary teams for acute stroke care and management (stroke expertise in all health care professionals responsible for the care or management of stroke patients)
- ◆ Wherever possible, concentration of stroke patients in the same ward or unit with stroke expertise (stroke units, either real or “virtual”)
- ◆ Timely (under an hour) access to CT scanning and expert interpretation 24 hours a day, 7 days a week (in some locations, this may necessitate the use of telecommunications linkages)
- ◆ Development of linkages with community organizations and resources for rehabilitation and secondary prevention.

1.5 When a person survives a stroke, evidence-based rehabilitation enables survivors to maximize their quality of life on many levels, including the physical, cognitive, emotional, communication and social levels.

There are a number of serious limitations in the current system of stroke rehabilitation in Ontario. Changes are required if individuals who experience a stroke are to have timely access to the appropriate intensity and duration of

rehabilitation services they require, delivered in a comprehensive and coordinated way to patients and families by agencies and practitioners expert in stroke care.

1.6 By leveraging current opportunities, Ontario could become a world leader in stroke prevention, care, rehabilitation and research.

Within the past two years, there have been a number of key developments that could allow Ontario to become a world leader in stroke care. These include:

- ◆ The changing paradigm of stroke: In the past, it was commonly thought that stroke could neither be prevented nor treated. It is now recognized that stroke can be both prevented and effectively treated if evidence-based “best practices” are utilized.
- ◆ The Coordinated Stroke Strategy: In 1998, regional coordination of organized stroke care was launched with the Coordinated Stroke Strategy. Chaired by the Heart and Stroke Foundation of Ontario, sites currently participating in the strategy include Hamilton (the Hamilton Health Sciences Corporation), Southeastern Ontario (the Kingston General Hospital), London (the London Health Sciences Centre) and the West Greater Toronto Area (a consortium of hospitals and community organizations, including the Trillium and Humber River Regional Hospitals, the William Osler and St. Joseph’s Health Centres, the West Park Hospital and area Community Care Access Centres).
- ◆ Canadian Stroke Network: In February, 2000, the government of Canada announced funding for the first seven years for the Canadian Stroke Network, a new Network of Centres of Excellence. Projects within the four main themes of the Network (Stroke Prevention, Acute Care, Salvaging Brain Cells [basic research] and Rehabilitation and Recovery) afford a number of opportunities for collaboration with provincial initiatives and leveraging of resources.

To date, although organized stroke care is being developed in many parts of the world, most of these projects involve individual hospitals, hospital networks or relatively small jurisdictions (e.g. city of Calgary). Taking advantage of the opportunities afforded by the Coordinated Stroke Strategy and the Canadian Stroke Network could make Ontario a world leader in stroke care.

1.7 In order to take advantage of recent developments in stroke prevention, treatment and rehabilitation and to positively impact the quality of life, mortality and morbidity of Ontarians, the province requires a coordinated stroke strategy.

This strategy should:

- ◆ Integrate services between sectors: To ensure that stroke care remains client-centred, linkages should be built between all parts of the continuum of care (e.g. between acute care, primary care, chronic care, rehabilitation and community services). A systems approach to stroke planning must be taken to ensure there is appropriate utilization of existing resources and to ensure that incentives in one sector do not impact detrimentally on others.
- ◆ Build on existing capacities: Across the continuum of care, coordinated stroke care should build on existing programs and capacities. This will require reorganization and further development of resources that already exist.
- ◆ Recognize the need for, and nurture the development of, stroke expertise: At all stages in the continuum of care, there is evidence that stroke expertise is required to optimize outcomes.
- ◆ Be organized on a regional basis: Stroke care must be organized across the province so all Ontarians have access to the best available stroke care. Regions should not be artificially imposed but should emerge in consultation with Ministry of Health and Long-term Care Regional Offices, District Health Councils, established networks, natural hospital referral patterns and community organizations such as Community Care Access Centres. Responses should be flexible in order to accommodate local conditions, particularly in remote parts of the province and northern Ontario.

1.8 Analysis of models of acute stroke care suggest that regions should organize stroke care around Regional and District Stroke Centres, with the exact nature of the system dependent upon local conditions and needs.

An analysis of current neurological resources in Ontario was conducted to determine which acute care hospitals had the resources required to operate as Regional Stroke Centres or District Stroke Centres. Prerequisites to becoming a Stroke Centre are:

District Stroke Centre: Written stroke protocols for emergency services, emergency department and acute care, including transport and triage

protocols; ability to offer thrombolytic therapy to suitable ischemic stroke patients (timely CT scanning and expert interpretation; clinicians with stroke expertise); linkages to rehabilitation and secondary prevention.

Regional Stroke Centre: All of the requirements of a District Stroke Centre, plus neurosurgical facilities and interventional radiology.

Based on current resources, there are 15 hospitals in Ontario capable of becoming Regional Stroke Centres and 43 eligible to become District Stroke Centres. Another 119 acute care hospitals were deemed to not currently have the resources required to act as either Regional or District Stroke Centres.

An economic analysis by scientists at ICES showed that the greatest cost avoidance in stroke care could be achieved if Ontario adopted a regional approach to stroke management in which most strokes were triaged to either Regional or District Stroke Centres (called the “two-level” model). For example, over five years, compared to the current system (the status quo) a two-level system would avoid costs of approximately \$85 million (discounted). Costs are avoided due to the ability of organized stroke care and thrombolytic therapy to reduce mortality, morbidity (length of stay and bad outcomes) and subsequent need for chronic care.

However, the two-level model may not be appropriate or feasible in all parts of the province. In some regions a three-level model, in which community hospitals are included in stroke planning and care, might be preferred or necessary (e.g. concerns with transport times and the desire to keep patients within their communities). Analysis showed that compared to the current status quo, a three-level system could avoid costs of \$47 million over the next five years. Thus, although a two-level system may be economically preferable, there are significant benefits to even a three-level system.

1.9 Stroke should be made a priority of the Ministry of Health and Long-Term Care, with an ongoing commitment for coordination and implementation of organized stroke care.

Stroke meets the criteria of a Priority Program, such as:

- ◆ Specialized human resources are required (health care professionals with expertise in acute stroke care, prevention and rehabilitation)
- ◆ The condition in question (stroke) is costly to the Ministry of Health and Long-term Care and to Ontario society
- ◆ The number of strokes is anticipated to increase by at least 9% over the next ten years; moreover, the proportion of the population at risk will climb

dramatically after the year 2010 as the “baby boom” generation passes the age of 65.

- ◆ Highly specialized programs are required in order to offer Ontarians the best possible stroke care
- ◆ Recent developments, such as thrombolytic therapy and organized stroke care, are available to reduce the toll of stroke – if implemented.
- ◆ Stroke is highly disruptive to the quality of life for patients and their families and caregivers.
- ◆ Stroke needs to be organized on a provincial basis to prevent inequities in the quality of care
- ◆ Stroke is in need of a clear systems management process in order to address specific problem areas (e.g. remote areas, hospitals without neurological support or CT scanners) and to ensure optimal impact.

Stroke is not limited to the institutional sector but extends across the continuum of care. It may therefore necessitate a unique approach that expands the current definition of a priority program. A funding formula should be developed for those hospitals that take on leading roles in regional stroke care.

1.10 Currently, there appear to be disparities across the province in the distribution and skill mix of health care providers with stroke expertise.

If Ontario is to effectively respond to the anticipated increase in the number of stroke patients over the next decade (as the population ages), stroke prevention, care and rehabilitation must be viewed as a priority in health human resources planning. There is good evidence that outcomes are improved when specialized stroke expertise is available across the continuum of care. There is a need for training and education of health care providers who deal with stroke patients and survivors, such as hospital personnel, emergency medical services, rehabilitation specialists, and health promotion and disease prevention specialists. A human resources plan must be developed in order to ensure that future needs for stroke expertise can be met.

1.11 There is need for education of the general public on stroke.

Currently, there is evidence that the general public has a generally poor understanding of the warning signs and risk factors for stroke. Warning signs of stroke include: sudden weakness, paralysis or numbness in the arm, face or leg

(typically on one side); sudden trouble speaking or understanding speech; sudden unusual or severe headache; sudden vision trouble, particularly in one eye; and sudden dizziness, lightheadedness or unexplained falls, particularly in combination with any of the other warning signs. Modifiable risk factors for stroke include smoking, high blood pressure, diabetes, inactivity, being overweight, excessive alcohol consumption, heart disease, and previous stroke. There is a need to increase awareness of stroke in order to reduce delays in accessing acute care and to increase compliance with risk factor management.

1.12 Data collection and analysis (measuring and monitoring indicators and outcomes) is needed throughout the entire continuum of stroke care.

Currently, Ontario does not have a provincial monitoring system to measure and evaluate the provision of stroke care, its impact on patient outcomes and the health care system. Without data, it is impossible to analyze needs, evaluate how well programs are working or determine the effectiveness of interventions. A province-wide system for stroke measuring and monitoring that integrates existing data sources, is consistent with developments in other parts of the continuum of stroke care and coordinates with new national initiatives (e.g. the Canadian Stroke Network) should be developed. This system should ensure that data collection is useful, user-friendly, cost-effective and efficient, comprehensive, coordinated, timely, integrated, accessible, evaluated and flexible.

1.13 There is a need to formalize the research agenda for stroke across all phases of the continuum of care (prevention, acute care and rehabilitation).

Currently, there are gaps in the evidence base for stroke care across the continuum of care. Examples of these gaps include research on stroke rehabilitation and recovery (particularly “best practices” in community and home-based rehabilitation) and pediatric stroke. Changes are required to ensure that good research is conducted at all points in the continuum of care.

2 RECOMMENDATIONS OF THE JOINT STROKE STRATEGY WORKING GROUP

PREVENTION

Recommendation 1: The Ministry of Health and Long-term Care should support health promotion efforts that contribute to the primary prevention of stroke.

The modifiable risk factors for stroke include high blood pressure, smoking, a sedentary lifestyle, being overweight, excessive alcohol consumption, high cholesterol, diabetes and heart disease. Many of these risk factors (e.g. smoking, a sedentary lifestyle and being overweight) are also risk factors for other chronic diseases (e.g. heart disease and cancer). There is good to strong evidence that population-based health promotion programs can be effective in reducing the prevalence of risk factors for heart disease and stroke. To strengthen these efforts it is necessary that a primary prevention/health promotion framework be adopted by the Ministry of Health and Long-term Care which emphasizes:

- ◆ Integration and coordination of efforts and programs
- ◆ Primary prevention in primary care
- ◆ Strengthening of existing primary prevention resources and programming (e.g. physical activity, nutrition and tobacco)

Stroke prevention should be integrated into population-based chronic disease prevention programs and new population-based health promotion components on high blood pressure and excessive alcohol consumption developed. In the development of such programs, the full attributable health benefit and associated cost avoidance should be used to develop an appropriate funding formula. Funding should be sufficient to achieve the province's prevention objectives as described in the Mandatory Health Programs and Guidelines (1998).

Strategies within a health promotion approach to stroke prevention would include:

- ◆ Coordinated and systematic planning be undertaken to complete the development of provincial risk factor strategies which are associated with cardiovascular disease, including stroke. The risk factor strategies associated with the prevention of cardiovascular diseases should incorporate into their planning the program requirements for stroke prevention.
- ◆ The Health Promotion Resource System should be enhanced to support and build community capacity to implement the proposed

cardiovascular programs for preventing high blood pressure and stroke and added nutrition and physical activity programs.

- ◆ Remaining planned provincial initiatives in Active Ontario (the physical activity strategy) should be funded and integrated into the cardiovascular disease prevention program in order to provide the necessary outreach to adults. This would include the Active Workplace initiative, Active Homes (planned to reach families and adults not connected with other settings in the Active Ontario strategy and particularly relevant for seniors), and brief advice programs for primary care physicians.
- ◆ A nutrition strategy should be planned to develop intervention programs for key community settings that focus on adopting healthy eating practices relevant to prevention of cardiovascular disease, high blood pressure and stroke. This strategy would emphasize increasing fruit and vegetable consumption, reducing fat and salt consumption and maintaining a healthy body weight.
- ◆ The Ontario Tobacco Strategy should be sustained so a provincial focus is maintained on tobacco use and key programs are available for smoking prevention and cessation and protection from environmental tobacco smoke. In addition, the following should be considered:
 - ◆ Workplace programs to reach adults who are below age 35.
 - ◆ Supporting smoking prevention and cessation in primary care.
 - ◆ Review of the Tobacco Control Act with the emphasis upon eliminating, as opposed to merely controlling, exposure to second-hand smoke, particularly in the workplace.
 - ◆ Programs to increase public awareness of the health implications of second-hand smoke.
- ◆ Although excessive alcohol consumption is a significant, modifiable risk factor for stroke, currently there is no provincial health promotion strategy addressing this issue. Thus, it is recommended that a population health approach to reducing excessive alcohol consumption and associated health risks be developed and implemented as part of existing health promotion programs.
- ◆ There is strong evidence that the prevalence of stroke can be reduced by programs that prevent and/or improve control of high blood pressure. Currently, there are no provincial programs with specific emphasis on blood pressure. Thus, it is recommended that a high blood pressure prevention component and resources be developed by the Ministry of Health and Long-term Care and integrated into current chronic disease programs of Public Health.

Recommendation 2: Stroke Prevention Clinics should be developed to improve secondary stroke prevention and to provide support to ongoing prevention efforts in the primary care, acute care and rehabilitation sectors.

Working closely with the acute care sector, primary care and rehabilitation, Regional and District Stroke Prevention Clinics would be responsible for regional organization of secondary stroke prevention services. Stroke Prevention Clinics would reduce delays and inefficiencies in risk factor management of high-risk patients, as well as to facilitate access to carotid endarterectomy. Whenever possible, such clinics should be linked and share resources with cardiac prevention services and/or community-based prevention clinics.

Resources required for Stroke Prevention Clinics include:

- ◆ Advanced Practice Nurses (Stroke Specialists), to be shared with Regional or District Stroke Centre (acute care) (number of positions required dependent upon patient volumes)
- ◆ Administrative support (e.g. to communicate with primary care providers, schedule clients and ensure seamless care)
- ◆ For the Regional Stroke Prevention Clinic, depending under patient load, approximately 0.2 FTE psychologist or behavioural modification specialist to assist in lifestyle modification (risk factor reduction)
- ◆ Access to diagnostic services or equipment adequate to meet, in a timely fashion, the volume of patients received and the types of services required for risk factor management (e.g., District Stroke Prevention Centres would require access to CT scanners, carotid ultrasound, echocardiography and holter monitoring; additional resources required for Regional Stroke Prevention Clinics would be angiography and access to MRI)
- ◆ At Regional Stroke Prevention Clinics, increase in operating room time and resources to support access to carotid endarterectomy within less than one month after diagnosis (number of incremental operating room hours and associated beds dependent upon volume), with the goal of wait times of less than one week.

Recommendation 3: Stroke prevention by primary care providers should be supported by the Ministry of Health and Long-term Care.

This support should consist of:

- ◆ In partnership with local boards of health, non-governmental agencies and appropriate professional organizations, the development and dissemination of

brief advice programs on smoking cessation, active living, nutrition and other lifestyle risk factors for stroke;

- ◆ Incorporating strategic blood pressure monitoring and control strategies into primary care. If further primary care pilot sites are developed, “best practice” procedures in blood pressure monitoring and control should be demonstrated, documented and evaluated.
- ◆ The Ministry of Health and Long-term Care should take steps to ensure an adequate and effective compensation mechanism to encourage primary care providers to undertake risk factor counseling;
- ◆ A Ministry of Health and Long-term Care Work Group should develop mechanisms to encourage the systematic use of evidence-based stroke prevention guidelines and continuous quality improvement in primary care. Examples of possible mechanisms include primary care provider education, feedback and/or educational auditing and should be developed in collaboration with District and Regional Stroke Prevention Clinics and partners such as the Heart and Stroke Foundation and the appropriate professional colleges.

Recommendation 4: Inclusion criteria of the Ontario Drug Benefit Plan should be reviewed to ensure “best practices” in stroke prevention.

The inclusion criteria of the Ontario Drug Benefit Plan should be reviewed to ensure that those medications most likely to prevent stroke are available. Inclusion criteria should take into account not just efficacy but adverse effects, long-term compliance and the cost of non-adherence and switching. The use of drugs with fewer or less severe side-effects has been shown to increase long-term compliance with treatment. This improved long-term adherence will not only increase the effectiveness of the drugs needed for stroke prevention but will also reduce the costs of non-adherence and switching. Studies have shown that non-adherence and switching account for up to a third of the cost of blood pressure treatment.. Specific examples of agents which should be reviewed against these suggested criteria include the angiotension antagonist class of antihypertensives and the antiplatelet agents clopidogrel (Plavix) and ASA/dipyridamole (Aggranox).

EMERGENCY/ACUTE CARE

Recommendation 5: Stroke should be designated a priority of the Ministry of Health and Long-term Care.

The nature and criteria for this funding and program “deliverables” should contain the following components:

- ◆ organized stroke care (all hospitals treating stroke patients to have evidence-based stroke protocols, triage and transport protocols and stroke teams)
- ◆ protocols that make possible timely CT scanning and expert interpretation 24 hours a day, 7 days a week (either on site or through telecommunications links)
- ◆ formal linkages with other hospitals and parts of the continuum of care (rehabilitation and prevention) throughout the region
- ◆ data collection and analysis (see Recommendation 13)

Recommendation 6: A system of Regional and District Stroke Centres should be established linking all acute care hospitals in Ontario.

Each acute care hospital in the province should be part of a regional stroke system consisting of a Regional Stroke Centre and one or more District Stroke Centres. Stroke system would be established in keeping with existing referral patterns and linkages and in flexible manner to meet local conditions and resources. Designation as a Regional or District Stroke Centre would depend upon current stroke resources or feasibility to upgrade to meet the specified requirements. Additional funding will be required for those hospitals that are designated as District or Regional Stroke Centres.

Requirements for designation as a Stroke Centre include:

For Designation as a District Stroke Centre: Organized stroke care (written stroke protocols for emergency services, emergency department and acute care); interdisciplinary stroke teams; around-the-clock emergency departments; timely, around-the-clock access to CT scanning; protocols for timely expert CT interpretation (on site or by telecommunications link); linkages to other parts of the continuum of stroke care (rehabilitation and secondary prevention).

For Designation as a Regional Stroke Centre: All of the requirements of a District Stroke Centre, as well as neurosurgery and interventional radiology.

Regional Stroke Centres would take on the role of coordinating stroke care throughout their region and across all points in the spectrum of stroke care (clinical and secondary prevention, acute care, rehabilitation and home care). Following natural referral patterns and established linkages (e.g. the Rural and Northern Framework) and in consultation with Ministry of Health and Long-term Care Regional Offices, District Health Councils, community agencies and key stakeholders, Regional Stroke Centres would determine the need and appropriate location of District Stroke Centres and assist all hospitals in their region to put the principles or organized stroke care into practice (e.g. stroke protocols and interdisciplinary stroke teams).

The following resources would be required to undertake the incremental work of coordinating and maintaining regional stroke care:

- ◆ **Regional Stroke Coordinators:** As well as the developing and maintaining the regional network, the Stroke Coordinator is responsible for ensuring that stroke care is organized throughout the entire spectrum of care (from primary prevention, to acute care, rehabilitation and secondary prevention) and across institutions and agencies. The Stroke Coordinator also identifies and coordinates education and training needs across the network. Results from the sites participating in the Coordinated Stroke Strategy suggest that Stroke Coordinators are essential for the development and implementation of regionalized, organized stroke care. To ensure overall coordination throughout the spectrum of care, as well as the development and implementation of necessary protocols, depending upon volume, the equivalent of at least two FTE's should be funded for an initial phase of three years. At the end of the initial phase, FTE requirements could be reviewed and reassessed.
- ◆ **Medical Director of Stroke Team:** 0.25 FTE would be required for the medical director of the Stroke Team at the Regional Stroke Centre, a permanent position with both medical and administrative responsibilities.
- ◆ **Stroke Team Leader:** In order to attract and maintain physicians to take 24-hour on-call duty for acute stroke emergencies, a per diem reimbursement is recommended for a Stroke Team Leader in the Regional Stroke Centre.
- ◆ **Nurse Stroke Specialists:** It is recommended that funds be made available for Advanced Practice Nurses at the Regional and District Stroke Centres, based on some agreed-upon volume indicator (e.g. 1 FTE Advanced Practice Nurse for every 150 additional stroke patients per year). These positions are required both to address the increased stroke patient load in the Regional and/or District Stroke Centres and to act as a

liaison with other components in the continuum of care (e.g. Stroke Prevention Clinics, stroke rehabilitation and primary care).

- ◆ Additional Beds: Due to the increased proportion of stroke patients directed to those hospitals acting as District and Regional Stroke Centres (e.g. changes in patient flow), there will be a need for an incremental increase in acute care beds and associated nursing support. The allocation of additional beds should be considered by the Ministry, in consultation with the Regional Stroke Centres and in light of estimated increased patient load an appropriate funding formula developed.

Recommendation 7: To further the development of “telestroke”, the Ministry of Health and Long-term Care should move to address the legal and funding implications of using telecommunication linkages for remote diagnosis.

In order to not only test but to subsequently implement “teleradiology” or “telestroke”, a number of legal, liability and reimbursement issues will need to be addressed. The Ministry should work with appropriate partners to address and resolve these and related issues. As well, pilot demonstration projects in telestroke should be launched during the first year of implementation of the stroke plan (see Recommendation 13).

Recommendation 8: To support organized acute care of stroke and implementation of thrombolytic therapy for ischemic stroke, public education should be conducted on the warning signs of stroke.

Currently, lack of public awareness of the warning signs of stroke and knowledge about what to do results in long delays in seeking medical attention. To reduce these delays, public education is required. This education should be conducted in collaboration with non-governmental organizations and agencies and acute care and be based on results of the ongoing Heart and Stroke Foundation of Ontario trial of mass media in stroke awareness (results of which will be available by late fall, 2001).

REHABILITATION

Recommendation 9: The Ministry of Health and Long-term Care and the Heart and Stroke Foundation of Ontario should promote the development of regional stroke rehabilitation systems.

