



# **Enhancing Capacity for Surveillance of Chronic Disease Risk Factors and Determinants**

**Advisory Committee on Population Health  
and Health Security Surveillance Systems  
for Chronic Disease Risk Factors Task Group**

*June 2005*



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Ce document est aussi offert en français sous le titre : *Accroître la capacité de surveillance des facteurs de risque et des déterminants reliés aux maladies chroniques*

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Report  
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*Prepared by*

Advisory Committee on Population Health and Health Security  
Surveillance Systems for Chronic Disease Risk Factors Task Group



# Table of Contents

Executive Summary. . . . .	ii
Mandate of the Task Group . . . . .	1
Context. . . . .	2
Principles for Comprehensive Surveillance . . . . .	3
Risk Factor Surveillance. . . . .	5
Building a Surveillance System . . . . .	8
Principles of Surveillance Systems . . . . .	11
Developing Capacity for Risk Factor Surveillance: Current Situation . . . . .	15
Coordination/Collaboration . . . . .	17
Identifying Data Requirements. . . . .	19
Data Collection/Collation . . . . .	20
Data Analysis and Interpretation. . . . .	23
Surveillance Products, Dissemination and Use . . . . .	24
Management . . . . .	26
Legislation and Regulation . . . . .	27
Summary . . . . .	28
Strategy . . . . .	29
Vision . . . . .	29
Goal . . . . .	29
Outcomes . . . . .	29
Recommended Strategic Areas . . . . .	29
Conclusion . . . . .	34
Appendix A: Surveillance Systems for Chronic Disease Risk Factors Task Group. . . . .	35
Appendix B: Consultations . . . . .	36
Appendix C: Schema of Coordinated System for Surveillance of Chronic Diseases . . . . .	37
Appendix D: Glossary of Acronyms . . . . .	39

# Executive Summary

The mandate of the Surveillance Systems for Chronic Disease Risk Factors Task Group<sup>1</sup> is to develop a strategy to strengthen Canada's capacity at all levels to coordinate and conduct surveillance for chronic disease risk factors and determinants to support evidence-based decision-making and monitor progress for initiatives such as the pan-Canadian Healthy Living Strategy.

The development of the strategy is based on the premise that all levels of government (federal/national, provincial /territorial, and regional/local) will enhance the efficiency and effectiveness of surveillance activity by working together.

## Current Context

Chronic diseases such as heart disease, stroke, asthma, cancer, chronic obstructive pulmonary disease (COPD), diabetes, obesity, arthritis and mental illnesses exert a significant burden on Canadian society. They are major contributors to poor quality of life, loss of productivity, hospitalization and other health care costs, and death. By a conservative estimate, the major chronic diseases account for \$83 billion per year in direct and indirect health care costs in Canada.<sup>2</sup> Communicable diseases also cause serious sequels among those with chronic disease; the control of chronic disease will have a positive effect on the control of communicable disease.

Much can be done to prevent these chronic conditions by translating existing knowledge about risk factors and determinants into effective policies, programs and services. Success requires interventions at both the community and individual levels, within the public health and primary care systems, in workplace and school settings, and in community programs. Surveillance is an essential knowledge tool to guide decisions about these interventions. It tells what is

happening in the population, for example the proportion who smoke or who know about the harmful effects of tobacco, or the proportion of municipalities that have tobacco control by-laws.

In spite of the importance of chronic disease and the potential for prevention, Canada lacks comprehensive systems at all levels of government for surveillance of these diseases and their risk factors and determinants. Decisions about programs and policies are based on less-than-optimal population-based information, in part because Canada has not developed an effective surveillance response to the transition from communicable to chronic disease as the dominant health problem.

Several recent events have intensified the need for high quality surveillance on chronic disease risk factors and determinants:

- ◆ The First Ministers Accord committed governments to work on a Pan-Canadian Public Health Strategy and set goals and targets for improving the health status of Canadians. Surveillance is an essential tool to monitor and measure progress on these commitments.
- ◆ Enhancing surveillance of chronic diseases has been identified as a top priority by the Public Health Agency of Canada, the Canadian Public Health Association, multiple institutes of the Canadian Institutes of Health Research (including Population and Public Health, and Nutrition, Metabolism and Diabetes), the Research and Surveillance Working Group of the Pan-Canadian Healthy Living Strategy, and the Chronic Disease Prevention Alliance of Canada (CDPAC), among others.
- ◆ Several organizations have been tasked with reporting on the health of Canadians – the Public Health Agency of Canada, Statistics Canada, the

<sup>1</sup> Quebec participated in the Task Group to share information. Quebec reserves the entire responsibility for planning and implementing surveillance activities within the province. Quebec will continue to exchange information and expertise with other governments of Canada but does not intend to participate in a pan-Canadian strategy.

<sup>2</sup> Health Canada. *Economic Burden of Illness in Canada, 1998*. Includes cancer, cardiovascular disease, digestive diseases, endocrine and related diseases, mental disorders, musculoskeletal diseases, nervous system/sense organ diseases, and respiratory diseases.

Canadian Institute for Health Information, and more recently the Health Council of Canada. The work of these organizations needs to be facilitated by a strong and well co-ordinated system for chronic disease surveillance.

- ◆ Pan-Canadian initiatives such as the Healthy Living Strategy and the Diabetes Strategy require surveillance data to monitor their impact on risk factors and health status at the population level.

## Current Capacity

The Task Group reviewed the literature, conducted key informant interviews, and held focus groups across the country<sup>3</sup> to identify strengths and weakness in the capacity to effectively conduct surveillance for chronic disease risk factors and determinants in Canada.

### Summary of Strengths

- ◆ Surveillance is recognized as a core public health function at all levels.
- ◆ Many public health organizations are actively involved in creating the components for effective surveillance.
- ◆ Nationally-led initiatives have identified some of the key indicators for surveillance.
- ◆ Several ongoing population-based databases provide needed data at the national, provincial/territorial and sometimes the regional level.
- ◆ The investment in the National Diabetes Surveillance System that uses physician billing, hospital, laboratory and pharmacare and mortality data has built some capacity within provinces and territories to use these databases for surveillance.
- ◆ The Regional Health Survey coordinated by the National Aboriginal Health Organization is able to collect data from First Nations reserve communities.
- ◆ Some staff training and development is provided by federal government, academic centres and public health organizations.

- ◆ A variety of dissemination approaches are used, including reports and web-based access to aggregate data and tables.
- ◆ Coalitions, public health organizations, non-government organizations and government have used surveillance information to shape policies.
- ◆ Standards have been developed for some indicators and data collection methods.
- ◆ Some initiatives are collating data across sectors.
- ◆ Some provinces have established a resource function to assist local/regional public health with surveillance.

### Summary of Gaps

- ◆ Many public health organizations still lack the staff and resources to conduct surveillance, analyze surveillance data and interpret the results.
  - Organizations may not be able to make surveillance a priority.
  - Recruiting individuals to positions may be impeded by a lack of trained personnel or lack of interest among individuals in relocating to northern or rural health units.
  - Lack of time, limited access to appropriate training and/or resources to support skill acquisition may limit an organization's ability to build capacity.
- ◆ Various organizations have identified the type of data (indicators) needed for surveillance but it has not been collated in one place.
- ◆ Existing data collection systems tend to focus on self-reported lifestyle risk factors and chronic conditions. Major gaps exist in the data for social determinants of health, such as access to healthy, affordable foods; some lifestyle risk factors, including direct health measures such as blood pressure, physical fitness, height and weight, the predisposing, enabling and reinforcing factors that influence lifestyle such as knowledge, attitudes, social norms; and the availability and use of programs. Ongoing sources of community data are also lacking (e.g.

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<sup>3</sup> Quebec had already done its own consultations within the province and this information was provided to the Task Group to support their work.

smoking bylaws, bicycle paths and recreation opportunities that influence health and behaviour).

- ◆ Administrative and clinical databases have the potential to provide useful data for surveillance of more chronic diseases and risk factors than those for which they are presently being used. These databases need to be linked to provide a more complete source of surveillance data. Additionally, the electronic health record in the clinical setting is a potentially rich data source, but the requirements that need to be met to use this data for surveillance purposes are not usually considered in the development of work.
- ◆ The capacity for analysis and interpretation of surveillance data does not meet the demand in Canada at all levels – national, provincial/territorial, and regional/local. This limits the ability of public health organizations to analyze the data from existing databases in order to meet their surveillance needs.
- ◆ Lack of use in policy and program decision-making. This is in part due to the reliance on passive dissemination methods through existing communication channels by national surveys. In addition, weak connections between the people who would use the data and those who collect it prevent the surveillance system from becoming an integral part of the management cycle.
- ◆ Lack of overall coordination among the various participants in surveillance activities. Surveillance is a complex undertaking with many players. The identification of priorities, standard development, communication, improving access to data sources, clearinghouse of resources, and professional development would all be enhanced with better coordination.
- ◆ The Aboriginal community (First Nations, Metis and Inuit) faces additional challenges in surveillance because of their lack of human resources, geographic diversity, jurisdictional issues, and the difficulty in identifying Aboriginal people within many of the existing databases used for surveillance.
- ◆ Most jurisdictions have health surveillance legislation, particularly pertaining to communicable disease, but legislation enabling chronic disease risk factor surveillance is not uniformly present across the country.

## **Strategy to Enhance Capacity for Surveillance**

### ***Vision***

Canadians have reduced burden of chronic disease as a result of changes in policy, programs and services based on timely surveillance

### ***Goal***

To improve capacity in Canada for surveillance of chronic disease risk factors and determinants.

### ***Outcomes***

The strategy should contribute to the following outcomes:

1. Public health organizations conduct surveillance using data from existing population databases, and use the information in decision-making.
2. Public health organizations have access to surveillance data collection systems that are timely, rapid and flexible to meet their information needs, and use this information in decision-making.
3. Existing administrative and clinical databases are used effectively for surveillance purposes.
4. Data users and data owners from health and other related sectors, such as recreation, education, transportation and social services, work collaboratively to increase data availability and ensure its use for chronic disease risk factor and determinants surveillance.
5. The environment within which public health functions encourages the use of surveillance information in decision-making.
6. Coordination of surveillance activities facilitates high quality, timely, representative, accessible and useful data, and its meaningful analysis, interpretation and use.

## Recommended Strategies

The following recommendations were developed after broad consultations<sup>4</sup> across the country and through discussion with individuals involved in effective surveillance capacity building activities. The solution for delivering cohesive, efficient and successful chronic disease surveillance capacity at every level cannot be found by simply choosing to implement any one of the recommendations below. A variety of interconnecting issues continue to hamper the effectiveness of the expansion of surveillance initiatives and they require an integrated approach. Regions must be included in the policy creation process to ensure that their needs are being met.

Provinces and territories are at different levels of capacity for surveillance at this time. These strategies and activities can be phased in over time in keeping with the availability of resources. Some provinces and territories already have one or more of the activities in place.

The work of the Surveillance Systems for Chronic Disease Risk Factors Task Group has been coordinated with the Healthy Living Task Group and the Strengthening Public Health System Infrastructure Task Group. The recommendations proposed here are consistent with the recommendations from these Task Groups.

### Strategy #1

***Enhance Federal, Provincial, Territorial and local/regional capacity to analyze, interpret and use surveillance data.***

#### Activities:

- a. Develop surveillance plans linked to chronic disease prevention programs by public health organizations.
- b. Develop a central coordinating function within the Public Health Agency of Canada to facilitate access to resources, information about databases, definitions of indicators, analyses, and standards for data collection tools and methods.
- c. Enhance access to existing surveys and databases, and expand resources for analysis and interpretation for surveillance purposes.

- d. Provide E-learning, conferences, and workshops to increase knowledge and skills.
- e. Establish surveillance support systems with universities and others for the analysis, interpretation, and use of data of existing surveys and databases to build local/regional public health unit capacity.
- f. Develop a public health human resource strategy led by the Public Health Agency of Canada (recommendation from the Public Health Task Group on Public Health Infrastructure.)

### Strategy #2

***Expand data sources to fill gaps in surveillance knowledge.***

#### Activities:

- a. Establish locally/regionally coordinated ongoing flexible public health data collection systems (such as the Rapid Risk Factor Surveillance System in Ontario).
- b. Build on existing data sources to fill gaps in data.
  - Expand the monitoring of physical activity managed by the Canadian Fitness and Lifestyle Institute for more frequent data collection of individual and environment indicators.
  - Expand and coordinate across student-based school surveys and other setting-based tools and methods.
  - Provide ongoing funding for the Statistics Canada Physical Measures Survey.
  - Use technology to access information from databases housed in other sectors and settings
  - Build on the National Diabetes Surveillance System that uses health administrative databases to collect data on other risk factors, health problems and further details about conditions currently in the surveillance system.

<sup>4</sup> Quebec had already done its own consultations within the province and this information was provided to the Task Group to support their work.

- Use primary care research networks to collect risk factors data on those attending family physicians offices.
- Support risk factor and determinant data collection systems for Aboriginal Peoples.

### **Strategy #3**

*Enhance collaboration, planning and evaluation for surveillance among all the stakeholders.*

**Activities:**

- a. Establish a Pan-Canadian Issue Group for Surveillance of Chronic Disease within the Pan-Canadian Public Health Network that includes representatives of government, local/regional public health, database managers, research bodies, academia, professional associations, and non-government organizations.
- b. Establish a coordination, planning and evaluation function for surveillance within the Public Health Agency of Canada.

