

Prepared for  
Canadian Cardiovascular Society (CCS)  
Public Health Agency of Canada (PHAC)

**PAN-CANADIAN DATA DEFINITIONS**

**BACKGROUND PAPER**

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## Introduction

Canada currently has a number of valuable cardiovascular (CV) disease patient registries dispersed across the country; each collecting varying types of data and often only when a patient has experienced an event such as angiography, surgery or hospitalization. There is not yet pan-Canadian consistency in the quality indicators and data definitions used by all of the registries. This lack of standardization makes it very difficult to pool data and undertake meaningful data comparisons and analysis to improve patient care. The opportunity to develop nationally consistent clinical patient data indicators and definitions beyond the current administrative data collected by CIHI would be an important step towards benchmarking clinical data, improving research on CV disease, informing health policy and, ultimately, helping to improve the delivery of CV care to Canadians.

The Canadian Heart Health Strategy and Action Plan (CHHS-AP) released February 2009 identified the priority need to standardize indicators and data definitions across the country. As a national organization, the Canadian Cardiovascular Society (CCS) was identified by the CHHS-AP as the potential lead for facilitating pan-Canadian stakeholder input to this initiative. In late 2009, the Public Health Agency of Canada (PHAC) agreed to provide CCS with funding for Phase I of the project – to develop an understanding of what is required to standardize national indicators and standardize data definitions among Canadian cardiovascular registries. The following paper provides an overview of the current CV database environment in Canada including opportunities and challenges.

## Cardiovascular Database Environment in Canada

These are several groups in Canada using cardiovascular data to improve the health of Canadians, at the level of investigators, and at a provincial or federal level.

In Canada, the 5 major provincial cardiovascular databases, in no particular order, are as follows:

- Nova Scotia: From ICONS to Cardiovascular Health Nova Scotia (CVHNS)
- Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS) - Tertiary Cardiology Evaluation Unit in Quebec
- Cardiac Care Network of Ontario (CCN)
- Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH)
- Cardiac Services BC Registry

Other organizations maintaining large cardiovascular registries include the Institute for Clinical Evaluative Sciences (ICES) an independent, non-profit organization, whose core business is to conduct research that contributes to the effectiveness, quality, equity and efficiency of health care and health services in Ontario; and, the Canadian Institute for Health Information (CIHI) not-for-profit institute to help the public and the people running Canada's health system get a clearer picture of what's being spent on health care, what kind of care is being delivered, who's delivering it and the factors influencing the health of Canadians.

The following tables in Appendix I provides a snapshot of each registry including origin, governance, scope, IT infrastructure and outcomes.

## **Opportunities and Challenges:**

A paper published in the Canadian Journal of Cardiology in 2004 entitled “Issues Influencing Development of the Canadian Cardiovascular Information Network” – RA Davies et al; outlines the opportunities and challenges of a Canadian cardiovascular database from key stakeholder interviews.

The four main goals identified from interviews were to: enable improvements in quality patient care; facilitate evidence-based decision making and resource allocation; disseminate information to decision makers, and improve management of cardiac waiting lists. The challenges to be considered included: respect for the integrity of existing databases; agreement on data definitions; sustainability of the project; and, support for local database needs.

The opportunities for establishing Pan-Canadian data definitions are clear. With the standardization of data definition, data from the various registry sources can then be linked and pooled 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.

However, with any initiative involving numerous stakeholders, there are challenges. The various Canadian registries employ a variety of inception cohort designs and have developed advanced purpose-built software and house important resources including years of legacy data, as well as leading expertise to collect, manage and analyze data on a provincial basis. This existing infrastructure may not be easily modified without significant resource and cost implications.

There also needs to be a willingness to work collaboratively to achieve consensus on the data elements and definition and a willingness to share and report data. This willingness to collaborate has been positively echoed among members of the steering committee.

