Chronic Disease Surveillance in Canada

A Background Paper

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Executive Summary

The primary focus of this background document has been to identify the business processes associated with chronic disease surveillance (here defined as surveillance that encompasses all aspects of chronic disease, from determinants to final outcomes) in order to identify needs and potential strategies for strengthening chronic disease surveillance infostructure.

There are a number of chronic disease surveillance initiatives in Canada, ranging from established surveillance systems to less developed initiatives. In all cases, numerous sources are used to provide the required data on determinants, risk factors, diagnoses, interventions, and outcomes. However, there is no existing blueprint for chronic disease surveillance to achieve integration of efforts, reduction of duplication and maximum quality of surveillance information.

The Background Paper shows that although the health surveillance process is fundamentally applicable to chronic and communicable disease prevention and control, there are issues pertaining to data sources, data collection, analysis, and temporality that preclude the uniform application of communicable disease surveillance approaches to chronic disease surveillance.

Stakeholders have identified a series of requirements to improve the overall capacity for conducting chronic disease surveillance: directed efforts towards coordination, enhancement of data collection methods, facilitated access to data, inclusion in the process for defining standards, formal training in chronic disease surveillance, better information dissemination to both professional and public stakeholders, and improvements to human resource capacity.

These requirements exist in the context of Canada moving towards the establishment of electronic health records that will track health information at the level of the individual, whereby surveillance data will be recorded as a by-product of health care delivery. Because this is a long term solution, methods must now be developed to improve the electronic integration of databases; guidelines need to be developed for the periodic and routine assessment of data quality in specific databases that are accessed for surveillance; strategies must be identified for evaluating new and emerging databases that are likely to be useful for chronic disease surveillance, and data quality improvement strategies must also be developed.
Additional benefits of taking on these short term tasks is that they will contribute to the development of the surveillance standards for the electronic health record.

A co-ordinated, multi-partnered approach, with clearly defined surveillance priorities, is needed as it builds the capacity for chronic disease surveillance, and leads to a common understanding of the necessary steps for improvement while minimizing duplication of effort and expenditure.

1. Introduction

1.1 Contextual History: The Chronic Sub-Group and a Vision for Surveillance

In 1999, the Conference of Deputy Ministers of Health approved the formation of the Network for Health Surveillance in Canada, a partnership of public health surveillance stakeholders engaged in a collaborative effort to build the capacity to undertake surveillance at local, provincial/territorial and national levels. The Health Surveillance Working Group (HSWG), reporting directly to Advisory Committee on Health Infostrucutre (ACHI), was then formed to oversee and guide the development of the Network.

The Chronic Non-Communicable Disease Surveillance Sub-Group of the HSWG (Chronic Sub-Group) was constituted to advise the HSWG on surveillance issues specific to chronic diseases and the infostructure required for effective management. With membership comprising provincial/territorial jurisdictions, non-governmental organizations, academia, Health Canada, Statistics Canada and Canadian Institute of Health Information (CIHI), the Sub-group has moved forward in its mandate by producing, through consultation, a paper titled *National Surveillance Networks for Chronic Disease in Canada: Charting a Path Forward* [1] that introduces a fundamental vision for chronic disease surveillance in Canada. The membership for the Sub-Group is found in Appendix 1.

The vision for chronic disease surveillance in Canada is one of an integrated surveillance network that blends continued disease/condition specific surveillance with a national coordinating function for development of: common tools, methods and standards; data development and access; strategic directions and priorities; and capacity development.

This vision does not aim to develop a new single surveillance system. Rather, it accommodates the realities of chronic disease surveillance in Canada, recognizing the many existing initiatives and the varying capacity for conducting surveillance amongst initiatives and jurisdictions. The vision uses a long-term approach, working from a blueprint to incrementally improve capacity, with a focus on cross-cutting issues across a broad range of disease interests. Working collaboratively, and benefitting from the already developed methodologies, and standards as well as the “lessons learned” of the more mature initiatives (cancer surveillance, for example) the vision aims to assist in the enhancement of capacity at the local, provincial/territorial and national levels - eventually building a common infostructure that addresses the needs common to many surveillance initiatives.

The Chronic Sub-Group began, through a series of consultations, to identify and address some of the cross-cutting issues affecting overall public health capacity for chronic disease surveillance: directed efforts towards coordination, enhancement of data collection methods, facilitated access to data, development of standards, and improvements to human resource capacity. The *Situational Analysis for Chronic Disease Surveillance Systems and Networks in Canada (2002)*[2] lists the following nine recommendations for addressing the issues:

1. Construct and promote an integrated surveillance network that blends continued individual disease/condition specific surveillance with a national co-ordinating function.

2. Assign a lead role in coordinating chronic disease surveillance activities in Canada to Health Canada.

3. Develop a chronic disease surveillance communications strategy.

4. Ensure that all jurisdictions have the functional capacity to perform chronic disease surveillance.

5. Establish the national standards to permit comparability of information across jurisdictions.

6. Support regular, long-term data collection for the full continuum of chronic disease surveillance, from determinants to eventual outcomes.

7. Develop appropriate methodologies for data collection, access and analysis.

8. Develop the mechanisms to enable jurisdictions to efficiently and effectively utilize surveillance information.

9. Investigate the benefits and risks of establishing legislation for chronic disease surveillance.

A key consideration for these recommendations is that they cannot be realized in isolation of other efforts. The plan to improve chronic disease surveillance capacity is nested within Canada's larger vision for an improved overall health infrastructure.[3,4] For example, the goal of establishing an electronic health record will assist and be assisted by efforts to improve chronic disease surveillance capacity, eventually allowing information to flow bi-directionally between surveillance systems and the electronic health record (EHR).

As a follow-up to the consultative work described above, in March of 2002, the F/P/T Advisory Committee on Health Infostructure directed the Chronic Sub-Group to develop a document outlining:
1. the business requirements for chronic disease surveillance;
2. current gaps in infostructure for chronic disease surveillance;
3. short-term and longer-term options for addressing the gaps.

In June of 2002, a re-alignment of federal/provincial/territorial advisory committees was announced at the Conference of Deputy Ministers of Health. This re-alignment included sun-setting the Advisory Committee on Health Infostructure, to which the Health Surveillance Working Group and its Sub-Groups report. Consequently, the completion of this paper marked the conclusion of the Chronic Sub-Group's work.

1.2 Concepts and surveillance model

Chronic diseases are those conditions that are generally incurable, are often caused by a complex interaction of factors, and have a prolonged clinical course.[2] Heart disease, diabetes, cancer, arthritis, depression, and asthma are all chronic diseases. Chronic conditions often have long latent periods where disease is not evident, and although non-communicable, may have a communicable origin. Cervical cancer, for example, can result from exposure to the communicable human papilloma virus.

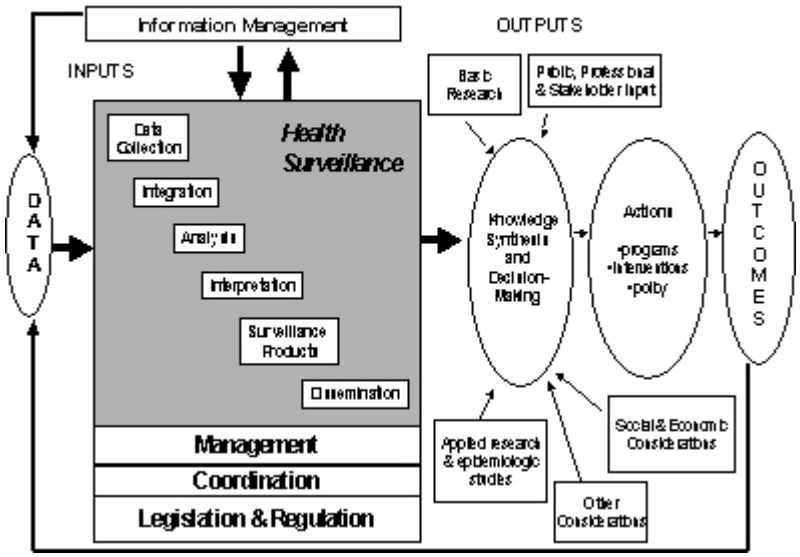
Surveillance is defined as "tracking and forecasting any health event or health determinant through the ongoing collection of data, the integration, analysis and interpretation of that data into surveillance products and the dissemination of that resultant surveillance product to those who need to know."[5]

Surveillance is a cornerstone of public health; its purpose is to provide the information needed by practitioners and health decision makers undertaking population health assessment, health promotion, disease and injury prevention, and health protection activities .[6] Surveillance information informs policy and decision-making for population level interventions (including prevention, treatment and palliation services), and is also pertinent at individual health management level, for health care providers and consumers.