### **Strategy #4**

*Build capacity across jurisdictions for congruent public health legislation supportive of chronic disease surveillance.*

**Activities:**

- a. Develop model public health legislation related to surveillance in collaboration with provinces, territories and the federal government, in particular the Public Health Agency of Canada, Health Canada and Canadian Institute on Health Research.
- b. Encourage jurisdictions to consider the model legislation when reviewing and revising their health legislation.
- c. Support creation of a centre of expertise in public health law within the Public Health Agency of Canada, and a national interest group in public health law linked to the Public Health Network. (from Strengthening Public Health System Infrastructure Task Group Report of ACPHHS)

# Mandate of the Task Group

The Surveillance Systems for Chronic Disease Risk Factors Task Group<sup>5</sup> was established in September 2003 by the Advisory Committee on Population Health and Health Security to develop a strategy to strengthen Canada's capacity at all levels to coordinate and conduct surveillance for chronic disease risk factors and determinants to support evidence-based decision-making and monitor progress for initiatives such as the pan-Canadian Healthy Living Strategy.

The Task Group was to build on previous work done in this area by other F/P/T Groups and work in collaboration with stakeholders to recommend:

- ◆ Mechanisms for leadership, coordination and management of collaborative surveillance activities
- ◆ Types of data required for chronic disease prevention and mechanisms to select useful indicators for collaborative surveillance activities

- ◆ Mechanisms for collaborative data collection/collation and access to data;
- ◆ Mechanisms to facilitate the appropriate analysis, dissemination and use of surveillance information in policy and practice.
- ◆ Appropriate legislation, and
- ◆ Processes for the development and maintenance of standards.

The development of the strategy is based on the premise that working together at all levels (federal/national, provincial/territorial, and regional/local) will enhance the efficiency and effectiveness of surveillance activities.

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<sup>5</sup> Quebec participated on the Task Group to share information. Quebec reserves the entire responsibility for planning and implementing surveillance activities within the province. Quebec will continue to exchange information and expertise with other governments of Canada but does not intend to participate in a Pan-Canadian strategy.

# Context

Chronic diseases such as heart disease, stroke, asthma, cancer, chronic obstructive pulmonary disease (COPD), diabetes, obesity, arthritis and mental illnesses exert a significant burden on Canadian society. They are major contributors to poor quality of life, loss of productivity, hospitalization and other health care costs, and death. By a conservative estimate, the major chronic diseases account for \$83 billion per year in direct and indirect health care costs in Canada.<sup>6</sup> Communicable diseases also cause serious sequelae among those with chronic disease; the control of chronic disease will also have a positive effect on the control of communicable disease.

Much can be done to prevent these chronic conditions by translating existing knowledge about risk factors and determinants into effective policies, programs and services. Success requires interventions at both the community and individual levels, within the public health and primary care systems, in workplace and school settings, and in community programs. Surveillance is an essential knowledge tool to guide decisions about these interventions. It tells what is happening in the population, for example, the proportion who smoke or who know about the harmful effects of tobacco, or the proportion of municipalities that have tobacco control by-laws.

In spite of the importance of chronic disease and the potential for prevention, Canada lacks comprehensive systems for surveillance of these diseases and their risk factors and determinants at all levels of government. Decisions about programs and policies are based on less-than-optimal population information, in part because Canada has not developed an effective surveillance response to the transition from communicable to chronic disease as the dominant health problem.

Several recent events have intensified the need for high quality surveillance of chronic disease risk factors and determinants:

- ◆ The First Ministers Accord committed governments to work on a Pan-Canadian Public Health Strategy and set goals and targets for improving the health status of Canadians. Surveillance is an essential tool to monitor and measure progress.
- ◆ Enhancing surveillance of chronic diseases has been identified as a top priority by the Public Health Agency of Canada, the Canadian Public Health Association, multiple institutes of the Canadian Institutes of Health Research (including Population and Public Health, and Nutrition, Metabolism and Diabetes), the Research and Surveillance Working Group of the Pan-Canadian Healthy Living Strategy, and the Chronic Disease Prevention Alliance of Canada (CDPAC), among others.
- ◆ Several organizations have been tasked with reporting on the health of Canadians – the Public Health Agency of Canada, Statistics Canada, the Canadian Institute for Health Information, and more recently the Health Council of Canada. The work of these organizations needs to be facilitated by a strong well co-ordinated system for chronic disease surveillance.
- ◆ Pan-Canadian initiatives such as the Healthy Living Strategy and the Diabetes Strategy require surveillance data to monitor their impact on risk factors and health status at the population level.

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<sup>6</sup> Health Canada. *Economic Burden of Illness in Canada, 1998*. Includes cancer, cardiovascular disease, digestive diseases, endocrine and related diseases, mental disorders, musculoskeletal diseases, nervous system/sense organ diseases, and respiratory diseases.

# Principles of Comprehensive Surveillance

## 1. Surveillance is a foundation for essential public health functions.

All organizations (public health, government, non-government) with a mandate to prevent chronic diseases in the population need information from the surveillance of chronic disease risk factors and determinants to guide their work. As a first step, they must decide which risk factors and determinants need to be tracked to inform decision-making about their policies, programs and services. Second, data needs to be collated from existing sources or collected *de novo*. Third, the data needs to be analyzed and interpreted so that it becomes useful information that is effectively disseminated. Finally, decision makers use the information to mobilize their resources in response to population needs. For the data to be meaningful, it must be gathered from the appropriate level of the organization's jurisdiction and in sufficient detail to ensure that the information is useful.

Building capacity among public health organizations at all levels (local, provincial/territorial and national) is a central theme of this paper. Not all public health organizations, particularly at the regional/local level, have the capacity to carry out all of the above functions, and as a result, are not able to fulfill their mandates. Many lack the adequate and skilled human resources or technology to make use of existing databases and do not have the financial resources to collect the ongoing additional data that they need. Better coordination and sharing of existing resources would enhance surveillance capacity. Other organizations, such as schools, workplaces, recreation programs, and social service agencies, have data that could fill some of the gaps: intersectoral collaboration could

increase the pool and the depth of data for surveillance.

## 2. The three levels of government (national, provincial/territorial and regional/local) must work together, while focusing on their jurisdiction's needs, to build surveillance systems for risk factors and determinants.

Given limited resources, working collaboratively to develop and implement surveillance systems maximizes resource utilization and ensures that organizations benefit from work done by others. Sharing the tasks of surveillance, such as developing questionnaires or collecting data, builds on the specific expertise and resources of individual organizations. Working together in developing common definitions, data elements and data collection methods facilitates valid data comparison among jurisdictions. Comparing one geographic area to another helps identify areas that are doing well. Further study in these areas can identify successful programs or policies that can be adapted by other communities. For planning purposes, surveillance data can also identify areas that have a high level of risk and identify the characteristics of those at risk. Surveillance data can also be used by researchers to generate hypotheses about causation. In order to function as intended, a surveillance system requires appropriate infrastructure and investment at all three levels of government. Unfortunately, at present, investment in resources for data collection through Statistics Canada has not had commensurate universal investment for analysis and reporting at the regional/local and provincial/territorial levels.

**3. Chronic disease risk factor surveillance needs to take place within an integrated chronic disease approach that addresses the broad determinants of health.**

Surveillance is a tool to enhance policy and program decisions. What data is collected is determined by research that identifies important health problems and their risk factors and determinants, and by the intended outcomes of the programs directed at these factors. It is also used to identify emerging health problems.

Many chronic diseases share common risk factors, such as smoking, alcohol abuse, inadequate nutrition, unhealthy eating, physical inactivity, obesity and stress. They also share the same risk conditions or determinants that contribute to these risk factors, including low income, lack of education, lack of social support, stigma and environmental influences. It follows that policies, programs and services to reduce the prevalence of risk factors and improve the determinants would have an impact on many chronic diseases.

Surveillance of these common risk factors would require similar data and could use the same sources as collection points. Thus, it is more efficient and effective to carry out surveillance for chronic disease risk factors and determinants in an integrated fashion. Effective coordination among the various stakeholders is the key to making this work.

**4. Chronic diseases are influenced by factors at the community level in addition to individual factors.**

Chronic diseases are influenced by a range of determinants that operate at the individual, family, neighbourhood, community, nation/state or in whole societies. Surveillance systems need to collect data not only on individual level measures such as awareness, knowledge, attitudes and risk behaviours, but also measures of other factors, which also influence our health. Some examples of these factors are:

- Education sector – availability of healthy food options in cafeterias, school yard equipped for physical activity, regular physical activity part of curriculum
- Transportation sector – bike paths and bike lanes on roads
- Environment – air quality, water quality, policies on environmental tobacco smoke exposure
- Community – education opportunities, discrimination, social capital and social trust at the neighbourhood level, access to quality food.

Many of these factors lie outside of the health sector, so intersectoral collaboration is essential for effective surveillance.

# Risk Factor Surveillance

***"Health surveillance may be defined as the tracking and forecasting of any health event or health determinant through the continuous collection of high-quality data, the integration, analysis and interpretation of those data into surveillance products (such as reports, advisories, warnings) and the dissemination of those surveillance products to those who need to know. Surveillance products are produced for a specific public health purpose or policy objective. In order to be considered health surveillance all of the above activities must be carried out."***

Surveillance and research are linked. Research plays a vital role in surveillance by helping to identify the elements that need to be monitored in a surveillance system; in addition, robust research methods ensure the reliability and validity of the collected data. At the same time, research benefits from the surveillance process: the results of surveillance lead to the creation of new hypotheses that direct future research, both within and outside of the surveillance process. A formal process to link those doing surveillance with those doing research will ensure that each group benefits from the other's work.

Surveillance products can empower individuals, health providers, governments and communities by providing the information needed to take action in

protecting and improving health. Specific uses include:<sup>8</sup>

- ◆ Systematic monitoring of trends and geographic variations in risk factors and their determinants;
- ◆ Improving the understanding of the determinants of health and facilitating research;
- ◆ Identifying clusters of risk factors and determinants, threats to health and emerging issues;
- ◆ Developing policies and programs to manage preventable health risks (see inset on Tobacco);
- ◆ Planning health services and projecting future trends;

## Guiding Tobacco Control Campaigns

The Canadian Tobacco Coalition anxiously awaits the semi-annual report from the Canadian Tobacco Use Monitoring Survey (CTUMS) – a monthly national survey of over 20,000 Canadians funded by Health Canada. The Coalition partners are planning a program to control environmental tobacco smoke and need data from the extra questions added to the latest survey. They are encouraged by the lower smoking rates the survey reports but know that they must continue their efforts to advocate for tobacco control funding to build on the downward momentum in the population.

### Key Success Factors

- ◆ Existing coalition recognizes need for surveillance
- ◆ Ongoing funding for a flexible, timely survey
- ◆ Expertise on tobacco issues and surveillance

### Key Limitations

- ◆ Lack of community-level data

<sup>7</sup> National Health Surveillance Network Working Group; Integration Design Team. Proposal to Develop a Network for Health Surveillance in Canada, 1999, p. 6.

<sup>8</sup> List adapted from: Health Canada. Health Surveillance Working Group. Canadian Health Infrastructure Health Surveillance Tactical Plan, 2001;2.

- ◆ Identifying population groups and geographic areas needing service; and
- ◆ Evaluating health policies, programs and services.

Figure 1<sup>9</sup> describes how surveillance 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. In essence, surveillance data drives decisions about the program, and program needs drive the data requirements.

The use of surveillance information should be an ongoing part of the management cycle. To function in this way, the surveillance system needs adequate funding and a business environment that encourages and supports not only the collection, analysis and interpretation of data, but also its use. (see inset on Physical Activity)

**Surveillance of Physical Activity**

Physical activity has a powerful influence on the prevention of chronic diseases. In 1995, the Federal/Provincial/Territorial (F/P/T) Committee on Fitness and Recreation identified the need for population data on level of physical activity to guide program and policy decision-making. The Physical Activity Monitor (PAM) was established under the auspices of the Canadian Fitness and Lifestyle Research Institute (CFLRI) to collect national and provincial/territorial level data annually and report to the provincial/territorial and federal governments on key indicators.

CFLRI used an innovative approach to identify key progress indicators by bringing together the research community, policy-makers, and NGOs. The monthly survey complements other national surveys by collecting data on the factors that influence behaviour as well as data on physical activity itself *within a health determinants framework*. Through collaboration with a private survey initiative, the sample size of the survey has been expanded to increase its value. Recognizing that the community environment plays a critical role in physical activity, surveys are also conducted in workplaces, schools and municipalities. Annual progress reports are provided on the key indicators to the F/P/T Committee using data from PAM and other data sources.