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<b>Nova Scotia: From ICONS to Cardiovascular Health Nova Scotia (CVHNS)</b>	
<b>Lead Contact</b>	Jafna Cox & Neala Gill
<b>Website</b>	<a href="http://www.gov.ns.ca/health/cvhn">www.gov.ns.ca/health/cvhn</a>
<b>Origin</b>	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 burdensome cardiac conditions across an entire health care system.
<b>Mandate</b>	CVHNS is responsible for: developing guidelines and service delivery models; working with District Health Authorities to improve cardiovascular health; monitoring and reporting cardiovascular health outcomes; facilitating professional development opportunities for health providers; and working with others to reduce the risk and burden of cardiovascular disease.
<b>Scope</b>	CVHNS is one of nine condition-specific programs of the Nova Scotia Department of Health. Initially, its focus was cardiac disease but, very soon after its inception, this broadened to include stroke as well. Data has been collected on all admissions for AMI, CHF and unstable angina in the province since October 1997. An audit has been completed on all admissions for stroke in 2004/2005 using the Registry of the Canadian Stroke Network. Plans are underway to develop methods for ongoing surveillance for stroke and to expand reporting of cardiovascular data across the continuum through linkages with additional data sources.
<b>Governance</b>	ICONS transitioned from a short-term, private sector funded research project into a publicly-funded provincial health strategy: Cardiovascular Health Nova Scotia (CVHNS). The program team, supported by clinical and scientific advisors as well as a multi-stakeholder Advisory Council, reports to a Director of Acute & Tertiary Care who in turn reports to the Executive Director of Acute & Tertiary Care who then reports to the Associate Deputy Minister
<b>Funding</b>	Funded by the province - Nova Scotia Department of Health
<b>IT Infrastructure</b>	The cardiovascular data is entered in Lotus Notes and the transferred to an Oracle database, using processes developed in 1997. The program is currently undergoing a complete IT and business process review to identify requirements for a re-engineered, user-friendly, efficient, accurate IT infrastructure.  Linkages to additional sources of data to provide a better picture of cardiovascular health and care are being explored, as are linkages with other chronic disease registries to provide a better understanding of the burden of chronic diseases.
<b>Reports</b>	<ul style="list-style-type: none"> <li>• Annual reports to district health authorities of performance on key cardiovascular quality indicators (district compared to province) linked to guidelines (e.g., <i>Nova Scotia Guidelines for Acute Coronary Syndromes</i>) <ul style="list-style-type: none"> <li>○ STEMI</li> <li>○ Non-STEMI</li> <li>○ CHF</li> </ul> </li> <li>• Provincial report of performance on key cardiovascular quality indicators (district to district comparison over 3 year period) nearing completion <ul style="list-style-type: none"> <li>○ STEMI</li> <li>○ Non-STEMI</li> <li>○ CHF</li> </ul> </li> <li>• Provincial stroke audit</li> <li>• Operational plan for stroke service enhancements</li> </ul> Reviews, reports, position statements as requested by the department of Health, district health authorities and others.
<b>External Relationships Collaboration</b>	CIHI through Staff at NS Department of Health (participating in validation of CVD and stroke indicators), Canadian Stroke Strategy and Canadian Stroke Network, NS Department of Health, NS Department of Health Promotion and Protection, Diabetes Care Program of Nova Scotia, Nova Scotia Renal Program.
<b>Data Dict.</b>	YES (of key quality indicators)
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• Evaluation of impact of provincial ACS guidelines pending (released mid 2008)</li> <li>• Stroke audit data utilized to develop operational plan and funding formula for stroke service locations and enhancements</li> </ul>