The term chronic disease surveillance applies to surveillance for all aspects of chronic disease: determinants, events, health care utilization and outcomes.

The surveillance model used by the Chronic Sub-Group to describe chronic disease surveillance highlights the iterative nature of what is essentially a knowledge generation process: the collection, analysis and interpretation of data into information for action.

Figure 1: A High-Level Health Surveillance Model



The model, as seen in Figure 1 above, describes a cyclical process where information, derived from data and supplemented by other information, leads to greater knowledge and decision-

making capabilities. This prompts actions that will have an impact on disease incidence, risk behaviours and other determinants and (ultimately) produce better health. There are six core functions of surveillance: data collection, data integration, data analysis, interpretation, development of surveillance products, and dissemination. These are supported by the appropriate infrastructure and functions of management, coordination, information management and in some instances, legislation and regulation.[5]

Enhanced surveillance will better inform and thus strengthen all the peripheral elements included in Figure 1: knowledge synthesis and decision making, interventions, research, public and professional involvement, legislation and policy, and through this network of interrelated mechanisms will make an important contribution to improving the health of Canadians. Improved chronic disease surveillance capacity increases the amount of available information on population health, leading to improved understanding of individuals' health within a population, permitting descriptive and analytic comparisons between individuals - in terms of risk, health status, health services use and other outcomes.

1.3 Chronic non-communicable disease and communicable disease surveillance

The model as described above is applicable to both chronic (non-communicable) and communicable disease surveillance. Fundamentally, the two areas conduct surveillance for the same reasons: for prevention and control of disease and risk reduction or elimination. However, chronic disease relies more heavily than communicable on data and information collected through systems established primarily for purposes other than for protecting or promoting health (e.g., administrative data sets). Types of data, sources of data, methods for collecting data, approaches to interpretation and analysis, and temporality issues may differ for communicable and chronic disease surveillance.[7] It is useful to consider the major distinctions (as noted in Table 1 below) so that the differences are well understood and the similarities that facilitate integration into an overall public health information system are clearly identified.

Table 1: Chronic and Communicable Disease - Challenges for Surveillance.[7-14]

issue	chronic	communicable
temporality	Latent causality - exposure to causal factors decades before onset of disease.	More immediate causality - exposure to infectious agent often days or hours before disease onset.
disease course	Usually protracted - response to treatment can lag, exacerbations and remissions can occur.	Can be short - response to treatment tends to be rapid, cure is often likely.
cause of disease	Complex interaction of risk factors, determinants, infectious triggers.	Identified infectious agent (may have other contributing factors).
public health intervention	Often at the population level - focus tends to be on population-based interventions (e.g. screening) rather than individual treatment interventions.	At the individual and population level - focus is on case-based reporting with follow-up as well as population-based interventions.

issue	chronic	communicable
data sources	It is practical to exploit existing databases that are not usually designed for surveillance.	For notifiable communicable diseases, individual reporting of cases (may be with identifiers) and clinical details in surveillance databases.
data collection	Tends to be event-oriented at present (i.e., number of hospitalizations for AMI in past year at institution X).	Often person-oriented (i.e., 25YO female with hepatitis B, reported to health unit).
legislation and regulations	With the exception of legislation around the reporting of cancer, no legislation for reporting of chronic disease.	Specific statutes and enforceable regulations aimed at containment and eradication.
co-morbidity	Diseases often co-exist: heart disease & diabetes - Important for service planning. Treatment for one has impact (positive or negative) on another. Surveillance of one risk factor applicable to prevention/control for several diseases.	Occurs (not as commonly), with similar implications: HIV infection and hepatitis C, and/or tuberculosis.

Temporality is a significant difference. Generally, communicable disease has adjacent causality - exposures and other causal factors are in effect a short time before expression of disease. This shortens all aspects of the surveillance cycle and heightens the importance of timeliness at each step. In chronic disease, latency is important; the impact of causal factors (including behaviours) accumulates over time, often beginning decades before clinical disease becomes apparent. Chronic disease has a protracted course, with both asymptomatic and symptomatic phases. Responses and outcomes related to preventive interventions and treatments are also subject to long lag times, and this lengthens the period of the surveillance cycle. In addition, the causes of chronic disease are often multi factorial: behavioural, occupational and environmental risk factors; genetic predisposition; socio-economic determinants and infectious triggers. The causal and temporal complexities of chronic disease require that surveillance of individual patients occur over a long time period (from diagnosis through treatment, palliation and death). There may also be a significant retrospective element to chronic disease surveillance, in order to consider the effect of determinants.

Thus, in terms of public health control measures, one focus for chronic disease is primary prevention that may not result in immediate control and eradication. Conducting surveillance on major risk determinants that can be modified gives the information needed to inform sound and effective health policy that in turn leads to effective control and prevention of major chronic diseases in the population. Another focus is the continued monitoring of: morbidity and mortality for health service planning, screening for secondary prevention, and evaluation of interventions (both clinical and policy).

The following scenarios are provided to further highlight and compare some of the issues concerning communicable disease and chronic disease surveillance.

Scenario 1: Communicable Disease

Jane Doe falls ill within hours of eating a chicken salad sandwich from restaurant A. She is seen at the emergency department of the hospital and treated for GI symptoms, all of which are recorded, along with a brief food history. This data collection was triggered by a cluster of 10 other cases coming to the same emergency department within the last 24 hours. The information for all cases seen is transmitted to the public health office on the same day. The chicken salad from Restaurant A is implicated as the likely source of contamination, and inspectors visit the site for follow-up action (testing of food, inspection of food handling practices, testing of food handlers).

The regional epidemiologist reviews reports of food borne outbreaks in the area on a weekly basis - this latest episode is added to the database, and further analysis shows an excess of cases associated with eating in Restaurant A over an extended time. Restaurant A's food licence is subsequently withdrawn.

Scenario 2: Non-Communicable Disease

In the six years since Jane Doe's heart attack at age 45, she has made attempts to modify her lifestyle. She has put on 35 pounds since quitting smoking. Jane is a single mother of two preteen children, and has just been laid off from her job. Jane takes oral medication, has regular checkups with her family physician and also sees a cardiologist once a year. Six weeks ago, she enrolled in a public health nutrition/activity clinic to try to reduce her weight. Recently, she has experienced bouts of dizziness, fatigue, and excessive thirst. Jane is booked for her annual cardiac exam later this week.

The regional epidemiologist is working with the regional health authority to gather the available evidence for a service planning exercise within the region where Jane resides. She reviews reports of cardiovascular disease prevalence for the province, results from the most recent survey on dietary intake (national survey in 1970s), physical activity from a local survey, reports of cardiovascular disease and diabetes prevalence in the region (from the Canadian Community Health Survey), outcome data generated through the region on wait times for cardiac diagnostic procedures, and some of the most recent socioeconomic indicators for the province from the 2001 National Census. From this data, she generates a model for estimating future demands on the region, thereby helping the Regional Health Authority to manage future service delivery issues.