**Key Success Factors**

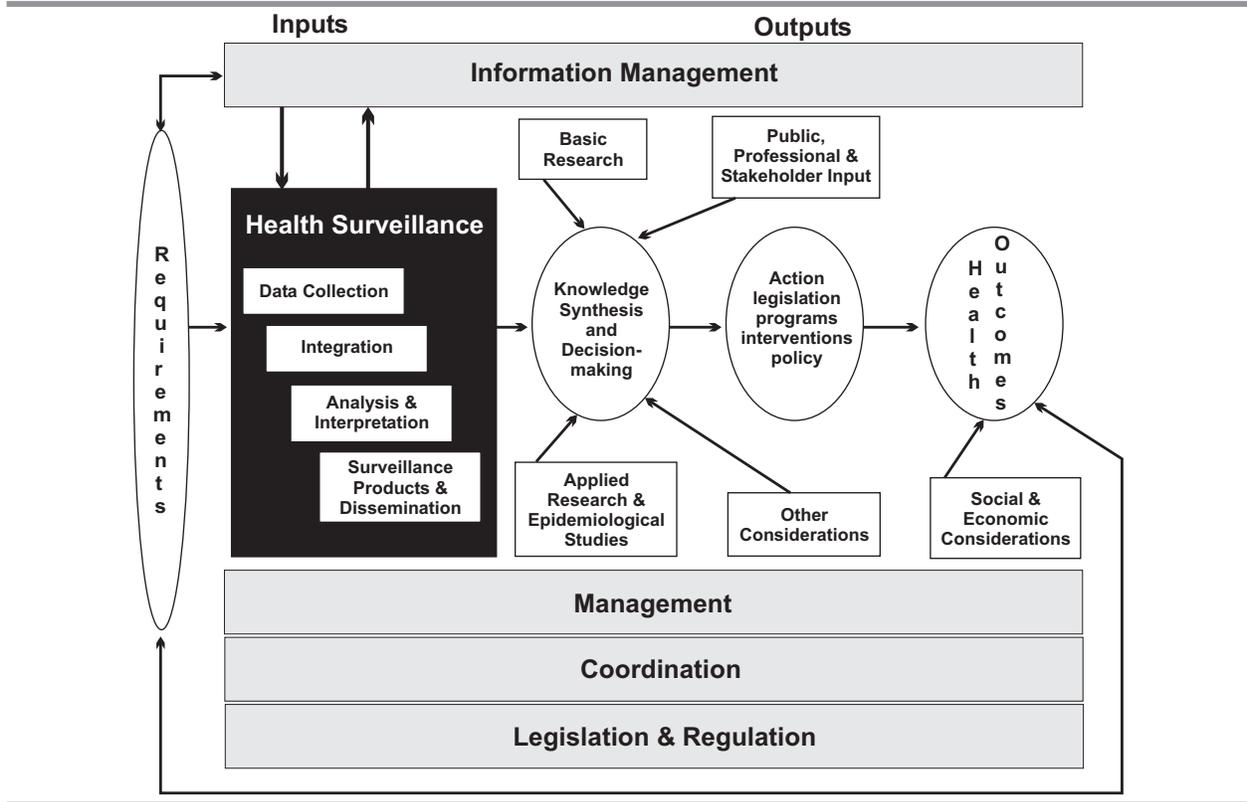
- ◆ Creative leadership with a vision
- ◆ Content expertise and use of web technology
- ◆ Ongoing investment of funds from both federal and provincial/territorial governments
- ◆ Private-public partnership expands survey size
- ◆ FPT relationships – right people at the table and political will

**Key Limitations**

- ◆ Lack of community-level data

<sup>9</sup> National Health Surveillance Network Working Group; Integration Design Team. Proposal to Develop a Network for Health Surveillance in Canada. 1999.

**Figure 1: Contribution of Health Surveillance to Evidence-based Decision Making**



# Building a Surveillance System

## Functions of a Surveillance System

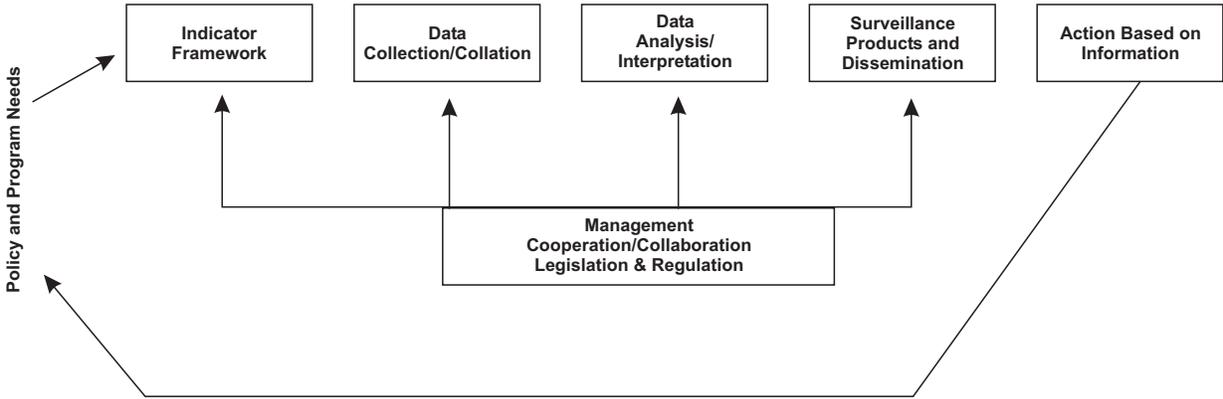
A surveillance system is a coordinated sequence of activities among one or more committed organizations designed to carry out surveillance of health status, healthy behaviours, a disease or diseases and their risk factors, determinants or preventive interventions,<sup>10</sup> in the most effective and efficient means possible. Figure 2 outlines the eight key functions of a health surveillance system.

- ◆ **Indicator framework** – Identifying the policy or program issues that need surveillance information is the first step in identifying the indicators (data that will be collected) of the surveillance system. The users of the information need to be involved in this process to ensure that it meets their needs. In the world of health information technology, this is considered the “user requirement” phase of the project.
- ◆ **Data collection/collation** – Data for the surveillance system can be collected *de novo*, or it can be obtained from existing data collection

systems. Accessing multiple data sources increases the breadth of available data and the levels at which it is collected (regional/local, provincial/territorial, national). It also increases the likelihood of populating the measures in the indicator framework.

- ◆ **Data analysis and interpretation** - Once data is analyzed, it needs to be interpreted to help users understand “what it means”. Analysis needs to be ongoing and responsive to the varied needs of the data users.
- ◆ **Surveillance products and dissemination** - A variety of surveillance products tailored to a variety of target audiences helps to ensure that the analysis is understood. The Internet and other electronic applications provide the ideal means of providing many people with access to the data in a timely fashion. Effective use of existing distribution channels helps the surveillance products reach the interested parties.

Figure 2: Key Elements of a Surveillance System



<sup>10</sup> For example, breast cancer screening recruitment; tobacco control by-laws.

- ◆ **Use of information** – Appropriate application of the disseminated information to decision making is the ultimate goal of a surveillance system.
- ◆ **Management** - Coordination of day-to-day activities, management of human resources (including ongoing training and mentorship), development and maintenance of standards and guidelines, mechanisms for resolving differences between standards, management of physical resources, management of information, and evaluation to determine whether information that is provided is meeting the needs and expectations of the user groups. Managers need to ensure that those involved in the surveillance system have the expertise and experience to do the job.
- ◆ **Coordination/Collaboration** – Working together can improve the effectiveness and efficiency of surveillance activities. For example, the coordination of one organization's surveillance activities with others permits data comparisons and resource sharing to enhance surveillance.
- ◆ **Legislation and Regulation** – Legislation governs the reporting of cancers, the census and vital statistics. Other legislation ensures confidentiality and privacy, the security of data, the secure release of data, and the access, use and disclosure of data.
- ◆ **Process** – Defines both the personal health processes and the health system business processes that will be supported by the health infostructure. Personal health processes are those used by a person to manage his or her own health, irrespective of whether they use the health system. Health system business processes are those that service providers, managers, researchers and policy makers use to deliver health services or influence other sectors, as well as plan, manage and evaluate the health system and the health of populations.
- ◆ **Information** – Defines the health information, data holdings and data needed to support communication among health professionals and their inter-sectoral partners, as well as the decision making and learning related to health and health care required by public health and other professionals.
- ◆ **Technology** – Defines the application and network components providing the technology that supports the health infostructure.
- ◆ **Standards** – Defines the rules that enable organizations and people to communicate, the tasks to be carried out, the information to be shared, and the technology to inter-operate. Standards are the glue enabling people to work together and speak the same language through a network of connected information systems.

## Business Requirements

Developing and implementing a surveillance system is a complex undertaking. The following business requirements are essential for creating a successful system.<sup>11</sup> At present, capacity is lacking in all these areas thus slowing down existing and emerging surveillance initiatives.

- ◆ **Organization and People** – Defines the human resources required to create the health data and information, build the technology supporting the infostructure, use the infostructure to receive, deliver, maintain and improve health-related services, and provide governance for the development and use of the infostructure.

## Community Surveillance System Models

Surveillance data needs to be representative of the people in the geographic area for which policy and program decisions are being made. Four different models of surveillance system can provide this data at the community level.<sup>12</sup>

- ◆ **Community-based** system – The community decides what data it needs for its own purposes, and collects and analyzes the data on its own.

*Example:* Public Health Unit specific survey.

<sup>11</sup> Health Canada. Health Surveillance Working Group. Canadian Health Infostructure Health Surveillance Tactical Plan, 2001; p. 15. Infostructure includes the necessary organizations and people and the over-arching architecture to support the coordination of their efforts, business processes and the policies to make them work within and between jurisdictions, and standards for the use and support of the health surveillance system.

<sup>12</sup> National Aboriginal Health Organization. First Nations Centre. Surveillance Tool Kit. Available at: [http://www.naho.ca/firstnations/english/pdf/Surveillance\\_Toolkit.pdf](http://www.naho.ca/firstnations/english/pdf/Surveillance_Toolkit.pdf). Accessed on February 3, 2004.

- ◆ Use data from a **provincial/territorial or national system** – If data is not available at the community level, then data from provincial/territorial or national surveys can provide estimates of community status. If the community is similar to the province as a whole, this can provide useful data.

*Example:* Physical Activity Monitor (PAM) of the Canadian Fitness and Lifestyle Research Institute (CFLRI).

- ◆ **The roll-up approach** – Data is collected at the community level in a consistent way in all communities so that it can be rolled up to the provincial/territorial and national levels, which use the data for their own purposes. The impetus for the data collected comes from the communities who decide what data they need. The provincial/territorial and national levels may be consulted.

*Example:* Rapid Risk Factor Surveillance System of 20 Ontario public health units has the potential to provide provincial level data.

- ◆ **The roll-down approach** – A provincial/territorial or national-level system has sufficient sample size to allow for estimates to be made at the community level. The impetus comes from the provincial/territorial or national level, which decides what data is required. The communities may be consulted about their needs.

*Example:* Canadian Community Health Survey (CCHS) of Statistics Canada.

The present surveillance systems for chronic disease risk factors and determinants are a blend of these four models. From the community's perspective, it is essential that it has data to meet the needs of its own jurisdiction. Regardless of the model used, the community must have the resources to complete its role in a collaborative system.

# Principles of Surveillance Systems

Surveillance systems for chronic disease risk factors and determinants ideally are based on the following principles - acceptability, simplicity, flexibility, quality data (sensitivity, high positive predictive value), representativeness, timeliness and stability.<sup>13</sup> Adhering to these principles will help not only to ensure that a system is effective and efficient, but also that it makes a significant contribution to decisions on policy, programs and services to reduce chronic disease risk factors and improve their determinants. Each principle includes examples of its application in a surveillance system.

## Acceptability

*The system is acceptable to participating individuals and organizations*

- ◆ **Data linked to decision making.** The purpose of surveillance is to guide decisions about policies, programs and services. Thus, a system must be “needs driven”, requiring a direct link among the data collectors, the data managers and the data users. It must be part of the business process.
- ◆ **Consensus-based.** Acknowledge jurisdictional autonomy and seek to standardize data, processes, and technologies only where there are compelling requirements to do so.
- ◆ **Security, confidentiality, privacy and protection of information.** Protect personal health information, privacy and confidentiality.

## Simplicity

*The system is simple in both structure and ease of operation.*

- ◆ **Accessibility.** Surveillance systems must improve the accessibility of chronic disease risk factor information, policies, technology and standards. In ensuring accessibility, the systems must also recognize the different levels in both skill and access to technology among stakeholders.
- ◆ **Ease of integration.** Develop modular and loosely coupled systems with a high degree of reusability.
- ◆ **Proven technology.** Use industry-accepted standards, such as messaging standards, proven technologies, and open architectures. (Note: The Web/Internet, as a widely used technology, could provide the capacity, integration, and inter-connectedness needed for a pan-Canadian health surveillance system).

## Flexibility

*The system can adapt to changing information needs or operating costs (time, personnel or allocated funds).*

- ◆ **Interoperability.**<sup>14</sup> The ability of hardware and software from different vendors to understand one another and exchange data, either within the same network or across dissimilar networks. The ability of autonomous systems to work with

<sup>13</sup> Guidelines for Evaluating Surveillance Systems. Centres for Disease Control and Prevention. On CDC WONDER. Cwus@cdc.gov. Atlanta, USA.

<sup>14</sup> Canada Health Infoway. Electronic health record solution (EHRS) blueprint: an interoperable EHR framework. July 2003

other dissimilar systems. Interoperable systems interact through standardized interfaces. Often loosely coupled, they exchange information in an asynchronous manner. Interoperable systems can function without knowing the internal processes, functions, and data representations of other systems.

### Data Quality

*The system is sensitive in the proportion of events detected by the system and accurately predicts the proportion of individuals who have the risk factor (validity).*

- ◆ **“Good enough data”.** The quality of data in the surveillance system needs to be “good enough” to give a sense of what is happening in the population. The surveillance system must balance the quality of the data with available resources. For example, the ideal way to measure obesity in the population is to carry out physical measures of height and weight, or to obtain data from the family physician who has measured the individual’s height and weight. Both of these methods are currently more expensive than surveys that ask people for the information. Research evidence suggests that the survey method has reasonable accuracy in detecting changes over time. In the future, the development of an electronic health record may change the preferred method of data collection.

