Strengthening information systems for heart health in Canada

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Information plays a key role in monitoring, management, evaluation and policy development related to cardiovascular diseases. Canada currently lacks a comprehensive, integrated pan-Canadian system to address the growing burden of cardiovascular diseases, including reliable and timely data that can be used by policy-makers, health care providers, researchers and the public. Theme Working Group 1 (one of six Theme Working Groups) aimed to address different aspects of the Canadian Heart Health Strategy and Action Plan, with a focus on strengthening information systems. Members of the group, who are experts in the cardiovascular field and/or information systems, defined the scope of the issue, identified gaps and solutions, and discussed priorities. The process is described and suggestions for final recommendations are presented. These suggestions were made taking into consideration the needs of health care providers, patients and consumers, the needs for planning, innovation, evaluation and system improvement, and the needs for information on populations and environments. A sustained integrated system that meets cardiovascular information needs requires a major commitment of expertise, leadership and funding.

Key Words: *Canadian Heart Health Strategy and Action Plan; Cardiovascular surveillance; Information systems*

While mortality rates from cardiovascular diseases have decreased over the past 20 years, the actual number of people with cardiovascular diseases is expected to increase as a result of the aging and general growth of Canada's population as well as the rapid rise in prevalence of diabetes and obesity (1). In Canada, cardiovascular diseases remain a leading cause of death (2) and they are a leading contributor to the economic burden of disease (3).

Increasingly sophisticated information regarding cardiovascular health and disease is available, from prevention to acute care to end-of-life planning. However, it is the coordination of data collection, standards and information that is the key to success in planning and providing care. Many different levels of care exist within the Canadian health care system, each collecting and maintaining a wide range of administrative, population-based health and health services data (4). The many information systems used along the continuum of care result in patient information being stored in various forms with varying levels of accessibility.

In October 2006, the Canadian federal government announced funding for the development of a new heart health strategy to address cardiovascular diseases in Canada. A 29-member expert Steering Committee was established to develop a comprehensive, independent, stakeholder-driven Canadian Heart Health Strategy and Action Plan (CHHS-AP). Six Theme Working Groups (TWGs) were formed to address different aspects of the strategy. In recognition of the key role that information plays in monitoring, management, evaluation and policy development related to cardiovascular diseases, one of the TWGs focused on strengthening information systems (CHHS-AP

Renforcer les systèmes d'information en santé cardiaque au Canada

L'information joue un rôle de premier plan dans la surveillance, la prise en charge, l'évaluation et l'élaboration de politiques reliées aux maladies cardiovasculaires. Le Canada ne possède pas de système pancanadien intégré et complet pour traiter du fardeau croissant des maladies cardiovasculaires, y compris des données fiables et opportunes que peuvent utiliser les décideurs, les dispensateurs de soins, les chercheurs et le public. Le groupe de travail thématique 1 (l'un des six groupes de travail thématiques) cherchait à aborder divers aspects de la Stratégie canadienne de santé cardiovasculaire et plan d'action, et surtout à renforcer les systèmes d'information. Les membres du groupe, qui sont des experts dans le domaine de la santé cardiovasculaire ou des systèmes d'information, ont défini la portée de l'enjeu, repéré les écueils et les solutions et discuté des priorités. Le processus est décrit et des suggestions de recommandations définitives sont présentées. Ces suggestions tiennent compte des besoins des dispensateurs de soins, des patients et des consommateurs, des besoins de planification, d'innovation, d'évaluation et d'amélioration des systèmes ainsi que des besoins d'information sur les populations et les environnements. Pour obtenir un système intégré durable qui respecte les besoins d'information en santé cardiovasculaire, il faut un engagement majeur du point de vue des compétences, du leadership et du financement.

TWG 1). The present paper summarizes the process of the TWG 1 and suggestions made in the final report of the TWG 1.