In the case of the communicable scenario, effect follows closely on cause - there is an opportunity to intervene and limit further episodes of illness, both on an individual and population level, and detailed, pertinent information is available immediately at an individual level. Information related to Jane's health and clearly associated with Jane is captured for surveillance at several points - through the physician visit, the laboratory report from the sample, and the inspector's visit to the restaurant. In addition, as there is very little lag time between Jane's exposure, diagnosis and treatment, there is also a short surveillance cycle: data collection on exposure and diagnosis, the analysis and interpretation of data, and the subsequent preventative action - completed within days, with prevention of further cases achieved.

For the chronic scenario, the process becomes more complicated, and the surveillance cycle is not as well circumscribed - the epidemiologist must select and relate various elements from numerous sources to obtain the measures of interest. The factors most amenable to public health intervention are the precursors to disease, and they are present years before disease becomes evident. Therefore, most of the opportunities for effective intervention for Jane have passed by. Some of the risk factors for the disease and complications are simply not known on an individual level, and there are future issues for planning related to co-morbidity. Ideally, Jane's multiple contacts with the health care system would be captured longitudinally so that an

individual level there would be a link between Jane's risk factor information and Jane's outcomes. This information would then be used for both clinical decision making for Jane, and also allow for population based analyses to identify risks that can be modified or interventions to reduce or eliminate complications. Although all of the information sources used by the epidemiologist are useful for health planning that will benefit Jane in the future, none are likely to effect an immediate change in Jane's risk profile or health outcome, and the planning action will not, in the short term, prevent more cases like Jane's from occurring.

2. Chronic Disease Surveillance in Canada - Current realities

2.1 The scope of and data requirements for chronic disease surveillance

As noted in the previous section and illustrated in Figure 2 below, surveillance for chronic disease necessitates a broad scope approach, encompassing: determinants, risk behaviours, environmental influences, disease manifestations, treatments, other interventions and outcomes.

Figure 2: The Scope of Interest for Chronic Disease Data[15]

Determinants ←	Pre-clinical ←	Clinical ←	Outcome
DATA EXAMPLES: **genetics:** *prevalence of breast cancer gene* *familial disease* **risk behaviour:** *smoking* *dietary fat intake* **environment:** *occupational exposure* **socioeconomic:** *housing* *income level* *education*	**DATA EXAMPLES:** **screening:** *PAP testing* *blood pressure* *blood glucose* **risk reduction:** *smoking cessation program uptake* *physical activity rates*	**DATA EXAMPLES:** **diagnosis:** *modes of diagnosis* *time to diagnosis* **treatment and procedures:** *surgery* *systemic therapy* *radiation* *palliation* **service use:** *hospitalization* *physician visits* *home care* *ambulatory care* *palliative care* **pharmaceutical:** *drug use* *complications and interactions*	**DATA EXAMPLES:** **mortality:** *cause specific deaths* *survival rates* **morbidity:** *complications* *degree of disability* *quality of life*
DATA SOURCES*: *surveys* *census* *workplace monitoring*	**DATA SOURCES*:** *screening databases* *surveys* *public health program databases* *primary care physicians*	**DATA SOURCES*:** *hospital databases* *Discharge Abstract Database* *registry data* *provincial data repositories*	**DATA SOURCES*:** *vital statistics* *coroner's database* *multiple causes of death*

* these are potential sources, not necessarily currently available

The constraints and conditions outlined in section 1.4 also have implications for the continued development of chronic disease surveillance, particularly when the pertinent measures (including outcomes, exposure factors, prevalence and incidence) come mainly from existing structures, resources, expertise and data sources.

2.2 Data Sources - The Current State

The data are obtained, with some exceptions, in a diffuse, repetitive and fragmented fashion. For example, information on acute MI occurrence in Canada is derived through the hospital

inpatient record system, with hospitalizations (events, not persons) recorded by clinical code, and selected patient characteristics added (age, gender, location of hospitalization). Information about the risk factors for acute MI, such as smoking, dietary factors, activity levels, coexisting disease and determinants of disease and outcome (socioeconomic data, mental health, genetic predisposition) are found through surveys, research data bases, registries and hospitalization records. Although it is technically possible to link such records via unique identifiers, there are often issues around privacy, confidentiality and completeness of identifiers that must be dealt with in order to build longitudinal records.

Some of the information that has the greatest impact for primary prevention - determinants, risk behaviours and environmental influences, may not be available at all.

Access to data can be problematic; in addition to outright costs, the issues of acquiring rights to data, limitations on linking to other records, protracted waiting times, complicated access protocols and restrictive use agreements all have an impact on how available the data actually are. Within some jurisdictions, selected institutions are authorized to link data sets and undertake research. However, individual level risk factors may not be captured, although, from a clinical perspective, this information is used by practitioners to modify individual treatment regimens.

Even when access to data is relatively unimpeded, there are issues such as what constitutes the appropriate secondary uses of data, consent for use, and the practice of linking data sets - all affected by legislation existing within provincial, territorial and federal jurisdictions.

Most Canadian jurisdictions have legislation pertinent to health surveillance in general. Relevant statutes include: public health legislation respecting reporting requirements for notifiable diseases (very rarely applicable to chronic disease); freedom of information and privacy legislation, regarding access to and protection of government-held information; health information protection legislation specific to government-held health information; other privacy legislation establishing cause of action for individuals; health administration legislation such as that stipulating the powers and functions of a health ministry or administration of health insurance schemes; and vital statistics or other statistics legislation, such as the federal Statistics Act, that direct the reporting of vital events and the collection, analysis and publication of statistics.

Data sources for chronic disease surveillance are not ideal - they are not built for the purpose of surveillance, so there are often requirements for data transformation, for linkage to other sources of key information, for adjusting data sets to accommodate differences - all of which contribute to the “front-end” resource requirements for assembling the adequate data for surveillance.

Table 2 below outlines some of the major characteristics of the various data sources.

Table 2: Information sources currently used for chronic disease surveillance

source	information retrieved	considerations
administrative databases: designed for: case management, accountability & financial purposes, program delivery.	hospital discharge data health insurance files drug use files mortality, morbidity health services utilization	**Pro:** long period of data collection with many events often population-based relatively inexpensive **Con:** event oriented, not person oriented. Availability and quality vary amongst jurisdictions **However:** provided technical and privacy issues are addressed, linkage provides huge potential for longitudinal records with incidence and prevalence estimates. N.B.: capability for person oriented information (POI) now being developed at Statistics Canada.
registries: data from hospitals and treatment centres internally linked.	disease specific incidence mortality	**Pro:** high level completion with detailed information, including disease details, intervention and outcome information. **Con:** lag time between event reporting and final data confirmation. Can be expensive to maintain.
surveys: data derived from national and provincial/territorial surveys.	risk factor data self-report. disease & disability economic data demographics	**Pro:** population-based data for a range of health-related variables (risk factor information applicable to multiple diseases). Some potential for case ascertainment in self-reported disease and cases not requiring hospitalization. Can get some retrospective data. **Con:** not linked to outcome, and are less useful if not repeated frequently enough to detect trends. Self-reported data generally unconfirmed. General surveys may not reach special populations (e.g. hospitalized persons)
vital statistics legal requirement for collection	birth death	**Pro:** usually complete ascertainment of cases, nationwide collection of cases, and a large amount of data accumulated with which to track trends over time. **Con:** problems of record completeness, lag time in reporting, and interpretation of underlying versus immediate cause of death especially when linked to other sources. **However:** if linked, can provide outcome data.
census	population estimates births deaths (including cause-specific) economic data socioeconomic indicators	**Pro:** complete count of population provide denominator data

2.3 Existing Initiatives

There are several surveillance systems for chronic disease in Canada. The most well established is the system using cancer registries, covering the whole population, with all provincial and territorial registries reporting to the Canadian Cancer Registry (CCR). Although the registries differ somewhat in their approaches and methods, procedures for registration are fairly consistent, and comparable data for surveillance are reported up to the CCR level. The CCR has the capacity for internal linkages and has developed the potential for linkage with other health information sources. It is also noted that work on cancer therapy surveillance is

now underway through the Canadian Cancer Surveillance Alliance as well. The system is managed by a partnership between provincial/territorial cancer registries and the Health Statistics Division at Statistics Canada, and information is released annually. Coverage for incidence data is estimated to be at least 95%.[16] A combination of financial incentives, policies, and enabling legislation has helped to maintain the effectiveness of this system.

