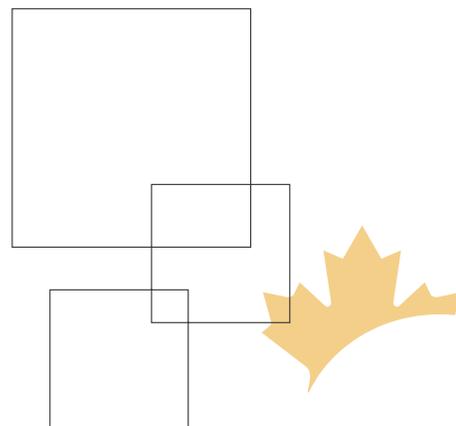


Working Together

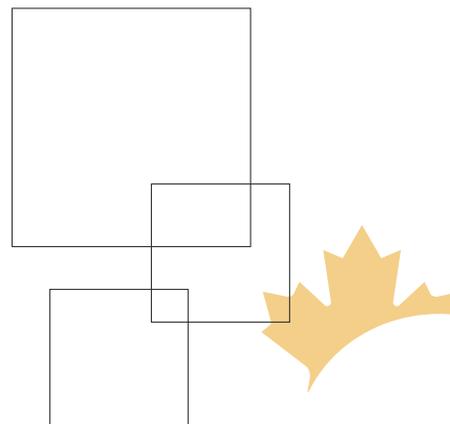
to Develop Common Data Standards
for Cardiovascular Databases in Canada



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Abstract

A workshop was held at Canadian Cardiovascular Congress in Toronto, October 2008, entitled: Canadian Cardiovascular Data Standards Workshop – Can We Work Together? Dr Eldon Smith opened the workshop with a review of the Canadian Heart Health Strategy and Action Plan, and one of its key recommendations to develop common national data standards. This was followed by presentations by representatives of the five major provincial or regional cardiovascular organizations who outlined the roles of their respective databases. These databases share many characteristics. Initially, some were set up to monitor access to open heart surgery, and subsequently expanded to cardiac catheterization and angioplasty. Other provincial databases began by measuring outcomes or addressing care gaps, and evolved into tools to monitor procedures. Nevertheless, comparing access to cardiac services or outcomes between provinces has been hampered by a lack of common data definitions. Dr Blair O'Neill reviewed the initiative of the Canadian Cardiovascular Society (CCS) to improve access to care and Anne McFarlane discussed the role of the Canadian Institute for Health Information in supporting national data standards. This was followed by a panel discussion of the potential benefits of common cardiovascular data standards and an action plan to move the idea forwards. Subsequently, the CCS obtained funding from the Public Health Agency of Canada to develop a Pan-Canadian Data Definitions Work Plan.

I. Introduction

In 1995, a Consensus Conference of the Canadian Cardiovascular Society (CCS) on "Indications for and Access to Revascularization" recognized a wide variation in rates of coronary angiography, angioplasty and bypass surgery between different regions of the country and recommended that invasive centres should participate in a national observational database.¹ Subsequently, the CCS, the Heart and Stroke Foundation and Health Canada held an inaugural database meeting in Ottawa in 1997. In 1999, these organizations along with IBM as an industrial partner, obtained a Health Infostructure Support Program grant to develop steps toward a Canadian Cardiovascular Database. Five provincial database organizations, the Canadian Institute for Health Information (CIHI), Statistics Canada and two epidemiology research groups from across Canada joined the partnership. The initial relationship between provincial and national representatives was challenging, however, this improved with time. The database owners emphasized the importance of recognizing the autonomy of local database activities and the need for a governance structure. Cardiac waiting lists were identified as the first priority and two questions were asked: how many surgical revascularization procedures were performed across the country and what were the wait times between heart catheterization (cath) referral, cath, surgical consult and coronary artery bypass grafting (CABG). Initial data elements to begin to answer these questions were identified and categorized as core, desired and future. An information technology workshop was held to determine what data were available in existing databases and how to link them together. Then a task force was created to compare waiting lists for CABG between Ontario and Alberta. However, this work was handicapped by different definitions for when the queue for surgery began. It was recommended that a first step toward a national surveillance system would be development of a consensus about standardizing data definitions.² It was identified that this would require sustained funding.