These systems would be linked to the other sectors in the continuum of stroke care and consistent with the Ministry's Rehabilitation Reform Initiative. Through a collaborative approach and with linkages to community-based services, the systems would provide timely, appropriate, client-centered rehabilitation by specialists with stroke expertise. Essential elements would include:

- ◆ Dedicated staff time by Regional Stroke Coordinators to facilitate the development of the regional stroke rehabilitation system;
- ◆ Designation of dedicated stroke units for stroke rehabilitation and Ministry of Health and Long-term Care support for additional beds/funds consistent with Health Services Restructuring Commission guidelines, based on proposals that include dedicated stroke units and outpatient services;
- ◆ Funding for outreach services to support enhanced consultation in rural, northern and remote areas of the province;
- ◆ Support for pilot projects to identify best practices to strengthen and improve coordination of stroke rehabilitation, especially in the case management of the transition between hospitals and from hospital to community-based care;
- ◆ Support for pilot projects to identify best practices for home-based stroke rehabilitation, including community ambulatory programs;
- ◆ Mandating the provincial use of an objective assessment tool(s) for rehabilitation that are sensitive to the issues in stroke;
- ◆ Consideration of recommendations from regional stroke systems on the reinvestments required to meet regional needs. Such recommendations would be based on monitoring of the waiting lists and other indicators for both hospital and community-based ambulatory and home-based stroke rehabilitation.

MEASURING AND MONITORING

Recommendation 10: An information system should be developed to further data collection and monitoring across the continuum of stroke care.

Without consistent, standardized collection of data, it is difficult to identify problems or to monitor progress across the continuum of care (e.g. delays in seeking medical attention, wait times for CT scanning and interpretation, proportion of ischemic strokes eligible and receiving thrombolytic therapy, wait times for rehabilitation, carotid endarterectomy, costs, etc). With expert representation from the Cardiac Care Network of Ontario, the Canadian Institute for Health Information, the Canadian Stroke Network, the Heart and Stroke Foundation of Ontario, the Institute for Clinical Evaluative Sciences and the Ministry of Health and Long-term Care, a Measuring and Monitoring Work Group should be established. This committee will review all opportunities to collect data related to stroke care in Ontario, identify opportunities for integration with other systems and the evaluation questions to be answered, select indicators to monitor, define the data collection processes, propose and implementation budget and oversee the development of a comprehensive, responsive, useful and cost-efficient system of data collection and analysis.

Resources required for the measuring and monitoring would include salary support for a provincial (central) data analyst and funds to ensure the capacity for data collection at Regional and District Stroke Centres. The FTE equivalent at the Regional and District Stroke Centres should be volume dependent, according to reasonable formula established by the Measuring and Monitoring Work Group.

HUMAN RESOURCES

Recommendation 11: The Ministry of Health and Long-term Care should develop a plan to determine and address future needs for human resources in stroke.

Health professionals with expertise in stroke are critical to stroke prevention, acute care and rehabilitation. Already, there are shortages in many key health human resources areas, particularly for those with stroke expertise. Such shortages will become more critical as the number of stroke patients increase over the coming decade. A number of health professions should be studied in terms of the ability to meet projected increases in the number of stroke victims in Ontario. They include residency positions (particularly residencies in neurology, neurosurgery and interventional radiology), fellowships, and nurses and

rehabilitation specialists in stroke. As part of the measuring and monitoring process, projections should be developed to assess future human resources needs in stroke prevention, care and rehabilitation.

Recommendation 12: A committee responsible for stroke training should be established to administer a provincial stroke training fund.

A training fund and core training elements should be established provincially for health professionals requiring training in stroke. Priority areas for training should be established (e.g. emergency medical services, acute care, primary care, public health and rehabilitation) and where possible, existing resources should be leveraged (e.g. use of existing training materials such as those developed by the Heart and Stroke Foundation and the Ontario College of Family Physicians).

In consultation with key stakeholders (e.g. Regional Offices of the Ministry and municipalities), Regional Stroke Centres should develop plans for stroke training using the provincial core elements and taking into account both initial training and the need for continuous upgrading. Criteria for assessment of plans would include:

- ◆ Demonstration of local involvement and support (e.g. in the case of emergency medical services, commitment by the municipal government)
- ◆ Comprehensiveness and quality of regional plan
- ◆ Addressing of gaps (e.g. rehab, home care)

IMPLEMENTATION AND DEVELOPMENT

Recommendation 13: To advance the evidence base for specific issues in stroke care, the Ministry of Health and Long-term Care should support a number of pilot projects linked to the regional reorganization of stroke care.

The pilot projects, which should be launched as quickly as possible, would include:

- ◆ Three pilot projects in “telestroke” or “teleradiology” to develop and test methods and guidelines for the use of telecommunication linkages in stroke (e.g. to obtain expert CT interpretation in remote or under-resourced communities). Recommended pilot sites are: Stratford (which is already in the process of developing a telecommunications link with London as part of the southwestern Coordinated Stroke Strategy project); Timmins (which is

already experimenting with telecommunications in other medical specialties as part of the North Network); and an urban setting in which ambulance patterns are heavily influenced by traffic flow (such as the Greater Toronto Area).

- ◆ As described in the recommendations for rehabilitation, pilot projects to identify best practices to strengthen and improve coordination of stroke rehabilitation, especially in the case management of the transition between hospitals and from hospital to community-based care. Projects would also identify best practices for home-based stroke rehabilitation, including community ambulatory programs.
- ◆ A request for proposals should be made for projects that test best practices, including cost-effectiveness, in stroke prevention (e.g. management of high-risk patients in secondary prevention and management of hypertension in primary care).

Recommendation 14: To ensure that all recommendations are realized in an orderly manner, an implementation structure should be developed to oversee a phased development of organized stroke care.

a) Implementation Structure

To direct and support the implementation of the recommendations of the Joint Stroke Strategy Working Group and to provide a focus for the monitoring and further development of a province-wide stroke strategy across the continuum of care, the following implementation structure is proposed (see Figure 1).

◆ Stroke Implementation Steering Committee

The Stroke Implementation Steering Committee would include expert members from all phases of the continuum of care and have co-chairs internal and external to the Ministry of Health and Long-term Care. Tasks of the Committee would include overseeing the mandate for the implementation process (in accordance with the approved strategy), overseeing and guiding the implementation process, providing ongoing expert input and advice on new developments, best practices, etc., providing a forum for “macro” provincial issues, problem solving and identification of policy issues. During the first phase of the implementation process, this group would act as the implementation steering committee; in later phases, it would be responsible for providing ongoing support of community sites. Representatives from the community level would be involved from the earliest stages to ensure that the provincial program is developed with direct input from potential implementers at the community level.

◆ Work Groups

Work Groups would be developed by each program area to direct development of a single component within the continuum of care with intergration at the Steering Committee level. Work Groups would provide technical input, would review the experience, methods and materials of the pilot sites, would draft requests for proposals (RFP) or related section of a RFP for regional rollout, determine support materials required for implementation, problem solve and identify and document issues for provincial-level resolution. Examples of Work Groups to be developed include the Measuring and Monitoring Work Group and Training Work Group. Resources required for the Work Groups would include funds for development of materials and meeting and travel costs.

◆ Forum of Regional Stroke Centres

Key representatives from all phases of the continuum of care in the proposed eleven stroke system regions would be invited to compose a Regional Forum. This group would meet regularly to share key information, identify gaps and collectively resolve common problems, share data, etc. Administrative support for the Forum would be provided both externally and through the Ministry Management Team. Where appropriate, Ministry of Health and Long-Term Care regional offices support would also be sought.

◆ Ministry Management Team

The Ministry Management Team would be composed of representatives from all branches and divisions involved in stroke care across the continuum (e.g. Emergency Health Services, Rehabilitation, Public Health, Health Promotion, Program Policy, Operational Support, Community Programs, Long-term Care, etc.). The Team would ensure coordinated, “seamless” approach to implementation of the stroke strategy across all programs within the Ministry of Health and Long-Term Care and would liaison with Work Groups, pilot sites and Ministry Regions (Regional Directors). Resources required for the Ministry Management Team would be 2 FTE Coordinators.

b) Implementation Plan

In order to proceed in an orderly and manageable fashion, the development of Regional Stroke Networks should be undertaken in a staged or phased manner:

Year 1

General Developments:

- ◆ Meet with key stakeholders to discuss planning for first year implementation

Report of the Joint Stroke Strategy Working Group

- ◆ Ministry of Health and Long-term Care program area to arrange letters of agreement or addenda as required
- ◆ Develop, endorse and implement joint communications strategy between Ministry of Health and Long-term Care and Heart and Stroke Foundation of Ontario
- ◆ Obtain Ministry Management Committee approval for the proposed strategy, including Priority Program designation for stroke
- ◆ Prepare detailed costing analysis in support of Management Board Submission:
 - ◆ Includes developing a funding approach and formula for determining resource needs (e.g. beds) for proposed Regional Stroke Centres
 - ◆ This analysis could be undertaken by a Joint Policy and Planning Committee (JPPC) working group (including representation from key Ministry areas, hospitals and the Institute for Clinical Evaluative Sciences)
- ◆ Confirm implementation structure and designate representatives/members and staffing resources for Stroke Implementation Steering Committee and other related bodies/committees. For those institutions designated during Year 1 as Regional Stroke Centres, hiring of Regional Stroke Coordinators to be a priority.
- ◆ Establish and confirm ongoing formal liaison with the Canadian Stroke Network.
- ◆ Sectors from existing sites across the continuum of care to meet and exchange “lessons” learned”
- ◆ Development of information package for Ministry of Health and Long-term Care Regional Offices, District Health Councils and hospitals (e.g. model of regional plans and “lessons” learned from Coordinated Stroke Strategy sites).

Prevention: Health Promotion and Primary Prevention

- ◆ Develop health promotion plan for approval of Stroke Implementation Steering Committee
- ◆ Agree on a development plan for each component (Risk Factor Strategy Development such as Physical Activity, Nutrition Strategy and Tobacco Strategy; Heart Health Program; and Health Promotion Resource System)
- ◆ Report progress to Stroke Implementation Steering Committee

- ◆ Stroke Implementation Steering Committee to appoint a work group to review and recommend best approaches for continuing medical education on stroke for primary caregivers.

Prevention: Secondary Prevention

- ◆ Establish, staff and resource secondary prevention clinics in all designated Regional Stroke Centres (i.e., the four to be established in Year 1)

Emergency/Acute Care

- ◆ Paramedic/Emergency Services training to take place within four months in designated Stroke Centres using training materials already developed by Coordinated Stroke Strategy
- ◆ Once a funding formula has been finalized and all criteria have been satisfied, the four present pilot sites of London, Hamilton and Kingston and the West Greater Toronto Area (GTA) should be designated Regional Stroke Centres and provided with priority funding. Final designation of the GTA sites should be made pending recommendation of the deliberations of the District Health Councils of Toronto and the Greater Toronto Area. These deliberations should be concluded within six months.
- ◆ Pending confirmation of technical costs and capabilities and in collaboration with the Canadian Stroke Network, establishment of at least two telestroke pilot projects (Stratford and Timmins), with another telestroke project to be developed for an urban setting such as the Greater Toronto Area.

Rehabilitation

- ◆ Design and establishment of pilot projects to:
 - ◆ Identify best practices for improving coordination of stroke management (particularly in the management of transition between hospitals and from hospital to community-based care); and
 - ◆ Identify best practices for home-based and community ambulatory stroke rehabilitation.

Measuring and Monitoring Outcomes

- ◆ Establish the Stroke Measuring and Monitoring Work Group to:
 - ◆ Review the Ontario Stroke Strategy as approved by senior management of the Ministry of Health and Long-term Care;
 - ◆ Select performance indicators and data collection processes by consensus, through consultation with representatives of the Canadian

Stroke Network and in light of experience in the Coordinated Stroke Strategy pilot sites with the Stroke Registry.

- ◆ Identify and implement the most efficient and cost-effective process for data collection, analysis and dissemination.

Years 2 and 3:

- ◆ Stroke Implementation Steering Committee to develop, in collaboration with Heart and Stroke Foundation of Ontario and other non-governmental organizations, an approach and plan for public education on warning signs of stroke.
- ◆ Coalitions of District Health Councils, Ministry Regional Directors, municipalities, hospitals and other stakeholders should be established to develop regional stroke networks in the following parts of the province:
 - ◆ Northwestern Ontario (please note that Thunder Bay Regional Hospital has many of the resources required to become a Regional Stroke Centre, including neurosurgery, 24-hour CT with PACS technology, and high speed internet access)
 - ◆ Northeastern Ontario (Sudbury Regional Hospital also has many of the resources required to become a Regional Stroke Centre, including neurosurgery, 24-hour CT with PACS technology in one site, and high speed internet access)
 - ◆ Central Ontario (for which the Regional or District Stroke Centre may be Barrie, which has neurosurgery and 24-hour CT scanning but no PACS technology or high speed internet access)
 - ◆ Ottawa Region (of which the Regional Stroke Centre would be the Ottawa Hospital Corporation)
 - ◆ Designation of further regional sites in Greater Toronto Area

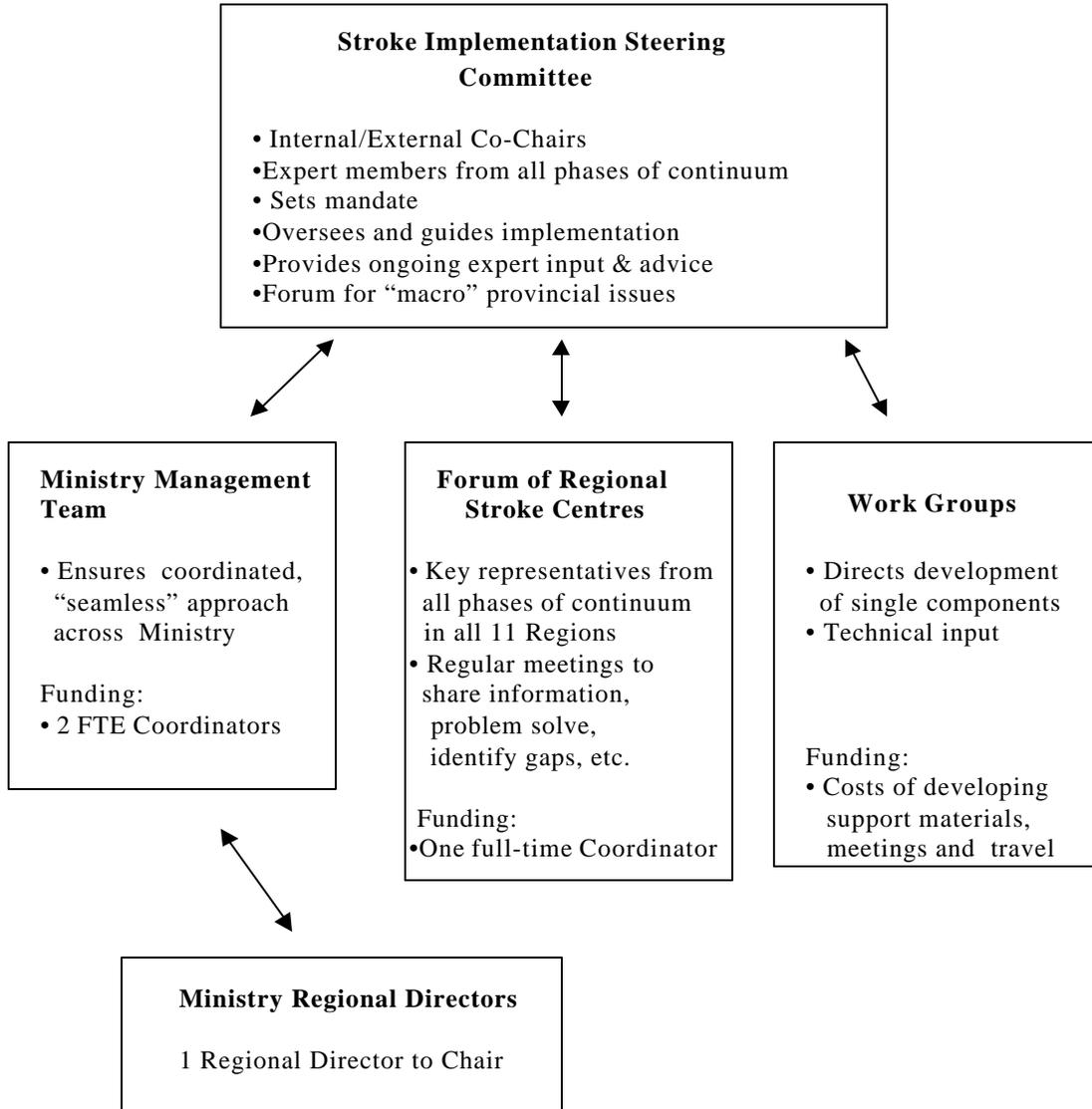
As is the case for the Greater Toronto Area, the planning process should be time-limited (e.g. deadline for submission of a plan within six months). The plan should justify the number and location of hospitals to be designated as Regional and District Stroke Centres and provide the groundwork for application for training funds.

- ◆ Phased implementation of remaining Regional Stroke Systems
- ◆ Development of District Centres (including resources and linkages).
- ◆ Evaluation of, and implementation of learnings from pilot projects and progress to date.

Recommendation 15: A coordinated and intensified approach to the funding of stroke research should be developed.

The Joint Stroke Working Group recommends the development of a coordinated and intensified approach to research in all areas of stroke. This approach should establish a shared agenda between efforts, both nationally and provincially, and build upon the progress of the Canadian Stroke Network. Many areas of stroke research are currently underdeveloped and underfunded (e.g. pediatric stroke, rehabilitation and recovery, prevention). Research is required to ensure that standards of care and guidelines across the spectrum of care are evidence-based.

Figure 1: Implementation Structure



CONTEXT: STROKE IN ONTARIO

A stroke is a sudden loss of brain function caused by the interruption of the flow of blood to the brain or the rupture of blood vessels in the brain. There are two main types of stroke: ischemic (caused by a blood clot blocking an artery to the brain) and hemorrhagic (the rupture of a blood vessel and uncontrolled bleeding into the brain).

The effects of a stroke depend upon how much of the brain is affected (the size of the stroke) and which part of the brain are involved (its location). Depending upon its size and location, the effects of a stroke can include:

- ◆ Motor deficits such as paralysis on one side (e.g. of the arm and/or leg)
- ◆ Communication deficits such as the inability to speak, write, read and/or understand speech (*aphasia*)
- ◆ Sensory or perceptual deficits such as the inability to feel, see or hear
- ◆ Cognitive disorders such as memory lapses or difficulty problem-solving
- ◆ Difficulty swallowing (*dysphagia*)
- ◆ Emotional disorders, such as depression
- ◆ Dizziness, unsteadiness, slurred speech
- ◆ Even small strokes markedly increase the risk of dementia (senility)

Traditionally, stroke was commonly viewed as sudden, unpredictable and untreatable. However, recent developments have shown that a substantial proportion of strokes can be prevented and treated. It is important that Ontario take full advantage of these important new developments. As well as being one of the leading causes of death, stroke is the major cause of adult neurological disability and increases both the number of patients transferred to long-term care facilities and their length of stay¹. Having a stroke puts you at increased risk of having another stroke and of developing Alzheimer's Disease². The incidence of stroke increases dramatically with age – an important issue in light of the fact that the proportion of the Ontario population over age 65 is expected to double by the year 2031.

Terms of Reference

The Joint Stroke Strategy Working Group was convened by the Ontario Ministry of Health and Long-Term Care and the Heart and Stroke Foundation of Ontario. Terms of Reference are attached in Appendix 1. The mandate of the Joint Stroke

Strategy Working Group was to make recommendations to the Ministry of Health and Long-term Care to:

- a) identify existing critical gaps and develop new approaches for strengthening current stroke prevention programming;
- b) establish a coordinated, responsive system of emergency and acute stroke care that provides stroke victims with timely access to diagnostic testing and the most effective available treatments on a province-wide basis; and
- c) in concert with the broader reform of provincial rehabilitation programming, examine the unique challenges of stroke rehabilitation.

Any system for stroke must take into account the entire spectrum of care; all parts must support one another if there is to be sustainable improvement and a reduction of the burden of stroke. In order to cover the entire spectrum of stroke care, the following Task Groups were convened by the Joint Stroke Strategy Working Group:

Health Promotion/Stroke Prevention
Emergency/Acute Care
Measuring and Monitoring

Membership of each Task Group consisted of representatives from the Ontario Ministry of Health and Long-term Care, the Heart and Stroke Foundation of Ontario and key stakeholders from across the province (e.g. consumers and health professionals). Each Task Group was charged with developing, through a collaborative process, evidence-based recommendations for strengthening and augmenting initiatives in their specific area, such that would contribute to a comprehensive stroke strategy for the province.

Input on rehabilitation and recovery was provided by the consensus panel on stroke rehabilitation created in 1999 by the Heart and Stroke Foundation of Ontario in consultation with the Ministry of Health and Long-term Care. The Panel included representatives of the Ministry of Health and Long-term Care, the HSFO and key stakeholders from across the province representing both consumers and providers. It was agreed that the Panel would provide advice to the Joint Stroke Strategy Working Group.

Incidence of Stroke

How many strokes occur in Ontario each year? According to the Canadian Institute for Health Information (CIHI), in 1997, there were 24,748 discharges from Ontario acute care hospitals for which the most responsible diagnosis was

cerebrovascular disease. This rather broad category (International Classification of Disease or ICD codes 430 to 438) includes:

- 430. Subarachnoid hemorrhage (a form of hemorrhagic stroke)
- 431. Intracerebral hemorrhage (another form of hemorrhagic stroke)
- 432. Other and unspecified intracranial hemorrhage
- 433. Occlusion and stenosis [blockage] of precerebral arteries
- 434. Occlusion [blockage] of cerebral arteries
- 435. Transient cerebral ischemia (Transient Ischemic Attack)
- 436. Acute but ill-defined cerebrovascular disease
- 437. Other and ill-defined cerebrovascular disease
- 438. Late effects of cerebrovascular disease

As there is currently no registry of strokes, it is impossible to determine exactly how many of the almost 25,000 hospital admissions in Ontario in 1997 represented strokes, were stroke-related or were not stroke-related. Research^{3 4} has suggested that the most reliable ICD codes for designating strokes may be ICD 430 and 431 for hemorrhagic¹ stroke and ICD 434 and 436 for ischemic² stroke. ICD 435 represents Transient Ischemic Attack (TIA)³.

Using the codes for hemorrhagic and ischemic stroke, the Institute for Clinical Evaluative Sciences (ICES) estimates that there were 14,937 strokes in Ontario in 1998 (see Appendix 2 for the entire report). It should be noted, though, that this may be a conservative estimate of the number of strokes in Ontario. The CIHI data ICES used includes only strokes in which the person was hospitalized (i.e. it does not include those people who did not go to hospital, were not admitted or who died before arriving at the hospital). In one American study⁵, it was found that only 86% of first-stroke patients were hospitalized; furthermore, of the hospitalized patients, only 76% were assigned a principal discharge diagnosis code within the cerebrovascular disease range (ICD 430-438).