There are other disease registries who have also instituted surveillance operations in Canada. The Canadian Organ Replacement Registry, managed by CIHI, organizes organ replacement and end stage renal failure records for all 84 organ replacement centres. The Canadian Trauma Registry has accommodated the records of all Ontario accidental injuries and is currently expanding to cover all Canada. Also, the Institute for Clinical Evaluative Sciences (ICES) has recently received Canadian Institute for Health Research (CIHR) funding to develop a Canadian stroke registry.

The more recently established National Diabetes Surveillance System (NDSS) employs a pragmatic approach by utilizing linked administrative data, originating in provincial/territorial jurisdictions (with varying capacity for data collection and analysis), to provide national level surveillance information on diabetes. The functional model involves linkage of health administrative databases, application of standard algorithms for case definitions, and production of nationally comparable data on diabetes prevalence, incidence, mortality, co-morbidity and health care utilization.[17] A project is now underway to test the feasibility of this methodology for several cardiovascular diagnoses.

A new surveillance initiative with a focus on palliative/end-of-life care is now in development, under the auspices of the National Action Plan on Palliative/End of Life Care.

Provinces and territories use their own health services administrative data sets to conduct some surveillance activities, and in some cases, also develop the information systems: Alberta We//net, Saskatchewan's Health Information Network, and B.C. HealthNet, for example. Ontario's Institute for Clinical Evaluative Services (ICES) has a repository of administrative data that provides data for the production of annual statistical reports, among other uses. CIHI maintains and extracts from administrative databases data relevant to system performance, health care utilization, and indicators of population health. The data are drawn from a variety of sources, including the Discharge Abstract Database (DAD) and the Hospital Morbidity Database. Data are used within CIHI as well as externally.

Examples of Canadian surveys used for chronic surveillance include the Canadian Tobacco Use Monitoring Survey (CTUMS), which concentrates on tobacco-related risks and provides timely estimates of tobacco use trends. In addition, the longitudinal National Population Health Survey (NPHS), with linkages to mortality and morbidity databases, has the potential for some long term follow-up surveillance on a selected population, and the Canadian Community Health Survey (CCHS), with information collected at the health region level, consists of core components and customized components to reflect regional needs, to be collected in two year cycles. The survey covers health determinants, health status and health system utilization. The CCHS seeks permission from individuals to link survey results to provincial medical records for longitudinal data.

In terms of vital statistics, Statistics Canada's records of births and deaths are used at local, provincial/territorial and national levels for surveillance purposes (i.e. Canadian Perinatal Surveillance System), and mortality files are used in a number of initiatives that track outcomes.

The data collected every five years in Canada's national census, together with inter-censal population estimates, provide the geographic distribution for denominator data. In addition, socioeconomic data from the census form the basis of the non-medical determinants of health in the Health Indicators Framework (developed by CIHI and Statistics Canada), including, but not limited to, education levels, unemployment levels, and housing.

As previously noted, in most cases, surveillance initiatives have relied on passive surveillance methodologies using secondary data sources: administrative data sets, vital statistics, disease-specific registries, surveys and censuses. However, there have been more recent efforts worldwide to establish active surveillance for chronic disease: the WHO's SEARCH program for cancer, and CINDI for cardiovascular disease, for example. In addition, several European countries, under WHO leadership, have applied a sentinel health event approach for chronic disease surveillance. The CDC has also developed a mixed scheme of passive and active surveillance for chronic disease. Development of chronic disease surveillance infostructure should consider such approaches and maintain the ties necessary to allow for collaboration and eventual international comparability.

2.4 Roles and responsibilities for surveillance

Public health surveillance for chronic disease is fundamentally a responsibility of governments, at federal, provincial and territorial levels, with responsibility further distributed at the regional and local level. All jurisdictions have the responsibility for protecting and maintaining the privacy and confidentiality of data. Provincial/territorial data are compiled into national datasets, usually in the data holdings of CIHI, Statistics Canada and Health Canada. However, it is Health Canada and the provincial/territorial jurisdictions who have the responsibility for development of policy and programs in response to the surveillance information.

The Canadian Institute for Health Information(CIHI) is mandated to coordinate the development and maintenance of a comprehensive and integrated approach to health information for Canada; and to provide and coordinate the provision of accurate and timely data and information. Current core functions relevant to chronic disease surveillance include: conduct of special studies and health services research, development of national indicators and survey instruments (in partnership with Statistics Canada), development and maintenance of databases and registries, access to health data, production and dissemination of reports, and standards development.

Statistics Canada's responsibilities relative to health surveillance include: production of health-related statistical information and analysis, and promotion of sound standards and practice, allowing for: greater efficiency in data collection; less duplication; use of data-sharing agreements; and use of common concepts and standards for better quality data. Statistics Canada is responsible for the conduct of national surveys used in surveillance, related to risk factors, behaviours, determinants, and health indicators, screening and outcomes, as well as for the Canada Census.

Health Canada conducts surveillance as an essential component of its regulatory mandate. It also has a leadership role in ensuring that all orders of government can undertake health surveillance. This is accomplished through the promotion of partnerships, development of standards, enabling of linkages, and provision of support and expertise. Health Canada's mandate touches on all steps in the surveillance cycle, placing emphasis not only surveillance

and analysis, but also on interpretation of health information for public information, health policy and decision making at the national level. Within Health Canada, the Centre for Chronic Disease Prevention and Control has a long history of surveillance of risk factors and chronic disease trends. The First Nations and Inuit Health Branch (FNIHB) of Health Canada is directly involved in health surveillance through the provision of primary health services and public health programs in First Nations communities.

Although not directly involved in the conduct of surveillance, the Canadian Institutes for Health Research are in the position to both contribute to and benefit from health surveillance. In particular, The Institute for Population and Public Health is providing the opportunities to strengthen existing partnerships with relevant program areas: Health Canada, CIHI, and Statistics Canada that will advance population health. The IPPH is also working with Health Canada to facilitate the exchange and translation of knowledge into policy and practice; essentially the mechanism allowing surveillance findings to inform public health practice.

3. Why enhance chronic disease surveillance?

3.1 Benefits of chronic disease surveillance

Chronic disease is a major contributor to the burden of disease in Canada; cost estimates produced from 1993 data show that cancer, cardiovascular disease, diabetes, chronic respiratory disease and musculoskeletal disorders account for half of the 156.9 billion dollars in direct and indirect costs. Clearly, strategies for the prevention and control of chronic disease must continue to be implemented to address this burden, and surveillance is a foundation of any such strategy.

Comprehensive surveillance yields information across the full spectrum of chronic disease. It provides information on the distribution and trends for determinants and outcomes, provides profiles of sub-populations with elevated risk; estimates the burden of a disease in a population, and associated health care utilization; informs allocation of resources and services (at local, provincial and national levels); and provides, over time, evidence of effectiveness of interventions.