Cardiovascular Database Initiatives in Canada

Several groups in Canada are using cardiovascular data to report on service utilization and outcomes of care for Canadians at provincial and federal levels. For example, some of the investigators from the initial cardiovascular database initiative continued to work together, establishing the Canadian Cardiovascular Outcomes Research Team (CCORT) in 2001. CCORT focuses its research objectives on creation of cardiac 'report cards' in order to improve the quality of cardiac care received by Canadians. Other groups in Canada have developed clinical networks or databases, including the Canadian Heart Failure Network and the Canadian Adult Congenital Heart Network.

Several provincial cardiovascular organizations that manage databases have developed relationships with research groups or advisory bodies. Ontario makes data available from the Cardiac Care Network (CCN) to the Institute for Clinical Evaluative Sciences (ICES) to conduct research and inform decision makers. In Quebec, the Quebec Tertiary Cardiology Network (Réseau Québécois de Cardiologie Tertiaire or RQCT) advises on the research priorities of the Tertiary Cardiology Evaluation Unit (UECT) within the Agency of Evaluation of Technologies and Modes of Intervention (Agence d'évaluation des technologies et des modes d'intervention en santé or AETMIS).³

CIHI is an independent, not-for-profit organization that provides data and analysis on Canada's health system and the health of Canadians. It tracks data provided by hospitals, regional health authorities, medical practitioners and governments. CIHI working with Statistics Canada assesses national health indicators such as life expectancy and health expenditure per capita, that are used to compare health status and health-system performance. To assure these measurements are comparable and of similar quality, CIHI coordinates national health information standards.

The Federal Health Portfolio comprises Health Canada, the Public Health Agency of Canada (PHAC), CIHR, and other agencies. PHAC was created in 2004 to provide federal leadership on issues concerning public health and to improve collaboration within and between jurisdictions. Its mandate focuses on chronic diseases including cancer and heart disease.

International Cardiovascular Databases

The American College of Cardiology (ACC) started the National Cardiovascular Data Registry (ACC-NCDR) in 1997.⁴ The ACC defined a common data set and definitions, and then allowed organizations and vendors to license this data set. For a fee, this includes software transmission specifications to submit data to a central registry to compare with other participants. This began with cardiac catheterization and PCI procedures (CathPCI Registry), then expanded to include high risk STEMI/ NSTEMI patients (Action Registry- GWTG), carotid stenting and endarterectomy procedures (CARE Registry) and implantable cardioverter defibrillator procedures (ICD Registry). Some states mandate that cath labs submit data in ACC-NCDR format for accreditation. The ACC also publishes data standards either by themselves, such as the ACC Acute Coronary Syndromes Clinical Data Standards or in partnership with other organizations, such as the ACC/AHA Heart Failure Clinical Data Standards.

The Society of Thoracic Surgeons (STS) also maintains an outcomes-focused national database.⁵ Database participants need to purchase commercial software to submit surgical procedures to a data and analysis center located at the Duke Clinical Research Institute. The STS National Database has been utilized as the basis for a federally funded national randomized quality improvement trial.

Working Together

Recently, the CCN of Ontario updated its data elements and definitions related to acute coronary syndromes as it moved from a legacy database to a web-based SQL platform. As part of this process, CCN invited several consultants from across the country to assist with reviewing and revising its data definitions. These included representatives who had worked with ACC, STS, ICES, the Improving Cardiovascular Outcomes for Nova Scotians (ICONS) database and the Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH). This illustrates an opportunity for cost savings if provincial or regional cardiovascular databases in Canada can work together to develop common data standards.