<b>AETMIS - Tertiary Cardiology Evaluation Unit</b>	
<b>Lead Contact</b>	Laurie Lambert
<b>Website</b>	<a href="http://www.aetmis.gouv.qc.ca/site/en_equipe_cardiologie.phtml">www.aetmis.gouv.qc.ca/site/en_equipe_cardiologie.phtml</a>
<b>Origin</b>	The Tertiary Cardiology Evaluation Unit was created in 2004 at the request of the Quebec Tertiary Cardiology Network (RQCT) and the Quebec Ministry of Health and Social Services. The unit is a division within a larger organization established by the Québec government in 2000, Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS).
<b>Mandate</b>	Facilitate evaluation in the field of tertiary cardiology in Québec, both in the traditional form of health technology evaluation (upstream evaluation to aid 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.
<b>Scope</b>	The AETMIS provincial database of cardiac interventions originally linked medico-administrative data from 1993 – 2004 and has been updated to 2008. The data base allows identification and follow up of all major cardiac procedures such as PCI and CABG. AETMIS currently has data base that includes all Quebec STEMI patients for a 6 month period in 2006-7 and has started collection of data for the same 6 month period in 2008-2009 .
<b>Governance</b>	AETMIS is an independent organization that reports to Québec's Minister of Health and Social Services. The Agency's organizational structure relies on a network of experts: the Board of Members. They are appointed by government order and assume the dual role of a board of directors and a scientific board. The Agency also has an advisory committee made up of stakeholders from all sectors of health-care who help establish priorities with regard to assessment and disseminate its reports. The Tertiary Cardiology Evaluation Unit is under the direction of the Clinical Practice Support Directorate and made up of a team including scientists, clinical experts, methodologists and medical records professionals.
<b>Funding</b>	Funded by the province - Quebec Ministry of. Health and Social Services
<b>IT Infrastructure</b>	The Quebec provincial registry of medical service billings is the inception point to identify major cardiac procedures such as angiograms, PCI, CABG, valve surgery. This cohort of patients is then linked to : 1) Medical services billings registry (RAMQ) 2) Hospitalization registry (Méd-ECHO) 3) Death registry (FIPA) 4) Prescription registry (RAMQ) Linkage between the various provincial data bases permits us to describe patient history (previous hospitalizations, procedures and use of medications) as well as patient outcomes (readmission to hospital, new procedures, use of medications, death). Data elements and definitions must necessarily be in accord with those that already exist within these various data bases.
<b>Reports</b>	In general, AETMIS and its Cardiology Evaluation Unit generate reports in response to specific Ministerial requests. However, the requests in cardiology are often generated by clinicians through Quebec Tertiary Cardiology Network and communicated to the Ministry. We have submitted written reports based on a review of the literature, on meta-analyses as well as on analyses of the medico-administrative data. The results of our field evaluation of STEMI care was presented to clinicians and managers around the province in a slide show on a CD that was sent to the Ministry as well as to all participating hospitals. We have also presented results at various scientific conferences.
<b>External Relationships Collaboration</b>	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 the development of a "matching" of procedures codes between the two systems.
<b>Data Dict.</b>	Under development for STEMI
<b>Outcomes</b>	An intense and multi-faceted diffusion plan has catalyzed a provincial action plan, inter-disciplinary discussions of STEMI care in 11 of 15 health regions, the development of regional action plans and treatment protocols as well as other inter and intra-hospital initiatives to measure and improve STEMI care. A report on practice of PCI without on-site surgery has contributed important information for the decision-making process of the Ministry of Health and Social Services in terms of opening and closure of PCI centres in Quebec.