Surveillance information can guide appropriate responses: screening programs; public information messages; development of best clinical practice (e.g., protocols for combined sexually transmitted disease and Pap screening, given the link between human papilloma virus and subsequent cervical cancer); monitoring of performance indicators; and identification of optimal points for intervention. Good surveillance can also help researchers target and refine their areas of study in etiology, clinical interventions and other areas.

A combination of surveillance and research data may be used to estimate future disease burden in the population based on both current risk factor prevalence and analysis of health service utilization patterns. This information can help anticipate future impacts on health care services.

From all of these points comes information for planning - creation and placement of services, identification of under served areas and barriers to access, and identification of subsets of the population with special requirements.

Surveillance is also necessary to provide timely and credible information for quality assessment improvement, and tracking of indicators of health system performance relative to quality and cost - the interim report on Canada's Commission on the Future of Health Care in Canada identifies improved accountability as a way to address quality issues in the health care system, citing the need to continue to develop and share consistent, comparable, timely information about health outcomes. At the national and provincial/territorial levels, the evidence to indicate progress made in meeting health targets comes from surveillance; and this extends to regional health authorities as well, who have a significant role in the planning and delivery of a full spectrum of health services.

Table 3 below provides some Canadian examples of the use of surveillance information for monitoring, making projections, planning and policy development, evaluation of interventions and programs, and accountability.

Table 3: Examples of the Uses of Surveillance Information [17, 19-31]

uses	examples	result (R) and action taken (A)
Monitoring of health events	Population-based database of cases of clinically diagnosed diabetes in Manitoba, 1986-1991.	**R**: increased age-adjusted prevalence. **A:** inauguration of the National Diabetes Surveillance System (NDSS), part of the National Diabetes Strategy.
	Analysis of numerous sources of surveillance data and economic data.	**R:** ***Economic Burden of Disease in Canada*** report. **A:** Monitoring of direct and indirect health costs.
Early warning of health events and projections	Household population database used to examine the prevalence of respiratory diseases in children exposed to environmental tobacco smoke.	**R:** Evidence for a possible epidemic of chronic respiratory disease in the population due to environmental tobacco smoke. **A:** Health agencies used results in efforts to enact legislation re. smoking in public places.
	Utilization of several large databases, including the Canadian Mortality Database.	**R:** Estimate of the impact of the decreased prevalence of smoking in Canada. **A:** Dissemination of prevalence projections made for 1999, 2009 and 2019.
Development of interventions and programs	Study using linked hospitalization and death records.	**R:** Patterns of recurrence and survival of patients following first acute myocardial infarct. **A:** Redesign ambulance service in NS and SK.
	NPHS database used to monitor risk factors for diabetes, based on large scale population-based database.	**R:** monitoring risk factors for diabetes **A:** formulation of practical recommendations for public health agencies
	Analysis of national surveillance data on Chronic Obstructive Pulmonary Disease (COPD).	**R:** The COPD Strategic Plan. **A:** input taken to the PEI Strategic Plan for COPD Prevention and Control.
	Analysis of available asthma surveillance data	**R:** ***Asthma in Canada Report/ Strategic Plan***. **A:** Provided direction for the Ontario Ministry of Health's Asthma Prevention and Control Strategy.
Evaluation of interventions & programs	Assessment of current CVD prevalence, treatment and behavioural risk evidence, including surveillance results . Cervical cancer screening surveillance.	**R:** National CVD committee review . **A:** made evidence-based recommendations for health care professionals on lifestyle changes to prevent and control hypertension in adults. **R:** Cervical Cancer Screening Surveillance Rpt 1998. **A:** provided surveillance information on screening practices across the country
Accountability	Analysis of existing information on health, use of health care services, availability of services, expenditures.	**R:** 21 measures describing Manitoba's health care system. **A:** Produced report used for public accountability: ***Health in Manitoba: Are we doing better?***
	Analysis of health care services, expenditures, human resources, outcomes of care.	**R:** Range of performance measures for the Health Indicators Report, at both regional and provincial/territorial levels. **A:** Produced and disseminated the Health Care in Canada 2002 report, used for public accountability.

4. Defining business requirements for chronic disease surveillance

4.1 Framework for business requirements for surveillance functions

The business requirements for sustainable chronic disease surveillance are the conditions under which data can be regularly and efficiently collected, analyzed, interpreted and disseminated to those who need to know, in order to undertake the actions needed to protect and improve the health of Canadians.

Appendix 2 contains the framework for defining the business requirements for chronic disease surveillance (with a focus on use of secondary data sources), organized by the six core functions of surveillance as seen in Figure 1: data collection, data integration, data analysis, interpretation, development of surveillance products, and dissemination. The framework is intended as a guide for developing disease-specific requirements; the detailed disease-specific business requirements for specific chronic diseases preclude the direct application of the framework, as all components are not applicable to every chronic disease.

The framework contents, developed in a recent workshop (see Appendix 3 for workshop participant list), have been summarized and regrouped into the five essential components of the Canadian Health Infostructure (organization and people; process; information; technology and standards), as outlined in the ACHI Tactical Plan[4].

4.1.1 Component 1: Organization and people

This component concerns the people, agencies, groups and organizations involved in chronic disease surveillance.

Key players in chronic disease surveillance include the individuals from whom health information is collected, the health care providers who produce and use the surveillance data for planning and intervention at every level, and the organizations that conduct surveillance or use surveillance products. The legislation and policy frameworks that pertain to the surveillance cycle also comprise this component.

The related business requirements are:

1. Provision of adequate human and financial resources at all levels.
2. Provision of the means and training to fully use new technologies applicable to surveillance.
3. Adherence to jurisdictional privacy and confidentiality requirements.
4. Adequate university level preparation of health professionals in health surveillance.

4.1.2 Component 2: Process

The bulk of health surveillance business requirements are grouped within this component, reflecting the actual conduct of health surveillance - from data collection through to development of surveillance products and dissemination. However, there is considerable overlap with the remaining components, and some of the requirements will be further explored in the subsequent sections.

In terms of the surveillance process, the business requirements are:

1. A clear definition of the purpose of surveillance, with a link between information produced and achievable actions.
2. A surveillance cycle that is timely.
3. Knowledge transfer processes that make available, at the outset, existing surveillance information, contextual information and surveillance processes, so as to avoid duplication of effort and additional expenditures;
4. Identification of the types of data to be collected and the likely sources, for either primary data collection or for acquiring existing data.
5. Ability to assess data quality and make required enhancements and adjustments.
6. Ability to conduct the appropriate analyses of the surveillance data.
7. Provision of the mechanisms to allow consultation with subject area experts during analysis of data and interpretation of findings.
8. Access to resources and expertise that will allow production and dissemination of results in meaningful ways.
9. Adherence to best practices for knowledge transfer to maximize the likelihood of evidence-based action.
10. Provision for documentation, thereby creating appropriate metadata

4.1.3 Component 3: Information

The information component for health surveillance is concerned with data sources, data quality and access. The attendant business requirements are:

1. Stable and affordable access to regularly updated data that represent the population of interest.
2. Ability to obtain and use data from a variety of sources.
3. Partnerships, protocols, financial resources and specific agreements to permit data sharing and/or data transfer.
4. Access to metadata for all sources, delineating the method of collection, underlying population, and the attendant limitations of the data.
5. Ability to transform, and integrate and/or link disparate data sources.
6. Ability, under some circumstances, to link data in order to create person-oriented longitudinal information.

4.1.4 Component 4: Technology

Chronic disease surveillance requires the development of data warehouses and data marts in order to provide the depth and breadth of data for the detailed analyses that are needed for chronic disease surveillance. This requires technology and applications for improved data exchange, transfer and linkage. Additionally, there is the requirement to fully exploit the potential applications to the EHR. For example, along with facilitating the transfer of standard format data for health surveillance, applications could permit the timely return of both population level information and individual level information, such as automated prompts for screening based on patient level profiles.