### Representativeness

*The system accurately describes the prevalence of risk factors and determinants in the population as a whole and their distribution in the population by place and person.*

- ◆ **Population sub-groups.** The population is not homogenous but is made up of many sub-groups: children, youth, First Nations, Métis, Inuit and ethno-cultural groups, for example. Since policies, programs and services are tailored to these sub-groups, surveillance systems need to provide population data on these sub-groups to guide decision making.

- ◆ **Geography.** Surveillance tells us what is happening in the population. Decision-makers need data on their own geographic area to identify regional/local needs and the impact of programs.
- ◆ **Comprehensive.** It is important to ensure that health surveillance activities occur at all jurisdictional levels and for all subject areas and that jurisdictional variations in both technology and requirements are openly recognized.

### Timeliness

*The system minimizes the delay between components.*

- ◆ **Frequency of data collection.** The frequency with which data are collected depends on the volatility of the risk factor in the population (i.e., does it change on a monthly or annual basis?). The volatility can be influenced by such factors as seasons or interventions.
- ◆ **Data analysis and dissemination.** Once data is collected it must be analyzed and disseminated in a timely manner to ensure that they are received in time to be taken into account by decision-makers.

### Stability

*The system collects, analyzes and disseminates data continuously and consistently over time.*

- ◆ **Partnership.** Data owners, data managers and data users who form partnerships create opportunities for each to benefit from the others’ expertise and resources. The end result is a high-quality, responsive and stable surveillance system.
- ◆ **Capacity development.** Since surveillance is an essential public health function, all public health organizations at the regional/local, provincial/territorial and federal levels need the capacity to influence and take advantage of available risk factor surveillance information. Building ongoing capacity development (training and support,

resources) into the surveillance system will improve both the quality of the work and its effectiveness. It will also support the creation of a culture in which decisions are based on data from surveillance systems.

- ◆ **Sustainability.** Surveillance is an ongoing, continuous function and needs to be built to be sustainable and adaptable over the long term. Organizations involved in partnerships need to make a commitment to contribute in order to realize the benefits from surveillance on a continuous basis. Ideally, the ongoing collection of data becomes part of the business processes within the overall health system.

### **Ethics and Standards**

*Surveillance requires a living architecture that provides a standard for health surveillance as requirements evolve.*

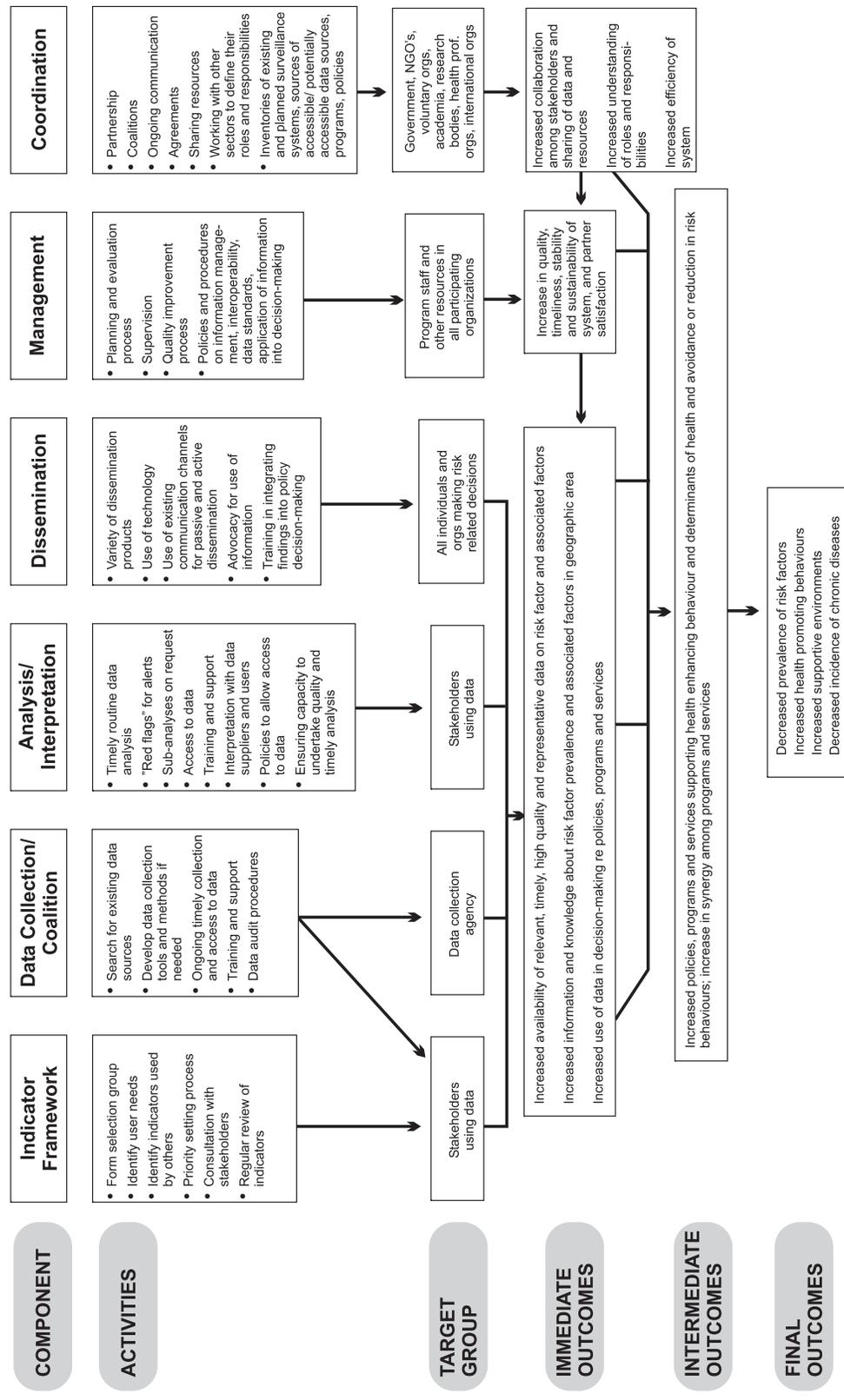
- ◆ **Ethics.** Ethical principles include confidentiality and privacy, informed consent, providing benefit

and not harm, and protection of vulnerable groups. Since surveillance is a public health function, it must also follow these guidelines. The Canadian Institutes of Health Research is preparing privacy best practice guidelines for the ethical use of data and these will provide valuable guidance for surveillance work.

- ◆ **Ownership.** The purpose of surveillance is to inform policy, program and service decision-making. Thus, the users of the surveillance information must feel sense of ownership of the surveillance system itself. This means that they can influence what data is collected and when with an expectation that they will receive the data in a timely way for decision-making. It also means that the organization invest resources in the system to meet its needs.

The following diagram (Figure 3) summarizes the essential components of a chronic disease risk factor surveillance system with its resulting outcomes.

**Figure 3: Logic Model for a Risk Factor Surveillance System**



# Developing Capacity for Risk Factor Surveillance: Current Situation

The overall capacity to participate in surveillance at the local, regional, provincial/territorial and national levels is dependent on the capacity to undertake each element of surveillance (indicator development, data collection/collation, data analysis and interpretation, dissemination and use) and supportive functions (management, cooperation/coordination, and standards).

Having the capacity to conduct surveillance does not mean that an organization must have the ability to conduct all aspects of surveillance by itself. Collaboration can increase efficiency and ensure that data is comparable for surveillance purposes. (see inset on Community Health Survey)

Resources can also be shared among different levels. This approach will only work, however, if each level has the capacity to perform the functions assigned to it.

Public health organizations need to have staff with the necessary knowledge and skills to conduct surveillance. They also need the appropriate computer technology. Larger organizations usually have this capacity in-house. Other organizations have linked with universities or research units to obtain this expertise.

The Aboriginal community faces additional challenges because of its lack of human resources, geographic diversity and jurisdictional issues. First Nations, Metis and Inuit people live throughout Canada. The Canadian Community Health Survey does not include people living on-reserve, and does not identify to which of the Aboriginal groups those living off-reserve belong. The First Nations Centre, National Aboriginal Health Organization, has developed the Regional Health Survey for the on-reserve population, but it

## Canadian Community Health Survey

Resources have been invested at the national level in Statistics Canada's Canadian Community Health Survey (CCHS) to provide national, provincial/territorial and health region level data. The National Population Health Surveys Advisory Committee determines the content of the common questionnaire and each province/territory and region can determine the content that it would like for its time on the survey. Statistics Canada carries out its own analysis of the data and provides data to provincial/territorial governments and regional/local health units for their own analysis.

### Key Success Factors

- ◆ Provinces have infrastructure in place to identify data needs
- ◆ Program people who need the data are involved in the process
- ◆ Incentives are in place to encourage use of data (e.g., need for a region health status report)
- ◆ Better analysis tools for user, specifically having the file set up for the bootstrap confidence interval analysis
- ◆ Staff has knowledge and expertise in surveillance
- ◆ Availability and use of technology

### Key Limitations

- ◆ Lack of resources at the regional/local level to analyze data
- ◆ Lack of flexibility and timeliness for regional/local levels

does not have sustained funding. Aboriginal Peoples understand very well that surveillance must be tied to community need and decision-making and want to be involved in all surveillance activities affecting their people. This is a challenge as off-reserve surveillance activities are not solely focussed on Aboriginal Peoples, and control and access to data are difficult issues to resolve.

Many public health organizations still lack the staff and resources to conduct surveillance. The organizations may not have made this a priority, or

recruiting individuals to positions may be difficult. Individuals may have an interest in conducting surveillance, but lack the skills. Practical considerations such as distance from educational institutions, lack of time, and lack of capacity for short-term staff replacements may also impede the acquisition of necessary skills. (see inset on Skills Enhancement)

### Skills Enhancement

An innovative program at PHAC provides education to public health workers who wish to enhance their surveillance knowledge and skills. The program works with a consortium of schools of public health from across Canada. The core component is a series of distance-learning, Internet-based training modules in English and French on epidemiology, surveillance and information management. This approach blends high tech with high touch. Easy, low cost access is provided from the worker's desk to the study materials. Support is provided through a Help Desk.

#### Key Success Factors

- ◆ Developed in collaboration with end-users
- ◆ High quality content with accessible and engaging information technology tools
- ◆ Use of adult learning principles
- ◆ Strategic but flexible: "Think big, but start small"
- ◆ Use of trained and supported on-line facilitators
- ◆ Pre-test modules, monitor and evaluate system

#### Key Limitations

- ◆ Lack of staff time to participate
- ◆ Lack of understanding of the value of surveillance and commitment of skill development
- ◆ Lack of resources to advertise and support use of the modules

## Coordination/Collaboration

### Question

*How can cooperation/collaboration be supported among public health organizations?*

Coordination and collaboration between stakeholders are essential functions in the development and maintenance of any surveillance system. The stakeholders involve the data owners and users. The data users are the public health organizations, the governmental and non-governmental organizations at the regional/local, provincial/territorial and national levels. Collaboration among the data users is essential to determine which data have to be collected and how they will be analyzed and disseminated. Coordination (as it relates to the establishment of everyone's responsibilities), and collaboration between data users facilitate human and material/technological resource sharing. Working relationships favour synergy. International coordination and collaboration ensure the comparability of Canadian data to data from other countries.

Collaboration may occur in different ways. At its simplest it brings organizations together to talk about their own initiatives. At the next level, the organizations consult each other and try to seek advice on programs. In a more elaborate way, it

relies on cooperation, with each organization supporting others' efforts. Then, the organizations can coordinate their activities to avoid duplication and strengthen their respective initiatives. Collaboration requires planning, and at times, even joint activities. (See inset CCSA)

Coordination and collaboration in the surveillance of chronic disease risk factors allow organizations to:

- Establish common strategic orientations and priorities;
- Facilitate the development and access to data;
- Develop common tools, methods and standards;
- Improve the capacities; and
- Obtain specialized support.

Whatever its form, the relationship must be acceptable to all parties and flexible enough to respond to the changes and needs of each partner. They need to be able to work together in a timely way, and with continuity and consistency. Partnerships take various forms. In some situations, a formal memorandum of understanding clarifies expectations and responsibilities.

Collaboration needs to extend beyond those who are most immediately involved in surveillance. For

### Canadian Cancer Surveillance Alliance

Supported by contributions from a number of agencies, this group of cancer surveillance stakeholders (representing provincial/territorial cancer registries, patients/survivors, clinicians, advocates, Statistics Canada and Health Canada) functions to ensure the development and dissemination of enhanced surveillance information, with a strong focus on the needs of data users, and to promote the standardization of information management so as to align evidence-based decision making across the cancer control spectrum. CCSA aims to improve the business of cancer control through the facilitation of active partnership and communication among Canada's numerous cancer surveillance stakeholders. An Annual Report is prepared with the latest statistics and disseminated widely.

