Chapter 14

National Health Surveillance

Diseases and Injuries

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Diseases and Injuries

Main Points

14.1 We observed weaknesses in national surveillance of diseases and injuries that, taken together, have clear national implications for public health. First, they compromise Health Canada's ability to detect, anticipate, prevent and control health risks associated with outbreaks of communicable diseases and with other health threats. Second, they compromise its ability to plan, carry out and evaluate public health programs and other programs that deal with the causes and treatment of diseases.

Background and other observations

14.2 Health surveillance is a core function of public health. National surveillance of communicable and chronic diseases and of injuries is conducted mainly by Health Canada's Laboratory Centre for Disease Control (LCDC), part of the Health Protection Branch. LCDC depends greatly on its interaction and collaboration with the provinces and territories and a variety of other federal departments and non-governmental organizations.

14.3 There is no specific legislation, policy or agreement that links separate components of public health functions at the various levels of government. Indeed, there is a void: current health surveillance activities are largely carried out on an ad hoc basis.

14.4 We found few formal agreements or protocols in place to prevent the entry into Canada of serious communicable diseases and to deal with disease outbreaks and threats to public health. The lack of attention to formalizing the way these threats are to be managed places the health of Canadians at undue risk.

14.5 Key surveillance systems that we looked at were not working as intended. For a number of reasons, they were not enabling Health Canada to effectively monitor communicable diseases such as influenza, AIDS, tuberculosis and food-borne disease. The same is true of systems for surveillance of injuries and chronic diseases such as cancer, diabetes, and heart disease and stroke. We also found that performance measurement and reporting of results need to be improved.

14.6 Work has begun on strengthening the Health Protection Branch's future surveillance capacity. An important step in this regard is the Branch's support of an integrated national surveillance network for public health information. It is unclear when such a network will be implemented, and it is paramount that all parties involved in this network remain committed to its implementation.

Health Canada's responses to our recommendations are included in this chapter. The Department concurs with the recommendations and has agreed to take corrective action. In some cases, this action is already under way.

Introduction

14.7 Health surveillance is a core function of the larger framework for public health. That framework links many institutions and disciplines to bring together scientific and technical knowledge in order to promote better health and to prevent and control communicable and chronic diseases and injuries.

14.8 According to the definition adopted by Health Canada, health surveillance is "the tracking and forecasting of any health event or health determinant through the ongoing collection of data, the integration, analysis and interpretation of those data into surveillance products and the dissemination of such products to those who need to know. Surveillance products are produced for a predetermined public health purpose or policy objective. In order to be considered health surveillance, all of the above activities must be carried out." The single characteristic that makes health surveillance distinct from other health information activities is the requirement for a direct link to a public health purpose or policy objective.

14.9 Surveillance at Health Canada is undertaken by a number of branches and directorates. National surveillance of communicable and chronic diseases and injuries is conducted mainly by the Laboratory Centre for Disease Control (LCDC) of the Health Protection Branch; it is Canada's national centre for the identification, investigation, prevention and control of human disease (see Exhibit 14.1). The provinces and territories and a variety of other federal departments and non-governmental organizations provide the data for input to LCDC's systems (Exhibit 14.2). Data include provincial and regional statistics on hospitalizations for injuries and the incidence and prevalence of communicable and chronic diseases, physicians' reports, and so on.

14.10 National surveillance systems produce and disseminate information for organizations involved in public health. This information is an essential tool that helps on a national level to identify, investigate, monitor, prevent and control diseases and injuries. At the international level, national surveillance information supports World Health Organization surveillance programs. It is also used in disease prevention and control efforts with other international health organizations and centres for disease control in other countries.

14.11 To the extent that the information provided by Health Canada's surveillance systems is up-to-date and accurate, it can play a valuable role in helping to prevent and control diseases and injuries and to develop policies and strategies for improving the health of Canadians. At the same time, incomplete or otherwise deficient information can hamper the efforts of public health authorities to understand and respond appropriately to potential health risks.