2. Vision- The Canadian Heart Health Strategy and Action Plan

In October 2006, the federal government launched the Canadian Heart Health Strategy and Action Plan (CHHS-AP). The strategy was developed by a 29 member Steering Committee with the help of 6 Working Groups. The final documents were presented to the federal Minister of Health in February 2009.⁶

Of the 6 Working Groups, the first one was entitled 'Strengthening information systems for monitoring, management, evaluation and policy development'. This recognized 2 important conclusions of the Steering Committee – first, it is impossible to manage what one can't measure, and secondly, that Canada lacks accurate and timely information on cardiovascular risks, diseases and treatment. Canada needs a comprehensive surveillance system to permit determination of prevalence and incidence rates of risk factors or disease. Although provincial administrative databases exist for most services provided, they afford only limited knowledge on timeliness of services and only rudimentary knowledge of outcomes. Although causes of death can be gleaned from Statistics

Canada reports, we have no insight into what services were received prior to death.

The Working Group surveyed information sources available across Canada and acknowledged excellent work being performed, but identified gaps and recommended solutions in a report to the Steering Committee. The conclusions are summarized in a recent publication.⁷

The Steering Committee made 6 major recommendations; one of these was "build the knowledge infrastructure to enhance prevention and care." It was recognized that most deficiencies in surveillance would be addressed with the eventual availability of electronic health and medical records – and in the meantime PHAC was encouraged to continue to develop surveillance systems for specific cardiovascular risks and diseases through the use of linked data sources. Statistics Canada was urged to link the death certification process to provincial/territorial administrative data and to complete the development of their Longitudinal Health Administrative Data initiative. A specific recommendation was made to have cardiovascular risk factors and other appropriate baseline measures included in the long term cohort study being implemented by the Canadian Partnership Against Cancer. Finally, and in recognition of the value of regional patient registries currently existing in Canada, the Strategy recommended that an effort now be made to develop common data definitions and standards so that data from these sources can be linked and pooled, in order to provide a more representative national picture of risks and risk predictors, outcomes from specific interventions and allow comparison of regional differences and their causes.

Whereas the complexity of this initiative should not be underestimated, it was deemed to be an achievable target with many long term benefits. For this reason, the PHAC agreed to provide the CCS with some project support during 2010-2011.

3. Provincial Cardiovascular Database Organizations

Nova Scotia: From ICONS to CVHNS: Transitioning from Study to Provincial Program

The Improving Cardiovascular Outcomes in Nova Scotia (ICONS) project was originally conceived to test whether a broad stakeholder health management partnership, relying primarily on repeated measurement and feedback, would lead to enhanced care, especially the more optimal use of evidence-based discharge therapies, and result in improved outcomes for patients hospitalized with cardiac conditions across an entire health care system. The rationale and methods of this large prospective interventional cohort study have been previously published.⁸

Briefly, between 1997 and 2002, project-specific data were compiled through chart abstraction on all Nova Scotia residents consecutively hospitalized with acute myocardial infarction, unstable angina, congestive heart failure or atrial fibrillation at any of the provincial health care institutions managing adult cardiac disease. The outcomes of interest included in-hospital and one-year all-cause mortality, which were obtained through record linkage to the provincial vital statistics registry, and re-hospitalization, which was tracked through ongoing case surveillance.⁸

The partnership constitution of ICONS⁹ was built upon an earlier province-wide health outcomes project.¹⁰ A steering committee met twice a year to review the accrued data, develop consensus around targets for improvement and implement data-responsive interventions. Working groups convened more frequently to solve region-specific issues and to manage sub-studies, while ICONS project members communicated regarding project direction and sharing of best practices.⁹ The Nova Scotia Department of Health saw the value of the ICONS partnership-measurement paradigm to assess the state of cardiovascular care and outcomes throughout the Province, but also to work collaboratively with patients, providers and other healthcare stakeholders to analyze such care and outcomes and optimize them