#### Key Success Factors

- ◆ Pooling of expertise
- ◆ Good representation of interests
- ◆ Comprehensive mandate
- ◆ Experience in all aspects of surveillance
- ◆ Connected to the Canadian Strategy for Cancer Control

#### Key Limitations

- ◆ Adequate resources
- ◆ Infrastructure to support work

example, the Chronic Disease Prevention Alliance of Canada (CDPAC) is a recent partnership of all stakeholder groups and individuals interested in the prevention of chronic disease in Canada. One of its priorities is to champion the surveillance of risk factors and determinants. (See inset Saskatoon's System)

Investments are also often made in generic information infrastructures that support a variety of information needs, such as the Health Canada Information Portal or the development of the electronic health record. It is essential that those involved in risk factor surveillance collaborate with these generic initiatives to be sure that the latter are responsive to surveillance needs.

## **Gaps**

One of the major challenges with the collaborative model is funding the collaboration process. Assembling and managing the necessary resources and time to operate the surveillance activities requires committed ongoing support by the partners. When the collaborative process involves different levels (federal provincial/territorial and regional/local, as with the CCHS) organizations must fund representatives to be part of the collaborative process. In some areas, public health infrastructure is inadequately funded and not well organized. Public health organizations thus find it difficult to contribute to collaborative surveillance activities. Another issue is balancing the diverse interests of different stakeholders who require different types of data.

### **Saskatoon's Comprehensive Community Information System**

Planning by various sectors at the municipal level is often done in isolation from one another. A new initiative in Saskatoon is poised to change this situation by coordinating the sharing of community data from the various sectors.

The Comprehensive Community Information System (CCIS) is an initiative of the Saskatoon Health Region in partnership with the Regional Inter-sectoral Committee (RIC). RIC member agencies include municipal government, social services, education, justice, and First Nations groups.

The data provided through the CCIS will create a comprehensive view of the community for program planning and evaluation across the continuum of services. CCIS will provide Web-portal access to analysed aggregate data from a broad range of community service organizations and will feature tabular, graphical and GIS (geographic information system) map formatting. The key features of this tool are flexibility in accessing low-level aggregate data by various demographics (such as age group, gender), geographic boundaries (neighbourhoods, administrative boundaries for each of the partners), and timeframes. This tool will improve the timeliness, relevance, comprehensiveness and quality of data for planning and policy making. Its users include community groups, agency partners and researchers.

#### **Key Success Factors**

- ◆ Leadership by Saskatoon Health Region
- ◆ Existence of a coordinating body with a mandate for inter-sectoral issue identification, planning and policy-making
- ◆ Common vision among senior level managers in participating sectors
- ◆ Initial capital and human resources provided by Saskatoon Health Region
- ◆ Cooperation among regional agency partners in data sharing and expertise
- ◆ Advances in information technology and local innovation, creating the capability for dynamic data access and display
- ◆ Involvement of senior representatives from the partner agencies in overcoming policies and practices that inhibit data sharing

#### **Challenges**

- ◆ Resources (financial and human) within partner organizations to make use of the Web portal access to community data
- ◆ Setting up appropriate safeguards to protect confidentiality
- ◆ Ongoing funding to maintain and keep building the system

## Identifying Data Requirements

### Question

**What do public health organizations need in order to identify the data required to plan, monitor and evaluate policies, programs and services for reducing risk factors and improving determinants of chronic diseases?**

Most chronic diseases are caused by the interaction among several risk factors and determinants. Some risk factors and determinants are disease-specific while others are common to many chronic diseases.

Figure 4 outlines the relationship among these groups of factors for selected chronic diseases:

- ◆ Non-modifiable (such as genetic predisposition, age or sex);
- ◆ Behavioural (such as tobacco use or physical inactivity and their predisposing, enabling and reinforcing factors<sup>15</sup>);
- ◆ Environmental (such as environmental or workplace contaminants);
- ◆ Socioeconomic (such as income and social status);

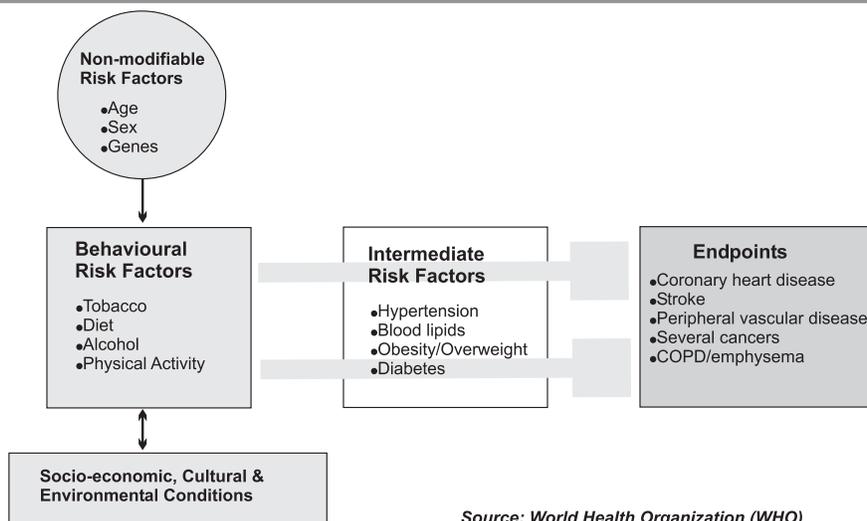
- ◆ Cultural (such as support networks); or
- ◆ Intermediate risk factors (such as hypertension or diabetes).

In addition to the factors listed above, the policies, programs, and services that are directed at changing behaviour, treating a biological condition or reducing exposure to a risk factor also need to be included in the surveillance system.

The purpose of a surveillance system is to collect data to inform decision making about policies, programs and services to improve the health status of the population. Thus, the selection of the indicators (what will be measured) for the system needs to be directly linked to the need for specific knowledge about the population.

Comparing data among communities, regions, provinces/territories and countries requires consistency in both the risk factors and determinants that are chosen to be monitored and their definitions. The World Health Organization (WHO) has developed a list of risk factors for surveillance purposes to ensure international comparability.<sup>16</sup> This includes tobacco and alcohol abuse, patterns of physical inactivity, low fruit and vegetable intake, raised blood pressure, raised cholesterol, and diabetes.

**Figure 4: Example of Major Selected Non-Communicable Disease (NCD) Risk Factors and Determinants**



Source: World Health Organization (WHO)

<sup>15</sup> Green LW, Kreuter MW. Health promotion planning: an educational and ecological approach. 1999. Mayfield Publishing Company, California USA p. 35.

<sup>16</sup> Bonita R, de Courten M, Winkelman R. WHO Global NCD Risk Factor Surveillance. Geneva: World Health Organization. Cited 2002 June. Available from url: <http://www.who.int/mipfiles/1967/WHOGlobalNCDRiskFactorSurveillance.pdf>

Several challenges exist in identifying the data (indicators) that should be included in a surveillance system. Planners of surveillance systems must decide what is possible to be monitored with available resources. Data collection systems designed to meet the needs of multiple stakeholders face several additional challenges. Stakeholders have a variety of data needs, based on geography and mandate. While some stakeholders are interested in all chronic diseases, others are interested only in their specific disease group. (See inset Alberta)

### **Gaps**

Existing data collection systems tend to focus on self-reported lifestyle risk factors and chronic conditions.<sup>17</sup> Major gaps exist in trend data for some lifestyle risk factors, such as nutrition; physical measures; social determinants of health, such as access to healthy, affordable foods; the predisposing, enabling and reinforcing factors that influence lifestyle such as knowledge, attitudes, social norms; and the availability and use of programs.

## **Data Collection/Collation**

### **Question**

***How can public health organizations obtain quality data for surveillance of chronic disease risk factors and determinants?***

The essential feature of a surveillance system is the ongoing collection of data. To be meaningful, the data must also be representative of the population for which decisions are being made. For example, if international comparisons are being considered, data must represent the entire Canadian population. If a decision is being made about services for preventing risk factors at the local level, the data needs to represent the local population. (See inset RRFSS)

The data must be timely and accurate in reflecting trends in the population. The required frequency of data collection depends on both the indicator and the available resources. Data on indicators that change slowly need only be collected every year, every second year or at longer intervals. Indicators that can change quickly, however, need to be measured more often to truly understand what is happening in the population.

### **Alberta: Selecting Common Indicators from the Canadian Community Health Survey**

Following the latest reorganization of Alberta health regions (from 17 regions to 9), regions felt the need for better coordination of surveillance in general. Alberta health regions are now working together to address common surveillance challenges through a technical working group. The group is currently co-chaired by individuals with surveillance expertise and responsibility from Alberta Health and Wellness and one of the larger regions. One of the first tasks of the group is to coordinate the identification and analysis of a consensus set of indicators from the Canadian Community Health Survey (CCHS). Some regions lack skilled personnel to do the work, some lack the basic infrastructure e.g. cannot meet security requirements for receiving the data. The group is looking at ways to overcome this.

#### **Key Success Factors**

- ◆ Existing relationship among regions
- ◆ Leadership from province and regions
- ◆ Shared attitude of helping each other
- ◆ Recognition of need for surveillance data for planning and the benefit of comparable data

<sup>17</sup> Reference; Data Sources for Risk Factor Surveillance – Discussion Paper, Surveillance System for Chronic Disease Risk Factors Task Group, March 2005.

Flexibility must be built into the data collection method in order to respond to changing needs. At the same time, to ensure the system's sustainability over the long-term, the method must be simple and acceptable to the individuals and organizations participating in data collection. To permit valid comparisons, data collection must not only be continuous, but also consistent over time. In order to effectively balance flexibility with consistency, the data selection process needs to be dynamic.

An organization with an interest in surveillance of risk factors and determinants for chronic disease does not have to carry out primary data collection itself. Instead, it can collate data from other organizations. Working in collaboration with the data owner, the data user can identify how that data can meet its particular needs. Multiple data sources can be used for surveillance of chronic disease risk factors and determinants.

### **Gaps**

While several ongoing surveys collect data on chronic disease risk factors and determinants, the lack of sufficient sample size at the regional and sub-regional levels presents a challenge to ensure that the information is useful to regional/local public health decision-makers. There are emerging challenges as well; new telephone technologies that allow people to identify the source of the call and avoid answering result in lower survey response rates and decreased representativeness of the results.

Most provinces have ongoing school-based surveys. In addition, several one-time surveys have been conducted at the national, provincial/territorial and regional/local levels. (See inset Nutrition Data) The methodologies developed for these surveys can form the basis for subsequent surveys. In many cases, however, lack of ongoing funding has prevented their repetition.

### **Ontario Rapid Risk Factor Surveillance System (RRFSS)**

Health Canada, Cancer Care Ontario and the Durham Regional Health Department in Ontario recognized the need for timely, local surveillance data for health promotion and prevention programs. They jointly funded a pilot project to adapt the Centre for Disease Control (USA) Behaviour Risk Factor Surveillance System to Ontario. The pilot was very successful and the project has been taken up by 20 health units in the province.

The RRFSS in Ontario is managed by public health units who name health unit people to sit on the management committee, which will act on their behalf. The management committee also includes the data collection organization that is responsible for managing this component. Each of the health units donates its time to the management process.

The monthly telephone survey is carried out by a university-based survey unit, and each health unit pays directly for its sample and conducts its own analyses. The questionnaire has common and optional modules, and can be modified easily to respond to local needs. The RRFSS complements the data obtained from the CCHS. The Durham Region Health Department provides the syntax for the analysis program and the Central East Health Information Partnership maintains the Web site through which the data is accessed. The RRFSS provides data to assess how well the health unit is complying with Mandatory Health Program and Service Guidelines.

#### **Key Success Factors**

- ◆ Leadership from health unit management
- ◆ Partners value collaboration with others
- ◆ Association of Public Health Epidemiologists in Ontario (APHEO) provides leadership and an infrastructure for collaboration
- ◆ Development resources from initial partners
- ◆ Ontario Mandatory Health Program and Service Guidelines provide a framework for the survey and the incentive to obtain local data

#### **Key Limitations**

- ◆ Resources to manage the system
- ◆ Resources in health units to analyze and use the data
- ◆ Competition for resources for this initiative with other public health programs as public health is under-funded in general

In addition to exploring personal lifestyle behaviours, some surveys also investigate chronic disease prevention policies. For example, Health Canada conducts a survey of regional tobacco control bylaws on an ongoing basis. Public opinion polls also serve as sources of data.

Some data on environmental risk factors for chronic disease are collected through environmental assessment at the regional/local, provincial/territorial and national levels. Linking the environmental measures with health outcomes presents a challenge.

Although data on nutrition factors is generally lacking, some data collection systems do exist. The provincial nutrition surveys conducted through the 1990s shed some light on the food and nutrient consumption of Canadian adults. The data, however, are province-specific. Statistics Canada annually compiles and reports data on food available for consumption on a per capita basis. These data reflect changes in the food supply. Limited ongoing data sources are available at the national level on the individual and collective determinants of eating behaviour.

Statistics Canada is currently planning a physical-measures survey that will include several risk factors for chronic diseases, such as blood pressure, height, weight and physical fitness, as well as blood tests for biochemical and haematological risk factors. While this kind of survey is essential for several risk factors, it is very expensive and lacks an ongoing source of data for physical measures. In addition, it will not provide data at the regional/local level where the bulk of programming is delivered.

While administrative and clinical databases have the potential to provide useful data for chronic disease risk factor surveillance, their use for this purpose is minimal at the present time. The National Diabetes Surveillance System (NDSS) plans to link collect risk factor data from physician-billing administrative databases in the future. Some jurisdictions are exploring the use of an electronic health record to capture data available in the clinical setting.

Community data is lacking on factors such as smoking bylaws, bicycle paths and recreation opportunities that influence health and behaviour.