Sound health surveillance information can save lives

14.12 The strengths — and any weaknesses — in health surveillance affect Canadians directly. For example, anticipating the timing of a flu epidemic and identifying the particular strain of the virus involved can save the lives of children and the elderly, who are especially vulnerable to influenza and its ensuing complications. Surveillance information is also essential to detecting patterns of diseases such as cancer: it can be used, for example, to identify possible links between the disease and what we eat and drink. It can also play a key part in looking on a national basis at prevention, screening and treatment to determine where the "success stories" are — what has worked and may have the potential to save lives.

The Laboratory Centre for Disease Control is Canada's national centre for the identification, investigation, prevention and control of human disease.

Exhibit 14.1

Laboratory Centre for Disease Control – Organization and Activities

In 1999–2000, LCDC has a budget of approximately $43 million and over 270 employees. It is divided into nine bureaus, with staff located mainly in Ottawa (with the exception of the Bureau of Microbiology, located in Winnipeg) and over 30 program areas addressing various public health issues.

Bureau	Division(s)
1. Cancer	Prevention Environmental Risk Assessment and Case Surveillance Behavioural Risk Assessment Cancer Control Assessment and Surveillance
2. Cardio-respiratory Diseases and Diabetes	Cardiovascular Disease Respiratory Disease Diabetes
3. Reproductive and Child Health	Child Injury Reproductive Health Child Maltreatment
4. HIV/AIDS, Sexually Transmitted Disease and Tuberculosis	HIV Epidemiology HIV/AIDS Surveillance National HIV/AIDS Laboratories Sexually Transmitted Disease Prevention and Control Tuberculosis Prevention and Control Blood Safety
5. Infectious Disease	Respiratory Diseases Enteric, Foodborne and Waterborne Diseases Disease Surveillance Immunization Bloodborne Pathogens Nosocomial and Occupational Infections
6. Microbiology	Bacteriology Zoonotics and Level 4 Programs National Laboratory for Enteric Pathogens Sexually Transmitted Diseases Host Genetics and Prions Disease Viral Diagnostics Core Services and Business Development
7. Global Surveillance and Field Epidemiology	Quarantine and Migration Health Travel Medicine Program Field Epidemiology Training Program Global Public Health Intelligence Network
8. Canadian Blood Secretariat	
9. Office of Biosafety	Importation and Biosafety Biocontainment and Certification Biosafety Services
10. Operations, Planning and Policy	
11. Directorate Management/ Secretariat	

Source: Laboratory Centre for Disease Control

14.13 Health surveillance is critical in responding to a changing reality. Global factors have dramatically increased the danger of communicable diseases being transmitted on a worldwide basis. Increased travel and migration, global food-supply lines, the return of old communicable diseases and the emergence of new "super bugs" have lent a new urgency to surveillance. These factors have the potential to pose serious threats to the health of all Canadians.

14.14 **Surveillance at work.** There are examples that show how health surveillance has benefited Canadians. For example, through a voluntary standard, new baby walkers have not been sold in Canada since 1989. However, surveillance information from Health Canada's Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP) showed that in Winnipeg there were still one or two babies injured each month in accidents involving baby walkers. In April 1997, acting on CHIRPP information, officials launched a one-day blitz in Winnipeg to encourage parents to turn in any remaining baby walkers. The response was immediate, and 168 baby walkers were brought to a collection depot. In the eight months following the local campaign, only four walker injuries were seen at the Winnipeg pediatric centre.

14.15 There have also been cases of sudden public health threats to which LCDC has had to turn its attention. During the recent Kosovo refugee operation, Citizenship and Immigration Canada (CIC) as the lead department requested LCDC's participation. LCDC was

Exhibit 14.2

Key Players in Health Surveillance in Canada

Laboratory Centre for Disease Control (LCDC)

- Located in the Health Protection Branch at Health Canada, LCDC is the national centre for the identification, investigation, prevention and control of human diseases. Its core activities are national health surveillance, disease prevention and control. It relies largely on provincial and territorial surveillance data in order to create a national picture of health risks, patterns and trends across Canada.