further.¹¹ Accordingly, they worked with the ICONS investigators to transition from a short-term, private-sector funded research project to a sustainable, public-sector funded operational system. This led to the evolution of ICONS into a publicly-funded provincial health strategy: Cardiovascular Health Nova Scotia (CVHNS). CVHNS was created to monitor and help improve cardiovascular health and care, across the continuum, throughout Nova Scotia. It is tasked with developing or recommending care standards, service delivery models and funding recommendations. The evolution of ICONS into CVHNS has been one of the most important results of the research study. It provides an example of how committed people armed with timely and relevant data can improve both the care of patients with a given disease as well as the system within which that care is delivered. However, benchmarking practices requires gathering comparable data from across Canada.

Quebec Tertiary Cardiology Network (Réseau Québécois de Cardiologie Tertiaire or RQCT)

Founded in 2000, the RQCT is a permanent advisory board to the Quebec Health Care Minister.¹² The executive board has representatives from each tertiary cardiology center, regional agencies (agences de santé et des services sociaux), health care ministry cardiology division, and provincial cardiology and nursing associations. Its mandate is to advise the minister on access to care in cardiology based on medically acceptable waiting times proposed by the RQCT (defined for all of the Province of Quebec and approved by the Quebec Medical College of Physicians), introduction of new technologies and clinical guidelines, and initiatives to assess outcomes after invasive cardiology procedures. The RQCT also has a strong collaboration with the Tertiary Cardiology Evaluation Unit at the Agency of Evaluation of Technologies and Modes of Intervention (AETMIS).¹³

First introduced in response to a shortage of resources in cardiac surgery and angioplasty in the early 2000s, the RQCT closely collaborated in the development of a mandatory provincial database (SGAS: système de gestion de l'accès aux soins et services) to monitor

wait times for tertiary procedures (open heart surgery, coronary angioplasty and diagnostic catheterizations, and electrophysiology procedures).¹⁴ Experts from each subspecialty proposed clinical criteria to establish priorities and medically acceptable waiting times. Later, the RQCT collaborated with the CCS Access to Care Working Group to review its recommended benchmarks. Wait list surveillance in Quebec has resulted in additional capacity to improve access to cardiac surgery, angioplasty and soon electrophysiology procedures.

The RQCT supports the urgent need to initiate a national collaboration to insure that data collected will correspond to common definitions. Provincial initiatives are oriented towards better care for its patients, however, this would be strengthened by comparisons between different jurisdictions.

Agency of Evaluation of Technologies and Modes of Intervention (Agence d'évaluation des technologies et des modes d'intervention en santé, or AETMIS) – Tertiary Cardiology Evaluation Unit

In 2004, the Tertiary Cardiology Evaluation Unit (UECT) was created within AETMIS at the request of the RQCT and the Quebec Ministry of Health and Social Services. It is mandated to facilitate evaluation in the field of tertiary cardiology in Québec, both in the traditional form of health technology evaluation (upstream evaluation of decision making) and in the form of evaluation of outcomes by collecting and analyzing data concerning the use of cardiac services and related health outcomes.¹⁵ In general, the Tertiary Cardiology Evaluation Unit prepares reports in response to specific Ministerial requests which are often generated by the Quebec Tertiary Cardiology Network (RQCT) and communicated to the Ministry.³

The Tertiary Cardiology Evaluation Unit uses the Quebec provincial registry of medical service billings as the inception point to identify all major cardiac procedures (angiograms, PCI, CABG, valve surgery, insertion of pacemakers). This cohort of patients is then linked to the

medical services billings registry (RAMQ), hospitalization registry (Med-ECHO), death registry (FIPA) and prescription registry (RAMQ).