The figures in Appendix 2 also do not include strokes that are the result of complication (e.g. a stroke that occurs during hospitalization for another condition). Data from CIHI suggest that in 1998, 424 strokes occurred as a result of medical complications. Although prevention strategies may not be able to

¹ In hemorrhagic stroke, there is a rupture of a blood vessel and uncontrolled bleeding (hemorrhage) into the brain. The brain cells in the area flooded by the hemorrhage may be damaged or killed. There are several types of hemorrhagic stroke. In *subarachnoid hemorrhage*, the bleeding occurs from a blood vessel on the surface of the brain. In *intracerebral hemorrhage*, the bleeding occurs inside the brain.

² In an ischemic stroke, blood flow to a part of the brain is interrupted by a blood clot blocking an artery. This type of stroke is similar to a heart attack (in which a blood clot blocks the flow of blood to part of the heart); as a result, it is sometimes referred to as a "brain attack." About 85% of all strokes in Ontario are ischemic.

³ A transient ischemic attack (TIA) is defined as a stroke with symptoms that resolve (go away) in less than 24 hours. Although TIAs do not have long-term effects, there are important warning signs that the person is at high risk of a major ("completed") stroke.

target these events, such strokes utilize resources within the acute care and rehabilitation sectors.

To summarize, we know that there are 24,748 hospitalizations in Ontario each year for cerebrovascular disease, of which 14,937 can be described with confidence as strokes. Another 424 strokes occur during hospitalization as the result of complications. However, the number of strokes that occur without hospitalization is unknown. Thus, the figure of 15,361 can be said to represent a baseline or conservative estimate of the number of strokes in Ontario each year. The actual number is probably somewhat higher (e.g. between 15,000 and the 20,000 estimated by the Heart and Stroke Foundation of Ontario).

Recent research in the United States has challenged most existing estimates of the number of strokes. In an article published in *Stroke*, Williams and associates⁶ made what they called a “conservative estimate” that the number of first-ever and recurrent strokes in the U.S. in 1995 was 750,000 – significantly more than the 500,000 figure based on Framingham Heart Study data and cited by the American Heart Association. Unlike previous studies based on relatively small, homogenous, population-based stroke registries, this study utilized a database composed of 20% of all 1995 U.S. inpatient hospital discharges. A review of two population-based stroke incidence studies led the researchers to estimate that 68,000 stroke patients were not hospitalized during the study year.

Transient Ischemic Attack (TIA)

It should also be noted that the figure of 14,937 developed by ICES is for completed strokes and so does not include TIAs. According to hospitalization data analyzed by ICES, there were 3,529 TIA patients discharged from hospital in 1998 (the full report is attached in Appendix 3). Again, however, this may be a very conservative estimate. The health professionals consulted for this project believe that the proportion of TIA patients admitted to hospital has decreased sharply over the past decade. Experts in the London area, for example, estimate that as few as 10% of TIA patients are admitted to hospital. If we estimate that even 25% of TIAs are hospitalized, the number of actual events could be as high 7,000.

According to data from Rochester, Minnesota, the age- and sex-adjusted incidence rate for TIA in 1985-1989 was 68 per 100,000 population⁷. Applying this rate to the population of Ontario over age 15 (approximately 9.2 million) suggests the number of TIAs in Ontario could be around 6,300. Thus, it is likely (but not proven) that the number of TIAs in the province is at least twice that captured by CIHI data.

Prevalence of Stroke

How many Ontarians are living with the effect of stroke? Using a conservative estimate of the number of strokes in Ontario, it is estimated that there are approximately 10,600 who survive one month and are discharged from the hospital. At the same time these 10,600 new stroke survivors come into the population, there is a 33% mortality rate at 1 year, a 50% mortality rate by 5 years, and 87% by 10 years.

It has been estimated that there are about 6 stroke survivors per 1000 people in the population^{8 9}. In 1996, Ontario had a population of almost 8.3 million between 20 – 85+. This means Ontario could have at least 50,000 stroke survivors in any year.

A higher estimate is obtained by analyzing data from the National Population Health Survey (1996-97). According to the Survey¹⁰, the point prevalence of the number of community-living Ontarians who report living with the effects of stroke is 88,000. The level of neurological impairment, disability and handicap of these community-living stroke survivors varies considerably.

Moreover, the figure of 88,000 represents only part of the burden of stroke. Statistics Canada estimates that 22% of institutionalized adults 65 years of age or older have had a stroke¹¹. Thus, the figure of 88,000 should be considered only the baseline of the number of stroke survivors in Ontario.

Stroke Mortality

Despite improvements in stroke care and prevention, it appears that the absolute numbers of deaths in Ontario due to ischemic stroke, intracranial hemorrhage and all cerebrovascular disease have increased over the past fifteen years. Due to year-to-year fluctuations, there is no clear long-term trend in the number of deaths due to subarachnoid hemorrhage.

Table 1 that follows shows the number of deaths in Ontario between 1985 and 1997 for the various types of stroke and all cerebrovascular disease.

**Table 1: Deaths Due to Cerebrovascular Disease and Stroke
Males and Females, Ontario, 1985 - 1997**

Year	Subarachnoid Hemorrhage (ICD 430)	Intracranial Hemorrhage (ICD 431)	Ischemic Stroke (ICD 434 & 436)	All Cerebrovascular Disease (ICD 430-438)
1985	294	490	3,575	5,339
1986	266	506	3,560	5,283
1987	281	480	3,466	5,223
1988	277	489	3,782	5,492
1989	295	452	3,829	5,462
1990	270	545	3,622	5,261
1991	274	511	3,797	5,470
1992	265	597	3,779	5,542
1993	255	560	4,069	5,937
1994	265	549	4,031	5,948
1995	300	602	3,938	5,966
1996	297	576	3,964	6,012
1997	276	639	4,040	6,152

Stroke Outcomes and Costs

The economic burden of stroke is considerable. According to a study published in 1994¹², the acute-care hospital costs for treating a patient with a first stroke in Toronto ranged from \$15,000 (for what is categorized at the acute care stage as a mild to moderate stroke) to \$80,000 (a severe stroke). The average cost was calculated to be \$27,000 per patient.

However, acute care is only part of the overall cost of stroke. In a recent economic analysis¹³, it was found that stroke accounted for 3.9% of acute care hospital costs in Ontario (ranging from a low estimate of \$252.2 million a year to a high of \$273.7 million). The total direct costs of stroke (including acute care, emergency health services, drugs, etc) were estimated to be approximately \$528.7 million a year. Indirect costs such as lost productivity and pensions were estimated to range from \$244.5 million to \$375.8 million. In total, the combination of direct and indirect costs of stroke to the economy of Ontario was estimated to range from \$718.5 million to \$964.0 million a year.

Stroke is more than an economic issue, however. Data collected on 2.9 million stroke survivors as part of the Framingham Study¹⁴ found that 16% are subsequently institutionalized, 31% required assistance with the activities of everyday life, 20% needed help walking and 71% were vocationally impaired. Among those under the age of 65, 34% were unemployed, presumably as a result of their stroke.

Although the majority of stroke survivors return to the community or to their homes, up to 87% are left with some form of restriction in the activities of everyday living¹⁵. Stroke survivors frequently require home care and other forms of assistance with the activities of everyday living.

In many cases, family members (frequently a spouse, who may also be elderly) take on the role of caregiver for a stroke survivor. According to a report from Statistics Canada¹⁶, although caregiving may be undertaken voluntarily and may be seen as personally rewarding, it is not without costs. Those caregivers who spent the most time providing care experienced the highest level of psychological and emotional burden, as well as personal consequences such as extra expenses and postponed job opportunities. The impact on families and caregivers should be included when considering the impact of stroke.

Future Trends

Is the number of strokes in Ontario expected to increase, decrease or stay the same over the next one to two decades?

Answering this question is difficult, as a number of factors need to be considered. For example, although data suggests that the rate of ischemic stroke may be decreasing, the rate of hemorrhagic stroke appears to be increasing. Moreover, the number of strokes is sensitive to the age distribution of a population.

Previously, the Heart and Stroke Foundation of Ontario and the Laboratory Centre for Disease Control (LCDC) of Health Canada projected dramatic increases in stroke. For example, the Heart and Stroke Foundation predicted that *if stroke rates were to remain constant*, the aging of the population would result in a 26% increase in the number of strokes in the 15 years between 1995 to 2011. Using the broad categorization of “cerebrovascular disease,” LCDC also projected that the number of hospitalizations and deaths would continue to increase over the next twenty years¹⁷.

Using CIHI data, scientists at ICES calculated the number of strokes to be expected in Ontario over the next 10 years, i.e. until the year 2010 (see Appendix 2 for the full report). According to their calculations, over the next ten years the number of strokes in Ontario should increase by 9% (from 14,937 in 1998 to 16,979 in 2010). Supporting this conservative estimate is data from the World Health Organization showing declines in stroke rates in several populations¹⁸. However, decreases in stroke incidence were not observed in all populations studied (of the 17 populations, there were declines among men in 13 and among women in 15). In Denmark, the number of strokes remained stable despite a decrease in the age-adjusted stroke attack rate, due to the increased proportion of the population which was elderly¹⁹.

The unknown variable in such calculations is what will happen to stroke rates in the future. In the United States, concerns have been expressed that the stroke rate declines witnessed during the 1960s and 70s have slowed down or even plateaued²⁰. For example, in Rochester, Minnesota, the 5-year incidence rate of stroke remained constant between 1980-84 and 1985-89, at a rate 13% higher than that in 1975-79²¹. Data from the longitudinal Framingham Study tracks a decrease in stroke severity among subjects aged 55-64 years over the past three decades (1953 to 1973)²² but no significant declines in overall stroke and transient ischemic attack incidence or prevalence.

It has been said that Canada has one of the largest “baby boom” cohorts in the world. By 2010, the “front wave” of the baby boom cohort will just be reaching age 65. In other words, estimates to 2010 do not show what will happen to the number of strokes once the bulk of the baby boom cohort passes age 65.

Gender Issues in Stroke

In a typical year, there are slightly more male than female hospitalizations for ischemic stroke and intracerebral hemorrhage; the reverse is true for subarachnoid hemorrhage. However, as females tend to have their strokes later in life, when they are more likely to have other diseases or to be frail, female deaths from stroke outnumber male deaths. In 1997 in Ontario there were approximately 2,000 male deaths from stroke and 3,000 female deaths.

The impact of stroke is much greater than hospitalizations or even deaths. In many cases, women take on the critically-important role of caregivers for stroke survivors. (In fact, one Ontario-based study found that male survivors with spouses had better recoveries at one year than those without²³.) Current evidence suggests that stroke caregivers have elevated levels of depression during both the acute and chronic phases²⁴. Partners of stroke patients typically have feelings of heavy responsibility, uncertainty about the patients' care needs, constant worries, restraints in social life and feelings that the patients rely on only their care²⁵. In one study, almost all caregivers reported adverse effects on their emotional health, social activities and leisure time and more than half reported adverse effects on family relationship²⁶.

It is important that caregivers be supported. Moreover, it should be recognized that although many men are acting as caregivers for stroke survivors, the majority are women. Women who take on the role of caring for a stroke survivor (be it spouse, parent, family member or friend) are assuming an important and very demanding task.

Leveraging Opportunities

Within the past two years, there have been a number of important opportunities for improving the management of acute stroke.

The Changing Paradigm

In the past, health care providers and the public took a pessimistic view of stroke, often assuming that little could be done to either prevent or treat them. In keeping with this philosophy, medical care centered almost exclusively on support care and rehabilitation. During the past decade, there has been a dramatic paradigm shift in the medical approach to acute stroke care. Stroke is now recognized as both preventable and treatable. Organizing stroke care and the use of stroke teams can substantially reduce mortality and morbidity and improve outcomes. Studies have also shown that treatment with the thrombolytic drug t-PA (tissue plasminogen activator) can literally stop ischemic strokes in progress. By dissolving the blood clots causing stroke, thrombolytic therapy such as t-PA can limit the extent of brain injury, improve the outcomes for the patients, and reduce health care costs. It has been estimated that thrombolytics could result in savings of \$4-5 million (US) per 1,000 patients treated²⁷.

Other treatments for stroke, such as neuroprotective drugs that protect brain cells from damage and death, are likely to emerge in the future. All of these treatments point to the need for timely access and coordination of stroke care.

Coordinated Stroke Strategy

In 1998, regional coordination of organized stroke care was launched with the Coordinated Stroke Strategy. Chaired by the Heart and Stroke Foundation of Ontario, sites currently participating in the Strategy include Hamilton (the Hamilton Health Sciences Centre), Southeastern Ontario (the Kingston General Hospital), London (the London Health Sciences Centre) and the West Greater Toronto Area (a consortium of hospitals and community organizations, including the Trillium, Humber River Regional, William Osler Health Centre, St. Joseph's Health Centre, the West Park Hospital and area Community Care Access Centres). The goal of the program is not just to organize acute stroke care within these hospitals but to ensure equitable access to the best possible stroke care across participating regions.

Each centre is responsible for organizing activities and organizations within their own region. They include development and implementation of:

- ◆ regional triage and transport protocols

- ◆ emergency department clinical pathways for stroke, including protocols for the identification and “fast tracking” of patients eligible for thrombolytic therapy
- ◆ protocols for Transient Ischemic Attack (“mini-strokes”)
- ◆ community-specific collaborative care plans (care pathways that reach out from acute care to rehabilitation)
- ◆ regional training and education of medical and emergency medical services personnel
- ◆ public awareness-building campaigns

Research and evaluation have also been integrated into the implementation of the Coordinated Stroke Strategy, both in the forms of a process evaluation (of the implementation process in each region) and outcomes evaluation (by means of a registry of stroke patients). The Strategy is making possible investigation of a number of health services and clinical issues. For example, scientists associated with the HEALNet project are currently undertaking a study in the Coordinated Stroke Strategy sites on the use of evidence in decision-making.

Some examples of the accomplishments to date of the Coordinated Stroke Strategy include the following:

- ◆ In Kingston, in eight months, 123 patients across the southeastern region were triaged through the acute stroke protocol and thrombolytic therapy was administered to 27.
- ◆ In London, a telecommunications link is being developed between the London Health Sciences and the Stratford General Hospital. This link will improve the ability of the local hospital to appropriately diagnose and treat acute stroke.
- ◆ In Hamilton, training materials have been developed for paramedics on emergency assessment and treatment of acute stroke.
- ◆ The West GTA consortium is focusing specifically on rehabilitation and community reintegration – an area of stroke care much in need of research and development.

Canadian Stroke Network

In February, 2000, the government of Canada announced the award of funds for the Canadian Stroke Network, a new Network of Centres of Excellence. A national collaboration, the Canadian Stroke Network is organized into four themes: Stroke Prevention; Acute Care; Salvaging Brain Cells (basic research); and Rehabilitation and Recovery. Under the Acute Care theme a number of activities and projects will be undertaken, including the implementation of a

registry of stroke patients (to be tested in 20 hospitals across Canada) and a pilot of telecommunications linkages for stroke diagnosis and treatment (“telestroke”). Such activities will undoubtedly produce valuable lessons in optimizing acute stroke care.

HEALTH PROMOTION/STROKE PREVENTION

Contrary to what used to be thought, most strokes are not entirely unpredictable. There are known risk factors that significantly increase a person's risk of stroke. Moreover, control or elimination of risk factors can significantly reduce a person's risk of stroke. There is a tremendous potential to reduce the toll of stroke in Ontario through effective, consistent prevention.

Terms of Reference

There are three main types of stroke prevention: health promotion, primary prevention and secondary prevention.

Health promotion is defined as the process that enables people to increase control over, and therefore improve, their health²⁸. Improved health is believed to contribute to increased resistance to disease. Strategies used in health promotion programming include education, social marketing, healthy public policy, community development and organization, community-wide prevention and diffusion of innovations.

Primary prevention is aimed at preventing disease before it occurs. In the context of stroke, primary prevention usually refers to risk factor modification aimed at preventing a first stroke. Primary prevention may be accomplished at the population level (i.e., through health promotion programming) or at the individual clinical level (primary clinical prevention).

Secondary prevention involves the early detection of disease, either when it produces symptoms (i.e. is symptomatic) or even before symptoms are noticed (i.e. is asymptomatic). In secondary prevention of stroke, the goal of secondary prevention is to prevent the disease from progressing to a completed stroke or to prevent another stroke (recurrence). People targeted for secondary prevention include those who are at very high risk of stroke (e.g. those with asymptomatic carotid stenosis) and those who have experienced transient ischemic attack or non-disabling stroke.

Stroke Risk Factors

There are a number of factors that significantly increase a person's risk of having a stroke (risk factors). It has been estimated that about 90% of the people who have a stroke have one or more of the major risk factors²⁹. The more risk factors a person has the greater the risk of stroke.

Risk factors are usually divided into two categories: unmodifiable and modifiable^{30 31}.

Unmodifiable Risk Factors: Those that you cannot change or control. They include:

- **Age:** After age 55, a person's risk of stroke doubles every ten years. Currently, 12.5% of the population of Ontario is age 65 and over. By the year 2011, that proportion is expected to increase to approximately 14%. By 2031, it is expected that close to a quarter of the population of Ontario will be 65 and over.
- **Family History:** A family history of premature stroke (i.e. before the age of 65) increases a person's own risk of stroke.
- **Male Sex:** Men have a 19% greater risk of having a stroke than women. However, because women tend to live longer, more women than men die of stroke each year.
- **Ethnicity:** American studies indicate that the risk of stroke is 30% higher among African-Americans, due in large part to a higher prevalence of high blood pressure. There is some evidence that the risk of stroke may be higher among Canadian aboriginal women, as opposed to non-aboriginal women³².
- **Socioeconomic Status:** Stroke death rates are highest among people of lower income and educational levels. Differences in the prevalence of stroke risk factors (e.g. smoking) may account for some of this difference.

Modifiable Risk Factors: Risk factors that you can change (e.g. by stopping smoking) or control through lifestyle changes or medication. For example, diabetes increases the risk of stroke but diabetics can reduce their risk by lifestyle changes (e.g. maintaining a healthy weight and regular physical activity) and using insulin to control their blood sugar levels. Modifiable risk factors include:

- **High Blood Pressure:** People with untreated high blood pressure have a 3-4 times greater risk of stroke. It is estimated that about 22% of Ontarians age 45 know they have high blood pressure (see Table 2); significantly more probably have elevated blood pressure and don't know it. Effective treatment of high blood pressure can reduce the number of strokes by 38% and the number of fatal strokes by 40%³³. Even among those above age 80, the number of strokes can be reduced substantially (40%)³⁴ by effective treatment.
- **Sedentary Lifestyle:** As well as being an independent risk factor for stroke, inactivity increases the risk of high blood pressure, becoming overweight, diabetes and heart disease³⁵. A recent Canadian review of lifestyle modifications for the treatment and management of high blood pressure found

Grade B level of evidence to support the recommendation that adults exercise regularly³⁶. Observational studies have shown that people who integrate regular physical activity into their lives have the greatest success in attaining and maintaining a healthy weight³⁷.

Over half (59%) of the population of Ontario age 45 and over is inactive. In a survey conducted for the Heart and Stroke Foundation of Ontario by the Angus Reid Group in 1996, only 20% of Ontarians mentioned (unaided) “lack of exercise” as a risk factor for stroke. There is a need to make Ontarians more aware of the importance of regular physical activity in reducing the risk of stroke.

- ◆ **Overweight:** Being overweight increases the risk of stroke, high blood pressure, high cholesterol and diabetes. Up to 46% of the adult population of Ontario is classified as being overweight, yet in the 1996 Heart and Stroke Foundation survey only 13% mentioned (unaided) “being overweight” as a major risk factor for stroke.
- ◆ **Smoking:** A recent study that adequately takes into account passive smoking suggests that active smoking increases the risk of stroke six-fold and passive smoking nearly doubles the risk. Seventeen percent of Ontarians age 45 and over are smokers (see Table 2). In both the Framingham Study³⁸ and the Nurses’ Health Study³⁹, cessation of smoking led to a prompt reduction in stroke risk (e.g. major risk was reduced within 2 to 4 years). This reduction in risk occurred throughout the age spans, in both sexes and in heavy, as well as moderate, smokers.
- **Excessive Alcohol Consumption:** Exceeding the low-risk drinking guidelines (more than 1-2 drinks per day, with weekly maximums of 14 for men and 9 for women) and binge drinking can double the risk of ischemic stroke and increase the risk of hemorrhagic stroke two- to three-fold. Excessive alcohol consumption increases the risk of stroke by raising the blood pressure and contributing to obesity. About 7% of Ontarians age 45 and over drink at unhealthy levels (see Table 2).
- **High Cholesterol:** High levels of cholesterol in the blood (lipids) can double the risk of ischemic stroke. High cholesterol also increases the risk of heart disease, which is an independent risk factor for stroke. It is estimated that 31% of Ontarians age 45 and over have unhealthy cholesterol levels (see Table 1).
- **Atrial Fibrillation:** Atrial fibrillation is a heart rhythm disorder that can contribute to the development of blood clots. People with atrial fibrillation have a 3-5 times greater risk of having an ischemic stroke. International research suggests that about 3% of the population age 45 and over probably has atrial fibrillation³¹ with the prevalence rising to 5.9% among those age 65 and over.⁴⁰ With each successive decade of life above age 55, the incidence of atrial fibrillation doubles.