<b>Cardiac Care Network of Ontario (CCN)</b>	
<b>Lead Contact</b>	Kori Kingsbury
<b>Website</b>	www.ccn.on.ca/
<b>Origin</b>	The Cardiac Care Network of Ontario (CCN) was created approximately 20 years ago in response to a cardiac surgery crisis in Ontario. Over the past 20 years, CCN has evolved its focus from cardiac surgery to include other adult cardiac procedures, and the continuum of cardiovascular care, including prevention and rehabilitation.
<b>Mandate</b>	CCN is responsible for developing, maintaining and reporting on provincial cardiac wait list registry for all patients waiting for selected adult advanced cardiac procedures in Ontario. CCN develops strategies, based on best practices, to better manage cardiovascular disease across the continuum of care, including strategies to prevent acute hospital readmissions, decrease demand on emergency departments and decrease the need for initial and repeat procedures.
<b>Scope</b>	CCN has evolved its focus from cardiac surgery to include other adult cardiac procedures, and the continuum of cardiovascular care, including prevention and rehabilitation. In addition to the cardiac registry used to monitor wait times and advanced cardiac procedures, CCN also has the following data holdings: transcatheter aortic valve registry, primary PCI /STEMI registry, pulmonary thromboendarterectomy registry, and electronic referral (prototype).
<b>Governance</b>	CCN is a funded agency accountable to Ministry of Health and Long-Term Care (MOHLTC) in Ontario. 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.
<b>Funding</b>	Funded by the province - Ministry of Health and Long-Term Care (MOHLTC) in Ontario
<b>IT Infrastructure</b>	The IT infrastructure is SQL2000 and SQL2005; the majority of data is entered by way of web-based systems, although some applications use a paper-based / fax system with data entered by CCN. Data elements (variables and data definitions) are regularly reviewed by CCN clinical sub-specialty working groups and the application is updated as required. The CCN reporting system uses Business Objects and Crystal Reports. All web-based applications use the highest strength of SSL encryption certificate to ensure security of all personal health information.
<b>Reports</b>	CCN has prescribed registry status from the Office of the Information and Privacy Commissioner of Ontario. CCN has a Research & Publications Committee to govern the use of CCN data. CCN works with other agencies (ICES, PATH, OHTAC, CIHI) and health services researchers to generate research products including reports and publications. In an effort to make data more available and to create a transparent process, CCN has established an on-line Research Portal to facilitate communication between the research community and CCN (accessed through www.ccn.on.ca). Each data request is reviewed by the Research and Publications Committee and is required to undergo review and approval by an ethics review board.
<b>External Relationships Collaboration</b>	CCN works with other agencies (ICES, PATH, OHTAC, CIHI) and health services researchers to generate research products including reports and publications.
<b>Data Dict.</b>	YES
<b>Outcomes</b>	<p>CCN has prescribed registry status from the Office of the Information and Privacy Commissioner of Ontario. CCN holds Participation Agreements with all hospitals in Ontario that provide advanced cardiac services, with a requirement for data to be submitted to CCN.</p> <p>Data from the Cardiac Care Network is used to determine outcomes for isolated coronary artery bypass surgery and other cardiac procedures. In addition, CCN collects the provincial data on Primary PCI, however to date, we have not analyzed the data in a risk-adjusted outcomes context. We are moving forward with an initiative to provide regular standard risk- adjusted outcome reports for cardiac surgery and PCI back to the hospitals as a quality improvement initiative.</p> <p>CCN provides regular monthly reports for advanced cardiac procedures (and includes wait times) for cardiac surgery, PCI, cardiac cath, transcatheter aortic valve replacement procedures, electrophysiology and ablation (simple and complex) by hospital. Aggregate provincial data is also available.</p> <p>CCN is the source for public reporting on wait times for cath, PCI and elective CABG; reported by CCN and other organizations such as the Wait Times Information Office, Ontario Health Quality Council, and other groups such as CIHI.</p> <p>CCN has established a Research &amp; Publications Committee to facilitate access to CCN data for the purposes of clinical and health services research. CCN has data sharing agreements in place with key stakeholders (e.g. ICES). A key project for CCN (2008-2010) has been the "Variation in Revascularization Practices in Ontario" study. Working with key partners (ICES and 18 member hospitals) this project has examined the variation in PCI:CABG ratios across the province of Ontario.</p>