This national data standards initiative can help the Tertiary Cardiology Evaluation Unit by standardizing definitions of comorbidities, clinical outcomes and procedures. These standards can be applied to analyses thereby facilitating inter-provincial or inter-regional comparisons of patient characteristics, rates of procedures and associated outcomes. Standardization of definitions are also useful in the development of the methodology for collection of clinical data and data elements pertaining to process of care measures and quality indicators. The challenge for this initiative will be to facilitate and simplify the standardization of data definitions across Canada rather than adding more data definitions to what already exists in the literature.

The Tertiary Cardiology Evaluation Unit within AETMIS is currently working with CIHI to compare counts of PCI and CABG that are derived from medical service billings as opposed to hospital discharge data. The goal of the project is to ensure that AETMIS and CIHI have comparable procedure counts and has initiated development of “matching” procedures codes between the two systems.

Cardiac Care Network of Ontario

The Cardiac Care Network of Ontario (CCN) was created approximately 20 years ago in response to a cardiac surgery crisis in Ontario. Since then, CCN has evolved its focus from cardiac surgery to include other adult cardiac procedures, and the continuum of cardiovascular care, including prevention and rehabilitation. CCN is funded by the Ministry of Health and Long-Term Care (MOHLTC) in Ontario to serve an advisory role pertaining to adult cardiovascular services. CCN manages the cardiac registry for Ontario, and monitors and reports on wait times for advanced cardiac services and other metrics pertaining to the access, quality and equity of care.

CCN ensures that there are standardized processes related to cardiovascular care in place throughout the province of Ontario. Patients are triaged and prioritized according to the same criteria, and the wait times for electrophysiology, cardiac cath, percutaneous coronary intervention and cardiac surgery are regularly monitored and reported. In addition, data from the cardiac registry are used to monitor and evaluate patient outcomes and health services planning and research.

CCN is accountable to the MOHLTC of Ontario. The network is comprised of the 18 member hospitals in Ontario that provide advanced cardiac care services. CCN holds participation agreements with each member hospital and the accountabilities of the hospital to the network are well defined. There are Regional Cardiac Care Coordinators and Data Entry Clerks in place at each member hospital, and there is a mandated requirement to participate in the cardiac registry and related quality monitoring processes of CCN. CCN has over 1 million patient records, and collects data on over 100,000 patients annually. CCN works with other agencies such as ICES and CIHI, and health services researchers to generate research products including reports and publications. In addition to the cardiac registry used to monitor wait times and advanced cardiac procedures, CCN also has the other data holdings including a transcatheter aortic valve registry, primary PCI /STEMI registry, pulmonary thromboendarterectomy registry, and electronic referral (development underway).

Institute for Clinical Evaluative Sciences (ICES)

The Institute for Clinical Evaluative Sciences (ICES) was founded in 1992 as an independent, non-profit organization, whose core business is to conduct research that improves health care and health services in Ontario. Its key objectives are to: carry out population-based health services research that is relevant to clinical practice and health policy development; document province-wide patterns and trends in health care delivery; develop and share evidence to inform decision-making; promote linkages among health services researchers and decision-makers; and train researchers and

promote a wider understanding of clinical epidemiology and health services research.

ICES receives core funding from the Ontario MOHLTC. In addition, its scientists compete for peer-reviewed grants from federal funding agencies, and project-specific funds are received from provincial and national organizations. ICES is organized by research groups of similar interests, such as the Cardiovascular and Diagnostic Imaging group. This group has initiated and maintained large cardiovascular registries, including the Enhanced Feedback for Effective Cardiac Treatment (EFFECT) project (to improve the quality of care and outcomes of acute myocardial infarction and heart failure patients), the Ontario Implantable Cardioverter-Defibrillator (ICD) Database (a registry of all adult patients undergoing defibrillator implantation in Ontario, which has been mandated by the MOHLTC) and the Registry of the Canadian Stroke Network (a hospital-based registry of patients presenting with acute stroke to 11 hospitals in Ontario).