The business requirements are:

1. Applications to fully use available information management applications.
2. Provision of technology and applications for data warehousing and data marts.
3. Provision of the technological base to permit routine transfer of data and information across systems.

4.1.5 Component 5: Standards

Within the standards component are the business requirements that apply to all aspects of health surveillance; first to facilitate the sharing and use of health information in the data collection/integration phase, to permit the comparability of results across time and location in the analysis/interpretation phase, and to express results in standard and unambiguous terms in the surveillance products/dissemination phase. It is crucial that experts in chronic disease surveillance be included in all aspects of the standards process, to provide the necessary expertise to deal with case definitions, the coding and classification standards that may vary across time, jurisdictions and users.

The business requirements include:

1. Process and mechanisms for identification and adoption of data standards: case definitions, definitions for risk factors and behaviours.
2. Availability of standard methodologies.
3. Achievement of interoperability for all systems used in surveillance.
4. Adherence to technical standards.
5. Identification of the various minimum data elements for national surveillance.

4.2 What is needed to enhance chronic disease surveillance?

Canada is moving towards the establishment of electronic health records that will track health information at the level of the individual - perhaps the ultimate solution to enhancing chronic disease surveillance. However, this is not an immediate solution**,** and action is needed in a number of areas to make current surveillance processes more effective (Table 4 below). When reviewing this information, it is important to keep in mind that good surveillance does not depend on perfect data and a perfect system - it depends on adequate data, available with enough detail, consistency and regularity to describe trends, and thereby provide a basis for action.

Table 4: Chronic disease surveillance: Gaps and solutions

component	existing gap	possible solutions
Component 1 Organization and people.	Human resource development: shortages and inadequate preparation of those now working.	Develop learning modules. ✓ Contribute to development of graduate studies in surveillance.
	Policy development re: data access, linkage, privacy, security , privacy impact assessments and data sharing agreements.	Address confidentiality and privacy issues that may jeopardize current systems. ✓
Component 2 Process	Surveillance lacking on: broader determinants of health, knowledge, attitudes and behaviours for screening, uptake and impact of screening, treatment practice patterns and influence on outcomes, palliative care service utilization.	Increase capacity to collect a full range of data for chronic disease.
	Knowledge transfer: Surveillance products not always disseminated to those who will take action; not presented in understandable formats; not timely enough; large volumes of pertinent information are not easily managed.	Develop applications to present information in a manner that facilitates use for public health actions. ✓ Champion use of information for evidence-based decision making and policy-making. ✓
	Validation and evaluation lacking for chronic disease surveillance: objectives; information leading to action; system operating effectively.	Develop outcome validation & evaluation frameworks for chronic disease surveillance.
Component 3 Information	Numerous data sources in use, with variations in data quality, degree of completeness and applicability.	Develop frameworks for routine assessment of data quality in databases for surveillance.
	Information on existing data sets and initiatives not readily available.	Develop inventory of chronic disease surveillance, including access protocols and metadata. ✓
	Difficulties in obtaining person-oriented longitudinal information.	Participate in the development of the electronic health record (EHR) to ensure inclusion of data elements for surveillance - including identifiers and privacy concerns.
	Lack of current information on some cross-cutting issues (i.e.,nutrition) .	Invest in ongoing data collection, i.e. surveys.
Component 4 Technology	Inadequate development of tools and methods for linkage of existing databases .	Invest in data linkage; develop applications and methods. Improve the electronic integration of databases or summaries thereof.
	Lacking the applications to permit automated analysis of data.	Develop analysis applications , with functionality for EHR use.
Component 5 Standards	Need access to standard: case definitions , determinant/risk factor questions and screening questions .	Develop inventory of case and risk factor definitions, data collection instruments, and coding. ✓
	Existing problems with incompatibility of systems.	Adopt standard methodologies for collection at all levels Develop and/or adopt technical standards.

Note: ✓ indicates work currently underway within the Centre for Surveillance Coordination.

5. Options for Action

5.1 Current State

As noted, several models for chronic disease surveillance exist in Canada:

1. Registry based surveillance (provincial cancer registries, CCR, Canadian Organ Replacement Registry);
2. Health administrative database type surveillance (Canadian Mortality Database, Hospital Morbidity Database, Canadian Diabetes Surveillance System);
3. Record linkages using administrative databases (Canadian Diabetes Surveillance System, POI development at Statistics Canada); and
4. Survey based surveillance for risk factors (Canadian Heart Health Survey, National Population Health Survey, Canadian Community Health Survey)

There is no single model for chronic disease surveillance at present on which to base a national system that will serve all interests. While registry-based surveillance offers high quality data, it is expensive and methodologically not suited to all areas of interest. Other methods must be used, including continued use of administrative databases and development of record linkage methods. At the same time, given the reliance on secondary sources of data, there is a requirement for the development of a dedicated resource for the ongoing application of validation and evaluation techniques for all methodologies; for example, the continued use of registry data and establishment of sentinel surveillance to ensure the capacity for validation of record linkage.

5.2 Necessary steps and options for action

The Chronic Sub-Group's goal was to build capacity for chronic disease surveillance, using strategies that are congruent with the ACHI Tactical Plan.

The Sub-Group's overall approach was to build on the concepts and values initially presented in the vision for chronic disease surveillance, including stakeholder involvement using collaborative, consensus building approaches, establishing and maintaining momentum by recognizing lessons learned, building incrementally on existing initiatives and a staged method to move from the simple to the complex in enhancing national surveillance capacity.
The intent is to strengthen existing surveillance capacity, by developing common tools, methods and other infostructure. Successful integration of effort will improve surveillance for chronic disease to the point where reliable, high quality surveillance information can be consistently produced at a national level.

The Sub-Group consulted on the vision, initiated some partnerships and collaborative projects, and produced a situational analysis on chronic disease surveillance capacity issues. With the development of the Background Paper, the Sub-Group also articulated a number of next steps.

5.3 Priority option

The Chronic Sub-Group identified the need for a national reference group with a staffed secretariat to assist in developing a strategy to improve chronic disease surveillance capacity in Canada. It was suggested that the group comprise chronic disease surveillance stakeholders, reflecting disease-specific content knowledge, surveillance expertise, provincial/territorial and regional public health experience, academia, non-governmental organizations, the federal government, and institutes such as CIHI and CIHR. The work of the group would include the following tasks:

1. establish surveillance priorities;
2. identify projects to address priorities;
3. foster continued collaboration between the Centre for Surveillance Co-ordination and the Centre for Chronic Disease Prevention and Control;
4. direct the secretariat to develop requests for proposals, administer contracts and perform general co-ordinating duties.

Initial project areas are outlined in Table 5 below. These are based on the tasks already identified in previous consultations, and include continuation of the work already initiated by the Chronic Sub-Group. As previously noted, the proposed model is one of integrated efforts in areas of common concern across surveillance initiatives. The table illustrates this by identifying areas of work that are within the scope of individual initiatives, and those that will have an integrated national focus.

The likely priority areas, consistent with WHO's identified chronic disease priorities, include three disease entities and their associated risk factors; cancer, cardiovascular disease and diabetes, with the risk factors of smoking, diet, physical activity, and selected physical measures. Following this, the project will focus on less well developed surveillance areas including arthritis, mental illness and some of the determinants of health.

Recent operational changes pertaining to Health Canada's federal/ provincial/ territorial advisory committees of the Conference of Deputy Ministers have resulted in the creation of several new groups, including the Advisory Committee on Population Health and Health Security (ACPHHS). A priority area under the ACPHHS is development of surveillance systems for chronic disease risk factors. The proposed Surveillance Systems for Chronic Disease Risk Factors Task Group of ACPHHS will work to provide evidence-based policy advice to strengthen the ability of federal, provincial and territorial jurisdictions to undertake surveillance for chronic disease risk factors. It is recommended that this paper be provided to the new Task Group, and that an oral presentation on the Background Paper be made to the group by representatives from the Chronic Non-Communicable Disease Surveillance Sub-Group.