Provinces and territories

- Responsible for health matters within their own jurisdictions. In the case of surveillance and prevention and control of diseases, among other things, responsible for: carrying out vital statistics registration; ongoing surveillance of health conditions within the province or territory; outbreak investigations within the province or territory; public health laboratory-based surveillance; and analysis and interpretation of notifications from physicians, health units and other reporting sources.

Statistics Canada

- Primarily responsible for the collection and reporting of health, morbidity and mortality statistics. While the Agency is not directly involved in surveillance of communicable diseases, it undertakes, often on contract to Health Canada, surveys and data integration activities relating to specific chronic diseases.

Canadian Institute for Health Information (CIHI)

- National, not-for-profit organization working to improve the health of Canadians and the health system by providing quality health information. Its mandate is to develop and maintain a comprehensive, nation-wide health information system. CIHI provides information that is needed to establish sound health policies, manage the Canadian health system effectively and create public awareness of factors affecting good health.

Non-governmental organizations

- Numerous coalitions and non-governmental bodies undertake disease surveillance in areas such as cancer, cardiovascular diseases and diabetes.

A key element in national health surveillance is collaboration — between Health Canada and the other organizations involved in public health, and among all of them.

involved in planning and overseeing medical aspects of the operation because of the health threat associated with this mass influx of refugees. Surveillance was a key aspect of this operation, identifying those with communicable diseases and monitoring their movement after their arrival. It also helped in estimating the potential tuberculosis problems and the associated immunization requirements, as well as the need to deal with the psycho-social problems associated with post-trauma stress disorders from which many refugees suffered.

Key players in health surveillance

14.16 LCDC is only one player — but a key one — in the health surveillance process. As we have noted, others supply the data to LCDC, and federal organizations and provincial and territorial health systems are responsible for implementing any strategies that may flow from LCDC's health surveillance activities.

14.17 Clearly, LCDC depends greatly on its interaction with the many and varied players who make a key contribution to the effectiveness of the health surveillance system. We recognize, therefore, that Health Canada's LCDC is not solely responsible for a number of observations that we discuss in this chapter — in areas such as the quality and comparability of surveillance information; data collection; and dissemination of surveillance information. Nonetheless, identified weaknesses need to be fixed, and LCDC needs to champion change by strongly promoting that all players work together to improve the surveillance on which Canadians rely to protect their health. This chapter raises other issues that are within Health Canada's control — in areas such as clarifying roles and responsibilities and improving performance measurement. These the Department could deal with on its own.

Collaboration among all players is essential

14.18 A key element in national health surveillance is collaboration — between Health Canada and the other organizations involved in public health, and among all of them. Such collaboration is necessary to agree on and develop common procedures and protocols for key activities. These activities range from collecting and reporting data from physicians and other sources (the foundation of subsequent efforts to identify health risks and ultimately to reduce or control them) to responding directly to outbreaks of communicable diseases.

14.19 By playing a leadership role in fostering greater collaboration among the various players — federal, provincial and territorial — Health Canada would be taking an important step toward improving health surveillance and thereby the health of Canadians. Regardless of who takes the lead, however, this and the other issues that we raise need to be addressed without delay.

Focus of the audit

14.20 We examined the way Health Canada carries out national health surveillance and control activities, and how those activities support the other components of the public health framework. The audit focussed on surveillance and control activities related to communicable and non-communicable diseases as well as to injuries. We examined the Department's processes for collecting, analyzing and interpreting data and disseminating information, and how that information has been applied to prevention and control activities. Our examination also looked at ongoing "transition" initiatives of the Health Protection Branch that affect national health surveillance. Further details on the audit scope, objectives and criteria are presented at the end of the chapter in **About the Audit**.

Observations and Recommendations

Lack of a National Framework for Public Health

14.21 The provinces and territories are responsible for providing many public health services; Health Canada is responsible for protecting Canadians against risks to health and the spread of diseases. However, there is no specific legislation, policy, or agreement that links separate components of public health functions at the various levels of government.