- **Coronary Heart Disease:** Having coronary heart disease (also known as ischemic heart disease) doubles the risk of ischemic stroke. People with coronary heart disease have hardening of the arteries (atherosclerosis), which may affect the arteries to the brain. They are also at greater risk of developing blood clots (that can catch in the arteries to the brain and interrupt blood flow). In the 1996/97 National Population Health Survey, 10% of Ontarian residents age 45 and over reported they had some form of heart disease. The prevalence of heart disease increases dramatically with age.
- **Diabetes:** Diabetes (diabetes mellitus) is an independent risk factor for stroke and is strongly correlated with high blood pressure, high cholesterol levels and being overweight. Diabetics have a 1.5-2.5 times greater risk of having an ischemic stroke. About 7% of Ontarians age 45 and over have been told that they have diabetes (see Table 2).
- **Transient Ischemic Attack (TIA):** TIAs are “mini-strokes” that produce stroke-like symptoms but no lasting damage. A person who has a TIA has an 8% risk of stroke in the following month, with the risk climbing to 12% risk within the first year and accumulating to 30% within the next 5 years⁴¹. There is no accurate measure of the number of Ontarians who have experienced TIA. The only available evidence suggests that about 2% of the population age 45-64 have had a TIA, increasing to 4% among those 65 and over³¹
- **Previous Stroke:** People who have had a stroke have a 5% annual risk of having another stroke. In the National Population Health Survey, 2% of Ontarians age 45 and over living in the community reported that they were living with the effects of stroke. This figure does not include stroke survivors who are hospitalized or living in long-term care facilities.
- **Asymptomatic Carotid Stenosis:** People who had hardening of the arteries (atherosclerosis) of the carotid arteries leading to the brain may not have symptoms such as TIA (i.e. they are asymptomatic). However, over 5 years, they have an 11% risk of having a stroke. Asymptomatic carotid stenosis can be diagnosed by a doctor by evaluating the blood flow through the carotid arteries. Unfortunately, there is no reliable estimate of the number of Ontarians with asymptomatic carotid artery disease.

Of the major risk factors for stroke, two (high blood pressure and low physical activity) increase the risk of both ischemic and hemorrhagic strokes by the same amount. Others (obesity, smoking, high cholesterol, atrial fibrillation, ischemic heart disease and diabetes) increase the risk of ischemic stroke more than they do hemorrhagic stroke. Excessive alcohol consumption increases the risk of hemorrhagic stroke more than it does ischemic stroke.

Other factors that can increase the risk of stroke include: coagulation disorders (i.e. blood clotting disorders), high red blood cell count, and certain kinds of drug abuse (intravenous drug abuse and cocaine use). Season and climate may also

be minor risk factors, as stroke deaths occur more often during periods of extremely hot or cold temperatures.

The incidence of stroke increases with age but people of all ages can and are stroke victims. Risk factors for pediatric stroke (stroke among children) include prematurity (premature babies are at increased risk of stroke), blood disorders (for example, sickle cell anemia) and coagulation disorders associated with heart surgery or cancer treatment. It has been estimated that the incidence of stroke among children under the age of 14 is 2.5 per 100,000⁴², a rate that is similar to that of brain tumours. Each child who has a stroke and doesn't recover completely faces many decades of handicap or disability. Because there has been little or no research on the topic of pediatric stroke (the Canadian Pediatric Ischemic Stroke Registry is one of the few exceptions), primary and secondary prevention is woefully undeveloped. Prevention is critical. For example, up to 20% of children who have a stroke subsequently have another one, in large part because there is currently little or no evidence on which to base treatment.⁴³ More research is needed on pediatric stroke prevention, treatment and recovery.

Population Attributable Risk

In weighing the importance of the different risk factors for stroke, three aspects must be considered:

- What type of stroke you're looking at: At least 80% of all strokes in Ontario are ischemic (meaning that they are caused by blood clots). Reducing the prevalence of factors that increase the risk of ischemic stroke will have a greater impact than those that reduce the risk of hemorrhagic stroke.
- How much the factor increases the risk of stroke: In Table 2, the Relative Risk (RR) of each factor is given. For example, the RR of hypertension (high blood pressure) is given as 3.0-4.0, which means that high blood pressure increases the risk of stroke 3-fold to 4-fold.
- How many people have the risk factor: Table 3 lists the percentage of the Ontario population with each risk factor, as well as the number of Ontarians at increased risk of stroke (i.e., the number of preventable strokes).

Combining information on the power and the prevalence of stroke risk factors gives us a statistic known as the Population Attributable Risk (PAR). The PAR shows us how much of the strokes that occur in Ontario are due to specific risk factors. From a public health point of view, the most important risk factors to

address are those that (a) carry a high population attributable risk and (b) can be modified.

The PAR statistic measures the potential benefit to be expected if the exposure to a specific risk factor could be reduced in the population. Please note, however, that these calculations exaggerate the effect of the risk factors because they deal with each one in isolation. In reality, risk factors tend to cluster: the person who has high blood pressure is also likely to be overweight and sedentary.

Economic Analysis of Stroke Prevention

Scientists at the Institute for Clinical Evaluative Sciences compared the economic costs and mortality associated with the current situation in stroke (the status quo) to those to be expected if stroke prevention programs were implemented. Results are summarized in Table 4. These effects would be independent of other interventions such as changes within the acute care sector. Moreover, they are based on a modest 25% reduction (approximately half of the anticipated effect of comprehensive, integrated and effective stroke prevention).

Table 4: Five Year Discharge Outcomes for Prevention

Over Five Years:	Status Quo	Stroke Prevention	Stroke Prevention vs. Status Quo
Total Cost	\$2.0 billion	\$1.5 billion	- \$500 million
Discounted Total Cost	\$1.9 billion	\$1.3 billion	- \$470 million
Number of Deaths	28,693	21,520	-7,173

As this table show, over five years even a modestly effective stroke prevention program could avoid costs of \$500 million (if discounted at 3% per annum, \$471 million) and 7,173 deaths. These estimates should be considered as highly conservative in terms of the cost avoidance potential of stroke prevention. To be achieved, however, both health promotion and clinical prevention efforts would be required.

Table 2: Population Attributable Risk (%) of Stroke in Ontario residents aged 45 and older: 1998

Risk Factor	Est. % of	R.R. of	R.R. of	Population (%)	Population (%)
	The Pop Ischemic	Ischemic	Haemorrhagic	Attrib. Risk	Attrib. Risk
	At Risk	Stroke	Stroke	Ischem. Stroke	Haem. Stroke
Hypertension ¹	22.10	3.0-4.0	3.0-4.0	31-40	31-40
Smoking ²	17.30	2.0	1.5	15	8
Atrial fibrillation ³	3.00	4.0-5.0	1.0	8-11	0
Alcohol ⁴	6.60	1.0-2.0	2.0-3.0	0-6	6-12
High cholesterol ⁵	31.00	1.0-2.0	1.0	0-24	0
Inactivity ⁶	59.40	1.5-2.5	1.5-2.5	23-47	23-47
Overweight ⁷	26.10	1.5-2.0	1.0	12-21	0
Diabetes ⁸	6.80	1.5-2.5	1.0	3-9	0

*Estimated % of the Population at Risk values were taken from the Ontario Health Survey 1996-97 for risk factors 1,2,4,6,7,8. Prevalence estimates for risk factors 3 & 5, as well as all of the Relative Risk values were taken from Purdue M, Hunter D, Spasoff R, Dorland J. Estimating The Need for Evidence-Based Stroke Services in Eastern Ontario. October 1998, Table 7. Based on 1998 Population values from Census.

Table 3: Number of Preventable Strokes in Ontario residents aged 45 and older: 1998

RISK FACTOR	Population (%)	No. Preventable	Population (%)	No. Preventable
	Attrib. Risk	Ischemic	Attrib. Risk	Haemorrhagic
	Ischem. Stroke	Stroke	Haem. Stroke	Stroke
Hypertension	31-40	265,561-345,405	31-40	265,561-345,405
Smoking	15	100,025	8	53,994
Atrial fibrilla	8-11	9,711-12,601	0	0
Alcohol	0-6	0--16,019	6-12	16,019-30,171
High cholesterol	0-24	0-287,586	0	0
Inactivity	23-47	533,234-1,097,205	23-17	533,234-1,097,205
Overweight	12-21	118,112-211,7778	0	0
Diabetes	3-9	8,766-24,674	0	0

*Estimated % of the Population at Risk values were taken from the Ontario Health Survey 1996-97 for risk factors 1,2,4,6,7,8. Prevalence estimates for risk factors 3 & 5, as well as all of the Relative Risk values were taken from Purdue M, Hunter D, Spasoff R, Dorland J. Estimating The Need for Evidence-Based Stroke Services in Eastern Ontario. October 1998, Table 7. Based on 1998 Population values from Census.

Current Programming in Health Promotion and Population-Based Prevention: Nature and Effectiveness

What is known about the effectiveness of population-based health promotion programs? The needs/impact-based planning method (NIBMP) used by the Ontario Ministry of Health and Long-term Care⁴⁴ categorizes the effectiveness of health promotion interventions as: Works Well (corresponds to Level I or II-1); Works (Level II-2 or II-3); May Work (Level III); or Does Not Work (no corresponding level of evidence).

The risk factors for ischemic stroke (and to a certain extent, hemorrhagic stroke) are similar to those of all cardiovascular disease. In their overview and analysis on the effectiveness of public health interventions⁴⁵, the Central West Health Planning Information Network found that much of the research to date on the prevention of cardiovascular disease has focused on risk factor reduction (e.g. tobacco use, dietary fat, cholesterol/triglycerides, physical inactivity and obesity) rather than reductions in the incidence or prevalence of disease.

Programs were analyzed according to their primary approach: education and advocacy, policy and enforcement, or strategies for creating or nurturing supportive environments. Results of a recent literature review³⁹ are summarized in Appendix 4.

Overall, there is a trend for the research literature to show education and advocacy programs for the reduction of risk factors to be effective. More journal articles report that these programs work well, work or may work than have been shown to not work (93 vs. 22). However, there are few data on the effectiveness of policy/enforcement strategies for the reduction of risk factors relevant to stroke, particularly in the area of activity. In terms of supportive environmental strategies there are more journal articles showing that they work well, work or may work than show they don't work (76 vs. 9). Optimizing health promotion efforts are thought to be achieved through a combination of programs and methods (which, as described below, is the approach of the Ministry of Health and Long-term Care).

Public Health: Mandatory Health Programs and Services Guidelines

The Chronic Disease Prevention program standards contain strategies for all ages to increase awareness and education, build skills and improve the social and physical environment to support tobacco-free living, healthy eating, healthy weights and regular physical activity. Programs are implemented to work with schools and other education facilities, workplaces, health professionals, community agencies and groups, restaurants and grocery stores, recreational facilities and the community at large.

Strategies to reduce the misuse of alcohol and other substances are associated with the Injury Prevention Including Substance Abuse Prevention section of the Mandatory Programs.

Program standards support a comprehensive approach to chronic disease prevention. Specific programs such as Heart Health are a means for the Public Health Units to achieve these standards. All of the modifiable risk factors for an integrated approach to cardiovascular disease prevention (ischemic heart disease, high blood pressure and stroke) are included in the guidelines which form program policy for the Public Health Units.

Health Promotion Program Framework

Mandate: The mandate of the Health Promotion Program (HPP) is to plan, develop, implement and evaluate health promotion strategies that facilitate community action and the development of personal skills for health and the prevention of chronic disease for the population as a whole.

Goals: The HPP planning framework for comprehensive population health promotion has three common goals: (1) health enhancement; (2) risk avoidance; and (3) risk reduction.

Approaches: To accomplish these goals, a variety of approaches are integrated which include increasing the awareness, knowledge, and skills in individuals; creating supportive environments that make healthier choices easier and more accessible (realistic); and addressing public policies. These approaches utilize four key sites to channel activities: workplace; school; home; and community-at-large.

Health Promotion Funded Programs

This government is providing over \$20 million to promote health and chronic disease prevention in communities across Ontario in partnership with national, provincial and community-based not-for-profit health agencies. Aimed at reducing tobacco use, unhealthy eating and physical inactivity; alcohol and other drug abuse prevention; and healthy growth and development of children, these programs represent big strides towards the chronic disease prevention.

Ontario Heart Health

The Ontario Heart Health Program (OHHP) promotes health and prevents chronic disease by funding and delivering heart health programs across the province. The goal of the program is to reduce the prevalence of the modifiable risk factors associated with cardiovascular disease. In partnership with agencies such as the Heart and Stroke Foundation, the Canadian Cancer Society and the Lung Association, we are raising the awareness of risks associated with smoking, physical

inactivity and unhealthy eating and providing programs to support changes in behavior and attitudes.

The provincial objectives are grouped into three categories: programming, knowledge, and behavior with specific targets established in each for children, youth, and adult men and women. Women have also been identified as a priority for local heart health initiatives.

Heart health projects use a comprehensive population-based approach to program planning and implementation. This comprehensive approach incorporates the following:

- ◆ setting local objectives to support the objectives of the OHHP;
- ◆ addressing the needs of different audiences, e.g. youth;
- ◆ working through various channels or sites to reach the intended audiences, e.g. schools;
- ◆ using a variety of intervention approaches that will influence changes in behavior, e.g. education, including media, self-help, and skill building activities; and
- ◆ targeting each of the modifiable risk factors.

In recognition of the common risk factors shared by cardiovascular disease and stroke, a number of the heart health projects are moving towards incorporating stroke prevention messages into their activities.

FOCUS Community Program

The Ontario FOCUS Community Program prevents problems, including injuries associated with alcohol and other drug abuse in 22 high-risk communities across the province. Specific targets have been set to decrease the rate of alcohol consumption in young people and adults, increase the level of awareness regarding the risks associated with alcohol and other drug abuse and their consequences in the entire population, and decrease the rate of alcohol-related injuries and deaths. Preventing substance abuse among children and youth is a priority, with each project being asked to allocate one third of their budget to activities directed at young people.

Ontario Tobacco Strategy

The Renewed Ontario Tobacco Strategy is aimed at reducing tobacco use among all people in Ontario especially youth and women. Highlights of specific programs include:

- ◆ \$3.2 million for a province-wide television and print media campaign - Heart and Stroke Foundation of Ontario
- ◆ \$1 million for a toll-free support line to help smokers quit – Canadian Cancer Society
- ◆ \$400,000 for school-based smoking prevention program – Lung Association

Physical Activity Strategy

Research to date shows that regular physical activity is most effective in lowering the risk of stroke among men, as opposed to women, younger, as opposed to older, adults and Caucasians as opposed to visible minorities⁴⁶. “Moderate physical activity” is usually defined as being physically active for a minimum of 20-30 minutes at least 3 or more times a week. A dose-response relationship between increasing amounts of physical activity and the reduction in the risk of stroke has not been consistently shown; in fact, it has been suggested that the most benefit is gained by those who exercise moderately. In other words, excessive or very vigorous exercise may not be necessary to prevent stroke and may even be counterproductive. Rather, stroke prevention may be maximized by moderate but regular physical activity.

Active Ontario – New Directions and Partnerships - is a part of the physical activity strategy under development which is implemented through a joint partnership between the Ministry of Culture, Citizenship and Recreation and the Ministry of Health and Long-Term Care. The objective is to encourage inactive Ontarians to become physically active to benefit their health and enrich their lives. Through partnerships with provincial agencies such as the Ontario Physical Health and Education Association, ParticiPaction and Parks and Recreation Ontario, seven provincial initiatives have been developed to support Ontarians in becoming more active at home, school, work and in their communities.

Nutrition Strategy

Nutritional strategies target a number of issues, including:

- ◆ Healthy weights: Being overweight or obese (a Body Mass Index that is more than 25% higher than the healthy range) can increase the risk of ischemic stroke 1.5-2 times.
- ◆ Fat intake: According to the Canadian Heart Health Survey, 40% of Ontarian adults have elevated blood cholesterol levels. However, in the 1996 Heart and Stroke Foundation survey by the Angus Reid Group, only 10% of respondents mentioned (unaided) cholesterol as a major risk factor for stroke.
- ◆ Fruit and vegetable consumption: Research has found that consumption of fruits and vegetables protect against the risk of ischemic stroke. This protective effect may be a result of the antioxidants present in fruits and vegetables (which are

thought to protect against the development of atherosclerotic plaque), vitamins such as folic acid, vitamin B₆ and B₁₂ (implicated in the development of homocyst(e)inemia) and minerals such as potassium that effect blood pressure. In some studies, as the number of servings of fruits and vegetables or the levels of carotene and vitamin C in the blood increased, the number of stroke events decreased^{47 48}. However, according to 1990 Ontario Health Survey, 56% of Ontarians consume less than the minimum five daily servings of fruits and vegetables.

- ◆ Salt consumption: In its review of the literature, the Canadian Task Force on Hypertension⁴⁹ concluded that the evidence did not support the recommendation that people without high blood pressure restrict their salt intake. It was concluded that salt restriction was much less effective than other strategies, such as weight loss, in preventing high blood pressure. However, in recognition of the fact that salt intake is high in North American (due in large part to industrially processed foods), the committee recommended that people should choose foods low in salt (e.g. fresh fruits and vegetables), to avoid foods high in salt (e.g. pre-prepared foods), to refrain from salt at the table and minimize the amount of salt used in cooking, and to increase their awareness of the salt content of food choices in restaurants. It should be noted, however, that these recommendations are based not on experimental data but on consensus statements and practice guidelines.

The Nutrition Program (under development) promotes healthy eating and the prevention of chronic diseases through a series of nutrition education programming and resources that are delivered across the province by health agencies, such as public health units and community health centres.

Health Promotion Resource System

Planning, implementing and evaluating health promotion programs is a complex challenge in which many groups, organizations and individuals across the province are involved. These champions of health promotion include health professionals in community health centres, public health departments, voluntary organizations, the private sector, and individuals from communities who participate on their own or as a part of a coalition or network.

The Health Promotion Program provides support to these health professionals and volunteers through the Ontario Health Promotion Resource System (OHPRS), the cornerstone of the HPP planning framework. The OHPRS is a group of 15 organizations that provide a range of services, such as training, consultation, and access to information and program materials to their clients across Ontario.

The OHPRS:

- ◆ Works with communities to improve their capacity to plan, implement and evaluate health promotion programs;

- ◆ Ensures access to knowledge and innovation despite language, cultural and geographic barriers; and,
- ◆ Encourages innovation at the same time that it promotes research-based best practices.

Low Risk Drinking Guidelines

As discussed earlier, although moderate consumption of alcohol may reduce the incidence of cardiovascular disease, including stroke, excessive consumption can double the risk of ischemic stroke and can double or even triple the risk of hemorrhagic stroke.

It is estimated that 4%-10% of the population are severely alcohol dependent and 15%-25% have a drinking problem. In medical screenings, rate of severe to mild alcohol dependency have averaged 25%, with some studies reporting rates as high as 36%.⁵⁰

Moderate alcohol consumption has been associated with a reduced risk of cardiovascular disease but this protective effect is lost as alcohol consumption increases. Because of this "J-shaped" association between alcohol consumption and stroke, application of the Low-Risk Drinking Guidelines⁵¹ (as released by the Addiction Research Foundation in 1997) may be suitable for population-based stroke prevention. Key recommendations in the Guidelines include:

- ◆ People should drink no more than two standard drinks on any day.
- ◆ Men should limit themselves to 14 drinks a week and women should drink no more than nine.

The Guidelines (which were endorsed by the Ontario Public Health Association, the Association of Local Public Health Agencies and the College of Family Physicians of Canada) specify that there are certain people who should not drink at all, or who should drink less than the suggested amounts. These include people with health problems such as liver disease or certain psychiatric problems; people taking medications such as sedatives, sleeping pills and pain killers; women who are trying to conceive, are pregnant or are breast-feeding; people operating heavy machinery; and people with a personal or family history of serious drinking problems.

Public Awareness (Heart and Stroke Foundation of Ontario)

Is the public aware of the risk factors for stroke? In a study conducted in Saskatchewan, 14% of an urban population⁵², 18% of a rural population⁵³ and 50% of a First Nations population⁵⁴ were unable to identify any of the risk factors for stroke. Preliminary results from unpublished research conducted by the Heart and Stroke Foundation of Ontario suggests that although unaided awareness of some risk

factors may be good (e.g. 38% of respondents named smoking as a risk factor for stroke), recognition of others may be poor (e.g. less than 5% of respondents mentioned age or diabetes). Moreover, it is not clear whether those who named such things as smoking and diet were aware of the relationship between such lifestyle choices and stroke. It is possible respondents were simply naming lifestyle choices that they have been taught are “bad for you.”

Issues in Health Promotion and Population-Based Prevention

The critical element in improved population health approaches for preventing and reducing the risk factors for stroke is integration. Fragmented development of separate chronic disease initiatives for ischemic heart disease, high blood pressure and stroke must be avoided. For example, program components for high blood pressure should be developed that can be integrated into current health promotion programs concerned with Heart Health. Gaps in approaches and programs should be addressed for an effective, integrated prevention initiative.

Table 5 summarizes the main components for an integrated system that would enhance the prevention of stroke by building on current health promotion programs. The role of Risk Factor Strategies such as Active Ontario is to ensure that evidence-based intervention programs are developed. These programs are utilized by health units and community partners in implementing the Heart Health Program. Additional cardiovascular disease prevention components for high blood pressure and stroke awareness should be integrated into the existing Heart Health Program to produce a unified cardiovascular disease prevention program. The role of the Health Promotion Resource System is to develop the local community capacity to implement all the relevant program components for stroke prevention.

The benefit of this approach is that it minimizes developmental costs and avoids creating separate and redundant initiatives, which would strain government-funded and non-governmental agencies. Each component would not only contribute to the population risk of stroke but would also enhance the prevention for other cardiovascular risks such as heart attack.

Regarding the funding of these health promotion programs, it is recommended that the full attributable health benefits and associated cost avoidance should form the basis of an appropriate funding formula. Funding should be sufficient to achieve the province's prevention objectives as described in the Mandatory Health Programs and Guidelines (1998).

Table 5: Integrated Provincial Health Promotion Program

Program Component	Function	Enhancements To Address Stroke	Rationale
Provincial Risk Factor Strategies	Planning and development of evidence-based interventions	<ul style="list-style-type: none"> • Complete development of Active Ontario – Physical Activity Strategy as planned • Development of a provincial strategy for Nutrition that builds on current provincial programs • Sustain the Ontario Tobacco Strategy 	Efficiency – a single set of programs for each risk factor are used with all related chronic diseases.
Heart Health Program	Planning and implementation of community-wide programs	<ul style="list-style-type: none"> • Develop programs for awareness and prevention of high blood pressure and stroke. • Enhance implementation to reach a large proportion of the people exhibiting one or more risk factors for cardiovascular disease. 	<p>Stroke and high blood pressure prevention is integrated with the current Heart Health Program.</p> <p>Implementation is enhanced to increase prevention of the unified cardiovascular disease prevention program.</p>
Health Promotion Resource System	Builds capacity for implementation	<ul style="list-style-type: none"> • Support enhanced programming for prevention of high blood pressure and stroke. • Enhance support to communities for physical activity and nutrition programming. 	<p>Increases the level of implementation of new programs.</p> <p>As Active Ontario and the Nutrition Strategy develop, support needs increase.</p>

Fragmentation

It is neither feasible nor desirable to launch behaviour change strategies for each chronic disease when the risk factors are in many cases the same. It is important that “disease silos” not develop and that all chronic disease prevention programs are integrated. The Chronic Disease Prevention standards for Public Health Units support such an integrated approach and should be extended to provincial risk factor strategies and Heart Health programs which are implemented through partnerships between government, non-governmental agencies and community organizations.