<b>Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease (APPROACH)</b>			
<b>Lead Contact</b>	Diane Galbraith		
<b>Website</b>	www.approach.org		
<b>Origin</b>	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.		
<b>Mandate</b>	The mandate of APPROACH is to improve outcomes, influence policy, and create a standard of care through best practices and benchmarking. Its mission is to “collect and process information to improve cardiac care for all Albertans.”		
<b>Scope</b>	APPROACH began with a cathlab and CV surgery database in Alberta in 1995. In the 15 years since APPROACH was launched it has expanded geographically across the country as well as conceptually to areas of waitlist management, ACS, nuclear medicine and most recently, CT angio.		
<b>Governance</b>	Members of the APPROACH team are responsible to the APPROACH Clinical Steering Committee (CSC) comprised of department and divisional heads. The CSC is responsible for the scientific integrity of research projects conducted on the APPROACH database, and assurance that the questions being asked are appropriate and properly supported by the data being collected. Duties of CSC include review of all data requests for feasibility and appropriateness, review and approval of all proposed research projects and manuscripts, and review and approval of policies on privacy and confidentiality		
<b>Funding</b>	Funded by a combination of government, health regions, industry – unrestricted grants and research grants. The APPROACH software is owned and licensed by DIH Services Ltd.		
<b>IT Infrastructure</b>	The IT infrastructure for APPROACH is based on Oracle SQL. The servers operate in a high availability VMWare virtual infrastructure supported by Dell PowerEdge servers, a Dell iSCSI SAN, a Dell Tape Library for backups and disaster recovery, and Checkpoint UTM-1 firewalls. The APPROACH and CARAT business and data services (server applications) operate on Windows 2003 R2 with a Microsoft SQL Server 2005 database. The APPROACH, CARAT, and QUERY clients are 32-bit installed applications. Our next generation web-based client software, APPROACH Online, is soon to be released and supports most popular browsers (IE8, Firefox, Chrome, Safari). Health care personnel will log on to the web and manually enter data. In addition, real-time data is linked via HL7 to the patient information systems as well as some cathlab hemodynamic systems.		
<b>Reports</b>	<p>Over the past decade APPROACH has developed numerous reporting tools to support the work of health care institutions. Report generation is aimed to optimize patient safety, promote quality improvement, enhance operational practices and facilitate clinical research based on appropriate use of consistent data. APPROACH reports provide data and information to record program changes and track program performance. Additionally, APPROACH software provides ready access to reports that maximize effective decision-making and program implementation. Categories of reports:</p> <table border="0"> <tr> <td style="vertical-align: top;"> <ul style="list-style-type: none"> <li>I. Cardiac Catheterization Laboratory</li> <li>II. Cardiovascular Surgery</li> <li>III. Waitlist Management</li> <li>IV. Patient Level - Clinical / Procedural</li> <li>V. Quality Assurance / Improvement</li> <li>VI. Audit &amp; Security</li> <li>VII. Myocardial Perfusion Imaging</li> <li>VIII. Acute Coronary Syndrome</li> </ul> </td> <td style="vertical-align: top; padding-left: 20px;">           Report Parameters by:           <ul style="list-style-type: none"> <li>I. Facility</li> <li>II. Unit</li> <li>III. Start &amp; End Date</li> <li>IV. Sort Order</li> <li>V. Procedures/ Diagnosis</li> <li>VI. Patient level details or Aggregate</li> <li>VII. Age /gender</li> </ul> </td> </tr> </table>	<ul style="list-style-type: none"> <li>I. Cardiac Catheterization Laboratory</li> <li>II. Cardiovascular Surgery</li> <li>III. Waitlist Management</li> <li>IV. Patient Level - Clinical / Procedural</li> <li>V. Quality Assurance / Improvement</li> <li>VI. Audit &amp; Security</li> <li>VII. Myocardial Perfusion Imaging</li> <li>VIII. Acute Coronary Syndrome</li> </ul>	Report Parameters by: <ul style="list-style-type: none"> <li>I. Facility</li> <li>II. Unit</li> <li>III. Start &amp; End Date</li> <li>IV. Sort Order</li> <li>V. Procedures/ Diagnosis</li> <li>VI. Patient level details or Aggregate</li> <li>VII. Age /gender</li> </ul>
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<b>External Relationships</b>	APPROACH has developed external research relationships. It has brokered partnerships with the Canadian Cardiovascular Outcomes Research Team (CCORT) and BC Cardiac Registry (BCCR). Aggregate data has been supplied to industry upon request – ie DES, BMS inventory.		
<b>Data Dict.</b>	YES		
<b>Outcomes</b>	<p>APPROACH studies short and long-term outcomes (mortality, revascularization and quality of life). APPROACH has had impact on many levels and has proven its utility to individual practitioners (in the form of patient data and coronary anatomy graphical summaries), to research teams (in the form of clinically rich and reliable data for analysis), to local administrator (in the form of utilization and outcome reports) and to provincial administrators (in the form of reports regarding wait times and outcomes). This initiative has led the way in streamlining reporting processes and integrating clinical information into daily health care processes.</p> <p>Some examples of impact are on the elderly and in women. Often patients who stand to benefit are not being treated because of exaggerated fear of risks of treatment. This phenomenon, often referred to as the ‘risk-treatment paradox’ is particularly true in the elderly. Through scientific presentations at national meetings and publication of a few manuscripts the APPROACH team has added important insights to this literature.</p> <p>Women have also been identified as undertreated. APPROACH studies have found that sex remains an independent factor predicting health related quality of life post catheterization. Work is underway to identify women with poorer quality of life at the time of cardiac catheterization so that earlier treatment can improve their symptoms, function and quality of life down the road.</p>		