Data obtained by ICES can be linked to administrative data anonymously because ICES is a prescribed entity in Ontario's Personal Health Information Protection Act (PHIPA). Many administrative databases are available for linkages that include data from the CIHI Discharge Abstract Database, Registered Persons Database, Ontario Drug Benefit plan and Ontario Health Insurance Plan. Many of the previous research investigations by ICES relate to comparison of care and outcomes across Canada, and between Ontario and the United States. Standardized definitions would improve the ease and validity of these regional comparisons.

Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH)

The Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease, APPROACH© was established in 1995 as a registry to collect clinical information and track long-term outcomes from all patients undergoing cardiac catheterization in Alberta. This initiative was developed in

response to a critical need for ongoing assessment of the processes and outcomes of care for patients with coronary artery disease. It began as an Alberta-wide, collaborative, prospective data collection initiative. The organization is now funded by a combination of government, health regions, and grants from industry and for research. More information about APPROACH can be found on its web site: www.approach.org. In brief, APPROACH's mandate is to improve outcomes, influence policy, and create a standard of care through best practices and benchmarking. APPROACH has proven its utility to individual practitioners (through patient data and coronary anatomical summaries), to research teams (through clinically rich and reliable data for analysis), to local administrators (through utilization and outcome reports) and to provincial administrators (through reports regarding wait times and outcomes). APPROACH has allowed streamlining of reporting processes and integrating clinical information into daily health care processes.

The registry was designed to introduce a minimally intrusive data collection process that draws on existing personnel for data entry (i.e. cath lab personnel, unit clerks, nurses and physicians) in order to be sustainable 24 hours per day, seven days per week. Although there is additional data entry work required, it is balanced with APPROACH features that facilitate streamlining of patient flow and reporting. These core data elements are supplemented by follow up quality of life assessments supported by research grants.

APPROACH has other modules—Waitlist Management (WLM) for cath/PCI, cath/PCI, WLM for surgery, cardiac surgery, WLM for nuclear testing, nuclear testing, ACS admissions, reporting, long term questionnaire. Participating sites can use one or all modules. When APPROACH began in 1995, cath was the inception point but now once the patient is registered, data entry can begin in any module.

Originally, there was a data committee and data elements selected were based on those necessary for assessment of the relationship between processes and outcomes of

care, with provision for appropriate risk adjustment. The APPROACH database has links with patient information systems. Data from the Alberta College of Physicians and surgeons is downloaded into the database monthly and from the Alberta Bureau for Vital Statistics quarterly. For research projects, an annual merge is performed with tertiary hospital administrative data to “enhance” the data. The APPROACH software has provided a data foundation upon which fruitful work has been conducted in quality measurement, surveillance, and research. Currently there is ongoing review with published data definitions. APPROACH has brokered partnerships with the Canadian Cardiovascular Outcomes Research Team (CCORT) and BC Cardiac Registry (BCCR). APPROACH recognizes that data standardization is important and looks forward to collaborating with experts in this field as part of a national initiative.

Cardiac Services BC Registry

The Cardiac Services BC Registry started life as the BC Cardiac Registry (BCCR). Its original database tracked waiting times for open heart surgery. From there, it evolved into a full scale clinical registry for open heart surgery, cardiac catheterization, pacemaker and ICD implants. The registry is in the process of replacing its old INGRESS database with a new web-based Microsoft SQL database, specifically the APPROACH database. The new registry will also include electrophysiology, percutaneous heart valves and ACS/AMI admissions. With the current registry, the main inception point is a cardiac procedure or device implantation. In the new registry, inception points will vary because the entire patient journey will be captured, not just procedures

Cardiac Services is an agency of the Provincial Health Services Authority (PHSA), which is funded by the BC Ministry of Health Services. A primary goal is to improve the way cardiac services are managed and accessed throughout the province. There are two committees that report to the Provincial Executive Director, Cardiac Services BC: the Steering Committee comprising senior Health Authority Administrators and Senior Clinical

Leaders, and the Provincial Panel on Cardiac Health, comprising senior cardiologists and cardiac surgeons from each of the acute care sites. There is also a Data Access and Research Review Board that reviews all requests for access to Registry data.