CHHS-AP TWG 1

The members of the TWG 1 were selected from across Canada based on their expertise in cardiovascular health and/or information systems. The TWG met during two face-to-face retreats in May and October 2007. At these meetings, TWG 1 members defined the scope of the issue, identified gaps and solutions, and discussed priorities. In addition, a roundtable discussion took place at the CHHS-AP Stakeholder Consultation in May 2007, where priorities and gaps were identified and addressed by TWG 1 members and other interested stakeholders from across Canada. Various conference calls with TWG 1 Co-Chairs took place to develop a draft report for review by all TWG 1 members. Input from this review process was incorporated into the final report submitted to the Steering Committee. The CHHS-AP was presented to the Minister of Health on February 24, 2009 (5).

CARDIOVASCULAR HEALTH INFORMATION IN CANADA: CURRENT STATUS AND CHALLENGES

Cardiovascular health information systems include data and information on individuals with cardiovascular diseases and the overall Canadian population. To address and strengthen cardiovascular health, information systems must focus on four main areas: information for health care providers, information for patients and consumers, information for planning, innovation, evaluation and system improvement, and information on populations and environments.

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Information for health care providers

To improve cardiovascular health outcomes, health care providers require access to comprehensive patient information, evidence-based practice guidelines, and ways to communicate with patients and colleagues.

Point-of-service information systems, such as those in hospitals, pharmacies or physician offices, are not currently well integrated with one another. Electronic health records, which are expected to improve integration of different systems and quality of care (6), are still in the developmental stages in most provinces (7). Another source of patient information is telehealth systems. Several provinces have mature telehealth systems, including Ontario, Manitoba, Nova Scotia, Alberta and New Brunswick, and further expansion to northern and First Nations communities is underway (8).

Several advanced but stand-alone cardiac patient registries maintained by specialists exist in Canada including the British Columbia Cardiac Registry, the Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH), the Cardiac Care Network of Ontario, the Quebec Acute Coronary Care Registry and Improving Cardiovascular Outcomes in Nova Scotia (ICONS).

Information systems are also important to promote evidence-based practice and communication among practitioners. To date, adoption of clinical support tools, including protocols and guidelines, has been limited (9). Further expansion of integrated information solutions in upcoming years (7) may help to improve care and clinical outcomes.

Information for patients and consumers

Consumers are becoming increasingly knowledgeable about health information and are taking more control of their health. To improve heart health in Canada, information is needed for people who have or are at risk for cardiovascular disease. Cardiovascular patients require access to understandable and accurate information about their own illness that they can use to confidently manage their own health. The Canadian public requires evidence-based information regarding risk factors and prevention that can be used by individuals and organizations to improve cardiovascular health.

Many governments and nongovernmental organizations (eg, the Heart and Stroke Foundation of Canada) provide online health information for consumers and patients. In Canada, online communities seeking and providing health support, such as HealthPost.ca, are still underdeveloped, although patients can also access American-based discussion groups such as HealingWell.com. Barriers to accessing electronic information exist for specific groups, such as older people, new Canadians and Aboriginal populations; these groups must be considered in heart health education and information system efforts.

An emerging method of providing information to patients is personal health record information systems. These systems track and give feedback on health status, issue alerts and reminders, and thus empower patients to be more actively involved in self-management and to improve their health outcomes. Personal access to electronic medical records (EMRs) is a very recent concept in Canada and is currently a challenge because EMRs are still not commonplace in physician offices, with considerable variability among provinces. Additional challenges that will need to be managed include privacy and security, patient interpretation, and integration with clinical care.

Information for planning, innovation, evaluation and system improvement

A pan-Canadian heart health strategy requires timely, accurate and comprehensive data on cardiovascular health services. This information is needed for managers, administrators and health services researchers to improve the quality of care and outcomes. Important information on cardiovascular patients includes demographics, health-related behaviours, use of health services, access, cost and health outcomes. To further heart health research, access to high-quality, linkable data across the continuum of care is required. Information

systems are also required to assist risk factor reduction and primary prevention at all levels – individual, family, community and the Canadian population at large.