### Ontario Collaboration to Obtain Provincial Nutrition Data

The Prevention Unit of Cancer Care Ontario (CCO) needed to know nutrition information about the population in order to determine strategy for policy, program and media interventions. It collaborated with the surveillance and research units within CCO as well as the Toronto Public Health Department, Ontario Ministry of Health and Long-term Care, York University, Ryerson University, American experts at the National Cancer Institute (NCI) and the U.S. Department of Agriculture (USDA). The result was the development and implementation of a nutrition survey that included food frequency data as well as psychosocial and food security measures. By combining resources, including additional money from the City of Toronto, the survey had greater sample size and was more comprehensive, was translated into several languages and the performance of the food-frequency instrument was calibrated. This resulted in the ability to provide estimates for both the province planning regions across Ontario, as well as specifics for the Toronto area.

#### Key Success Factors

- ◆ Staff in each organization knew each other and the realities of each other's organization and mandate
- ◆ Strong senior management support
- ◆ Strong leadership from within organization units managing the survey
- ◆ Organizations had expertise and resources to commit to project – low staff turnover
- ◆ Strong links between policy makers and program designers (data users) and surveillance and research experts (data providers)
- ◆ Drew upon expert resources available elsewhere (USDA and NCI)

#### Key Limitations

- ◆ Ongoing source of funding

A recent study *Data, data everywhere...: Improving access to population health and health services research data in Canada* (December 2004, CIHR) outlines the challenges that exist in accessing population-base data in a timely way. One of the report's recommendations is that custodians of population health and health services data... should be encouraged to work with privacy experts and the research community to create and make available public use microdata sets as well as to provide access to more detailed microdata sets for publicly funded research.

## Data Analysis and Interpretation

### Question

***What do public health organizations need to analyze and interpret the data?***

Data needs to be analyzed with a type and level of analysis that reflects its end use. The analysis must be timely and flexible – geared to the specific needs of each organization's surveillance purposes. Use of the data can be improved if people and organizations other than the owner of the data can also have access to it for tailored analysis.

Data are analyzed for surveillance purposes in several ways. Some organizations rely on published data tables. Interactive data tables on the Internet allow an organization to customize the analysis of data from a third party. Other organizations work in collaboration with the data owner to create customized analyses. In another model, data-sharing agreements give a second organization restricted access to the data for its own analysis. Effective collaboration between Statistics Canada and CIHR has facilitated effective use of surveillance data for research purposes. (See inset CCHS Analysis)

Within the NDSS, individual provinces send data tables to Health Canada for analysis. Within the Rapid Risk Factors Surveillance System (RRFSS) in Ontario (see page 21), individual organizations conduct their own data analysis using data obtained through a joint data collection process. In this approach, software to standardize and assist with the analysis is shared among the organizations to support data analysis.

When the data user differs from the data collector, interpreting the data may also be a challenge. Both want to ensure that the data are being interpreted correctly. The data owner wants to ensure that the data analysis is statistically accurate and that the

### CCHS Analysis

Statistics Canada has used creative approaches to increase the analysis and use of its Community Health Survey (CCHS) and National Population Health Survey (NPHS). Its Web site offers a great variety of options, including meta-data reports to increase an understanding of the data itself to help others in their analyses, data tables, and reports. Over one million hits were received on the Health Products Site in 2002/03.

Statistics Canada also provides workshops on using the data, public-use data files to health regions and partners, and consultation services to these users. It also provides a more in-depth share file to Health Canada and provincial/territorial Ministries of Health, and through third party agreements to some regions. Statistics Canada provides analysis tools for users. Special agreements allow researchers access to the data. Guidelines ensure that the data are analysed appropriately and with attention to confidentiality and privacy needs.

#### Key Success Factors

- ◆ Strong leadership with a commitment to making optimal use of data
- ◆ Effective Advisory Committee
- ◆ Use of Internet technology
- ◆ Collaborative partnerships in place
- ◆ End-users have expertise and resources and time to do their own analyses
- ◆ End-users have incentive to use data

#### Key Limitations

- ◆ Lack of adequate resources at the provincial/territorial and regional/local levels for analysis

interpretation is plausible and reflective of the data collection method. The data user is interested in the data's implications for policies, programs and services. Even different data users may have different interpretations on the same analysis. Currently, each data owner interprets its own data. In addition, various national organizations collaborate on interpreting risk factor surveillance data as it relates to their specific diseases.

### **Gaps**

Capacity to conduct the analysis is essential and requires both individuals who are skilled in statistical analysis and adequate technological equipment. In general, analytical capacity does not meet the demand in Canada at all levels – national, provincial/territorial, and regional/local. This limits the ability of public health organizations to analyze the available data to meet their own needs. In Ontario, the RRFSS provides data to each health unit for its own geographic area. However, health units that lack staff with adequate analytical expertise and time find it difficult to analyze the data in-house. For many public health organizations across the country, making optimum use of national surveys, such as the CCHS, is a challenge because of the technical skill and computer capacity required to conduct analysis with the complicated weighting procedures. At a minimum, all public health units need to be able to do descriptive analysis of the CCHS by person, place and time for their own locale.

## **Surveillance Products, Dissemination and Use**

### **Question**

*What do public health organizations need to communicate surveillance data internally and externally, and to encourage the use of surveillance information in planning and evaluation?*

Communicating the information to decision-makers for their use is an essential component of a surveillance system. If communication is poor, the investment of resources in data collection is for naught; good communication does not necessarily ensure effective utilization. People are busy and often unfamiliar with the use of population-based surveillance data for decision-making, so active support to encourage the use of data is necessary. Including surveillance as part of the overall management process can facilitate the effective use of surveillance data. For example, the 2000 analysis of available asthma surveillance data resulted in publication of the Asthma in Canada Report/Strategic Plan. This in turn provided the evidence used to shape directions for jurisdictional strategies, including the Ontario Ministry of Health's Asthma Prevention and Control Strategy. The annual Cancer Reports provide cancer incidence and mortality data and projections.

### **The Growing Burden of Heart Disease and Stroke in Canada**

The Heart and Stroke Foundation of Canada has led the biennial publication of a report on heart disease and stroke in Canada for the past 12 years. Its partners include the Centre for Chronic Disease Prevention and Control of the Public Health Agency of Canada, Statistics Canada, the Canadian Institute for Health Information (CIHI), and the Canadian Cardiovascular Society. The report is available on Websites and the hard copy is disseminated widely. It is used for advocacy, in teaching and health planning.

#### **Key Success Factors**

- ◆ Organization commitment to publication of the report every two years
- ◆ Strong team with epidemiological, content and policy expertise
- ◆ Detailed planning a year ahead with setting of a timetable
- ◆ Commitment of resources by partners and obtaining industry resources for printing and distribution
- ◆ Regular feedback and revisions to respond to end-users' needs

#### **Key Limitations**

- ◆ Lack of ongoing funding and the continual need to go to industry for contributions
- ◆ Lack of capacity at the national level for analysis and dissemination
- ◆ Lack of surveillance on physical measures such as blood pressure

Effective dissemination products and processes address the predisposing, enabling and reinforcing factors influencing whether the products will reach the right people, whether they will be read and understood, and whether they will be used for decision-making and then communicated to others. The dissemination process needs to be timely so that stakeholders have the information when they are making decisions. Otherwise they will make decisions with less-than-optimal information. (See inset: Growing Burden)

The dissemination product needs to have a clear and simple message and be disseminated using a method and manner that is acceptable and accessible to the targeted decision-makers. It must be flexible so that decision-makers can adapt the information to their own communication needs (for example, posting PowerPoint slides on a Web site to encourage others to use them for presentations to various stakeholders). The dissemination product must be representative so that it includes the people for whom decisions are being made. For example, a dissemination product, such as a written report or a web-based product targeted at regional/local public health units, ideally would include regional/local data. Regular ongoing release of dissemination products that are consistent in quality and style encourages use through familiarity with the products and confidence in the ability to use them.

Current surveillance systems for chronic disease risk factors and determinants use a variety of dissemination products and methods. Recent data are published in periodic reports, in set tables available through the organization's Web site, or through research papers published in journals.

Some dissemination products are interactive. For example, Web sites allow the user to customize the topic, date, place and characteristics of the individual (age and sex) of the data request. (See inset: InfoBase) Even more elaborate dissemination products allow direct access to the database through a restricted Internet portal.

### **Gaps**

The most serious gap in dissemination of surveillance information is its lack of use in policy and program decision-making. This is in part due to the reliance on passive dissemination methods through existing communication channels. In addition, weak connections between the people who would use the data and those who collect it prevent the surveillance system from becoming an integral part of the management cycle.

#### **InfoBase**

InfoBase is international database software that is interactive and produces maps of risk factor prevalence and other diseases. Pre-set tables populate this database, which allow the user to select years, place and age/sex groups for the risk factor or disease. The Public Health Agency of Canada is providing support to this project, which is carried out in collaboration with WHO.

##### **Key Success Factors**

- ◆ Simple concept: understandable and flexible
- ◆ Fulfills a need among partners
- ◆ Broad application to many risk factors and diseases
- ◆ Uses available technology
- ◆ Expertise available to build application

##### **Key Limitations**

- ◆ Lack of awareness
- ◆ Lack of ongoing resources

## Management

### Question

***How can public health organizations effectively manage surveillance systems for chronic disease risk factors and determinants?***

Maintaining and sustaining a high-quality surveillance system requires good management. The organizations that manage a surveillance system are responsible for all of the above functional components: indicator definition, data collection/collation, data analysis and interpretation, and surveillance products and dissemination. Several management models are possible, ranging from one organization doing it all, to a coalition of organizations sharing the functions and responsibilities.

Management includes five primary activities: planning, organization of resources, coordination of day-to-day activities, control through the development of standards and guidelines, and evaluation of both process and outcomes. Human and physical resources are required. Given the number of stakeholders involved in risk factor surveillance, mechanisms are needed to help people work together and resolve differences in standards and approaches. (See inset: NDSS)

The organization that manages the surveillance system or a component of the system must be both credible and acceptable to the stakeholders. The management team must include people with the necessary expertise and experience to do the job and handle the issues on a timely basis. These individuals must have clear roles and responsibilities. A simple, unlayered management structure enables timely decision making in both policy and management. Management decisions and processes must be transparent and appear open to all stakeholders. The management structure requires flexibility to respond to external forces, such as changes in stakeholders' needs and technology, and to internal forces, such as changes in resources and evaluation results. The same organization must manage the surveillance system or component for a sufficient length of time to develop quality and consistency in performance.

### Gaps

One of the most pressing challenges is securing adequate funding for the management function of the surveillance system. Another is developing effective mechanisms to ensure the adequate involvement of all stakeholders in identifying data needs, and in the collection and analysis of data.

### National Diabetes Surveillance System

The National Diabetes Surveillance System (NDSS) is a collaborative effort among governments to use provincial/territorial administrative databases (physician billing and hospitalizations) to determine new and prevalent cases of diabetes and their use of health services. The Public Health Agency of Canada invests resources within each provincial/territorial government to facilitate cooperation with the overall surveillance strategy. This investment builds the capacity to carry out surveillance in other areas as well. A National Coordinating Committee sets standards, interprets the data, and prepares reports.

#### Key Success Factors

- ◆ Leadership with a small group of dedicated people at the federal and provincial/territorial levels
- ◆ Pilot project to develop and prove concept
- ◆ Funding for five years
- ◆ Existing ongoing data collection system

#### Key Limitations

- ◆ Concern about sustained funding beyond the initial five year investment
- ◆ Quality of the data for some indicators
- ◆ Capacity to use data at the regional/local level

## Legislation and Regulation

### Question

***What legislation and regulations do public health organizations need to support their surveillance of chronic disease risk factors and determinants?***

In the Canadian context, privacy and data protection legislation, constitutional provisions, and other aspects in common and civil law apply to the practice of health surveillance (for both primary collection of data and secondary sources). In addition, the codes of ethics under which health professionals practise constitute standards of conduct and have some force in law. Issues such as what constitutes the appropriate secondary uses of data, consent for use, and the practice of linking data sets are all affected by legislation existing within provincial/territorial and federal jurisdictions.<sup>18</sup>

With the exception of the reporting of cancer, Canada lacks legislation that is specific to chronic disease surveillance. Eight out of 10 provinces have specific legislation that provides the legal basis for obtaining information on cancer cases within the province. Typically, the legislation is specific to cancer, but in some cases a public health act is used and cancer is defined as a notifiable disease. The exceptions (New Brunswick and Quebec) run

cancer registries, but do so under the authority of statutes or public health legislation that does not specify cancer as a notifiable disease.

Most Canadian jurisdictions have legislation pertinent to health surveillance in general. Relevant statutes include:<sup>19</sup>

- ◆ Public health legislation respecting reporting requirements for notifiable diseases (very rarely applicable to chronic disease);
- ◆ Freedom of information and privacy legislation respecting the access to and protection of government-held information;
- ◆ Health information protection legislation such as the statutes enacted in Alberta, Manitoba, and Saskatchewan (and under development in Ontario) that are 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 directs the reporting of vital events and the collection, analysis and publication of statistics.