Expanding the focus of programming (e.g. of Heart Health programming) to include stroke would require some change in focus, as well as further development to address gaps. Such activity would include:

- ◆ Revision of risk factor awareness materials
- ◆ For some clinical endpoints (e.g. blood pressure), some tailored components may be required
- ◆ Creation of linkages between risk factor modification and not just one but several clinical conditions or outcomes (e.g. increasing level of physical activity reduces risk of high blood pressure, ischemic heart disease and stroke).

To support an integrated cardiovascular disease prevention program which includes high blood pressure and stroke, the current Heart Health program may require additional resources. The Heart Health program should be enhanced in order to address this expanded mandate, as well as the Health Promotion Resource System which provides support and build community capacity.

In the field of nutrition and activity programming, some areas remain unfunded or underdeveloped. In physical activity, for example, there is a need to enhance public awareness, to develop a full workplace component and to support brief advice regarding lifestyle risk factors in primary care (e.g. by the family physician). Components of the Active Ontario plan such as the Active Workplace and Active Homes initiatives should be developed and implemented.

In nutrition, a basic set of provincial nutrition education programs for awareness, self-help and small group education has been developed and best practices for school nutrition programming and healthy food selection at point-of-purchase have also been investigated. However, gaps remain. For example, there needs to more emphasis on raising public awareness of the importance of fruit and vegetable consumption. School and retail setting initiatives which have been planned should be pursued. There is also a need for workplace programs.

Tobacco

Currently, the Ontario Tobacco Strategy has received funding for a renewal and enhancement project extending until September 30, 2000. Under the enhanced funding many current gaps are being addressed. However, there remain a number of important issues:

- ◆ Sustainability: Current funding extends only to September, 2000.
- ◆ Integration: Funding for interventions has been allocated to a number of health service providers and non-governmental organizations. It is important that initiatives be linked and the public perceives them to be part of a focus on smoking cessation.
- ◆ Best Practices: Ontario is one of the premier locations in North America for research in preventing smoking. It is important that this knowledge base be disseminated and applied.
- ◆ Community Involvement: Ontario has established an important base for smoking prevention in the Action Program for Alcohol, Drug Prevention and Tobacco Use Prevention. This program needs to be established consistently across the province and budgeted for appropriately.
- ◆ Environmental Tobacco: The Tobacco Control Act emphasizes the control of smoking but does not eliminate secondhand smoke in public places. There is a need to address this issue and to significantly increase public education and awareness on the health effects of environmental tobacco smoke.
- ◆ Given the importance of smoking and environmental tobacco smoke in stroke prevention, other measures may be required, such as:
 - ◆ Increase in tobacco taxes (a measure which has been shown to be effective in reducing tobacco use, particularly among the young)
 - ◆ Legislation to control smoking and environmental tobacco smoke
 - ◆ Enabling primary care providers to effectively assist their patients in smoking cessation (e.g. brief advice programs).

High Blood Pressure

Although this is probably the most significant modifiable risk factor for stroke, there is little health promotion programming in Ontario focusing on prevention, detection or management of high blood pressure. Many of the building blocks for a prevention initiative are in place (e.g. the Heart Health network and basic awareness materials) but coordinated development is needed to make this a reality. Development of a high blood pressure prevention component should be integrated within the Heart Health program and strategic blood pressure monitoring and control should be

incorporated into primary care. If further primary care pilot sites are developed, it may provide the opportunity for demonstration projects, documentation and evaluation of “best practices” in blood pressure monitoring and control.

Alcohol Consumption

As described earlier, the FOCUS Community Program is addressing the issue of alcohol and substance abuse, but only in 22 target (high-risk) communities. Media-based education on alcohol consumption and associated health risks has not been a major focus throughout the province as a whole. While it may not be feasible to develop a full risk factor strategy on alcohol consumption in the short-term, developing a component on alcohol and high blood pressure would assist in addressing stroke prevention. This recommendation will support the applicable Public Health program standards for alcohol consumption as a risk factor (such as described under the Injury Prevention mandatory program guidelines).

Awareness of Stroke Risk Factors

To date, there has been relatively little work on raising public awareness of the risk factors for stroke. Risk factors such as smoking, poor dietary choices, inactivity, etc., have been raised primarily in terms of heart disease or cancer. There has been relatively little public education on the relationship between blood pressure and risk of stroke.

Data Collection

There is currently little or no systematic data collected on stroke. Systematic data collection has been proposed at the acute care phase (the Stroke Registry) and the feasibility of collecting data on stroke prevention should be explored. Data collected could support both process and outcomes evaluations of programming and provide valuable lessons for continuous quality improvement.

Clinical Prevention:

Nature, Effectiveness and Numbers Needed to Treat

Primary prevention at the clinical/individual level is carried out by identifying high-risk patients and treating their risk factors. The health care providers who conduct primary clinical prevention may include physicians, Advanced Practice Nurses, dietitians, psychologists and others. The risk factors that are usually targeted include:

- Smoking (both active and passive)
- High blood pressure
- High blood cholesterol
- Diabetes

In the evaluation of medical therapies, effectiveness is usually categorized according to the following scheme:

- ◆ Level 1 Evidence: At least one prospective, randomized controlled study has shown that the intervention is beneficial.
- ◆ Level 2 Evidence: At least one non-randomized cohort comparison or multicentre case study or chronological series shows that the intervention is beneficial. Evidence may also be part of extraordinary results for randomized clinical trials.
- ◆ Level 3 Evidence: Professional guidelines in Canada, practice in other jurisdictions, descriptive studies, reports of an expert committee and/or Consensus Panel member's experience and/or expert opinion.

Table 6 summarizes the evidence on the effectiveness of primary prevention interventions. This table shows that there is good to excellent evidence supporting primary clinical prevention.

Table 6: Levels of Evidence in Primary Prevention of Stroke

Intervention	Level of Evidence
Pharmacologic Treatment of High Blood Pressure	Level 1 Evidence. Randomized control trials have shown reducing hypertension reduces the risk of stroke.
Non-Pharmacologic Treatment of High Blood Pressure (Lifestyle Modifications) ⁵⁵ : <ul style="list-style-type: none"> ◆ Maintaining a healthy body mass index ◆ Moderate alcohol consumption ◆ Regular, moderate physical activity ◆ Dietary salt restriction ◆ Behavioural interventions 	Evidence on lifestyle modifications to treat high blood pressure: Level 2 Evidence Level 3 Evidence Level 2 Evidence Expert opinion Level 2 Evidence
Pharmacologic Treatment of High Cholesterol	Level 1 Evidence Randomized controlled trials have shown lipid-lowering drugs and dietary changes can reduce the number of first strokes.
Diabetes	Level 3 Evidence National Stroke Association ⁴⁶ recommends rigorous comprehensive control of blood sugar levels for patients with diabetes.
Smoking Cessation	Level 2 Evidence Treatment with sustained-release bupropion alone or in combination with a nicotine patch resulted in significantly higher long-term rates of smoking cessation than use of either the nicotine patch alone or placebo ⁵⁶ .

Table 7 summarizes much of the current data on the numbers needed to treat in primary prevention with pharmacologic interventions in order to prevent one stroke. All of the studies showed effectiveness, in that the relative risks compared to placebos were below 1.0. However, depending upon the target audience, the numbers needed to treat in order to prevent a stroke varied. As a rule, the higher the risk of patients, the fewer that have to be treated in order to prevent stroke.

Table 7: Numbers Needed to Treat (NNT) in Primary Prevention To Prevent 1 Stroke⁵⁷

Study	Risk Factor	Treatment	Period	Relative Risk~ (95% CI)+	NNT (95% CI)+
MRC	High blood pressure	Blood-pressure lowering drug	5.5 yrs.		850
SHEP	High blood pressure	Blood-pressure lowering drug in the elderly	4.5 yrs	0.65 (0.51-0.83)	43 (27-95)
STOP	High blood pressure	Blood-pressure lowering drug in the elderly	4 yrs	0.55 (0.30-0.97)	34 (20-123)
MRC	High blood pressure	Blood-pressure lowering drug	5.8 yrs	0.76 (0.59-0.98)	70 (36-997)
WOS-COPS	High cholesterol	Cholesterol lowering drug	4.9 yrs	0.90 (0.61-1.34)	641 (135-no benefit)

~ compared to placebo
 + 95% Confidence Interval

Smoking Cessation and Prevention

Smoking cessation and the elimination of environmental tobacco smoke is important for all Ontarians and is critical for those at high risk of stroke. A study of university-affiliated community primary care clinics, for example, found that brief advice and support following the 1996 Agency for Health Care Policy and Research smoking cessation guidelines achieved a 11% smoking cessation rate at 9 month⁵⁸. Group counselling is another option in the primary care setting. Where warranted and safe, the primary care provider can also prescribe nicotine replacement and/or bupropion. To have maximum impact, however, these clinical interventions should be supported throughout all levels of society and in all settings (e.g. prevention and cessation programming in the home, school and workplace; legislation and enforcement; and taxation).

High Blood Pressure

Meta-analysis has suggested that a reducing the diastolic blood pressure of a population by a modest 5-6 mmHg can cause the number of strokes to fall by 42% in just three years⁵⁹. Treating high blood pressure prevents strokes not only in those who are young or middle-aged but among the elderly³⁴.

The first – and critical – step in the treatment of high blood pressure is diagnosis. According to results from the Canadian Heart Health Survey, up to 22% of Canadian adults (26% of men and 18% of women) can be identified as having high blood pressure. However, almost half (42%) of people with high blood pressure were unaware they had the condition.

Once identified, there are several treatment options. The first line of treatment is lifestyle modifications. As identified by the a consortium including the Canadian Hypertension Society, the Heart and Stroke Foundation of Canada and Health Canada⁶⁰, lifestyle modifications that are important in controlling high blood pressure include: weight loss, physical activity, reducing dietary salt (eliminating added salt and avoiding salty foods), alcohol restriction (no more than 9 standard drinks/week for women and 14/week for men) and stress management.

If lifestyle modification is not sufficient to reduce the blood pressure to a healthy range, drugs may be prescribed. There are a number of different types of blood pressure-lowering medications and physicians and patients may have to work together to find the drug or combination of drugs that are effective with minimal or tolerable side-effects. Compliance with therapy is a significant problem in treating high blood pressure, mainly because the condition itself usually has few visible effects unlike the drugs used to treat it.

High Cholesterol

For some time, it has been known that decreasing cholesterol levels can reduce the prevalence of heart disease. It is only recently that meta- analyses of randomized controlled trials have shown that cholesterol lowering can reduce the risk of nonfatal and fatal stroke by 30% in patients with no history of previous stroke. In high-risk patients with vascular disease, it is appropriate to use both diet and cholesterol-lowering drugs to reduce the risk.

Diabetes

Diabetes is an independent risk factor for stroke. It is also strongly correlated with other stroke risk factors, such as high blood pressure, high cholesterol and obesity. Diabetics have a 1.5 to 2.5 increased risk of ischemic stroke.

Adult-onset diabetes can be prevented by maintenance of a healthy weight through healthy nutrition and regular physical activity. At present, there is no conclusive

evidence that strict control of blood sugar can decrease the risk of cardiovascular disease (heart disease and stroke)⁶¹. However, it has been observed that poor blood sugar control is a major predictor of stroke in people with non-insulin dependent diabetes⁶².

Secondary Prevention:

Nature, Effectiveness and Numbers Needed to Treat

Persons who are candidates for secondary prevention include patients at very high risk of stroke, with and without symptoms of a stroke-related problem (i.e. those who are asymptomatic or symptomatic).

Asymptomatic persons at very high risk include those who have atrial fibrillation (a heart rhythm disorder that increases the risk of blood clots) or a build-up of atherosclerotic plaque in the carotid artery (called *asymptomatic carotid stenosis* as it is not yet producing symptoms).

Symptomatic persons are those who have experienced warnings of blood flow problems to the brain. Transient ischemic attacks (temporary “mini-strokes” that may go away in a few minutes or hours) are an important warning sign of stroke. Although transient ischemic attacks (TIAs) may not cause lasting damage, they are associated with increased risk of stroke. A person’s risk of stroke is approximately 5% during the first month after a TIA, 12% during the following year, and about 30% within the following 5 years⁶³. A person who has had a completed stroke is also at increased risk of another (approximately 5% annual risk).

In addition to aggressive treatment of risk factors such as high blood pressure, high cholesterol and smoking, a number of effective preventive strategies are available for those with asymptomatic or symptomatic cerebrovascular disease. These include:

- ◆ Anticoagulation (“blood-thinning”) therapy for those with atrial fibrillation
- ◆ Antiplatelet therapy to reduce the risk of blood clots formed by clumping of platelets (embolism)
- ◆ Surgery to remove atherosclerotic plaque build-up in the carotid arteries

The following table (Table 8) summarizes the levels of evidence supporting secondary prevention interventions.

Table 8: Level of Evidence in Secondary Prevention

Intervention	Level of Evidence
Anticoagulation	Level 1 Evidence Randomized controlled trials have shown that use of anticoagulants (e.g. warfarin) can reduce the risk of stroke among those with atrial fibrillation or previous heart attack.
Antiplatelet agents	Level 1 Evidence Randomized controlled trials have shown that ASA, ticlopidine, clopidogrel and dipyridomole and ASA combination can reduce the risk of stroke.
Carotid Endarterectomy	Level 1 Evidence Large randomized controlled trials have shown that carotid endarterectomy is an effective prevention for stroke among those with >50% carotid stenosis (blockage).

The following table (Table 9) summarizes recent data on the numbers needed to treat in secondary prevention to prevent one stroke from occurring.

Table 9: Numbers Needed to Treat (NNT) In Secondary Prevention To Prevent 1 Stroke⁵⁶

Study	Risk Factor Treated	Treatment	Period	Relative Risk~	NNT
CATS	Previous stroke	Antiplatelet drug	2 yrs	0.61 (0.44-0.84)	15 (9-41)
SALT	Previous stroke or TIA	Antiplatelet drug	2.7 yrs.	0.84 (0.65-1.08)	38 (16-85)
NASCET	Symptomatic carotid stenosis	Surgery (carotid endarterectomy)	3 yrs.		4
ACAS	Asymptomatic carotid stenosis	Surgery (carotid endarterectomy)	3 yrs.		29
ESPS2	Previous stroke or TIA	Antiplatelet drugs: ASA vs. placebo Dipyridamole vs. placebo ASA + Dipyridamole vs placebo	2 yrs.	0.82 (0.69-0.97) 0.84 (0.71-1.00) 0.63 (0.52-0.76)	18 (13-29)

~ compared to placebo
+ 95% Confidence Interval

Anticoagulation

“Anticoagulants” are drugs that are used to prevent the formation of blood clots. Anticoagulation with warfarin (coumadin) is considered highly effective in preventing stroke among patients who have clots originating in the heart (cardioembolic stroke)⁶⁴. About 5% of the adult population have a heart rhythm disorder called atrial fibrillation. On average, patients with atrial fibrillation have a 4.5% per year risk of stroke: anticoagulation can reduce this risk to about 1.5% per year (a 70% relative risk reduction)⁶⁵.

Antiplatelet Therapy

Antiplatelet agents are drugs that help to prevent the formation of blood clots formed when platelets clump together (forming an embolism). Common ASA (“aspirin”) is an antiplatelet agent that widely used to reduce the risk of both stroke and heart attack. It has been calculated that ASA reduces the incidence of stroke by about 25%, although the optimal dosage remains controversial. ASA has the advantage of being both effective and inexpensive. However, ASA is not without side-effects. Long-term use can increase the risk of gastrointestinal upset or bleeding and uncontrolled bleeding. It is important that patients do not self-medicate but consult their physicians before taking ASA on a regular, long-term basis. It used to be thought that ulcers made it impossible to take ASA because of the risk of bleeding. However, it is possible to cure ulcers with correct antibiotic treatment, which would eliminate this barrier.

Two recent studies^{66 67} have shown that the prescription antiplatelet agent ticlopidine can significantly reduce the risk of stroke in patients with TIAs. However, the absolute risk reduction is not as great as ASA and ticlopidine is associated with more serious side-effects. About 2% of patients who take ticlopidine develop neutropenia (a blood disorder associated with increased susceptibility to infection), with another 1% developing significant neutropenia. A number of deaths from ticlopidine-associated neutropenia have been reported in Canada. As well, about 12% of patients experience diarrhea and there is a 10% average increase in cholesterol. The guidelines recommended by the Ontario committee on drugs (DQTC) were that, because of the serious nature of its associated side-effects, ticlopidine should be a second line drug for patients who have had TIAs despite ASA or who cannot take ASA. Unfortunately, ticlopidine is so toxic and has such adverse side-effects that half of elderly patients stop taking it within a few months.

More recently, the CAPRIE study⁶⁸ has shown that the antiplatelet agent clopidogrel is effective in stroke prevention. An Ontario panel of experts recommended in 1999 that clopidogrel be provided for patients in Ontario who cannot take ASA or who have experienced vascular complications despite ASA. This position is supported by recent consensus statements^{69 70}.

Surgery (Carotid Endarterectomy)

Studies have shown that carotid endarterectomy performed by excellent surgeons with a low complication rate can significantly reduce the risk of stroke and death, particularly in patients with symptomatic and severe narrowing of the carotid artery (i.e. the artery is narrowed by 70% or more). The North American Symptomatic Carotid Endarterectomy Trial (NASCET), in which Ontario researchers played leading roles, showed a reduction in 2-year risk of stroke and death from 26% to 9%⁷¹. In this study, it was determined that treating only 4 patients could, over the next 3 years, prevent at least 1 major stroke.

The Asymptomatic Carotid Artery Surgery (ACAS) study looked at people who had narrowing (“stenosis”) of the carotid artery but no symptoms. The study found a reduction in projected 5-year risk of stroke, transient ischemic attack (TIA) and death from 11% to 5%. However, most of the events which were prevented were TIAs⁷². It was estimated that treating 29 patients would prevent at least 1 stroke in three years.

When performed on appropriate patients by skilled and experienced surgeons, carotid endarterectomy is an effective means of preventing stroke that is comparable to other treatments. Those patients at higher risk stand to benefit more from treatment.

Issues in Clinical and Secondary Prevention

There are a number of important issues and challenges facing the various clinical prevention programs and services.

Identification of High-Risk Patients

The vast majority (81%) of Canadians over the age of 12 visit a physician at least once a year⁷³. Such visits should provide valuable opportunities for detection and management of stroke risk factors. Evidence-based guidelines for detection and intervention maneuvers have been disseminated by the Canadian Task Force on the Periodic Health Examination. But it is recognized that guidelines are not enough: integrating clinical prevention into busy practices involve political and logistical processes⁷⁴. As a result, many family physicians and general practitioners provide preventive care to their patients at lower levels than what they consider satisfactory⁷⁵. Studies have shown that effective primary and secondary prevention can be delivered in the clinical setting⁷⁶; however, a number of system-related, patient-related and staff-related issues may need to be addressed⁷⁷. Some of the issues include:

- ◆ Reimbursement of physicians for preventive care under fee-for-service payment schedules

- ◆ The use and reimbursement of Advanced Practice Nurses for delivery of prevention services and case management
- ◆ Continuing medical education for health professionals (information and skills-building)
- ◆ Mechanisms to encourage the use of evidence-based guidelines.

Choice of Therapies

Although physicians in Ontario are free to prescribe those therapies which they believe have the greatest likelihood of success, the reality is that many seniors on fixed incomes cannot afford medications not covered in the Ontario Drug Benefit Plan. Thus, there are economic barriers to the prescription of certain drugs which clinical practice have shown to have fewer or less severe side-effects. Fewer or less severe side-effects may improve long-term compliance and persistence with treatment. For example, the first line antiplatelet drug in Ontario is ASA, with the second line drug being ticlopidine, an agent with some serious toxic effects. Up to half of people who are prescribed ticlopidine eventually cease taking the drug because of side-effects. Clopidogrel is not on the formulary, which poses a barrier to its use among seniors in Ontario.

There are similar economic barriers to the utilization for less toxic antihypertensive medications such as the angiotensin antagonists. Physicians need to be able to prescribe those therapies with the fewest adverse effects in order to encourage long-term adherence with medication.

Compliance

Persistence with therapy is a significant problem in the treatment of many stroke risk factors, particularly high blood pressure. Often, people find the side-effects of blood pressure-lowering medications more noticeable and bothersome than the condition itself. As a result, compliance with medication is a serious problem in blood pressure control.

There is limited evidence relating to improved patient compliance with medication. Haynes et al⁷⁸ concluded that the existing studies “provide little evidence that medication adherence can be improved consistently, within the resources usually available in clinical setting.” Many of the interventions which might be feasible in clinical practice showed some effect in changing the practicing behaviour of the clinicians; however, there are few studies that demonstrate an impact on patient outcomes. The interventions which addressed compliance for long-term medications were on the whole quite complex and labour intensive.

There is some evidence to support the idea that compliance is enhanced by having the same physician see the patient each time (continuity of care), by using as few pills as possible and by having medications with the fewest side effects. Bloom has

demonstrated that patients taking anti-hypertension medications with fewer side effects are more likely to be taking their medications at one year follow-up⁷⁹. Many of the newer drugs with fewer side-effects are more costly than other blood-pressure lowering medication. However, these up-front costs must be compared to the costs associated with uncontrolled high blood pressure and of switching therapies. Hughes and McGuire⁸⁰ estimated that the total cost of treating high blood pressure in the National Health Service in Britain was 76.5 million per annum, of which 26.9 million was attributed to the costs of discontinuing or switching therapies.

Treatment Delays

At the current time, stroke care in Ontario is not organized. As a result, there can be delays in accessing essential diagnostic services and treatment. An audit at the Hamilton Health Sciences of 122 neurosurgical TIA patients, for example, produced the following results:

- ◆ 54% of TIA patients had angiograms; of those who did, the average wait time was 73 days (~2 ½ months)
- ◆ for all patients, the best time to any form of imaging (angiograms, doppler ultrasound, etc.) was 56 days (almost 2 months)
- ◆ for those who went to the Emergency Department at the time of their TIA, the average wait time to surgery was 79 days (~2 ½ months)
- ◆ for those who didn't go the Emergency Department, the time from family physician referral to surgery was 109 days (~3 ½ months)

During the wait period, those who have had a TIA are at significantly increased risk of stroke. It is critical that wait times for diagnosis, treatment and risk factor management be reduced.