<b>Cardiac Services BC Registry</b>	
<b>Lead Contact</b>	Karin Humphries
<b>Website</b>	<a href="http://www.phsa.ca/AgenciesAndServices/Agencies/Cardiac/default.htm">www.phsa.ca/AgenciesAndServices/Agencies/Cardiac/default.htm</a>
<b>Origin</b>	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, diagnostic catheterization, percutaneous coronary interventions, pacemaker and ICD implants.
<b>Mandate</b>	Cardiac Services BC's goal is to improve the way cardiac services are managed and accessed throughout the province. We also provide confidential outcomes analysis of outcomes post cardiac surgery and post PCI, and we advise the Ministry of Health on future needs for tertiary cardiac services.
<b>Scope</b>	Full scale clinical registry for open heart surgery, diagnostic catheterization, percutaneous coronary interventions, pacemaker and ICD implants. Most recently, it has begun collecting data on percutaneous heart valves and will be adding modules for electrophysiology and hospital admissions for ACS/AMI.
<b>Governance</b>	Cardiac Services is an agency of the Provincial Health Services Authority, which is funded by the BC Ministry of Health Services. The Registry reports to the Ministry of Health Services. Cardiac Services BC is responsible for planning, coordinating, monitoring, evaluating and, in some cases, funding cardiac services across BC in collaboration with senior administrators and physicians in the other health authorities.
<b>Funding</b>	Funded by the province - BC Ministry of Health Services
<b>IT Infrastructure</b>	<p>Currently the registry using INGRESS for IT Management, but it is in the process of switching to Microsoft SQL. This currently uses a 'fat client, but the new registry will be completely web based.</p> <p>Previously, the registry did not have a formal process to determine and update data elements and definitions. With the development of the new registry, it has convened expert working groups. Once the new registry is up and running, it will retain smaller versions of these expert working groups to ensure that it stays up to date.</p>
<b>Reports</b>	With launch of the new registry (end of 2010), it will have a public website that will provide reports, wait list times, procedure volumes, disease burden by region, and information on how to access registry data for research. The registry has linked its data to other administrative databases such as Vital Statistics, Physician Billing Data, Hospital Admission Data, and Prescription Usage. It actively engages in its own research and encourages others to use its data for research purposes. The registry provide annual outcomes reports (blinded) for outcomes after cardiac surgery and PCI. In addition, it provides an annual report to each health authority describing their disease burden, use of cardiac services, population demographics and overall outcomes. The Provincial Health Services Authority is affiliated with the University of British Columbia. Applications for data are reviewed by the Data Access and Research Review Board.
<b>External Relationships Collaboration</b>	The Provincial Health Services Authority is affiliated with the University of British Columbia. PHSA is considered to be a health sciences centre and as such is affiliated with UBC.
<b>Data Dict.</b>	Not formally; but we have an internal dictionary for the analysts. A full dictionary will be offered with the new Registry
<b>Outcomes</b>	<p>Registry data was used to support the opening of a 5th cardiac centre in Kelowna BC. This site previously only did diagnostic catheterizations; as of Nov 2009 it is doing PCIs and in 2012 it will offer open heart surgery.</p> <p>Registry data is used to plan catheterization, open heart surgery, and device volumes for BC.</p> <p>Annual outcomes reports for cardiac surgeons have led to improved outcomes in BC.</p> <p>We are now working with the Ministry of Health Services to define and provide annual quality indicator reports to cardiac surgeons and interventionalists</p>