### Quebec Public Health Legislation

Quebec's *Public Health Act* includes a unique legislation which states that an "ongoing surveillance of the general population health status and its determining factors must be done to know its progress and be able to offer appropriate services to the population" (Chapter 1, Article 4). It also states that the ongoing surveillance function "is the Minister's and Public Health Directors' exclusive responsibility" (Chapter 4, Article 34). By supporting this function and identifying the people in charge, the Act gives to Quebec the means to implement and use surveillance to inform the population on its health status, support the decision making and socio-health planning process, review the orientations and choices and support decision making in related activity areas. Otherwise, the Act insists on the need that a Public Health Ethics Committee and, if needed, the Quebec Commission on Access to Information examines the information that will be needed.

#### Key Success Factors

- ◆ Strong commitment to public health
- ◆ Public health infrastructure to carry out the Act

#### Key Limitations

- ◆ Lack of resources to implement the Act

<sup>18</sup> June 2002, the Chronic Disease Surveillance Infrastructure Sub-Group of the Health Surveillance Working Group in its report, *Situational Analysis for Chronic Disease Surveillance Systems and Networks in Canada*; p. 14.

<sup>19</sup> Ibid.

In addition, the federal *Personal Information Protection and Electronic Documents Act* is now law, incorporating in it the CSA Model Privacy Code. This Act applies to federal undertakings and crown corporations, and interprovincial and international flows of personal information, including health information.

In several provinces, public health legislation defines public health activities. For example, Ontario's Mandatory Health Programs and Services Guidelines require regional/local public health units to publish a health status report that includes risk factors in the population. The Quebec *Public Health Act* identifies surveillance as a public health function at the same level as health promotion, prevention and protection. This Act also stipulates who has the responsibility for surveillance, what methods to use, and what are the goals and objectives of surveillance. It also stipulates that the National Public Health Institute, which manages public health activities at the national, regional and local levels, should have orientations, objectives and priorities concerning the ongoing surveillance of the population's health status as well as its determining factors (Chapter II, Article 8). (For more detail, see inset: Quebec).

## Summary

Surveillance of risk factors and determinants for chronic disease has the potential to make a major contribution to the shaping of policies, programs and services and to respond to community need. The surveillance activities described in this report highlight the essential elements of effective surveillance:

### Leadership

- ◆ Policy framework within which surveillance data fits
- ◆ Creative leadership with a vision
- ◆ Strong commitment to public health
- ◆ Recognition by senior management of the need for surveillance

- ◆ Political will
- ◆ Incentives to use surveillance data

### Operations

- ◆ Detailed planning
- ◆ Regular feedback and revisions
- ◆ Small dedicated group of people develop concept with a focus on end-users' needs
- ◆ Public health infrastructure in place upon which surveillance can be built
- ◆ Involvement in the surveillance process of program people who need the data
- ◆ Provide support to end-users
- ◆ Content and epidemiological expertise
- ◆ High-quality survey unit with strong interest in surveillance
- ◆ Access to expertise in surveillance
- ◆ Use of web technology
- ◆ Ongoing investment of funds from both federal and provincial/territorial governments
- ◆ Creative funding arrangements to expand survey size

### Collaboration

- ◆ F/P/T relationships – having the right people at the table
- ◆ Build on existing relationships
- ◆ Shared attitude of helping each other
- ◆ Existing coalition recognizes need for surveillance
- ◆ Supportive legislation
- ◆ Effective involvement of all three jurisdictional levels so that surveillance needs of all levels are met.

# Strategy

## Vision

Canadians have reduced burden of chronic disease as a result of changes in policy, programs and services based on timely surveillance

## Goal

To improve capacity in Canada for surveillance of chronic disease risk factors and determinants.

## Outcomes

The strategy will contribute to the following outcomes.

1. Public health organizations conduct surveillance using data from existing population databases, and use the information in decision-making.
2. Public health organizations have access to surveillance data collection systems that are timely, rapid and flexible to meet their information needs, and use this information in decision-making.
3. Administrative and clinical databases are used effectively for surveillance purposes.
4. Data users and data owners from health and other related sectors, such as recreation, education, transportation and social services, work collaboratively to increase data availability and its use for chronic disease risk factor and determinants surveillance.
5. The public health environment encourages the use of surveillance information in decision-making.
6. Coordination of surveillance supports public health organizations' surveillance activity.

## Recommended Strategic Areas

The following recommendations were developed after broad consultations across the country and through discussion with individuals involved in effective surveillance capacity building activities.<sup>20</sup> The solution for delivering cohesive, efficient and successful chronic disease surveillance capacity at every level cannot be found by simply choosing to implement any one of the recommendations below. A variety of interconnecting issues continue to hamper the effectiveness of surveillance initiatives moving forward, and they require an integrated approach. Regions must be included in the policy creation process to ensure that their needs are being fully met. All levels (federal/national, provincial/territorial, and regional/local) will enhance efficiency and effectiveness of surveillance activity by working together.

The work of the Surveillance Systems for Chronic Disease Risk Factors Task Group has been coordinated with the Healthy Living Task Group and the Strengthening Public Health System Infrastructure Task Group. The recommendations proposed here are consistent with the recommendations from these Task Groups.

Four strategies are recommended by the Task Group to build on the strengths of the present surveillance system and respond to the gaps.

1. Enhance Federal, P/T and local/regional capacity to analyse, interpret and use surveillance data.
2. Expand existing data sources to fill gaps in surveillance knowledge.
3. Enhance collaboration, planning and evaluation for surveillance among all the stakeholders.
4. Build capacity across jurisdictions for congruent public health legislation supportive of chronic disease surveillance.

<sup>20</sup> Quebec had already carried out its own consultations within the province; this information was provided to the Task Group to support their work.

Provinces and territories are at different levels of capacity for surveillance at this time. Some already have the activities identified above in place. These strategies and activities can be phased in over time in response to the availability of resources. Appendix C includes a schema of the system for surveillance of chronic disease risk factors and determinants and a list of the responsibilities of members of the system.

### **Strategy #1**

***Enhance Federal, P/T and local/regional capacity to analyse, interpret and use surveillance data.***

#### **Rationale:**

The federal government has made major investments in ongoing data collection systems such as the Canadian Community Health Survey, the Physical Activity Monitor, the Canadian Tobacco Use Survey, and the Longitudinal Survey on Children and Youth. Provincial and territorial governments maintain health administrative databases with physician billing, hospitalization, drug use, and other data. The investment in these databases is only worthwhile if the data is analyzed, interpreted and used effectively.

#### **Activities:**

- a. Develop surveillance plans linked to chronic disease prevention programs by public health organizations.

An essential first step to using existing data for surveillance is to identify the data needed for planning and evaluation. A surveillance plan outlines these data requirements, where the data comes from, how it will be analyzed and interpreted and to whom it will be disseminated. Public health organizations which have a surveillance plan are able to readily contribute to discussions about the data elements to be included on nationally coordinated databases such as the Canadian Community Health Survey. A surveillance plan clarifies why surveillance is done and what is being monitored. Identifying the indicators and available sources to be consolidated or developed enables the short, medium, and long term data management plans.

- b. Develop a central coordinating function within the Public Health Agency of Canada to facilitate access to resources, information about

databases, definitions of indicators, analyses, and standards for data collection tools and methods.

Collaboration on surveillance activity is facilitated if different groups are aware of each other's activities and if data collection tools and methods are standardized across the country. A central coordinating function could connect those involved in surveillance across the country, and using the Internet and other technology could facilitate information sharing among the group.

- c. Enhance access to existing surveys and databases, and expand resources for analyzes and interpretation for surveillance purposes.

Universities have a wealth of expertise and interest in analyzing existing population databases. They sometimes experience difficulties in accessing databases in a timely way. Governments also have expertise and interest but lack adequate resources to fully analyze and interpret existing databases.

- d. Provide E-learning, conferences, and workshops to increase knowledge and skills.

While much is happening now to build knowledge and skills, more is needed. The Public Health Agency of Canada has an effective e-learning program and Statistics Canada offers user workshops and prepares data files to facilitate use. Each of these programs can be expanded with special consideration for supporting equitable access across the country using technology such as videoconferencing.

- e. Establish surveillance support systems with universities and others for analysis, interpretation, and use of data of existing surveys and databases in order to build local/regional public health unit capacity.

The knowledge, expertise and technology to conduct effective surveillance exist in some but not all parts of the country. Developing surveillance support systems will help connect those with the knowledge and expertise to those without it. This approach has been effectively used in the research community. Academic centres, larger public health units, provincial/territorial governments would work directly with public health unit managers and others in a knowledge brokering capacity, assisting in the identification of surveillance

needs, access to data, interpretation and use. Incentives and additional resources will be needed to facilitate and coordinate this process.

- f. Develop a public health human resource strategy, led by Public Health Agency of Canada.

The deficit of experienced epidemiological personnel, or other fields such as demography, economy, sociology, etc, in all public health units has been one of the barriers to moving chronic disease surveillance activities forward at the local/regional level. The Strengthening Public Health System Infrastructure Task Group has also identified this as an important issue and has made recommendations for a sufficient and competent workforce.

## **Strategy #2**

***Expand data sources to fill gaps in surveillance knowledge.***

### **Rationale:**

Data collection is fundamental to surveillance: there has to be ongoing, valid, current, accessible, comprehensive, and timely data for whatever aspect of health is under surveillance – in this case, risk factors and determinants of health. The transformation of this data into the information for sound health policy development and decision-making strengthens chronic disease prevention and control measures at all levels.

Currently there are several data sources that are being used for surveillance of chronic disease risk factors and determinants. The background paper on Data Sources<sup>21</sup> describes these databases in more detail. Additional data is needed on social and community factors that influence health and behaviour choices; on policies, programs and services that address risk factors and determinants; on children and youth; and on physical measures such as high blood pressure, physical fitness, and weight.

Another critical issue is that these databases provide data mainly for national, provincial/territorial and in some case large regional population estimates. They do not have the sample

size, flexibility and content needed for regional/local public health surveillance.

### **Specific Activities:**

- a. Establish public health locally/regionally coordinated ongoing flexible data collection systems (such as the Rapid Risk Factor Surveillance System in Ontario (see inset page 21)).

Ontario public health units have developed a very effective approach to collected data for surveillance that meets regional/local needs. The Rapid Risk Factors Surveillance System complements the data provided nationally through the Canadian Community Health Survey. Data needs are identified by program managers. Monthly telephone surveys are carried out by a central survey unit using questions developed collaboratively by the health units. Results are provided to the health unit two weeks after the end of the month. The system is managed by a coordinating committee with representation from the participating health units. This approach is easily transferable to other provinces.

- b. Build on existing data sources to fill gaps in data.

Fortunately, expanding existing data sources can fill many of the data gaps. The Physical Activity Monitor managed by the Canadian Fitness and Lifestyle Research Institute has the methodology to conduct surveys on community, school and workplace policies. Statistics Canada is currently developing the methodology for a physical measures survey. Many provinces have developed school surveys and departments of health and education are currently collaborating on programs for healthy living. Primary care research networks and health administrative databases provide an opportunity to collect data on conditions for which people seek medical attention. Some public health units are developing a methodology to collate data from a variety of sectors.

- Expand the monitoring of physical activity managed by the Canadian Lifestyle and Fitness Institute for more frequent data

<sup>21</sup> Reference; Data Sources for Risk Factor Surveillance – Discussion Paper, Surveillance System for Risk Factors Task Group, March 2005.

collection of individual and environment indicators.

- Expand and coordinate across student-based school surveys and other setting-based tools and methods.
- Provide ongoing funding for the Statistics Canada Physical Measures Survey.
- Use technology to access information from databases housed in other sectors and settings.
- Build on the National Diabetes Surveillance System that uses health administrative databases to collect data on other risk factors, health problems and further detail about conditions currently in the surveillance system.
- Use primary care research networks to collect risk factor data among those attending family physicians offices.
- Support risk factor and determinant data collection systems for Aboriginal Peoples.

### **Strategy #3**

***Enhance collaboration, planning and evaluation for surveillance among all the stakeholders.***

#### **Rationale:**

Surveillance must operate within the larger context of disease prevention and control, with a connection between surveillance activities and decisions about policies, programs and services for risk factors and determinants. The Canadian action plans for Healthy Living, cancer, diabetes, cardiovascular disease, arthritis, chronic obstructive pulmonary disease and asthma have all recognized the need for surveillance as a cornerstone of effective prevention and control.

Collaboration is of key importance to successful capacity building. Collaborative input must be encouraged at all levels to ensure that every level of health care is included in policy making decisions, and to ensure that all levels are continually aware of ongoing improvement in chronic disease surveillance capacity nationwide. In addition, collaborative efforts with partners must be strongly encouraged to leverage the mutual benefits derived from encouraging a focus towards public health program development.

The planned Pan-Canadian Public Health Network is designed to provide a structure and process to link various public health initiatives. This could be an effective vehicle to improve collaboration, planning and evaluation of chronic disease surveillance while linking it to policy and program information needs. Chronic disease surveillance could be an Issue Group linked to both the Surveillance and Chronic Disease Expert Groups. The participants in this collaborative process would include both data collectors/managers and users. The data users are public health organizations, researchers, governmental and non-governmental organizations.

The advantages of coordination and collaboration between partner organizations in the surveillance of chronic disease risk factors include:

- Common strategic orientations and priorities;
- Development of surveillance indicators;
- Facilitation of the development and access to data sources;
- Development of common tools, methods and standards; and
- Capacity development.

The Public Health Agency of Canada (PHAC) is ideally suited to be the Resource Unit for the *Pan-Canadian Issue Group for Surveillance of Chronic Disease*. Surveillance is a key part of its mandate and it has strong relationships with the key stakeholders needed to build the collaboration. The PHAC collaborating centres can provide technical and resource support to the collaborative process.