The Cardiac Services BC Registry data is used to provide annual reports (blinded) for outcomes after cardiac surgery and PCI, health authority-specific annual reports describing disease burden, use of cardiac services, population demographics and overall outcomes, and to estimate future service needs for tertiary cardiac services. With launch of the new registry at the end of 2010, the registry will provide online reports for procedure wait list times, procedure volumes, disease burden by region, and information on how to access registry data for research.

During the design of the original registry data elements and definitions were determined using an informal process. With the development of the new registry, expert working groups have been utilized and smaller versions of these expert working groups will be retained to ensure data elements and definitions remain current..

The registry has linked its data to other administrative databases such as Vital Statistics, Physician Billing Data, Hospital Admission Data, and Prescription Usage, in order to answer targeted questions related to quality of care and outcomes. But such evaluations encompass only regions within BC. The development of national data standards would facilitate comparisons across provinces.

4. Why Should We Develop Canadian Standards?

Canadian Cardiovascular Society Access to Care Committee

Timely access to care continues to be of concern to Canadians and the CCS. A CCS working group that subsequently evolved into a Standing Committee on Access

to Care has been active since 2004. Furthermore, the CCS was one of the founding members of the Canadian Medical Association's Wait Time Alliance established in 2005. Since then, the cardiovascular community has reached consensus on a range of benchmarks for access to a number of common cardiovascular services and procedures including access to cardiovascular specialists and diagnostic testing such as Echocardiography and Nuclear Imaging, access to Cardiac Catheterization, Angioplasty, and Cardiac Surgery; access to Electrophysiologic studies, pacemakers and complex electrical devices; and access to Chronic Disease Management Programs such as Cardiac Rehabilitation and Heart Function Clinics.

The CCS has championed that access must be monitored along the entire 'cardiovascular continuum' in order to ensure optimal patient care. It stresses the importance of transparent and managed wait lists throughout the patient journey, beginning with initial access to cardiovascular specialists, through necessary diagnostic testing, and procedures, and also including access to disease management programs.

Although benchmarks for cardiovascular disease have been available for half a decade, surveys done by the CCS in 2007 showed that there is still much work to be done. While most large centres monitor access to procedures such as cardiac catheterization, PCI and surgery, only a few monitor access to consultation, noninvasive diagnostic tests or electrophysiology studies.

In addition, there is a need for standardization of wait time definitions to facilitate better comparison between jurisdictions. Wait time definitions also need to be considered from a patient perspective. Access to a specialist begins with referral from a primary care physician. Similarly, access to cardiac catheterization and revascularization in patients presenting with an acute coronary syndrome begins with presentation to hospital, even if that is initially to a centre without angiography. Access to cardiac surgery begins with the diagnostic cardiac catheterization or other imaging procedures that results in the indication for surgery.

Establishing wait-time standards and data collection and reporting is essential to improving access to care across the cardiovascular continuum. It is also incumbent upon practitioners to commit themselves to improving systems allowing improved access. This means a single point of entry to wait lists for cardiovascular practitioners, whether that is for access to consultation or procedures such as cardiac catheterization or cardiac surgery. These systems need to be regionally based to allow for equitable access to those many Canadians who live outside of urban centres. Finally, it is important to establish national networks to compare best practices to continually enhance access to care.

Wait lists are not inherently bad, since they allow for more efficient use of expensive resources. However, when poorly managed and left unmonitored, wait lists are a patient safety issue.