Setting for Preventive Care

Currently, the setting in which primary clinical prevention is carried out is primary care (i.e. family practice). The major health care provider in this setting is the primary care physician, although Advanced Practice Nurses, dietitians, psychologists and other professionals may be involved.

Secondary prevention may be conducted in hospital-based special clinics. In such cases, health care providers involved in this activity may include neurologists, internists, neurosurgeons, neuroradiologists, Advanced Practice Nurses, dietitians and others.

In both primary and secondary prevention, there are a number of issues and challenges. These include:

- ◆ Maintaining and increasing levels of knowledge about stroke prevention (e.g. development and dissemination of guidelines, continuing medical education of primary care physicians and specialists, and continuing education of other health professionals)
- ◆ Developing and maintaining an integrated, comprehensive, interdisciplinary approach to stroke prevention (e.g. prevention clinics at regional hospitals, outreach clinics in district hospitals, expanded use of advanced practice nurses in primary care, creation of multidisciplinary teams that can integrate non-pharmacologic and pharmacologic interventions)
- ◆ Availability of essential diagnostic tests and procedures (e.g. carotid ultrasound, CT scanning, echocardiography, angiography, or MRI)
- ◆ Improved access to specialists for stroke prevention follow-up care
- ◆ Increased resources for evidence-based procedures such as carotid endarterectomy (e.g. coordination of waiting lists, similar to that now undertaken for coronary artery bypass surgery).

Private practice or the hospital setting may not be the single most efficient setting for comprehensive risk factor management in clinical and secondary stroke prevention. There is evidence that specialized clinics can be effective in risk factor management^{81 82}. Stroke prevention clinics could offer cost-efficient, comprehensive, interdisciplinary case management of those at high risk of stroke.

Model for Stroke Prevention Clinics

Stroke prevention clinics should be developed in conjunction with the Regional and District Stroke Centres being proposed in the acute care sector. Such clinics could offer comprehensive, cost-efficient, organized and expert risk factor management for clinical primary and secondary prevention. Clinics should have close links with primary care, acute care, stroke rehab and cardiac rehab programs in order to ensure seamless care for patients and to reduce redundancy in services. As well as providing comprehensive care for high-risk patients, interdisciplinary stroke clinics can provide spouses and family members with both support (e.g. support for caregivers) and risk factor screening.

Benefits of stroke prevention clinics include:

- ◆ They would complement and build on the strengths of the system being developed in acute care (organized stroke care and District and Regional Stroke Centres);

- ◆ They could support and act as a resource for evidence-based stroke prevention in primary care (outreach, continuing education, follow-up, auditing and mentoring);
- ◆ They could act as a resource to ensure that secondary prevention is evidence-based and systematically integrated into acute care and stroke rehabilitation;
- ◆ They could offer specialized expertise in stroke prevention (e.g. multiple risk factor management for difficult high-risk patients; ensure adequate anticoagulation for those with atrial fibrillation)
- ◆ They could ensure that all patients with TIAs complete a thorough assessment (e.g. diagnostic testing) and are managed to reduce their risk of stroke;
- ◆ Through improved case management, reduce the waiting times for diagnostic testing and carotid endarterectomy;
- ◆ Undertake data collection to support continuous quality improvement (both within the clinics and among primary care in their respective catchment areas), outcomes assessment and research.

Successful models for a network of Stroke Prevention Clinics include the Stroke Prevention Clinic at the London Health Sciences Centre and the cardiac MULTIFIT program used in many hospitals in the United States. Such clinics combine evidence-based guidelines with case management techniques to optimize efficiency and compliance with treatment. For example, a schedule of phone and face-to-face contacts is followed, ensuring that clients do not “fall through the crack.” Appointments with appropriate specialists (e.g. nutritionist, psychologist, lipid clinic, anticoagulation clinic, etc.) are scheduled so as to reduce waiting times and inconvenience for both patient and practitioners.

Key to the success of Stroke Prevention Clinics would be the use of Advanced Practice Nurses. These nurses would be trained in risk factor management and responsible for: triage, needs assessment/evaluation, case management, expediting clinical investigations and appropriate management (including community liaison and follow-up and support), patient education, and counseling and lifestyle modification (in conjunction with resources such as dieticians, physical therapists and psychologists). The Advanced Practice Nurse would be the vital link between the clinics and primary care physicians.

It is essential that Stroke Prevention Clinics have the necessary resources to ensure timely testing and interpretation. The availability of equipment will have to be determined in each potential Stroke Prevention Clinic site to see if there are gaps. If so, remedial action will be required to ensure there is adequate access to the required equipment.

Patients who have been identified as requiring carotid endarterectomy are at high risk of stroke. The longer they wait for surgery, the greater their risk. Resources for carotid endarterectomy (e.g. neurosurgeons, operating room time and beds) should

be assessed and increased as required in order to reduce the current waiting time from approximately 2 ½ - 3 ½ months to a provincial average of less than one month. In some cases (e.g. centres such as London), it may be possible to reduce the wait to as little as one month.

Data collection (primarily through the District and Regional Stroke Prevention Clinics) will make it possible to track waiting times for assessment and treatment and determine demographics, risk factors, medication and outcomes of high-risk and stroke patients. This information can be used for outreach purposes, continuous quality improvement (both at the clinic and in primary care), and to answer clinical and epidemiologic questions. Common standards for data collection and analysis on stroke should be established, keeping in mind the need to integrate with existing information systems (such as MIS for operating plans and the proposed ambulatory care data system [NACRS]). Analysis of the resulting data base could be undertaken by either the Ministry of Health and Long-term Care or the Institute for Clinical Evaluative Sciences (which has already committed to data management for the Canadian Stroke Network). In summary, data collection should be integrated into the activities of the Stroke Prevention Clinics (e.g. via the Stroke Registry) in order to support evaluation and research.

Figure 2 illustrates the proposed flow of patients for primary and secondary clinical prevention through a Stroke Prevention Clinic model. Following Figure 2, Table 10 summarizes the roles and needed resources for effective prevention in primary care and Stroke Prevention Clinics.

Primary and Secondary Clinical Prevention Model

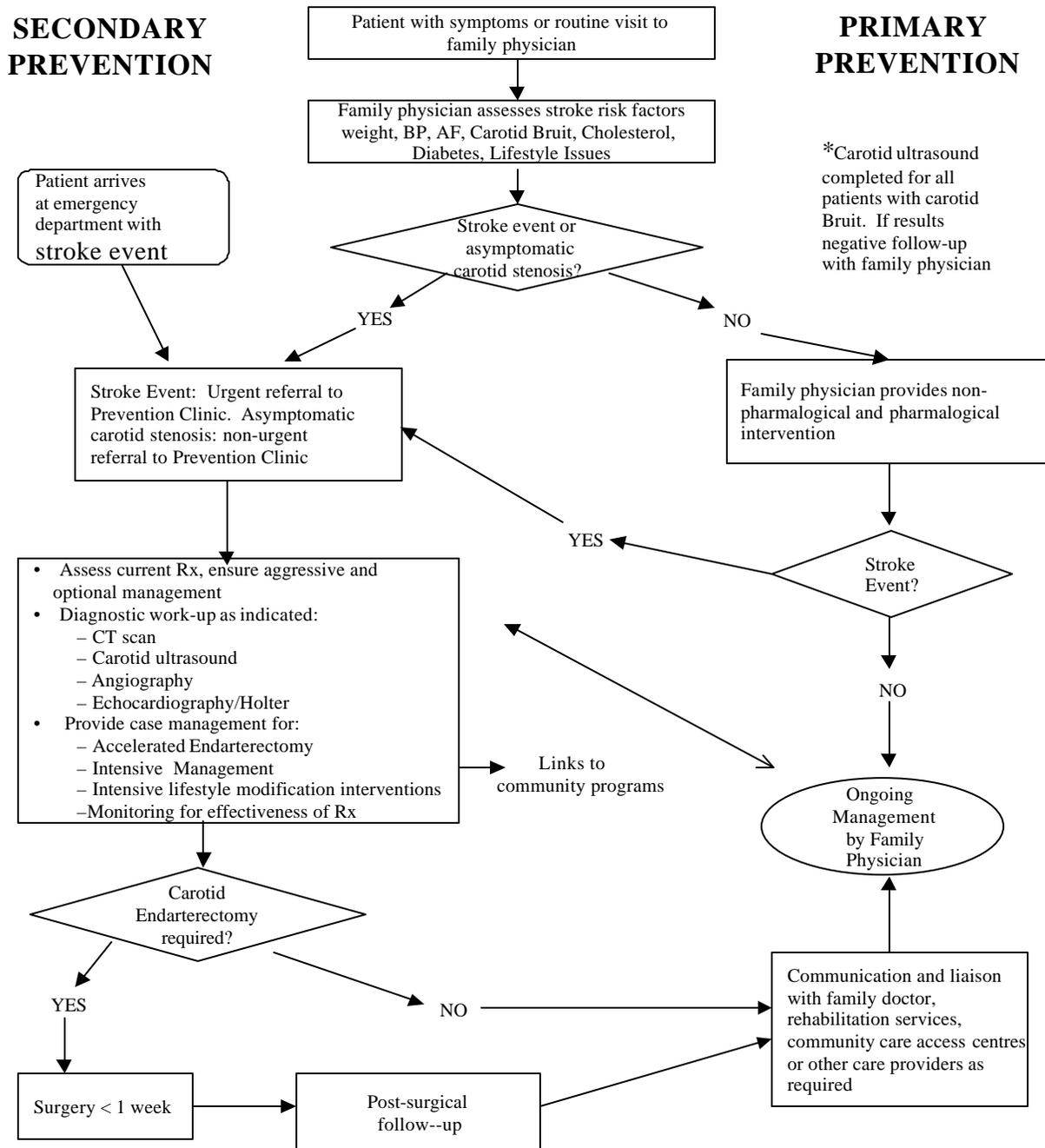


Figure 2: Primary and Secondary Clinical Prevention Model

Table 10: Settings for Clinical Stroke Prevention

Setting	Type of Patients	Referrals	Human Resources	Equipment	Services	Proposed Improvements
Primary Care	High risk of stroke (TIAs, carotid stenosis or bruits, uncontrolled high blood pressure, atrial fibrillation)	To: District or Regional Stroke Prevention Clinic From: Follow-up by Stroke Prevention Clinic	As exists (primary care physician)	As exists	<ul style="list-style-type: none"> ◆ Screening ◆ Referrals to Stroke Prevention Clinics ◆ Follow-up care 	<ul style="list-style-type: none"> ◆ Brief advice packages for risk factor management ◆ Reimbursement for brief advice ◆ Follow-up monitored by Stroke Prevention Clinic ◆ Continuing education and mentoring by Stroke Prevention Clinic
Community Hospital	TIAs, non-disabling acute stroke (not eligible for thrombolytic therapy or in need of surgery)	To: Family Physician; District or Regional Stroke Prevention Clinic	Stroke Team	As exists	<ul style="list-style-type: none"> ◆ Referral to Family Physician or District or Regional Stroke Prevention Clinic 	<ul style="list-style-type: none"> ◆ Stroke protocols (e.g. all TIAs to be referred for follow-up to family physician or Stroke Prevention Clinic)

Setting	Type of Patients	Referrals	Human Resources	Equipment	Services	Proposed Improvements
District Stroke Prevention Clinic	TIAs, acute stroke, high risk patients (carotid stenosis or bruits, atrial fibrillation, uncontrolled high blood pressure)	From: Primary care; community hospitals acute care; rehab To: Primary care (follow-up); Regional Stroke Prevention Clinic (if complicated case or eligible for carotid endarterectomy); community organizations (e.g. Community Care Access Centres)	<ul style="list-style-type: none"> ◆ Advanced Practice Nurse (shared with District Stroke Centre) ◆ 1 FTE administrative support ◆ Part-time data collection (0.2 FTE or depending upon volume) 	<ul style="list-style-type: none"> ◆ Access to CT scanner ◆ Carotid ultra-sound ◆ Echo-cardio-graphy ◆ Holter monitors 	<ul style="list-style-type: none"> ◆ Case management (scheduling of diagnostic procedures, risk factor management assessment & intervention) ◆ Optimization of risk factor management (lipids, anti-coagulation, smoking cessation, blood pressure control, etc.) ◆ Outreach to primary care (education, mentoring, auditing) ◆ Outreach to community organizations (e.g. Community Care Access Centres) to ensure adequate follow-up and services to patients in need ◆ Identification of cases eligible for carotid endarterectomy and referral to Regional Clinic 	<ul style="list-style-type: none"> ◆ Human resources for organized secondary stroke prevention ◆ Systems to ensure access to required equipment; upgrading of existing equipment as required ◆ Development of protocols for organized stroke prevention and case management (e.g. MULTIFIT model) ◆ Development of links with primary care, hospitals, rehab, and community organizations (e.g. Community Care Access Centres)

Report of the Joint Stroke Strategy Working Group

Setting	Type of Patients	Referrals	Human Resources	Equipment	Services	Proposed Improvements
Regional Stroke Prevention Clinic	TIAs, acute stroke, high risk patients (carotid stenosis or bruits, atrial fibrillation, uncontrolled high blood pressure) eligible for carotid endarterectomy or difficult to manage	From: Primary care; Community hospitals acute care; District and Regional Stroke Centres acute care; rehab To: Regional Stroke Centre for carotid endarterectomy; follow-up with primary care, rehab or community organizations (e.g. Community Care Access Centres)	<ul style="list-style-type: none"> ◆ Advanced Practice Nurses (shared with Regional Stroke Centre) ◆ Psychologist or behavioural modification specialist ◆ 0.2 data collection (or depending upon volume) 	<ul style="list-style-type: none"> ◆ Same as District Clinic AND <ul style="list-style-type: none"> ◆ Angio-graphy ◆ MRI (optional) 	<ul style="list-style-type: none"> ◆ Same as District Stroke Clinic AND <ul style="list-style-type: none"> ◆ Assessment for, and scheduling of, carotid endarterectomy 	<ul style="list-style-type: none"> ◆ Same as District Stroke Clinic AND <ul style="list-style-type: none"> ◆ Depending upon volume, incremental funds for additional operating room time and beds for carotid endarterectomy ◆ Systems and procedures to reduce waiting time for carotid endarterectomy to < 1 month (goal of 1 week)

EMERGENCY/ACUTE CARE

The acute phase of a stroke consists of the time from the onset of symptoms until the patient has been medically stabilized (i.e. there is no further medical or neurological deterioration), all necessary investigations (e.g. diagnostic testing) have been completed and a care plan has been developed. This is a critical time in the treatment of stroke. If care is timely and appropriate, permanent brain damage can be prevented or reduced.

How well patients do – whether they survive and, if so, the extent of permanent disability they suffer – depends on large part upon the type of care they receive during the first few hours after a stroke.

Current System

At the current time, few parts of Ontario have coordinated, responsive systems to ensure that stroke patients are quickly and accurately identified, diagnosed and treated. For example, in many jurisdictions in Ontario:

- ◆ Stroke victims are typically taken to the nearest acute care hospital – regardless of that facility's resources for diagnosing and treating stroke. For example, up to 7% of stroke patients in Ontario are taken to hospitals which do not have a CT scanner. As a result, either the patient does not receive a CT scan (which is recommended for all stroke patients) or the scan is delayed until the patient can be transported to another hospital. Transports for CT scans incur extra costs for our health care system.
- ◆ According to a survey of Ontario hospital conducted by the Institute for Clinical Evaluative Sciences⁸³ only a third (34%) of Ontario acute care hospitals have written clinical pathways to guide the care of stroke patients. Even fewer hospitals (24%) have stroke protocols for their emergency departments. Only 6 acute care hospitals in Ontario reported having stroke units. Without written, evidence-based clinical guidelines (care pathways) or stroke units, there is no means of assuring that acute stroke care is either standardized or based on the best and latest clinical and research evidence. Preventable complications can develop that extend the patient's length of stay and/or impede the patient's recovery. As well, delays in starting rehabilitation or moving a patient to a rehabilitation facility can significantly increase the acute care costs of stroke and threaten the patient's recovery.

Current acute stroke care in Ontario is disorganized, in that it is neither coordinated nor organized to meet the needs of individual patients (patient-centred care). From pre-hospital to rehabilitation, there are typically few, if any, mechanisms for

coordinating the delivery of services or ensuring that those delivered meet the needs of the patients.

Issues and Challenges

In order to optimize the quality of care and minimize costs to Ontarians, there is a need to establish a **coordinated, responsive system** of emergency and acute stroke care that provides stroke victims with **timely access to diagnostic testing** and **the most effective available treatment** on a **province-wide basis**. Such a system should be **evidenced-based** and developed through a **collaborative process**.

Timely Access

Acute stroke is a medical emergency. The longer the blood flow to the brain is interrupted, the greater the chance of permanent brain damage. Early and accurate diagnosis of stroke is a critical component of optimal stroke care. However, under the current system it is not uncommon for diagnosis and treatment to be delayed for hours after onset of symptoms. There are many reasons for this.

- ◆ **Poor public recognition of the warning signs of stroke.** In September, 1999, the Institute for Social Research at York University, on behalf of the Heart and Stroke Foundation of Ontario, conducted a telephone survey of residents age 45 years and over in four communities in Ontario (London, Hamilton, Kingston and Peterborough). Three of the four communities are regional Coordinated Stroke Strategy sites (London, Hamilton and Kingston). Results of the survey showed that approximately a third (34%) of Ontario age 45+ could not name even one of the five warning signs of stroke. Those at increased risk of stroke due to age or male gender had significantly poorer knowledge of the warning signs of stroke.

When respondents were asked what they would do if someone close to them were to suddenly experience dizziness, numbness on one side and trouble speaking, the majority (77%) reported they would seek immediate medical attention for the victim (call 911, call an ambulance or take the person to the hospital). However, it should be noted that these responses do not reflect actual events. Most studies of stroke have found that victims typically delay seeking medical attention after the onset of symptoms. Both lack of knowledge about the warning signs of stroke and denial of the severity of the problem undoubtedly plays important roles in this behaviour. To reduce the delay in seeking medical attention, the general public needs both to be more knowledgeable about the warning signs of stroke and more motivated to seek immediate care. The public needs to know that stroke is a medical emergency for which effective treatments are available.

- ◆ **Delay in seeking medical attention for stroke.** In one American study, only 24% of patients with stroke arrived at an emergency department within 3 hours of

the onset of their stroke symptoms; approximately half did not seek medical attention within 24 hours of the onset of symptoms.⁸⁴ Data from the stroke service at the Ottawa Hospital (General Campus) during the 12 month period of August, 1996 to July 1997, established that 21% of stroke victims presented to the hospital within 3 hours of the onset or symptoms or since they were “last seen normal”; 36% within 6 hours and 58% within 12 hours⁸⁵.

- ◆ **The EMS system needs to be organized to treat stroke as a medical emergency of the highest priority.** Two developments are required: training of EMS personnel to recognize acute stroke and the implementation of stroke management protocols. A recent Ontario study found that paramedics were accurate in identifying stroke 62% of the time⁸⁶. It is reasonable to expect that training could improve the accuracy of pre-hospital diagnosis of stroke. In one American study, for example, pre-hospital care providers were shown to be accurate in their diagnosis of stroke 72% of the time.⁸⁷
- ◆ **Not all Emergency Departments have protocols to triage stroke patients.** As a result, patients face a number of waits. In one Canadian study⁸⁸, the mean time from arrival at the hospital to first examination by a physician was 43 minutes. The average time between arrival at the emergency department and CT scanning was 15 hours. In the ICES study⁶, in hospitals with a CT scanner, the average time for an “urgent” CT scan of the head was 2 hours; in hospitals without a scanner, the wait was 12 hours. New triage guidelines should be implemented to reduce the waits and to ensure that stroke patients are seen within fifteen minutes or less.

Diagnostic Testing

A CT scan of the head is recommended for all stroke patients (see Table 1). It is also essential if the patient is being considered for thrombolytic therapy (to ensure that patients with a bleeding or hemorrhagic stroke are not given a “clot-busting” drug).

There are currently 88 CT scanners in operation or soon to be in operation in 60 hospitals across the province. The proportion of stroke patients who are taken to a hospital without a CT scanner ranges from a high of 17% in northern Ontario to a low of 4% in the Central West region. However, even when a hospital has a CT scanner on site, procedures may not be in place to ensure that stroke patients have immediate access. Not all scanners are available 24-hours a day, 7 days a week. As noted earlier, the wait for what is considered an “urgent” scan of the head can routinely extend from 2 to twelve hours. Moreover, even if a technologist is available to take a CT scan, an appropriate specialist (a radiologist or neurologist) may not be available to read the scan.

To give the best possible care for acute stroke, timely access to both CT scanning *and* expert interpretation are required. Ontario is fortunate in that many of its acute

care hospitals are equipped with CT scanners. The bigger challenge may lie in ensuring that expert interpretation is available on a timely basis.

Teleradiology

New communication technologies may be helpful in addressing the issue of 24-hour expert interpretation of CT scans. Currently, it is common for some experts to read CT scans on their home personal computers via the Internet. Research has shown that telemedicine and “teleradiology” are reliable⁸⁹, with reliability increasing as physicians become more familiar with the technology⁹⁰. Teleradiology also has a number of other benefits for small or remote practitioners and hospitals. For example, a French study⁹¹ found that a teleradiology link for stroke reduced unnecessary patient transfers by 50%, was satisfying to physicians and improve relations between the participating hospitals.

Teleradiology projects are already in development in several areas in Ontario and a pilot project has been included in the recently-funded Canadian Stroke Network. A survey by the Emergency/Acute Care Task Group of Ontario hospitals found that many already have the basic technology required for teleradiology and telestroke (e.g. CT scanners with PAC capability and internet access). Start-up costs for institutions without any of the technology in place has been estimated at about \$70,000 (this from the work being done as part of the Coordinated Stroke Strategy in southwestern Ontario, linking London Health Sciences with the Stratford General Hospital). However, costs could be appreciably lower as many institutions already have at least some of the technological requirements in place.