#### **Specific Activities:**

- a. Establish a Pan-Canadian Issue Group for Surveillance of Chronic Disease within the Pan-Canadian Public Health Network with representation from government, local/regional public health, database managers, research bodies, academia, professional associations, and non-government organizations.
- b. Establish a coordination, planning and evaluation function within the Public Health Agency of Canada.

## Strategy #4

***Build capacity across jurisdictions for congruent public health legislation supportive of chronic disease surveillance.***

### **Rationale:**

Public health legislation outlines the roles and responsibilities of *Public Health Act* to promote and protect health, and prevent health problems, and the role of the broader community in assisting with this mandate. Surveillance is a key public health function and needs to be part of public health legislation.

Several jurisdictions have recently undertaken extensive review of the legislation directly and indirectly related to chronic disease surveillance, and have developed comprehensive legal frameworks that serve to enhance and support this essential function within a public health context. Other provinces and territories rely on a less cohesive arrangement of statutes and regulations to support their public health surveillance activities. The experience of other jurisdictions such as Quebec in developing frameworks and revising legislation provide a valuable knowledge resource with which to inform other jurisdictions undertaking similar exercises.

In the Québec *Public Health Act*, surveillance is a function of public health, as are protection, promotion and prevention, and the minister and local public health directors are responsible for surveillance. This Act enabled the establishment of mechanisms to support the coordination of surveillance and to develop a common surveillance plan at the regional and provincial levels. Other aspects of the Act enhanced and framed the function of surveillance, in particular, the

establishment of an ethics committee in public health and of a national public health program. This program provides directions, objectives and priorities for the surveillance of health and determinants and has the authority to request non-identifiable information that is necessary for carrying out a surveillance plan among organizations and other departments.

At present, the federal legislation as it applies to all aspects of public health, including public health surveillance, is under review. A strategy for improving chronic disease surveillance must include review of any proposed legislation from a chronic disease surveillance perspective.

The Task Groups recommendation's are consistent with those of the Public Health Infrastructure Task Group of ACPHHS.

### **Activities:**

- a. Develop model public health legislation related to surveillance in collaboration with provinces, territories and the federal government, in particular the Public Health Agency of Canada, Health Canada and CIHR.
- b. Encourage jurisdictions to consider the model legislation when reviewing and revising their health legislation.
- c. Support creation of a centre of expertise in public health law within the Public Health Agency of Canada, and a national interest group in public health law linked to the Public Health Network. (from Strengthening Public Health System Infrastructure Task Group of ACPHHS).

# Conclusion

Surveillance is an essential tool for planning and evaluating policies and programs to address chronic disease risk factors and determinants. There are many exemplary activities across the country that demonstrate the power and utility of surveillance. However, major disparities in surveillance capacity exist among regions and among provinces and territories.

The Task Group has consulted extensively across the country<sup>22</sup> to identify the strengths and gaps in capacity for surveillance of chronic disease risk factors and determinants. The Task Group recommends the following four strategic areas for action:

Strategy #1	Enhance Federal, P/T and local/regional capacity to analyze, interpret and use surveillance data.
Strategy #2	Expand data sources to fill gaps in knowledge.
Strategy #3	Enhance collaboration, planning and evaluation among all the stakeholders.
Strategy #4	Build capacity across jurisdictions for congruent public health legislation supportive of chronic disease surveillance.

These strategies are interconnected and mutually supportive. Their implementation will vary among the provinces and territories in response to the availability of resources. Collaboration among those who collect and manage surveillance data and those who use it for decision-making and among the three levels of public health action is critical to ensure that the surveillance activity meets the needs of all involved.

The beneficiaries for enhanced surveillance capacity for chronic disease risk factors and determinants will be Canadians themselves. Timely, quality surveillance data will guide policies, programs and service to promote health and prevent chronic disease. This is the ultimate goal of surveillance for chronic disease risk factors and determinants.

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<sup>22</sup> Quebec had already carried out its own consultations within the province; this information was provided to the Task Group to support its work.

# Appendix A

## Surveillance Systems for Chronic Disease Risk Factors Task Group

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# Appendix B

## Consultations

The Task Group held consultations with key influencers and stakeholders in order to:

- a. explore with possible FPT users their potential contributions, current capacities and future capacity requirements for supporting a surveillance system for chronic disease risk factors
- b. to develop and discuss a framework/model that can be customized to different levels and situations.

The consultation involves brief (e.g., one four-hour) focused discussion with a select number of key interest groups identified by members of the Surveillance Systems for Chronic Disease Risk Factors Task Group. Participants were asked to review and provide feedback on a background paper and a draft framework. Discussion items for each group included:

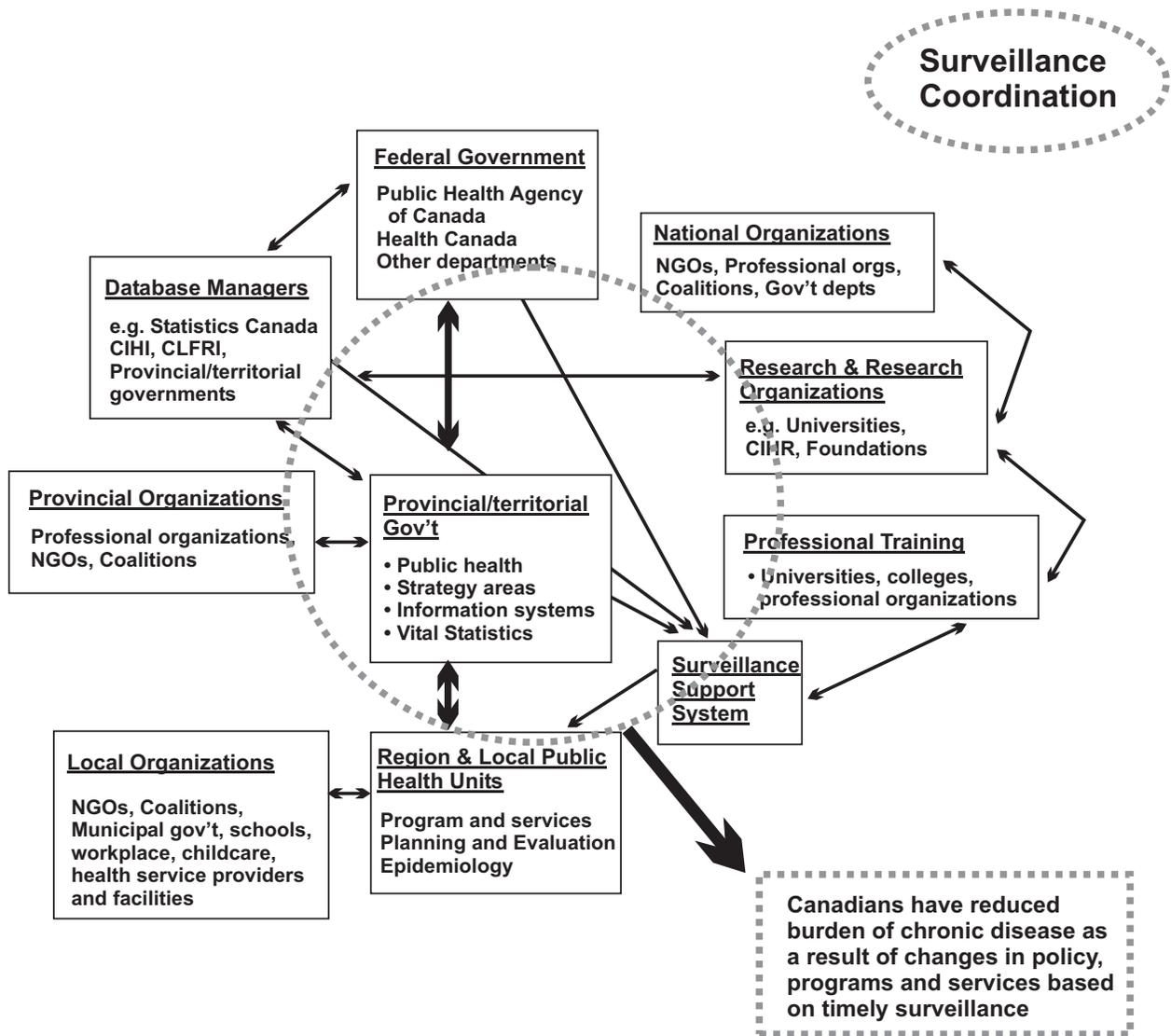
- ◆ a vision for a pan-Canadian surveillance system;
- ◆ key elements required in a coordinated pan-Canadian surveillance system;
- ◆ recommendations for taking action on key surveillance elements;
- ◆ what a collaborative, pan-Canadian surveillance system could add to what already exists;
- ◆ what each group could contribute to the development of a collaborative, pan-Canadian surveillance effort.

Groups consulted included:

- ◆ National Diabetes Surveillance System (NDSS) Steering Committee
- ◆ Chronic Disease Prevention Alliance of Canada (with local, regional, national and provincial levels of government and non-government organizations)
- ◆ Medical Health Officers Council of Saskatchewan
- ◆ Hypertension Surveillance
- ◆ Ontario Health Intelligence Partnerships
- ◆ Canadian Cancer Strategy Primary Prevention Group and Surveillance Alliance
- ◆ NWT Chronic Disease Strategy End-Users
- ◆ CIHR Institute of Population and Public Health and other Institutes; consultations to be done with selected experts
- ◆ Advisory Committee for Health Surveys Regular Meeting
- ◆ Canadian Council of Chief Medical Officers of Health
- ◆ Coordinating Committee, Ontario Rapid Risk Factor Surveillance System
- ◆ PEI Chronic Disease Strategy, Healthy Living Evaluation Sub-group

# Appendix C

## Schema of Coordinated System for Surveillance of Chronic Diseases



The following table outlines the major players and their roles and responsibilities in a coordinated approach to Surveillance of Chronic Disease.

<b>Player</b>	<b>Roles and Responsibilities</b>
Federal government ( <i>Public Health Agency of Canada, Health Canada, other Departments</i> )	<ul style="list-style-type: none"> <li>◆ Leadership</li> <li>◆ Coordination of national surveillance with other organizations</li> <li>◆ Collate and analyze data, disseminate and use in decision-making</li> <li>◆ Resource Unit for Coordination Function</li> <li>◆ Training and support</li> </ul>
Database Managers ( <i>Statistics Canada, CIHI, CLFRI, provincial/territorial governments</i> )	<ul style="list-style-type: none"> <li>◆ Identify data needs in collaboration with users</li> <li>◆ Make data accessible to users</li> <li>◆ Data standards, confidentiality, privacy</li> <li>◆ Disseminate reports</li> </ul>
NGO's, Professional organizations, Coalitions, Government departments	<ul style="list-style-type: none"> <li>◆ Identify data needs</li> <li>◆ Contribute data</li> <li>◆ Use information in decision-making</li> </ul>
Universities and Research Bodies (e.g. CIHR, NSERC)	<ul style="list-style-type: none"> <li>◆ Provide evidence for surveillance</li> <li>◆ Support data quality</li> <li>◆ Analyze, interpret &amp; report on surveillance data</li> <li>◆ Knowledge &amp; skill development</li> <li>◆ Research on surveillance needs, methods, uses</li> <li>◆ Consultation on data needs and use</li> </ul>
Professional Training ( <i>Universities, colleges, professional organizations</i> )	<ul style="list-style-type: none"> <li>◆ Knowledge &amp; skill development</li> <li>◆ Use information in decision-making</li> </ul>
Public Health, Provincial/territorial Gov't	<ul style="list-style-type: none"> <li>◆ Coordination of P/T surveillance</li> <li>◆ Analyze &amp; interpret P/T data, disseminate and use in decision-making</li> <li>◆ Support to regional/local public health</li> <li>◆ Contribute data to Public Health Agency surveillance</li> </ul>
Region & Local Public Health Units	<ul style="list-style-type: none"> <li>◆ Coordination of regional/local surveillance</li> <li>◆ Analyze &amp; interpret regional/local data, disseminate and use in decision-making</li> <li>◆ Contribute data to P/T gov't surveillance</li> </ul>

# Appendix D

## Glossary of Acronyms

ACPHHS	Advisory Committee on Population Health and Health Security
APHEO	Association of Public Health Epidemiologists of Ontario
CCHS	Canadian Community Health Survey
CCIS	Comprehensive Community Information System
CCO	Cancer Care Ontario
CCSA	Cancer Control Spectrum Association
CDC	Centres for Disease Control
CDPAC	Chronic Disease Prevention Alliance of Canada
CFLRI	Canadian Fitness and Lifestyle Research Institute
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institute on Health Research
COPD	Chronic Obstructive Pulmonary Disease
CTUMS	Canadian Tobacco Use Monitoring Survey
EHR	Electronic Health Record Solution
GIS	Geographic Information System
NCI	National Cancer Institute
NDSS	National Diabetes Surveillance System
NGOs	Non-government organizations
NPHS	National Population Health Survey
NSERC	National Science and Engineering Research Council
NWT	Northwest Territories
PAM	Physical Activity Monitor
RIC	Regional Inter-sectoral Committee
RRFSS	Rapid Risk Factor Surveillance System
SSCDRF	Surveillance Systems for Chronic Disease Risk Factors
USDA	United States Department of Agriculture
WHO	World Health Organization