14.22 Each province and territory has its own public health legislation covering the responsibilities of medical officers of health with respect to public health, surveillance and disease control. Their responsibilities include detecting and investigating cases of communicable diseases, and their powers extend to taking the necessary steps to limit the spread of diseases.

14.23 For example, in Alberta, provincial legislation requires a medical officer to investigate all cases of communicable diseases that must, by law, be reported in the province. The investigation is to establish the cause of the disease, the mode of transmission and the probable source, and to identify others who may be at risk. The medical officer takes whatever steps are reasonably possible to treat diseases in those who may already have been infected, protect those who have not already been exposed, break the chain of transmission and prevent the spread of the disease, and remove the source of infection.

14.24 While each province and territory has a legislated public health function, at the national level there is no formal public health function established that links the separate components in the provinces and territories. Instead, there is an informal system that relies on personal contacts rather than formal arrangements. As we note later in the chapter, there is a void; current health surveillance activities are largely carried out on an ad hoc basis.

Current national health surveillance activities are largely carried out on an ad hoc basis.

14.25 Health Canada should initiate discussions with provinces and territories on a national framework that would link separate components of public health functions at the various levels of government to protect Canadians against risks to health and the spreading of diseases.

Department's response: *Agreed; implementation is under way. Most recently, funding has been renewed and increased for the National Health Surveillance Infostructure (NHSI), the federal component of the Network for Health Surveillance in Canada now being developed, and planning is well advanced for the second phase. By the end of the year, the federal/provincial/territorial Working Group on Health Surveillance will prepare for the consideration of deputy ministers of health a strategic plan and a business plan for the development of the Network. In addition, surveillance is being considered in the context of Health Canada's review of federal health protection legislation.*

Need for Clearly Defined and Understood Roles and Responsibilities

Clearly understood roles and responsibilities are key to effective health surveillance and disease control

14.26 Globalization has created an environment for disease and for its transmission that never existed before. Health concerns are no longer always the responsibility of one jurisdiction, as diseases do not respect borders. This means that collaboration and co-operation between jurisdictions are vital to effective surveillance.

14.27 Given that national health surveillance and disease control involve

many jurisdictions and players, all those involved must clearly understand their respective roles and responsibilities. This is particularly important in responding to emergency situations and disease outbreaks.

14.28 LCDC is one of the key participants involved in national health surveillance and in investigating and controlling disease outbreaks. Accordingly, we would expect that other players in the health surveillance process would be aware of LCDC's central role and responsibilities in these areas. However, we found that Health Canada has not clearly communicated LCDC's role and responsibilities to provincial and local health authorities. Not surprisingly, they do not fully understand the part that LCDC plays in health surveillance and in the prevention and control of diseases.

Formal arrangements are important to clarify roles, responsibilities and procedures of all players so that authorities can act quickly when public health is at risk.

Participants in the health surveillance process want a more proactive Laboratory Centre for Disease Control

14.29 In November 1997, LCDC surveyed medical officers of health, epidemiologists, public health staff and laboratory directors at the provincial, regional and local levels. The survey found that participants would like LCDC to play a more proactive role in health surveillance. Some local practitioners indicated that LCDC's role is largely invisible; others were unaware of the surveillance-related support it offers beyond high-profile activities such as conferences and publications.

14.30 The survey also noted that LCDC's complex and ever-changing organizational structure is confusing to provincial and territorial participants. Often they are not sure whom they should call when they need advice or other support from LCDC. As well, the survey indicated that the provinces and territories strongly agree on the need for LCDC to provide leadership by carrying out national surveillance work and providing analytical support.

14.31 As part of its transition initiative, the Health Protection Branch has responded to this concern by initiating efforts to clarify roles and responsibilities within an integrated national health surveillance network. These efforts include consultations with stakeholders across Canada.

Protocols, Roles and Procedures for Handling Threats to Public Health

14.32 The success of national health surveillance depends largely on the ability of federal, provincial, territorial and local health departments and organizations to develop partnerships, to collaborate and to understand clearly what needs to be done to prevent diseases and mitigate their impacts — who should do it, and when and how it should be done. Where jurisdiction is shared, formal arrangements are important to clarify roles, responsibilities and procedures of all players so that authorities can act quickly when public health is at risk.