Effectiveness

The therapies for acute stroke care include:

- ◆ **Best medical management:** Even without new medical therapies, management of a stroke patient according to the principles of “best practices” can help to reduce mortality and improve outcomes (see Table 11 for the levels of evidence). Some are as simple as knowing when to lower a stroke patient’s temperature or blood sugar levels and when not to intervene. Others involve relatively inexpensive maneuver, such as swallowing assessment (that can prevent food aspiration and resulting pneumonia). Unfortunately, not all clinicians and facilities are necessarily up-to-date in what constitutes current best practices for stroke management.
- ◆ **Organized stroke care:** Optimal efficiency in treating acute stroke is best achieved when the human and medical resources of a hospital are organized to quickly and accurately treat stroke throughout the acute care phase (see Table 11). One of the key developments has been the recognition that stroke units can dramatically improve the outcome for stroke patients. Studies from around the world^{92, 93, 94} have shown that, whether they are established in medical, neurological or geriatric departments, units that are organized to specialize in

stroke care are significantly better than general hospital wards in reducing mortality, average length of hospital stay and costs and improving functional abilities of patients at discharge. A recent meta-analysis (a summary and analysis of 19 randomized or “pseudo-randomized” controlled trials) established that stroke units reduced the odds of mortality by 19%, of death or institutionalization by 25%, and of death or dependency on others for the activities of daily living by 29%. A recent study⁹⁵ of data from a national stroke registry found that even in the “real world” of routine clinical practice stroke units decreased mortality and the proportion who had to be institutionalized and increased the proportion of patients who could be discharged to their homes.

- ◆ **Surgery:** Some stroke patients (usually those who have a hemorrhagic stroke) may require surgery (see Table 11). It is critical that these patients be identified quickly. Currently, there are 25 hospital sites in Ontario with active neurosurgeons.
- ◆ **Thrombolytic therapy:** Based on the results of an international randomized controlled trial, both the American FDA and Health Canada have approved the use of t-PA for the treatment of acute ischemic stroke. However, current guidelines specify that thrombolytic therapy must be given within three hours of the onset of a stroke. Given these timelines, the pre-hospital and emergency phases are critical. If stroke care is not organized, few patients will make it to the hospital, be triaged, undergo CT scanning and appropriate blood work, and have the diagnostic data interpreted within this narrow, 3-hour window of opportunity.

Is there strong, scientific evidence that these various elements are effective? The answer is yes. Research has identified both medical practices and a model for the organization of stroke care that can improve the outcome for stroke patients. Below is a summary of this information showing the level of evidence for the various components of acute stroke care.

- ◆ **Level 1 Evidence:** At least one prospective, randomized controlled study has shown that the intervention is beneficial.
- ◆ **Level 2 Evidence:** At least one non-randomized cohort comparison or multicentre case study or chronological series shows that the intervention is beneficial. Evidence may also be part of extraordinary results for randomized clinical trials.
- ◆ **Level 3 Evidence:** Professional guidelines in Canada, practice in other jurisdictions, descriptive studies, reports of an expert committee and/or Consensus Panel member’s experience and/or expert opinion.

Table 11: Scientific Evidence for the Components of Acute Stroke Care

Component of Care	Strength of the Scientific Evidence
"Time is brain"	Level 3 Evidence A systematic review by the Cochrane Collaboration and expert opinion suggests that timely and appropriate treatment can reduce morbidity and mortality and improve outcomes ^{29 96} .
Organized stroke care in the form of stroke units	Level 1 Evidence. A number of randomized controlled trials and meta-analyses ⁶⁻⁹ have shown that stroke units can reduce mortality, shorten hospital stays and improve the functional ability of stroke patients. A recent trial has found that stroke units resulted in earlier mobilization, greater use of acetylsalicylic acid (ASA), more frequent administration of parenteral fluid and more frequent use of antipyretic and antibiotic therapy.
Written local protocols (e.g. care maps)	Level 3 Evidence. A number of expert committees and panels (Canada, the United States, and Europe) support written protocols to enhance care and reduce inefficiencies ^{97 98 99} .
Stroke networks of hospitals	Level 3 Evidence. The Coordinated Stroke Strategy project was developed in light of expert opinion that organizing hospitals for acute stroke care could improve care and increase proportion of patients considered for thrombolytic therapy ¹⁰⁰ . Evaluation of the pilot sites and the project is ongoing; interim results show a number of improvements in regional organization and patient care.
t-PA for the treatment of acute ischemic stroke	Level 1 Evidence. Clinical trials ^{101 102} and a systematic review of studies ¹⁰³ have concluded that t-PA, if given within 3 hours of the stroke, can reduce disability from stroke and improve outcomes. Based on this evidence, both the American FDA and Health Canada approved the use of t-PA in the treatment of acute ischemic stroke and clinical guidelines have been produced by several professional bodies ^{104 105 106} .
CT scanning for all acute stroke	Level 2 Evidence. Non-randomized studies have shown benefit of noncontrast CT scan of the head in initial evaluation of a patient with stroke (documents or excludes presence of intracerebral hemorrhage or subarachnoid hemorrhage) ¹⁰⁷ .

Component of Care	Strength of the Scientific Evidence
CT interpretation by telecommunications (“teleradiology”)	Level 1 Evidence. Studies have shown acceptable levels of sensitivity and specificity in interpretation of CT scans and diagnosis of stroke via telecommunications linkages ¹⁸⁻²⁰ .
Swallowing assessment	Level 2 Evidence. There is evidence from historical studies showing that diagnosis and treatment of swallowing disorders (dysphagia) in acute stroke management dramatically reduces rates of pneumonia from aspiration ¹⁰⁸ .
Blood pressure	Level 2 Evidence. Cohort and other non-randomized trials have shown that with certain exceptions, elevated blood pressure should not be routinely lowered in stroke patients (acute ischemic and subarachnoid hemorrhage) ^{109 110} .
Fever (temperature)	Level 2 Evidence. Cohort and other non-randomized trials have shown that lowering the body temperature can be beneficial ²⁶ .
Blood sugar (glucose)	Level 2 Evidence. Cohort and other non-randomized trials have shown that normalizing blood sugar levels (hypoglycemia or hyperglycemia) after stroke is beneficial ²⁶ .
Early mobilization	Level 1 Evidence. There is evidence from controlled trials showing the early mobilization and other measures can help to prevent circulatory complications such as blood clots in the legs or lungs (deep vein thrombosis, pulmonary embolism), ulcers, contractures and joint abnormalities ⁶ .
Surgery	Level 2 Evidence. There is evidence from at least 6 cohort and other studies that support: surgical clipping for patients with aneurysmal subarachnoid hemorrhage; surgical decompression and evacuation of large cerebellar blood clots that compress the brain stem ^{111 112 113 114 115} .

Equity of Access

Currently, not all Ontarians have access to the same level of acute stroke care. Stroke victims in large urban centres who are treated in teaching or tertiary hospitals are most likely to undergo CT scanning, to be managed according to a stroke protocol based on the latest scientific evidence and to be considered for tPA. Stroke victims in rural or remote parts of the province are less likely to receive this type of care.

These inequities are not unique to Ontario. In a small, national study¹¹⁶ it was found that:

- ◆ Fewer rural than urban stroke patients have a CT scan (11% vs. 49%)
- ◆ Rural patients wait longer for a CT scan than their urban counterparts (15 hours vs. 5 hours); only 4% of rural patients underwent CT scanning within 3 hours of arriving at the emergency department whereas for urban patients the proportion was 21%
- ◆ Rural patients are less likely to have their condition diagnosed by a neurologist (9% vs. 39% for urban patients).

Models for Emergency/Acute Stroke Care

To better treat acute stroke, Ontarians need care that is:

- ◆ Organized (e.g. from pre-hospital to discharge)
- ◆ Patient-centred
- ◆ Evidence-based
- ◆ Provides equitable access to effective treatments (e.g. thrombolytic therapy, neurosurgery, etc.)
- ◆ Cost-effective

There are a variety of ways in which stroke care in Ontario could be organized. For example, specialized stroke units could be established in tertiary care facilities. Although perhaps the “cadillacs” of organized stroke care, such units would necessarily be limited in number. As a result, their use could be limited to only those residents in the immediate community (thus denying this level of care to residents in the rest of the region and violating the principles of equitable access). Moreover, this sort of maldistribution of stroke resources would encourage patients to bypass closer facilities (e.g. their community hospital) in order to be admitted to the stroke unit, thus significantly impacting ambulance traffic and patient flow. Finally, concentrating acute stroke care and expertise in a limited number of tertiary facilities could have detrimental effects on the quality of stroke care in other, smaller or community hospitals.

Another possible model for stroke care is a two-level system. In this model (summarized in Table 12), based on their existing resources, hospitals volunteer to serve, or are designated as, District or Regional Stroke Centres. Designation as a District or Regional Stroke Centre would depend in large part upon the ability to administer thrombolytic therapy to appropriate ischemic stroke patients. Requirements for the administration of thrombolytic therapy for stroke include:

- ◆ Written stroke protocols and interdisciplinary stroke teams
- ◆ Timely (e.g. <1 hr), 24-hour, 7 days/week access to CT scanning and expert interpretation
- ◆ Timely (e.g. <1 hr), 24-hour, 7 days/week laboratory services
- ◆ Clinicians with stroke expertise (such as neurologists)

Table 12: Two-Level Model of Organized Stroke Care

Type of Hospital	Type of Patients*	Required Resources	Proposed Improvements
District Stroke Centre	All acute stroke not in need of surgery	CT scan Physician with stroke expertise	Written stroke protocols for emergency services, emergency department and acute care; Transfer protocols; Ability to offer thrombolytic therapy to suitable candidates, including: Timely CT scanning Timely expert consultation; Rehabilitation services
Regional Stroke Centre	All stroke patients who may require surgery; Local patients regardless of eligibility for thrombolytic therapy or need for surgery	CT scan MRI Angiography Neurologist Neurosurgeon	Written stroke protocols for emergency services, emergency department and acute care; Transfer protocols; Ability to offer thrombolytic therapy to suitable candidates, including: Timely CT scanning Timely expert consultation; Neurosurgical interventions; Interventional radiology (e.g. intra-arterial infusion of t-PA) Rehabilitation services

* Exceptions:

- patients who are airway compromised should be taken to closest acute care facility, regardless of resources, for urgent care
- patients who “walk in” or transport themselves to community hospital should be transferred to District or Regional Stroke Centre depending upon transfer protocols

Hospitals unable to act as either form of Stroke Centre would play a greatly reduced role in stroke care. With the exception of “walk ins” and patients who are airway

compromised, most stroke patients would be transported by emergency medical services directly to their District or Regional Stroke Centre.

The advantage of a two-level system is that it concentrates stroke patients in facilities with the required resources (e.g. CT scanners) and the mandate to organize and coordinate their stroke services (e.g. to implement clinical pathways and stroke teams). However, there are also disadvantages to such a system. Hospitals which agreed to act as District and Regional Stroke Centres would naturally accumulate a disproportionate share of the province's stroke patients. Ambulance traffic could be affected. Moreover, even a two-level system could threaten the integrity of stroke care in community hospitals (e.g. expertise would gravitate to District and Regional Stroke Centres and fail to be developed in community hospitals).

The opposite of centralizing stroke care is to optimize stroke care in all acute care hospitals. Naturally, it would not be feasible to make all stroke-related functions available in all acute care facilities in the province. Some functions, such as neurosurgery, must be restricted to a select number of hospitals by both economic and manpower limitations. Would it, however, be feasible to ensure that all acute care hospitals are capable of offering non-surgical treatments such as tPA?

Currently, many community hospitals would find it difficult to meet all of these criteria due to limitations in equipment (e.g. CT scanners) and manpower (e.g. 24-hour CT or lab technicians; enough health professionals to form interdisciplinary stroke teams). Developing and implementing stroke protocols and stroke teams could be a difficult exercise for some small hospitals.

In consideration of these factors, the Working Group developed another option. This option proposes a means of organizing stroke care on a regional basis, including community hospitals in a cost-effective manner.

Regional Organized Stroke Care

A system of organized stroke care based on three levels was initially proposed in the Stroke Care Ontario report by the Heart and Stroke Foundation of Ontario²⁵. According to this system, hospitals are identified as belonging to three categories: Community Hospitals, District Stroke Centres and Regional Stroke Centres. Hospitals are categorized according to both their resources and their willingness to act as stroke centres (see Table 13). District or Regional Stroke Centres not only act as specialized stroke treatment facilities but also help to organize and continuously upgrade stroke treatment in their respective geographic catchment areas. For example, Regional Stroke Centres would help the hospitals in their catchment area (i.e. District Stroke Centres and community hospitals) to localize and implement stroke protocols and stroke teams. With the leadership of the Regional Stroke Centre, District Stroke Centres and community hospitals could also build inter-organizational relationships throughout their respective catchment areas and across

the spectrum of stroke care (primary prevention, treatment, rehabilitation and secondary prevention).

Under this system, most acute strokes would be treated in the community hospital. Those patients who would be candidates for thrombolytic therapy would be transported immediately to the closest hospital capable of this treatment, i.e., a District or Regional Stroke Centre. Eligibility for thrombolytic therapy would be determined in the field by Emergency Medical Services according to the following criteria:

- ◆ Symptoms of acute ischemic stroke
- ◆ Stroke onset less than 3 hours ago
- ◆ Patient is not drowsy or has reduced level of consciousness (which can indicate a hemorrhagic stroke)

Table 13: Three-Level Model of Organized Stroke Care

Type of Hospital	Type of Patients*	Required Resources	Proposed Improvements
Community hospital	Acute stroke not eligible for thrombolytic therapy or in need of surgery	No extra resources particular to stroke required	Written stroke protocols for emergency services, emergency department and acute care; Transfer protocols for those who would be best served by Level II or III facilities; Linkages to rehabilitation services.
District Stroke Centre	Acute stroke eligible for thrombolytic therapy but not in need of surgery; all local stroke patients not in need of surgery (whether or not eligible for thrombolytic therapy)	CT scan Neurologist or clinician with stroke expertise	Written stroke protocols for emergency services, emergency department and acute care; Transfer protocols; Ability to offer t-PA to suitable candidates, including: <ul style="list-style-type: none"> ◆ Timely CT scanning ◆ Timely expert consultation; Rehabilitation services
Regional Stroke Centre	All stroke patients who may require surgery; Local patients regardless of eligibility for thrombolytic therapy or need for surgery	CT scan MRI Angiography Neurologist Neurosurgeon	Written stroke protocols for emergency services, emergency department and acute care; Transfer protocols; Ability to offer t-PA to suitable candidates, including: <ul style="list-style-type: none"> ◆ Timely CT scanning ◆ Timely expert consultation; Neurosurgical interventions; Interventional radiology (e.g. intra-arterial infusion of t-PA) Rehabilitation services

* Exceptions: patients who are airway compromised should be taken to closest acute care facility, regardless of resources, for emergency care.

It is estimated that in this sort of system, the proportion of acute stroke re-directed from community hospitals to District or Regional Stroke Centres would be minimized (estimated to be around 10%). A proportion of transported patients could subsequently be repatriated to their community hospital after treatment. Thus, the majority of patients would be treated in their own communities in hospitals following evidence-based stroke protocols developed with the assistance of their Regional Stroke Centre.

This model gives community hospitals the support they need to establish organized, evidence-based, patient-centered stroke care. As a result, it is anticipated that the number of complications could be reduced, outcomes improved, and discharge to rehabilitation facilities or to the home expedited. Community hospitals would also have links to primary and secondary prevention resources and programs, thus making it possible to reduce the number of future strokes.

By putting into place transfer protocols that bring patients eligible for, or requiring, advanced treatment (e.g. t-PA or surgery), a regional model should reduce the number of inter-hospital transfers and delays. As the Coordinated Stroke Strategy has shown in southeastern Ontario, regional organization of acute stroke care can increase the number of patients considered for thrombolytic therapy. It is anticipated that timely, accurate use of evidence-based, organized stroke care and thrombolytic therapy could significantly reduce stroke mortality and morbidity and the number and severity of permanent disabilities.

Impact and Costs

To assist in the evaluation, scientists from the Institute for Clinical Evaluative Sciences (ICES) conducted an economic analysis of three different ways of organizing stroke care. The method used was decision analysis, which is characterized by a systematic analysis of evidence to identify viable alternatives and their consequences or outcomes as determined by the best available evidence.

In this model, only ischaemic stroke and intracerebral hemorrhage were considered. A cohort of patients admitted to acute care hospitals in Ontario for these diagnosis during fiscal year 1997 were used to assess the distribution of patients with respect to diagnosis, initial and transfer hospital type and out-year outcomes. The outcomes of interest were defined as in-hospital death, discharge to a chronic care facility (defined as a nursing home or long-term institution), discharge to home or home care (which included temporary discharge to a rehabilitation hospital, followed by home care or nursing home placement), recurrent stroke within one year following hospital admission, post-discharge death within one year, or no subsequent sequelae following discharge. The analysis was conducted from the perspective of the provider, i.e. the Ontario Ministry of Health and Long-term Care.

The analysis compared three different scenarios: the current system (the “status quo”, in which stroke patients are typically transported to the nearest acute care

facility); the two-level model; and the three-level model. Both the two- and three-level models differed from the status quo in that they incorporated thrombolytic therapy and organized stroke care (thus, outcomes reflected the benefits from these developments). Hospitals were categorized as Level I, II or III based on results from a survey conducted by the Task Group on resources for stroke treatment (e.g. availability of CT scanners, neurologists, neurosurgeons, etc.). For a complete description of the analysis and its methods, please refer to Appendix 5.

Table 14 illustrates the impact of hospital organization upon the distribution of patients. Under the current system (“Status Quo”), the majority of stroke patients are treated in hospitals categorized as Level II (meaning that they have CT scanner on site and probably have a neurologist on staff), followed by Level I hospitals (which probably have neither CT scanners nor neurologists). The smallest proportion of patients are treated in the Level III hospitals (which have the greatest amount of neurological resources).

Table 14: Number of Patients Treated By Type of Hospital

Model of Care	Level I Hospitals (n=119)	Level II Hospitals (n=43)	Level III Hospitals (n=15)
Status Quo	3,455	5,154	2,767
Two-Level System	2,040	5,550	3,786
Three- Level System	3,458	5,150	2,768

If a two-level system of stroke care were adopted, the number of patients treated at Level I hospitals would fall and the numbers treated at Level II and III facilities would increase (by 8% and 37%, respectively).

What are the economic ramifications of the different systems? Table 15 summarizes the main economic outcomes to be anticipated in one year if stroke care were to be organized and access to thrombolytic therapy increased.

Table 15: Main Outcomes by Organization of Stroke Care (1 Year)

Outcomes	Status Quo	Two-Level System	Three-Level System
Total Program Cost (millions)	\$271.8	\$268.5	\$272.0
Average Cost/Patient	\$23,892	\$23,600	\$23,913
Total Deaths over One Year	3,765	3,549	3,685
Total Numbers Discharged to Chronic Care	1,980	1,726	1,825

This analysis suggests that, of the three alternatives, the current system (the “Status Quo”) has the greatest associated number of deaths and of patients discharged to chronic care. A two-level system is the least expensive of the three alternatives, both in terms of total program cost and average cost per patient. A two-level system is also associated with the smallest number of deaths and discharges to chronic care.

A five-year cost projection was also created by the ICES scientists using a Markov model. This model suggested favourable outcomes on both cost avoidance and mortality for the two- and three-level systems relative to the status quo. A two-level system could result in total cost avoidance of approximately \$85 million and potentially avoid 460 deaths over a 5-year period. These findings may be largely attributed to the significant reduction in discharge to chronic care (which not only results in higher incurred costs to the health care system but is associated with higher mortality). Similarly, the three-level system may also result in a cost avoidance relative to the status quo, although less so than the two-level system (over 5 years, a \$47 million cost avoidance and the avoidance of 285 deaths was projected).

The five year analysis suggests that the benefits of a two-level system can be maintained when up to 63 regional and district stroke centres are funded (each with three additional beds). The three-level system is more sensitive to the effects of the number of designated stroke centres and associated additional hospital beds.

Although a two-level system appears to be the most efficient means of organizing stroke care in Ontario, it is not without problems. As discussed above, a two-level would in many cases necessitate moving stroke patients out of their communities and away from their families. A two-level system concentrates stroke expertise in the Level II and III facilities. Finally, as shown above, a two-level system considerably changes current patient flows and substantially increases the number of stroke patients in a limited number of hospitals (the Level II and III facilities).

In contrast, a three-level system of stroke care has minimal impact on the distribution of stroke patients and makes it possible for more patients to remain within their own communities. At the same time, the development of networks of stroke hospitals makes it possible to reduce the number of deaths and discharges to chronic care. And these improvements are achieved with costs that are only modestly higher than the current system. For example, the total program cost for the three-level system is estimated to be only \$0.2 million more than that under the current system (\$272.0 million vs. \$271.8 for the Status Quo). Likewise, the average cost per patient for the three-level system is estimated to be \$23,913, which is only slightly higher than the Status Quo cost of \$23,892.

To summarize, the results of this analysis indicate that a two-level system should be favoured, due to its lower associated costs and favourable mortality profile relative to the status quo. However, feasibility issues such as ability to accommodate increased volume and the desire for patients to remain in their own communities are factors that

should be considered. Although the three-level system has slightly higher costs, a favourable cost-effectiveness ratio suggests that this option may be the most practical and effective means of re-organizing stroke care in Ontario. A reasonable compromise may be to develop a two-level system where feasible and a three-level system where it is not. The decision as to whether to develop an implement a two or three-level stroke system should be made on an individual basis, according to local, regional needs and resources.

REHABILITATION

Stroke rehabilitation is one of the key components of the spectrum of stroke care. When a person survives a stroke, rehabilitation is a critical enabler that helps survivors maximize their quality of life physically, emotionally and socially.

The importance of examining stroke rehabilitation as part of the entire spectrum of stroke care was recognized in the mandate of the Joint Stroke Strategy Working Group. The Heart and Stroke Foundation of Ontario (HSFO) in consultation with the Ministry of Health and Long-Term Care, established a consensus panel on stroke rehabilitation in 1999. The Panel included representatives of the Ministry of Health and Long-term Care, the HSFO and key stakeholders from across the province representing both consumers and providers. It was agreed that the Panel would provide advice to the Joint Stroke Strategy Working Group.

The work of the Panel can also be viewed in the context of the Reference Group established by the MOHLTC. The Reference Group is developing a policy framework and service delivery model to assist the MOHLTC as it begins to address various issues in the rehabilitation system. A significant priority of the Reference Group is to provide advice to improve coordination of rehabilitation services and to achieve a more seamless system. The Group submitted a final document to the Mental Health and Rehabilitation Reform Branch of the MOHLTC in March 2000. A draft of this document was given to the Consensus Panel to provide some additional context for its work on stroke rehabilitation.