In Canada, data on the burden of cardiovascular diseases are limited. Currently, nationally comparable data on causes of death are maintained through Statistics Canada, although the nature and location of deaths are not well documented. Nationally comparable data on hospital use are maintained by the Canadian Institute for Health Information. Additional potential exists for comparable data on the use of home care, emergency departments, community pharmaceuticals and continuing care, among others, through national databases maintained by the Canadian Institute for Health Information. In addition, each province maintains detailed databases on health care use (physician services, pharmaceuticals, hospitals, etc) that have the potential for linkage within the province at a record level. Several provinces have established provincial health research organizations, with data-sharing agreements existing to use these databases for health care research.

Although there are several cardiovascular registries in Canada, in general, cardiac databases lack standardization and there is limited grant and operational funding for data entry and database development. There are few data on morbidity and nonfatal events, particularly out-of-hospital events, and statistics regarding the number of new heart attacks that occur each year across Canada are not provided, although estimates can be obtained by linking various existing records and databases (10).

The research community has raised concerns about the difficulty of accessing and using health services data across care settings and jurisdictions (4). For example, a recent publication (11) assessing cardiac arrest, care and emergency medical services in Canada culled data from five different sources to provide a first national profile of cardiac arrest in Canada. The report found that data were difficult to match, difficult to compile and were incomplete. Additional efforts are needed to ensure that the collected data can be used effectively by enhancing data comparability and quality, and by establishing an understanding with common definitions for derived indicators. Despite these difficulties, several projects have demonstrated the power of linking and pooling data. Notably, the Canadian Cardiovascular Outcomes Research Team (CCORT) (11) successfully compiled information from clinical and administrative databases from multiple provinces and territories in the Canadian Cardiovascular Atlas project. An alternative but costly strategy would be to create a cohort study, similar to the Framingham study, that would follow individuals over time to determine their actual risk factors, use of health and other relevant services, as well as the natural history of any cardiovascular disease as it develops.

The public must also be aware of the importance of using their health data for health services research and management. The 2007 Electronic Health Information and Privacy Survey (12) showed that nearly two-thirds of Canadians believe there are few types of personal information that are more important than personal health information for privacy laws to protect. While 84% of respondents were supportive of researchers using their electronic health records for research if identifying information was removed, 66% were supportive of researchers linking personal health information, with consent, to other records that may be related to health outcomes.

In using cardiovascular health services data to support management and research, there are significant challenges with human resources. At the present time, there is a shortage of trained cardiovascular epidemiologists and statisticians, and a lack of statistical training for clinicians.

Information on populations and environments

Information on populations and environments is important for clinical care, research and health promotion. It is also essential for assessing the effectiveness of programs and for guiding policy development. Surveillance systems are required to provide information on cardiovascular risk factors and their impact on the cardiovascular health and health care use of the entire population. In Canada, some of this

information is available through national or provincial/territorial systems, or through national surveys.

The Public Health Agency of Canada has implemented a cardiovascular surveillance program using existing data, and produces reports and allows access to interactive tools via the Internet for others to analyze cardiovascular disease data. However, timely economic data and physical measures risk factor data are limited. Costs related to cardiovascular diseases are escalating and, especially in the current economic climate, they must be tracked (13). The most recent available economic information was published in 1998 (14). A new Economic Burden of Illness in Canada report will soon be released. However, the report will provide data only to the year 2000. The most recent national-level data regarding risk factors that require personal measures, such as blood pressure, blood sugar for diabetes, blood lipids and physical activity, are more than 10 years old. This pattern of irregular surveillance has limited the capacity to measure, monitor and report on cardiovascular health risk and disease burden in a timely fashion. As a consequence, an accurate picture of risk factor profiles in Canada, and any regional variations, is lacking. However, recent developments are encouraging, including the 2004 Canadian Community Health Survey – Nutrition, which measured respondents' height and weight, and the Canadian Health Measures Survey (15), which is currently underway (cycle 1 completed) and includes several direct physical measures but only at the national level.