14.33 We expected that formal agreements or protocols would be in place to prevent the entry into Canada of serious communicable diseases such as drug-resistant tuberculosis, and to deal with disease outbreaks and threats to public health. However, we found that there are few formal agreements or protocols for dealing with these potential problems. In our view, the lack of attention to formalizing the way these threats are to be managed places the health of Canadians at undue risk.

Roles and procedures for controlling diseases at ports of entry are unclear

14.34 Globalization and ever-increasing international travel provide the opportunity for various communicable diseases or infected individuals to enter Canada. In 1978, Health Canada published

a Canadian contingency plan for handling viral hemorrhagic fevers and other unusual imported communicable diseases. The purpose of the contingency plan is twofold. First, it defines a co-ordinated response to the importation of suspected and confirmed cases of unusual or emerging communicable diseases. Second, it provides guidance on dealing with infected or potentially infected people and those with whom they have come in contact. The goal is to prevent diseases from being introduced into Canada and spread.

14.35 Although this plan was revised in 1985 and again in 1997, it still does not clearly define roles and procedures for those involved in this work — that is, the plan does not specify who is responsible for doing what. We found that contingency plans and protocols with clearly defined roles and procedures exist at ports of entry only in British Columbia and at Lester B. Pearson International Airport in Toronto. At the time of our audit, Health Canada officials expected that a protocol at Montreal International Airport, Dorval would be finalized in the near future. No protocols are in place at other ports of entry.

14.36 An incident involving a suspected case of a highly contagious disease occurred at Montreal International Airport, Dorval in August 1998. The case illustrates the importance of having clearly defined protocols to deal with such incidents.

14.37 In this case, Customs detained an arriving passenger suspected of being infected; the rest of the passengers were released. Federal quarantine officials were not consulted about either the initial detention of the individual or the release of the other passengers. The individual was eventually examined by Health Canada officials. If the individual suspected of having the disease had actually been infected, it would have been difficult to trace all the passengers who had been on the flight, in an effort to avoid an outbreak. At the time, there was no specific protocol at this airport that clearly specified roles and procedures for dealing with such incidents. Nor was there a formal memorandum of understanding between Health Canada and Revenue Canada (Customs) on how to manage this kind of incident. At the airport, there was significant confusion about who had what authority to detain or release passengers. Most of the federal and local officials who were involved (including officials from Revenue Canada and Citizenship and Immigration Canada) did not know that a Canadian contingency plan for viral hemorrhagic fevers and other related diseases even existed. Immediately after this incident, Revenue Canada issued interim instructions to its officials for quarantine situations. Exhibit 14.3 provides details of the incident.

Roles and procedures for LCDC in responding to outbreaks of food-borne diseases have not been defined

14.38 We noted that the only documented, formal arrangements concerning food safety matters were three agreements. In addition to a 1996 agreement between Health Canada, the Department of Fisheries and Oceans and Agriculture and Agri-Food Canada, in 1997 Health Canada and the Canadian Food Inspection Agency signed a Memorandum of Understanding dealing with food safety and related areas. The Canadian Food Inspection Agency and the Food Directorate of the Health Protection Branch also signed an MOU dealing with food safety emergency response. It gave Health Canada responsibility for conducting health hazard evaluations at the request of the Canadian Food Inspection Agency. However, there is no agreement that specifically covers the role of LCDC in the investigation of food-borne disease.

14.39 Nor do formal protocols exist between LCDC and the provinces and territories for investigating and responding

to interprovincial or national outbreaks of food-borne disease. Such protocols are important because many food products are so widely distributed that large numbers of people can become infected within a short time. At the time of our audit, an investigation protocol was being drafted among Health Canada, the Canadian Food Inspection Agency and provincial/territorial governments, but it had not been finalized.