Table 5: Activities for Enhancing Chronic Disease Surveillance Capacity

surveillance area	stand-alone activities	integrated activities - projects (co-ordination council)
Established surveillance systems and initiatives using a variety of methodologies: - Registry Oriented Chronic Disease Surveillance - Administrative Data Oriented Surveillance - Record Linkage Based Disease Surveillance - Survey Oriented Risk Factor Surveillance	All current data will be collected, linked, and analyzed by existing providers/owners.	Develop inventory of initiatives (with metadata) with the cooperation of participating initiatives. Identify minimum core data sets for national level reporting. Make core data available for multiple levels of government surveillance analysis. Coordinate analysis ➜ dissemination of national level surveillance data.
Quality Assurance, Validation, Evaluation	Continued internal quality assurance activities within initiatives	Develop outcome validation and evaluation frameworks for chronic disease surveillance. Establish national sentinel surveillance system. Establish and maintain national and international links to develop network of expertise.
Standards Development	Knowledge transfer practices to share standard definitions, methodologies.	Develop inventory of case and determinant definitions, data collection instruments, and coding. Adopt standard methodologies for collection at all levels Develop and/or adopt technical standards. Participate in the development of the electronic health record (EHR) to ensure inclusion of standard data elements for surveillance.
Training		Contribute to the development of graduate level preparation for chronic disease surveillance. Participate in development of training materials, such as identification of necessary skills and content for chronic disease surveillance skills training.
Communication and knowledge transfer	Continued initiative-specific activities.	Develop the mechanisms to efficiently and effectively utilize surveillance information allowing surveillance intelligence to be communicated to policy and program managers Promote inventory of chronic disease databases Highlight chronic disease surveillance capacities, outputs, benefits and accomplishments Disseminate information on chronic disease surveillance to the public, as well as public health sector and other stakeholders.

5.4 Partnerships for moving forward

The following table is intended to illustrate the range of potential partners that could play an important role in enhancing chronic disease surveillance capacity:

Table 6: Potential partners and roles in enhancing surveillance capacity

task	partners	role(s)
system development	Health Canada	Lead role and facilitator for infostructure to ensure that all levels of surveillance possible in Canada.
	Provincial/Territorial Health Ministries	Develop provincial level surveillance system and contribute to development of national surveillance system/activities.
	NGOs	Direct the information needs, specify the system requirements.
	Health Institutes/WHO/US CDC	Provide/develop surveillance mechanism/techniques/methods and tools/instruments. Conduct treatment surveillance for special needs. Establish international collaboration to adopt/adapt/exchange experience and technologies with WHO, US CDC and other developed countries. Outcome validation and system evaluation.
	Health professionals	Develop case definitions/guidelines, establish standards & perform surveillance validation/evaluation.
data provider	Health Canada	Provide national level aggregate data.
	Statistics Canada	Provide national level aggregate data on mortality, morbidity, risk behaviour, determinants. Provide micro-data and controlled access to inked data files.
	Environment Canada	Environmental Pollution Database.
	Provincial/Territorial Health Ministries	Provide provincial/territorial level data.
	Canadian Institute of Health Information	Provide service use, morbidity data, some registry information.
	Institute for Clinical Evaluative Sciences	Provide sub-national registry data: Respiratory Disease Repository, Stroke Registry.
	Provinces/Territories	Provide service delivery data
surveillance implementation	Health Canada	Conduct national surveillance. Participate in international surveillance activities/programs. Perform international comparisons.
	Provincial/Territorial Health Ministries	Conduct provincial surveillance, compare with national data, participate in nationwide surveillance activities, provide local pictures and assist with local surveillance activities
	Medical Officers of Health	Analyze local picture. Compare with provincial and national picture Perform field investigation and public communication and consultation.

6. Conclusion

The Chronic Sub-Group's purpose, since its inception in 2000, has been to build capacity to undertake chronic disease surveillance in Canada. The focus has been on the underlying infostructure and cross-cutting supports required by decision-makers for them to do their work rather than on the program and policy content. This is in keeping with the mandate of the Health Surveillance Working Group.

The Sub-Group has worked to identify and document the requirements, existing gaps and possible solutions concerning what is needed to conduct chronic disease surveillance. This has progressed gradually, with a number of collaborations and partnerships being established along the way.

The recent decision from the Conference of Deputy Ministers of Health - to launch the *Task Group on Surveillance Systems for Chronic Disease Risk Factors* (reporting to the new Advisory Committee on Population Health and Health Security) - provides an opportunity to focus on development of surveillance systems for chronic disease risk factors.

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Glossary of Terms and Acronyms

chronic disease: A disorder characterized by a complex interaction of disease variables, as well as by long latent periods, with a prolonged clinical course and a non-communicable or communicable origin.[2]

determinant: Any factor, whether event, characteristic, or other definable entity, that brings about a change in a health condition or other defined characteristic.[19]

health infostructure: the application of communications and information technology in the health sector to allow the public, patients, caregivers, providers, managers, policy makers and researchers to communicate with each other, share information and make informed decisions about their own health, the health of others, and the health services system.[5]

interoperability: the ability of hardware and software from different vendors to understand each other and exchange data, either within the same network or across dissimilar networks; and, the ability of autonomous systems to work with other dissimilar systems. Interoperable systems interact through standardized interfaces. They are often loosely coupled and exchange information in an asynchronous manner. Interoperable systems can function without knowing the internal processes, functions, and data representations of other systems*

public health: Society's collective actions to ensure the conditions in which people can be healthy, with actions undertaken by the public health agencies, institutions, other agencies and individuals.[18]

surveillance: Tracking and forecasting any health event or health determinant through the ongoing collection of data, the integration, analysis and interpretation of that data into surveillance products and the dissemination of that resultant surveillance product to those who need to know.[5]

ACHI	Advisory Committee on Health Infostructure
ACPHHS	Advisory Committee on Population Health and Health Security
CCHS	Canadian Community Health Survey
CIHI	Canadian Institutes of Health Information
CIHR	Canadian Institutes for Health Research
HSWG	Health Surveillance Working Group
NPHS	National Population Health Survey

*Health Canada Infoway. Electronic Health Record Solution (EHRS) Blueprint: an interoperable EHR framework. July 2003

Appendix 1 - Chronic Non-communicable Diseases Infostructure Sub-Group Membership

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Appendix 2 - Business Requirements

Table A1:
Health Surveillance Business Requirements Using Secondary Sources: Data Collection

REQUIREMENT	RELATED ISSUES
Define surveillance purpose and what data will be collected - what the health issue is and which particular data sets are required to address issues.	Is this already being done at some level? Who will use the collected data? Will there be multiple users for the results - if so, how will duplication of effort be avoided? Are there "lessons learned"?
Determine the statistical power required.	Can the issue be addressed via: sentinel surveillance ? sub-population surveillance (i.e. hospitalizations)? population-based surveillance?
Define the level of data collection needed.	Local, provincial/territorial; has implications for the available detail, comparability from source to source.
Determine where existing data are.	May need to uses several sources of data. Identify best source or point of contact to collect needed data. May need data-sharing agreements.
Confirm availability of data.	Are there access, use rights to consider? Is linking to other data permitted? Is there an authority required for data access? Is there a cost for the data?
Ensure attention to privacy and confidentiality.	May need to conduct (and/or pay for) a privacy impact assessment (PIA). May be restrictions on linkage - use of individual level data.
Assess data source in terms of use for surveillance purpose.	What was original data collection method (standards, population, time of collection, validation)? Can the data be analyzed for valid results? What data are missing? Will linkage be required?
Determine what underlying population the numbers are from.	The data available may not be most relevant to population of interest
Determine the minimum requirements for the data elements - what *must* be collected.	Need to assign responsibility for priority setting of required elements ie. "must have" vs."nice to have"
Establish and document the standards: case definition standard indicators	Method of defining case may be governed in part by available data source
Establish/document data collection systems: standard code of practice for data collection evaluation of process data transfer protocols	Data dictionary Performance indicators for collection Pilot testing of collection may be needed Ensure adequate security