Currently, by linking administrative data on health care use with population health survey and mortality data, it is possible to describe risks and utilization in populations, and to identify subpopulations in which interventions are especially needed to reduce the burden of disease. The Public Health Agency of Canada is leading the work in collaboration with researchers, provinces and territories to create case definitions of cardiovascular diseases and analytical plans to effectively use these databases to track disease incidence, prevalence, use of health services and outcomes in Canada. This is particularly important with respect to Aboriginal individuals in Canada who experience levels of cardiovascular disease far in excess of non-Aboriginal individuals. Linking data on First Nations, Métis and Inuit status with these health administrative databases provides specific information on these important population subgroups. As well, some ethnic populations in Canada have an increased risk of cardiovascular disease; however, linkage is handicapped by the lack of a register of immigrants. Linked information about risk factors, treatments and outcomes related to cardiovascular diseases enables decision-makers to provide better planning and evaluation of policy decisions regarding prevention and treatment for the general population and for specific populations.

Integrating this information to provide a comprehensive picture of the cardiovascular health of Canadians is challenging. Canada needs a surveillance strategy that can integrate information about risk factors, the physical environment, access to care, quality of care and the results of care (16). A critical challenge in collecting and linking cardiovascular health data is balancing the need for information against the right to privacy.

The data needs are sizable and the costs of data collection, and designing and maintaining information technology systems are high. Consequently, the challenge is to design surveillance systems that can collect high-quality, comparable data at a reasonable cost, while responsibly addressing privacy concerns.

IMPROVING CARDIOVASCULAR HEALTH INFORMATION SYSTEMS IN CANADA

Based on the findings and discussions listed above, the TWG 1 suggested several actions to support the development of a pan-Canadian heart health strategy. To improve the quality of cardiovascular health service delivery, the information available to providers and administrators should be enhanced through the following priority actions. First, accelerate the process of developing interoperable EMRs across all provinces and territories, including chronic disease management information systems. Second, support efforts to create and maintain an

authoritative electronic source of guidelines and best practices. Third, with respect to information for patients and consumers, enhanced efforts are needed to provide timely and appropriate information, including culturally appropriate information, on cardiovascular health promotion, care and services.

Several steps can be taken to enhance information for planning, innovation, evaluation and system improvement. First, existing surveys, databases and registries should be linked to improve the focus on patient care trajectories, and enable health service and population health-oriented analyses. Second, the challenges pertaining to human resources must be addressed by development of an education and recruitment strategy for epidemiologists, statisticians and others engaged in surveillance. Third, to increase the usefulness of the national vital statistics data, the collection should be extended to include health insurance identification numbers and access to real-time death certification.

Information on populations and environments can be used to improve the cardiovascular health of Canadians through several strategies. Existing and new cardiovascular health information should be pooled and linked to produce a periodic (eg, every two years), world-class Canadian Cardiovascular Health Report. In addition, a cardiovascular surveillance strategy to gather comprehensive cardiovascular health information on urban and rural First Nations, Inuit and Métis should be supported. Finally, an Expert Advisory Group is needed to provide leadership to facilitate the implementation, continuity and management of surveillance activities within the CHHS-AP.

CONCLUSIONS

The foundation for health information in Canada that has been set over the past few decades is impressive. However, there is much more that needs to be done to develop health information systems to address cardiovascular health promotion, disease prevention, care and management across the system. Canada currently lacks a comprehensive, integrated pan-Canadian system to address the growing burden of cardiovascular diseases, including reliable and timely data that can be used by policy-makers, providers, researchers and the public. Information systems to support cardiovascular health promotion and disease prevention should encompass both population health and clinical data, supporting the seamless flow of information across the continuum of care, from policy and prevention to acute care, chronic disease management, and end-of-life planning and care.

In spite of progress in the reduction of cardiovascular mortality, major challenges lie ahead, including an anticipated increase in the burden of disease due to aging of the population and the increasing prevalence of obesity, particularly among young Canadians. There is a need to develop and monitor targeted programs of prevention, improve the quality of care and secure equitable access, especially by reducing wait times across the country. These goals cannot be achieved without relevant, reliable and timely information. A sustained integrated system, in turn, requires a major commitment of expertise, leadership and funding.

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CONFLICT OF INTEREST: Anne McFarlane is the Executive Director of the Canadian Institute for Health Information in Western Canada. Andy Wielgosz is employed part-time by the Public Health Agency of Canada and is a member of the Board of Directors of the Heart and Stroke Foundation of Canada. Both were Co-Chairs of the Theme Working Group on Information Systems.