Definitions of Stroke Rehabilitation

For the purposes of this report, stroke rehabilitation is defined as a progressive, dynamic, goal-oriented process aimed at enabling a person with an impairment to reach his or her optimal, physical, cognitive, emotional, communicative and/or social functional levels¹¹⁷.

Stroke rehabilitation is multidimensional and consists of:

- ◆ prevention and treatment of medical complications;
- ◆ restoration of maximal independent functioning;
- ◆ facilitation of psychosocial coping and adaptation by the patient and family;
- ◆ promotion of community reintegration; and
- ◆ enhancement of quality of life for stroke survivors.

Stroke rehabilitation relies on both remedial interventions designed to reduce neurological deficits, and teaching compensatory techniques to enhance functional independence in the presence of neurological impairment.

The Current System in Ontario

Trends

A longitudinal analysis of stroke in Ontario from 1995 to 1998 found that the admission rate for stroke in the province was 157 per 100,000 population over the age of 20 (CIHI, 1999). The average age for stroke patients was 74 years, with 51% being female. Mortality was about 19% in the first 30 days post-stroke and 33% in the first year. (Research shows a 50% mortality rate by the fifth year⁸ and 87% by the tenth year¹¹⁸.) The average hospital length of stay was 18 days. A significant number of stroke patients – 45% – were discharged home, whereas an additional 15% went home with home care. The remaining 40% were discharged to another facility: 14% went to rehabilitation hospitals, 12% to chronic care hospitals, 9% to nursing homes and 5% to acute care hospitals. Older patients were more likely to be discharged to chronic care facilities and nursing homes, whereas younger patients were more likely to be discharged home.

A 1991/92 study¹² found that a major cost factor of stroke hospitalization in Toronto was the delay in discharging patients from acute care due to social factors. A follow-up study conducted in 1996/97¹¹⁹ found that a greater proportion of stroke patients were being discharged directly to home, fewer went to rehabilitation, fewer went to nursing homes or long-term care facilities and there were more deaths (this was probably a function of sample size). These results suggest that stroke survivors may not be receiving the same level of care as before and fewer are receiving stroke rehabilitation.

Throughout the 1990s, there have been significant changes in how patients are managed in hospitals due to such factors as advancements in technology, the development of new drugs, the shift from institutions to community-based care, and hospital restructuring. Not surprisingly, these factors have impacted on how stroke survivors are managed by hospitals.

Traditionally rehabilitation has focused narrowly on inpatient rehabilitation. Not surprisingly, resources for rehabilitation have also tended to be concentrated on the inpatient component of care. This emphasis on inpatient stroke rehabilitation is shifting for a number of reasons.

- Hospital length of stays are decreasing with more treatment being provided at home;
- The rehabilitation needs of ambulatory stroke survivors are being recognized;

- Attention is shifting to “psychosocial factors that influence post-stroke quality of life and subjective well being”¹²⁰; and
- Resolving acute co-morbidities may enable rehabilitation to occur.

The move towards more community-based rehabilitation means that a greater proportion of rehabilitation is being provided in community settings. A recent review of home visits for stroke rehabilitation by two community care access centres found that the number of home visits has increased. For example, compared to the number of visits conducted by the Toronto CCAC for stroke rehabilitation in 1996/97, visits increased 27% by 1997/98 and 37% by 1998/99. A similar trend was evident in the Lanark, Leeds and Grenville CCAC – stroke rehabilitation visits increased 23% from 1997/98 to 1998/99.

A number of innovative stroke integration projects that include rehabilitation are being conducted in Ontario. For example, the Peel District Health Council’s Regional Program Planning Committee developed proposals to coordinate rehabilitation in Peel (1997). This helped set the stage for Peel to become part of a pilot project on community-based stroke rehabilitation under the auspices of the Coordinated Stroke Strategy of the HSFO.

Survivor and Caregiver Perspectives

The Consensus Panel sought input on stroke rehabilitation from consumers and providers. Surveys were distributed through a number of organizations and input was obtained from members of the Panel who were stroke survivors and caregiver-family members.

Stroke survivors identified a number of key themes. Most survivors felt that there should be timely access to stroke rehabilitation. It was acknowledged that different services are needed at different times, even after one year, and that it is important for rehabilitation to carry on after two years. Fine-tuning one’s capacities can be a long process (e.g., speech can take up to four years to redevelop fully). The most frustrating or challenging parts of rehabilitation were speech and mobility issues, fear of another stroke, understanding what happened, being socially isolated, waiting for therapy, family changes, and issues about driving. Stroke survivors noted that they must deal with a lot of frustration, and loss of privacy and choice.

Urban-suburban health care professionals working in a rehabilitation facility identified four factors that reduce the effectiveness of rehabilitation:

- Lack of family support;
- Lack of understanding and unrealistic expectations by clients and their families about stroke and its effect on returning to functioning and recovery, and the institution’s responsibility;

- Characteristics of the client including the inability to take full advantage of rehabilitation due to clinical, communication (aphasia), cognitive, motivational or social reasons, a poor pre-morbid medical condition, and poor motivation or depression; and
- Availability of resources including inadequate space and equipment for treatment; lack of physiotherapy, occupational therapy, speech therapy and dietary clinical notes from acute care; insufficient professional skill; insufficient time for treatment; and no follow up with neurologists.

Two stroke survivors and a caregiver-partner who were members of the Panel, commented on their experiences with stroke rehabilitation. In terms of accessibility, it was noted that not all stroke survivors are offered rehabilitation so that a number of them slip through the rehabilitation system. As well, the health status of stroke survivors can change over time. Although benefits can be derived from rehabilitation three to four years post-stroke, it is not always easy to re-enter stroke rehabilitation programs. In terms of continuity of care, typically rehabilitation therapists from different organizations are involved with the same stroke survivor. However, efforts are not made to identify a team leader to coordinate the services in the best interests of the patient.

Provincial Reports

The most recent provincial examination of rehabilitation was conducted by the Health Services Restructuring Commission¹²¹. Although the HSRC primarily focused on inpatient bed requirements, it recognized and addressed issues about providing a more coherent local and provincial approach to rehabilitation. For example, the HSRC recommended that the Ministry of Health endorse the establishment of local and provincial rehabilitation networks, both of which would have widespread representation from multiple stakeholders. One key responsibility of both local and provincial networks was to advance coordination and integration of rehabilitation services across the continuum. The HSRC emphasized the fundamental need for a good provincial information system to provide data on the population's need for rehabilitation. It also noted that research was needed to develop definitions for the full range of institution- and community-based rehabilitation services, to develop a planning guideline for outpatient and ambulatory rehabilitation, and to develop and evaluate standards of care, referral criteria and outcome assessments for rehabilitation services.

Limitations of Stroke Rehabilitation in Ontario

As a result of conducting an environmental scan of the current system of stroke rehabilitation in Ontario, it was concluded that in general stroke survivors, their families and health professionals do not benefit from a well organized, well designed, high quality and monitored system that provides effective stroke rehabilitation to

reduce disability and handicap. The following limitations in the system of stroke rehabilitation in Ontario were identified:

- There is inappropriate access to stroke rehabilitation where care is delayed, or is of the wrong intensity or duration.
- There is inequitable access to stroke rehabilitation across the province. Examples of gaps include: specialized stroke services including outreach are not available in all communities; it is difficult to access interdisciplinary care even in the acute sector; there is inadequate transportation to stroke rehabilitation; there is inadequate provision for low intensity-longer duration rehabilitation; and there is insufficient home rehabilitation to treat the number of severe and moderate stroke survivors returning home.
- A seamless, coordinated approach to stroke rehabilitation across the continuum of care does not exist.
- Certain components of stroke rehabilitation are not that well developed. Examples include education for stroke survivors and their families, and understanding motivation in stroke survivors.
- There are limited positions to train stroke rehabilitation professionals.
- There is a lack of routine outcome information on how well stroke rehabilitation is reducing functional disability and handicap.
- An up-to-date reference for effective, evidence-based rehabilitation does not exist.

The Need for Stroke Rehabilitation in Ontario

It is unclear exactly how many people have strokes in Ontario. The Heart and Stroke Foundation of Ontario estimates that there are 15,000 to 20,000 strokes a year, with the Institute for Clinical Evaluative Sciences putting the number at 14,937 strokes. The ICES estimate does not include people who had strokes and were not hospitalized, strokes resulting from complications during hospitalization, or transient ischemic attacks (TIAs).

It has been estimated that there are about six stroke survivors per 1,000 population⁸.⁹ Extrapolating this to Ontario's population over the age of 20 indicates that there are about 50,000 stroke survivors in a year in the province. As discussed earlier, results from the 1996/97 National Population Health Survey¹⁰ suggests there are 88,000 Ontarians in the community who are living with the effects of stroke. As well, Statistics Canada¹¹ estimates that 22% of institutionalized adults 65 years of age or older are estimated to have had a stroke.

Determining the need for stroke rehabilitation is difficult since valid and reliable stroke rehabilitation data do not exist nor does an agreed-upon methodology to determine the need for rehabilitation. Although accurate data do not exist, it is reasonable to conclude that many people who suffer a stroke will require some rehabilitation. It is unclear, however, how much is actually needed since the level of neurological impairment, disability and handicap of these individuals varies considerably, as does the length and intensity of rehabilitation that is required. In Ontario, persons with a primary diagnosis of stroke are the largest category of patient in rehabilitation (facility and home care), and have the third longest length of stay in rehabilitation after spinal cord and brain dysfunction.

Research Literature

Over 600 articles from the literature and rehabilitation data were reviewed by the Panel's Evidence Review Subgroup, and their relative importance and contribution to the field of stroke rehabilitation were assessed. The levels of evidence framework used by the Panel was taken from the Report by the Health Information Partnership, Eastern Ontario Region/Queen's University³¹ which used the same levels of evidence as the United States Agency for Health Care Policy and Research in "Post-Stroke Rehabilitation".¹²²

The levels of evidence are:

- ◆ Level 1a or Strong: Supported by the results of two or more randomized controlled trials (RCT) or by a meta-analysis.
- ◆ Level 1b or Moderate: Supported by a single RCT or by two or more non-randomized analytic studies (case control or cohort studies).
- ◆ Level 2 or Limited: Supported by a single cohort or case-control study, by studies using quasi-experimental designs such as pre- and post-treatment comparisons.
- ◆ Level 3 or Consensus: Supported by a consensus statement from a panel of experts. This level implies no available evidence.

The Panel came to the following conclusions based on its review and assessment of the research:

1. Clinicians experienced in stroke should carry out the initial assessment.

Acute stroke patients should be assessed by an experienced rehabilitation clinician(s). He or she should use objective assessment criteria to determine the rehabilitation intensity and setting most appropriate for the patient (Level 1a evidence). The triage system used should be relatively simple, transparent and evidence-based.

2. There should be access to specialized, interdisciplinary stroke rehabilitation.

Following an acute stroke, patients who meet the criteria should have access to specialized (interdisciplinary) stroke rehabilitation (Level 1a evidence). As soon as these patients are medically stable, they should be mobilized and transferred to a specialized interdisciplinary rehabilitation program (Level 1a evidence).

3. Stroke survivors should have access to different levels of rehabilitation intensity.

Higher level stroke rehabilitation patients can be discharged following acute stroke care to outpatient or community-based interdisciplinary stroke rehabilitation programs (Level 1a evidence). Moderate and severe stroke patients should be managed on specialized inpatient rehab units (Level 1b evidence). Stroke patients should have access to outpatient interdisciplinary specialized stroke rehabilitation programs that can be hospital or community-based (Level 1a evidence).

4. Caregivers should have stroke rehabilitation support.

Stroke rehabilitation should include working with patients and caregivers to promote problem solving, ensure adequate community supports are available to caregivers, and facilitate reintegration of the stroke patient into valued family and social roles (Level 1a evidence). Resources need to be made available to support caregivers in the community. Such care should include homemaking support, respite, transportation and opportunities for re-socialization.

5. Long-term rehabilitation services should be widely available in nursing facilities, complex continuing care facilities, and in outpatient and community programs.

Long-term rehabilitation services should be widely available to stroke patients. The services that are provided should be based on demonstrated need and improvements in functional outcomes, and will often involve only one discipline (Level 2 evidence). Resources should be easily accessible to stroke patients and their caregivers. These caregivers will require education in developing stroke-related skills.

6. Strategies should be developed to prevent the recurrence of stroke.

Strategies to prevent the recurrence of stroke should be optimized (Level 1a evidence).

7. Outcome data are required for stroke rehabilitation.

An overall functional outcome score that is reliable, valid and easily administered should be used to assist with acute triaging, monitoring of rehabilitation progress and phasing out of rehabilitation support. Currently, the best overall functional measure is the Functional Independence Measure (FIM). It has highly reliable and valid, is well recognized across Canada, and has been endorsed by the Canadian Institute for Health Information (Level 1a evidence). Since FIM is inadequate for assessing communication and cognitive elements for stroke patients, additional elements or assessment tools in these areas will need to be developed. The final standardized outcome measure should be applied uniformly along the continuum of stroke care.

A System for Stroke Rehabilitation

Vision:

Individuals who experience a stroke will have timely access to the appropriate intensity and duration of rehabilitation services. These services will be provided in a comprehensive and coordinated way to patients and families, by agencies and health care providers who are expert in stroke care and practise rehabilitation principles.

Guiding Principles:

The following principles guided the Panel's development of a stroke rehabilitation system for Ontario.

1. Stroke rehabilitation will be client-centred, and will meet the diverse and changing needs of stroke survivors and their families.
2. Stroke survivors will have their rehabilitation potential assessed by experts, and will have timely and appropriate access to stroke rehabilitation expertise throughout the care continuum. This access includes re-accessing stroke rehabilitation if and when the need arises. The care continuum will:
 - Include well-coordinated local and regional resources, and be responsive to local and regional needs;
 - Implement local strategies to optimize clinical coordination and case management;

- Balance the consolidation of specialized stroke rehabilitation services that require critical mass, concentrated skills and clinical, academic and research expertise, with having care as close to home as possible recognizing the challenges faced by stroke survivors who are undergoing rehabilitation; and
 - Include effective transportation to ensure access to services.
3. Stroke rehabilitation expertise will be evident formally through certification or informally through recognized clinical leadership in the community. Expertise is maintained and enhanced by using rehabilitation principles while continuously working with stroke survivors. Consolidating stroke patients in each setting along the continuum of recovery helps to strengthen the development of rehabilitation expertise. (The settings include acute hospitals, rehabilitation facilities, complex continuing care facilities, outpatient settings, home care, nursing homes, homes for the aged, adult day programs, community health agencies and community support groups).
 4. Stroke rehabilitation will incorporate high quality, accurate and timely information, and information management. This includes communicating information about stroke, stroke disability and recovery to stroke survivors, their families and significant others, and healthcare providers. It also includes ensuring that information flows with the client and family across the continuum of care in a seamless and coordinated manner, while protecting the confidentiality of the client.
 5. New technologies such as telehealth will be used to support rehabilitation consultation, education, and service to northern, rural and remote communities.
 6. Stroke rehabilitation will be research and evidence-based.

Stroke rehabilitation will be supported with a sufficient number of appropriately trained health care providers (e.g., physicians, therapists, assistants).

MEASURING AND MONITORING

Data collection and analysis (measuring and monitoring indicators and outcomes) is critical throughout the entire spectrum of stroke care. Without data, it is impossible to analyze needs, evaluate how well programs are working or determine the effectiveness of interventions.

Need for Provincial Monitoring

Ontario does not have a provincial monitoring system to monitor and evaluate the provision of stroke care, its impact on patient outcome, and the health care system. Such a system would be useful to assess waiting times and other barriers to access care, and to evaluate quality of care and patient satisfaction.

Although some data are being collected independently in Ontario by hospitals and other health care agencies, data are not aggregated. This situation is complicated by concerns about validity of these statistics and the completeness of the data. The province lacks important information about stroke, the people affected and the outcome of their care and treatment.

This situation is in contrast to that of cancer and heart disease; also major causes of death in Ontario. In both areas, systems are in place to monitor (at provincial and regional levels) care outcomes and processes (i.e. Ontario Cancer Registry and Cardiac Care Network of Ontario¹²³). These systems provide for monitoring mortality, incidence and survival in addition to promoting standards for the collection and utilization of data.

Relevant Monitoring and Measuring Initiatives

A number of monitoring and measuring initiatives are already underway in Ontario. These have been reviewed to identify opportunities for collaboration (see Appendix 6). For example, the Ontario Stroke Registry is being implemented at the patient care level as part of the CSS 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 such as the Canadian Heart and Stroke Surveillance System be comprehensive and collect data

across the continuum of care, many of these initiatives are only in the planning stage of development.

It is the view of the Task Group that an Ontario-based initiative to monitor and evaluate stroke care should build on existing initiatives and should strive to aggregate comprehensive information on an ongoing basis. This will ensure that a provincial system to provide timely access to quality stroke services develops in a coordinated, efficient and cost-effective manner across the continuum of stroke

Vision for A Stroke Measuring and Monitoring System in Ontario

A single provincial system to monitor and evaluate stroke care is required to facilitate accountability at the systems and clinical level within the health care system. It will provide data and information to assess whether the stroke care system is providing quality care in a timely manner, whether services are readily accessible to patients and their families and providers, and whether service delivery and organization is effective and efficient.

Other important reasons to develop such as system are:

- ◆ To ensure that Ontarians across the province have access to quality stroke care on a timely basis;
- ◆ To obtain data on prevalence, incidence, morbidity and mortality, and utilization of health care resources which facilitate health systems planning and allocation of health care resources;
- ◆ To provide information on implementation of organized stroke care along the continuum of care including prevention, emergency, inpatient treatment and rehabilitation;
- ◆ To ensure that the interventions of proven efficacy are being used appropriately;
- ◆ To provide data to stimulate enhanced health service research, planning and resource allocation; and,
- ◆ To monitor and measure trends in the burden of stroke.

Critical Success Factors

According to Strauss and colleagues¹²⁴, a provincial measuring and monitoring system for stroke should strive to be:

- Useful: the system would provide appropriate information to support delivery of clinical services, enable management decisions and facilitate policy formulation;

- *User-friendly*: the system must be accessible and useful to government, as well as to the people who provide care;
- *Cost-effective and efficient*: the system would provide timely and relevant information without duplication;
- *Comprehensive*: the system would provide information on the full spectrum of stroke care;
- *Coordinated*: there would be provincial consensus on the system's content with data arising from a variety of available sources and linked electronically;
- *Timely*: information would be available to health service providers, funding agencies and planners soon after collection and analysis;
- *Integrated*: data collection would be part of routine stroke management and would be routinely incorporated into policy decisions at all levels;
- *Accessible*: information would be disseminated in a variety of methods and presented in formats useful to various audiences;
- *Evaluated*: the measuring and monitoring process, impact and outcomes would be evaluated routinely;
- *Flexible*: the system would be designed to allow modification when information needs change.¹²⁴

In addition, to be effective, it must be simple in both its structure and ease of operation. The process and content for data collection must also be acceptable to individuals and organizations that will participate in the system. With respect to the data collection tool(s), they must demonstrate: sensitivity in the proportion of events detected; positive predictive value (the proportion of the individuals identified as being a case who actually have the condition); and representativeness (i.e. accurately describes the occurrence of the event over time and its distribution in the population by place and person).¹²⁵

As the literature suggests, there is a broad menu of indicators to choose from for evaluation. Selection of specific indicators will depend on the priorities for measuring and monitoring, the availability of required data in existing databases, and the participating organizations' commitment to the evaluation process.¹²⁶ The Canadian Heart and Stroke Surveillance System implemented a process to identify and prioritize indicators useful to measure and monitor stroke. These criteria included:

- ◆ The importance or relevance of the indicator (evidence of a serious impact on health; significant number of people affected; significant impact on costs; potential for improvement of cardiovascular disease problems and health);

- ◆ Data quality (data collection tools and methods provide valid and reliable data); and,
- ◆ Feasibility (data is available at a reasonable cost in a timely manner; interest exists to support inclusion).

The Task Group also agreed that the 'controllability' of indicators should be considered. It was agreed that it would be most important to collect data on indicators that could be modified or influenced.

There is no active case reporting system for stroke in Ontario. There are however a number of databases which could be used for provincial monitoring and measuring of stroke. These include provincial death registries, national mortality database, hospital discharge abstract database administered by CIHI, statistics Canada person oriented database, national population health survey, and provincial physician billing database.¹²⁴

Implementation Challenges and Conclusions

There is an urgent need for a measuring and monitoring system for stroke care in Ontario. Timely and accurate information about the provision of stroke care and its impact on patients and the health system is lacking. This information is needed to make evidence-based decisions related to clinical care, program organization and funding and policy development. Consequently, it is proposed that a Stroke Monitoring Implementation Team be established to complete the following work plan over the next six to eight months:

1. Establish the Stroke Monitoring Implementation Team;
2. Review coordinated stroke strategy;
3. Select actual indicators by consensus;
4. Identify and implement the most efficient and cost-effective process for data collection, dissemination;
5. Evaluate and analyze the data.

To successfully establish the Stroke Monitoring Implementation Team and implement a measuring and monitoring system, the following issues need to be addressed:

- ◆ Leadership: a central group such as the Stroke Monitoring Implementation Team with responsibility for developing and evaluating the measuring and

monitoring system will be required. A champion for the stroke evaluation process will be need to facilitate the consensus building process;

- ◆ *Linkages*: an effective stroke surveillance requires linkages with the many stakeholders in this area to facilitate effective data collection and dissemination. Linkages will also be needed to integrate data collection with other related activities;
- ◆ *Privacy and Confidentiality*: a framework is needed to ensure the privacy and confidentiality of collection, use and dissemination of patient data and information. This needs to be balanced with the need to use data to support clinical processes, facilitate management decisions, and assist policy formulation;
- ◆ *Reporting Standards*: education programs aimed at communicating reporting guidelines to ensure data quality and integrity will be essential to implementing a high quality and reliable evaluation system;
- ◆ *Duplication*: the measuring and monitoring plan for stroke care must be implemented in collaboration with other initiatives to avoid duplication of effort, resources, and databases. Providers will be less inclined to participate in the process if there are multiple requests for the same data and information;
- ◆ *Human Resources*: greater numbers of professionals trained in health information management will be required in all settings to participate in the evaluation process;
- ◆ *Technology*: centers participating in the measuring and monitoring system must have the technology required to support data collection, use and dissemination;
- ◆ *Financial*: a budget will be required to support the next stage of development of the measuring and monitoring system and its implementation to ensure that it cost-effective;
- ◆ *Research*: data collected should be made available for research purposes to facilitate enhancements to stroke care.

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