<b>Institute for Clinical Evaluative Sciences (ICES)</b>	
<b>Lead Contact</b>	Dennis Ko and Jack Tu
<b>Website</b>	<a href="http://www.ices.on.ca">www.ices.on.ca</a>
<b>Origin</b>	Since its inception in 1992, ICES has played a key role in providing unique scientific insights to help policymakers, managers, planners, practitioners and other researchers to shape the future direction of the Ontario health care system. Our unbiased, evidence-based knowledge and recommendations, profiled in atlases, investigative reports, and peer-reviewed journals, are used to guide decision-making and inform changes in health care delivery.
<b>Mandate</b>	ICES is an independent, non-profit organization, whose core business is to conduct research that contributes to the effectiveness, quality, equity and efficiency of health care and health services in Ontario. The key objectives are to: <ul style="list-style-type: none"> <li>• Carry out population-based research that is relevant to clinical practice and health policy development;</li> <li>• Document province-wide patterns and trends in health care delivery;</li> <li>• Develop and share evidence to inform policy makers, managers, clinicians, planners and consumers;</li> <li>• Promote linkages among health services researchers and decision-makers; and,</li> <li>• Train researchers and promote a wider understanding of clinical epidemiology and health services research.</li> </ul>
<b>Scope (CV)</b>	The Cardiovascular and Diagnostic Imaging group has initiated and maintained several large cardiovascular registries. Several selected databases are listed: <b>Enhanced Feedback for Effective Cardiac Treatment (EFFECT) project:</b> The EFFECT project aimed to improve the quality of care and outcomes of acute myocardial infarction and heart failure patients. This abstraction project is one of the largest of its kind in Canada. Our group abstracted more than 400 predefined variables in 20,000 myocardial infarction charts and 20,000 heart failure charts across Ontario. <b>Ontario Implantable Cardioverter-Defibrillator (ICD) Database:</b> The Ontario ICD Database is an ongoing prospective clinical registry of all adult patients undergoing defibrillator implantation in Ontario, Canada. Such registry has been mandated by the Ontario Ministry of Health and Long-Term Care. Patient data are collected upon initial evaluation, at the time of defibrillator implant, and at each follow-up visit in the device clinic. Data in the ICD database were collected by electrophysiologists and trained research coordinators at each defibrillator implantation centre. <b>Registry of the Canadian Stroke Network Stroke (RCSN):</b> The Registry of the Canadian Stroke Network (RCSN) is a hospital-based registry of consecutive patients presenting with acute stroke to 11 hospitals in Ontario, Canada. All patients in this registry are identified prospectively and data are abstracted systematically during hospital stay and at the time of discharge by trained research nurses using a standardized case report form.
<b>Governance</b>	ICES is organized by research groups of similar interests. Dr. Jack Tu is the team lead of the Cardiovascular and Diagnostic Imaging group at ICES that comprises of 7 core scientists including three cardiologists (Drs. David Alter, Dennis Ko, Douglas Lee), an internist (Dr. Moira Kapral), and two statistical methodologists (Dr. Peter Austin and Therese Stukel), and 10 adjunct scientists.
<b>Funding</b>	ICES receives core funding from the Ontario Ministry of Health and Long-Term Care. In addition, our scientists compete for peer-reviewed grants from federal funding agencies, such as the Canadian Institutes of Health Research, and project-specific funds are received from provincial and national organizations. These combined sources enable ICES to have a large number of projects underway, covering a broad range of topics
<b>IT Infrastructure</b>	Many IT solutions are utilized at ICES based on the needs for individual projects. For data abstraction projects, ICES has a primary data collection service that provides laptop computers, built-in security and encryption software, built-in application software, support of the ICES IT department, and support of the ICES help-desk department assist in any technical issues. For web-based abstraction, cold fusion web interface has been used. Several projects have utilized Microsoft SQL servers.  Data obtained by ICES can be linked administrative anonymously even without patient consent because ICES is Prescribed Entity in Ontario's Personal Health Information Protection Act (PHIPA) <a href="http://www.ipc.on.ca">www.ipc.on.ca</a> . Our chief privacy officer and staff continues to maintain the highest level for confidentiality of data held at ICES. Many administrative databases are available for linkages that include data from the Canadian Institute for Health Information (CIHI) discharge abstract database, Registered Persons Database (RPDB), Ontario Drug Benefit, Ontario Health Insurance Plan. In addition, data from the Cardiovascular Network of Ontario are also available upon request for specific projects
<b>Reports</b>	The Cardiovascular and Diagnostic Imaging group at ICES has an extremely strong research and publication record, and over 550 peer-reviewed manuscripts. Dr. Jack Tu is also the team lead of the Canadian Cardiovascular Outcomes Research Team (CCORT), a research team that includes over 30 leading cardiovascular outcomes researchers from five Canadian provinces. In addition to collaboration with Canadian investigators, many of our scientists collaborate with international renowned researchers from the United States and the United Kingdom, and sits on many international committees and editorial boards.  Many reports are generated from ICES based on the requirement of the specific projects but they include reports that provide updated information for primary care providers, electronic bulletins that give highlights of recent ICES findings and implications in a quick-read format, and ICES atlases and investigational reports to stakeholders.
<b>External Relationships</b>	ICES continues to foster expanding partnerships, and thus expanding opportunities. Following the successful launch of the first satellite site of ICES at Queen's University in 2007, ICES is collaborating with staff at the Ottawa Hospital Research Institute (University of Ottawa) and the University of Toronto in planning new ICES satellites. These sites will open their doors in 2010 and will broaden the reach of our science programs, particularly in non-clinical areas, and enable more mentoring of research fellows and students. The next phase of our expansion will involve the building