REFERENCES

- Heart and Stroke Foundation of Canada. The Growing Burden of Heart Disease and Stroke in Canada. Ottawa: Heart and Stroke Foundation of Canada, 2006.
- Statistics Canada. Canada at a Glance 2008. Ottawa: Minister of Industry, 2008 (Catalogue no. 12-581-XPE). <www45.statcan.gc.ca/2008/cgco_2008_002-eng.htm> (Version current at August 5, 2009).
- Health Canada. Economic Burden of Illness in Canada, 1998. Ottawa: Minister of Public Works and Government Services Canada, 2002. <www.phac-aspc.gc.ca/publicat/ebic-femc98/pdf/ebic1998.pdf> (Version current at August 5, 2009).
- Black C, McGrail K, Fooks C, et al. Data, Data Everywhere...: Improving Access to Population Health and Health Services Research Data in Canada. Vancouver: Centre for Health Services and Policy Research and Canadian Policy Research Networks, 2005. <www.chspr.ubc.ca/files/publications/2005/chspr05-12R.pdf> (Version current at August 5, 2009).
- The Canadian Heart Health Strategy and Action Plan. <www.chhs-scsc.ca/web/?lang=en> (Version current at August 5, 2009).
- Booz Allen Hamilton. Canada Health Infoway's 10-Year Investment Strategy Costing, Pan-Canadian Electronic Health Record – Quantitative and Qualitative Benefits. Toronto: Canada Health Infoway, 2005. <www2.infoway-inforoute.ca/Admin/Upload/Dev/Document/ExecutiveSummary.pdf> (Version current at August 5, 2009).
- Canada Health Infoway. Vision 2015: Advancing Canada's Next Generation of Health Care. Toronto: Canada Health Infoway. <www.infoway-inforoute.ca/en/pdf/Vision_2015_Advancing_Canadas_next_generation_of_healthcare.pdf> (Version current at August 5, 2009).
- Canada Health Infoway. Telehealth. <http://www.infoway-inforoute.ca/en/WhatWeDo/TeleHealth.aspx> (Version current at August 5, 2009).
- Morgan MW, Zamora NE, Hindmarsh MF. An inconvenient truth: A sustainable healthcare system requires chronic disease prevention and management transformation. *Healthc Pap* 2007;7:6-23.
- Colburn H, Fair M, Johansen H, et al; Nova Scotia-Saskatchewan Cardiovascular Disease Epidemiology Group. Estimation of the incidence of acute myocardial infarction using record linkage: A feasibility study in Nova Scotia and Saskatchewan. *Can J Public Health* 1989;80:412-7.
- Vaillancourt C, Stiell I. Cardiac arrest and emergency medical services in Canada. *Can J Cardiol* 2004;20:1082-90.
- Canadian Cardiovascular Atlas. <www.ccort.ca/atlas.asp> (Version current at August 5, 2009).
- Electronic Health Information and Privacy Survey, 2007. <www2.infoway-inforoute.ca/Documents/EKOS_Final%20report_EN.pdf> (Version current at August 5, 2009).
- Muttitt S, Alvarez RC. Chronic disease management: It's time for transformational change! *Healthc Pap* 2007;7:43-7.
- Economic Burden of Illness in Canada, 1998. <www.phac-aspc.gc.ca/publicat/ebic-femc98/> (Version current at August 5, 2009).
- Tremblay, M, Wolfson M, Connor Gorber S. Canada Health Measures Survey: Rationale, background and overview. *Health Reports (Suppl)* 2007. <http://www.statcan.gc.ca/pub/82-003-s/2007000/article/10361-eng.pdf> (Version current at August 5, 2009).
- Health Surveillance Coordination Division, Centre for Surveillance Coordination, Population and Public Health Branch, Health Canada. Chronic Disease Surveillance in Canada. Ottawa: Health Canada, 2003. <dsp-psd.pwgsc.gc.ca/Collection/H39-666-2003E.pdf> (Version current at August 5, 2009).