Canadian Institute for Health Information (CIHI): The Need for Cardiovascular Standards

Across Canada, clinicians and administrators collect much data related to the continuum of cardiovascular care. However, the ability to both understand a patient's journey across this continuum and to compare care and outcomes between jurisdictions is quite limited. This is due to data comparability problems. Data elements as simple as date of birth, or as complex as diagnosis are collected and recorded differently in various databases. The Canadian Institute for Health Information (CIHI) working with the provinces and territories has made great strides to ensure the comparability of hospital data because Canadian hospitals have adopted uniform data standards. The potential exists for us to have more comparable data on cardiovascular care if we are able to create common data standards and link data from existing provincial databases. Comparable data will then allow us to improve the delivery of care and improve patient outcomes.

5. How Can We Develop An Action Plan? Next Steps

In December 2009, the federal government, through the Public Health Agency of Canada (PHAC), signaled its commitment to the Canadian Heart Health Strategy and Action Plan (CHHS-AP) by funding the development of a national action plan on achieving pan-Canadian data definitions for cardiovascular patient registries. The need for nationally consistent data definitions was one of the key recommendations from the CHHS-AP that was officially released in February 2009. The Canadian Cardiovascular Society was identified as the lead organization for facilitating stakeholder input to this important initiative.

6. Summary

Provincial and national organizations in Canada managing cardiovascular data serve an important clinical, administrative and research role in the health of Canadians. Representatives of these organizations came together in a workshop setting at the annual Canadian Cardiovascular Congress to highlight their achievements and to discuss how to work better together. One of the key recommendations of the Canadian Heart Health Strategy and Action Plan is development of common data standards amongst our existing and exemplary registries and databases. In response to this, the Public Health Association of Canada is providing funding to the Canadian Cardiovascular Society during 2010-2011 to work with stakeholders and take the next steps toward standardization of data definitions.

References

1. Canadian Cardiovascular Society Consensus Conference on Indications for and Access to Revascularization 1995 (revised June 1997). *Can J Cardiol* 1997; 13 (Suppl D): 1D- 72D.
2. Davies RA, Abdullah S, Cohen E, et al. Issues Influencing Development of the Canadian Cardiovascular Information Network. *Can J Cardiol* 2004; 20: 637-641.
3. RQCT Annual Report, 2007-2008.
4. Brindis RG, Fitzgerald S, Anderson HV, Shaw RE, Weintraub WS, Williams JF. The ACC-NCDR: Building a National Clinical Data Repository. *J Am Coll Cardiol* 2001; 37(8): 2240-2245.
5. <http://www.sts.org/sections/stsnationaldatabase/>
6. www.chhs-scsc.ca (accessed on February 14, 2010).
7. McFarlane A, Wielgosz A. Strengthening information systems for heart health in Canada. *Can J Cardiol* 2009;25:631-34.
8. Cox JL, on behalf of the ICONS Investigators. Optimizing disease management at a health care system level: the Improving Cardiovascular Outcomes in Nova Scotia (ICONS) study. *Can J Cardiol* 1999; 15: 787-96.
9. Montague T, Cox J, Kramer S, Nemis-White J, Cochrane B, Wheatley M, Joshi Y, Carrier R, Gregoire J-P, Johnstone D, for the ICONS investigators. Improving cardiovascular outcomes in Nova Scotia: ICONS, a successful public/private partnership in primary health care. *Hospital Quarterly* 2003; 6: 32-8.
10. Cox JL. The use and impact of registries for myocardial infarction on process of care and outcomes. Examples from Canada. *Journal of Thrombosis and Thombolysis* 1998; 5: S163-S169.
11. Cox J, Johnstone D, Nemis-White J, Montague T. Optimizing health care at the population level: Results of the Improving Cardiovascular Outcomes in Nova Scotia (ICONS) Partnership. *Health Q* 2008; 11: 29-41.
12. http://www.rqct.qc.ca/index.php?A_propos_du_RQCT_en
13. http://www.aetmis.gouv.qc.ca/site/en_equipe_cardiologie.shtml
14. http://www.rqct.qc.ca/index.php?Acces_aux_services_en
15. http://www.aetmis.gouv.qc.ca/site/en_equipe_cardiologie.shtml