<b>Collaboration</b>	and commissioning of new ICES sites at the University of Western Ontario, the University of Waterloo and McMaster University
<b>Data Dict.</b>	Each database has included a detailed data dictionary that allows abstractors to capture consistent and high quality data.
<b>Outcomes</b>	<p>Data at ICES have been used since its inception to generate relevant information to providers, planners, policy makers to evaluate and improve the effectiveness of the Ontario health care system. These information has been distributed widely to the public and key stakeholders by means of ICES research atlases, ICES research reports, e-bulletins, and newsletters. These reports are intended to provide an in-depth examination of various aspects of health care delivery in Ontario such as access, outcomes, utilization patterns, screening and treatment modalities, and technology. ICES faculty has authored and co-authored hundreds of articles that have been published in distinguished peer-reviewed journals such as the <i>New England Journal of Medicine</i>, <i>Journal of the American Association (JAMA)</i>, <i>Lancet</i>, and others.</p> <p>ICES has a close working relationship with many stakeholders such as the Ontario Ministry of Health and Long Term Care, the Cardiac Care Network of Ontario (CCN), Ontario Health Technology Advisory Committee (OHTAC) to ensure research conducted at ICES will continue to contribute to the effectiveness, quality, equity and efficiency of health care and health services in Ontario</p>

<b>Canadian Institute for Health Information (CIHI)</b>	
<b>Lead Contact</b>	Anne McFarlane
<b>Website</b>	www.cihi.ca
<b>Origin</b>	In the early 1990s, there were considerable gaps in information on Canada's health system and the health of Canadians. Canadians wanted to know how well our health system worked, how we could improve it and how healthy we were as a nation. But the answers were difficult to find. To respond to these questions, the provinces, territories and the federal government created an independent, not-for-profit institute to help the public and the people running Canada's health system get a clearer picture of what's being spent on health care, what kind of care is being delivered, who's delivering it and the factors influencing the health of Canadians. Since then, government bodies, hospitals, health authorities, professional associations, the media, the public and others have come to depend on the Canadian Institute for Health Information (CIHI) as an essential source of relevant, timely and dependable health information.
<b>Mandate</b>	<p>CIHI tracks data in many areas, thanks to information supplied by hospitals, regional health authorities, medical practitioners and governments. Other sources provide further data to help inform CIHI's in-depth analytic reports.</p> <p>CIHI's data and reports focus on:</p> <ul style="list-style-type: none"> <li>• Health care services</li> <li>• Health spending</li> <li>• Health human resources</li> <li>• Population health</li> </ul> <p>CIHI also identifies and promotes national health indicators—measures such as life expectancy or what we spend on health per capita—that are used to compare health status and health-system performance and characteristics. To make sure these measurements are comparable and meet the same quality requirements, CIHI coordinates national health information standards.</p>
<b>Scope (CV)</b>	The Discharge Abstract Database contains acute care data coded in ICD-9&10 CA/CCI.
<b>Governance</b>	Guidance for CIHI and its regional offices is provided by a strong, 16-member Board of Directors representing federal, provincial and territorial governments and non-governmental health-related groups.
<b>Funding</b>	Funded by the federal, provincial and territorial ministries of health,
<b>IT Infrastructure</b>	CIHI uses a wide range of IT solutions for data-related activities, including data collection, security and privacy, analysis and reporting. Data from the DAD can be linked to internal and external databases.
<b>Reports</b>	It tracks data provided by hospitals, regional health authorities, medical practitioners and governments. CIHI's data and reports focus on health care services, health spending, health human resources and population health. CIHI also 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 make sure these measurements are comparable and of similar quality, CIHI coordinates national health information standards.
<b>External Relationships Collaboration</b>	The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential data and analysis on Canada's health system and the health of Canadians. The Board of Governors is made up of representatives from federal, provincial and territorial governments and non-governmental health-related groups. CIHI works with hospitals, regional health authorities, medical practitioners and governments to collect data, perform analyses and report information.
<b>Data Dict.</b>	Yes, DAD dictionary.