Table A2:
Health Surveillance Business Requirements Using Secondary Sources: Data Integration

REQUIREMENT	RELATED ISSUES
Review the collection documentation (metadata) and establish the decision rules for data cleaning.	Establish the parameters for each data element to define outliers, cutoffs and exclusions. Inclusion / exclusion criteria, how to for integration of data from different jurisdictions using somewhat different parameters.
Assess the adherence to quality standards or develop equivalencies where no standards exist.	Standards may vary form jurisdiction to jurisdiction. Must reconcile differences.
Clean data.	Are consistent values being used for variables? What are the missing values? Consider running "sub sample" analysis to identify problems in integration / cleaning process early.
Identify mechanisms for input of data for integration.	If electronic, define messaging standards. Establish manual process processes for bringing different sources of data together. Improve electronic data linkage methods/accuracy.
Identify data elements required for linking vs analysis.	Linkage variables (identifiers) removed after data sets are linked.
Identify who will do the integrating when there are multi-owners (funding, etc).	May be pre-determined in access agreement, license or data- sharing agreement.
Develop/use surveillance case definitions.	
Develop/use appropriate methods for combining data.	May be combining survey-sourced risk factor data with hospitalization-derived outcome data, for example.
Define methods for computing measures.	Will need to anticipate sampling weights and error estimates.
Define specifications for data marts.	May want to collapse and group data for meaningful outputs.
Identify any limits to data breakdowns.	Compare with other sources to verify. Seek feedback on problems with the data.
Identify the remaining data gaps for the proposed analyses.	
Clarify and document what the data means exactly.	Identify advantages / positive factors and limitations of the data in terms potential to address issues of interest.

Table A3:
Health Surveillance Business Requirements Using Secondary Sources: Data Analysis

REQUIREMENT	RELATED ISSUES
Define hypotheses	Use questions defined earlier to drive the analysis Ensure analyses are appropriate to hypotheses/issue
Prioritize outputs	Establish priority needs; for example, first run limited information backed up by more detailed analysis later.
Define basic standard requirements for data analysis: data elements methods population for standardization	Given the question, what is the minimum analysis needed. Consider basic triad of person, place, time (PPT) in analysis.
Determine the characteristics of the data, including limitations and impact on the analyses.	Read the documentation. Browse the data. Stratify before standardizing. Identify spurious relationships. Compare new data with old (quality and trends).
Assess whether the planned methods are appropriate: standardization techniques	Consider the value of both qualitative and quantitative methods; some qualitative and descriptive information can enhance the understanding of findings. Frame results in creative ways, ways that make people care. Remove data analyses that do not meet minimum standards.
Ensure analytic staff have the appropriate analytic tools and resources.	May need to purchase software license(s).
Develop new methods if needed	For example, prediction methods.
Understand the assumptions, limitations of the statistical methods used.	Are the statistical methods robust? Ensure measures of variability are reported with all measures / indicators.
Develop metadata on the methods.	Share code, experience and strategies. Share analytical methods and developments. Define and document the computer programs for analysis.
Always check the analysis and interpretation again.	Consider all sources of possible errors and biases and evaluate their effect. Have peers review the analysis.

Table A4:
Health Surveillance Business Requirements Using Secondary Sources: Data Interpretation

REQUIREMENT	RELATED ISSUES
Ensure the original issue/question is being addressed.	Need to maintain focus on the surveillance form the point of data collection.
Identify the client/target for the information to come from the data.	Make the data interpretation appropriate for the audience.
Anticipate linking interpretation to the required action.	Define the level of detail needed for the decisions to be made. What are the relevant policy areas? What potential actions could come out from the conclusions?
Define the limitations of the analysis / data / integration.	Know the limitations of the data quality.
Provide the context and relevance to help guide the interpretation.	Know characteristics of the population contained in the numbers. Interpret data in a context of "what is going on" eg. relate results to potential causes.
Determine whether the analysis is applicable across other disease entities.	For example, does the information on risk factor prevalence have an impact on diseases other than the one under surveillance?
Know the subject specific / clinical information.	Establish an environment for cooperation of analysts and content experts. Bring in content people. Use a panel of experts.
Always check the analysis and interpretation again.	Consider all sources of possible errors and biases and evaluate their effect. Have peers review the analysis.
Evaluate the significance of the findings.	Consider the statistical significance. Consider the significance in terms of medical importance, impact on lifestyle, families, social and economic impact, etc.
Select the measures resulting from analyses that best illustrate findings.	Use graphs and data charts to create visual images of the issue. Illuminate issues. Use contextual information to provide a more meaningful interpretation.

Table A5:
Health Surveillance Business Requirements Using Secondary Sources: Surveillance Products

REQUIREMENT	RELATED ISSUES
Formulate the essential message for primary focus.	Define the message clearly. Define the objectives for the products: policy development? legislative review/change? Keep the topic narrow to maximize the message.
Define the design and possible venues for the surveillance products.	Use media relations and communications specialists. Determine who advocates / lobbyists are.
Describe the target audience(s).	Identify the audience's information needs: use surveys, focus groups, environmental scans to determine for various groups what are most trusted and effective sources and venues.
Ensure the information can be tailored (various levels of detail) to the audience.	
Provide a variety of products for the same information: policy, politicians, general public, media, peers, recalls.	Make the products real (show the relative risk / problem). Produce the formats that best suit the venue types eg. peer-reviewed, Internet, fact / information sheets, briefing note and other.
Prepare for strategic dissemination - deliver prioritized information.	Prepare media releases in addition to reports - “set the stage”.
Ensure products are kept current.	Update at a frequency equal to the rate of change of situations pertaining to the product, or the degree of interest.

Table A6:
Health Surveillance Business Requirements Using Secondary Sources: Dissemination

REQUIREMENT	RELATED ISSUES
Develop a coordinated dissemination strategy.	Develop a marketing strategy - actively market, not just disseminate the information. Focus on the message.
Plan the time and effort for dissemination.	Assign resources. Needed for continued updating, evaluation and follow-up to disseminated information.
Relate the dissemination activities to the initial requirements for the surveillance .	Ensure relevance of disseminated products.
Identify methods to reach the maximum number of intended audience.	Use media relations and communications specialists. Determine who advocates / lobbyists are. Identify partners.
Ensure the dissemination is timely.	Use advance notification; media releases, e-mail alerts. Be ready to respond quickly when an opportunity to deliver message presents itself.
Exploit all opportunities.	Leverage dissemination activities with partners (ensure the same message is communicated).
Communicate the contributions of those involved from data collection forward.	Acknowledge partners. Send information back to the data provider(s).
Evaluate the process.	Are the same questions still being asked? Was data/information used for action, such as policy change? Is there feedback for the system (from all stages, from all audiences)? Use media scans, literature reviews, comments.

Appendix 3 - Workshop on Framework for Defining Business Requirements (Participants List)

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Ms. Deborah Jordan	Director, Health Surveillance Coordination Division Centre for Surveillance Coordination, Health Canada
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Ms. Margaret Herbert	Acting Chief, Injury and Child Maltreatment Surveillance, Centre for Healthy Human Development, Health Canada
Mr. Gary Catlin	Director Health Statistics Division, Statistics Canada
Ms. Lorna Bailie	A/Director National Population Health Survey, Statistics Canada
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