14.40 LCDC prepared a draft emergency response plan for internal use in August 1997 that described all aspects of responses to various general emergencies (including outbreaks of communicable diseases). The plan directed that all LCDC employees be responsible for both familiarizing themselves with the plan and following the policies and procedures it outlined. We did not see any evidence that departmental

Exhibit 14.3

Responding to a Suspected Entry of a Dangerous Disease Into Canada

Background

- On 27 August 1998, Revenue Canada's Customs Intelligence received an anonymous call that an individual who would be entering Canada was infected with a dangerous disease and in possession of contraband narcotics. The information was considered to be "soft", but a "lookout" was issued to intercept this person on entry.
- On the evening of 30 August 1998, the individual arrived at the Montreal International Airport, Dorval from New York City and was detained at the airport in one of Customs search rooms. A local ambulance was called to transport the passenger to a hospital, but the attendants were hesitant to move the person. Someone also suggested isolating 15 staff who had had close contact with the individual after arrival. Other passengers were released after the airline obtained information on how to locate them should follow-up be required. Federal quarantine officials were not consulted. The plane then departed with a new cohort of passengers to New York City.
- Health Canada's Laboratory Centre for Disease Control (LCDC) was notified that evening. It contacted Customs officials, the federal stand-by quarantine officer in Montreal, the La Guardia Airport authorities in New York and the U.S. Centers for Disease Control and Prevention (CDC). CDC had not been aware of the situation since its on-site quarantine officers were not consulted.
- LCDC officials proceeded immediately to the airport to interview the individual (a returning Canadian) and review his travel documents. The individual was released soon after LCDC quarantine authorities determined that he was not infected with a dangerous virus.

Issues

- There was a significant breakdown in communication, and confusion as to who had what authority, in responding to this suspected dangerous disease incident.
- On 31 August 1998, LCDC officials attended a debriefing session with representatives of the Airport authority, the airline, RCMP, Revenue Canada, Citizenship and Immigration Canada and the local ambulance. Except for the RCMP, none was aware that there was a Canadian contingency plan for viral hemorrhagic fever and other dangerous communicable diseases, published by Health Canada.
- Revenue Canada's Customs Intelligence received the anonymous call on 27 August 1998, four days before the individual was identified and detained. However, it did not follow its procedure for notifying Health Canada when a health risk is involved. Had advance notice been given to LCDC, it could have worked out a plan in collaboration with the Airport authority to identify respective responsibilities and the necessary action if and when the individual was detained. Such action might have prevented the unnecessary delays and anxieties caused at the airport.
- There was no formal memorandum of understanding between Health Canada and Revenue Canada on the management of persons seeking admission to Canada with a suspected quarantinable disease. At the time of the incident, there were no formal protocols at this airport with respect to suspected importation of dangerous communicable diseases. It was unclear who had what authority. All the other passengers on that plane were released without consulting federal quarantine authorities. If the individual had been carrying the suspected virus, it would have been difficult to trace all the passengers who had been aboard the flight.

officials had consulted the plan in 1998 when a national outbreak of food-borne disease posed serious risks to many children. In fact, those directly responsible for managing the outbreak had never seen the plan. This outbreak of food-borne disease is discussed in Chapter 15 of this Report.

Roles and responsibilities for dealing with influenza pandemics need to be finalized

14.41 In 1996, LCDC co-ordinated the drafting of a contingency plan for pandemic influenza. The plan assigns Health Canada responsibility for co-ordinating its implementation in the event of a pandemic. The plan provides a framework for planning, preparing and implementing a response to a pandemic. It identifies the roles of a pandemic influenza committee, as well as federal departments, provinces and designated professional organizations. It also includes estimates of vaccine requirements for anticipated high-risk groups as well as the capacity of manufacturers for expanded production.

14.42 In June 1998, federal, provincial and territorial deputy ministers of health indicated that they wanted to develop a memorandum of understanding regarding their respective roles and responsibilities in the event of an influenza pandemic, and to agree on the creation of a pandemic influenza committee. As of May 1999, this memorandum of understanding was still being developed.

14.43 The last pandemic was in 1968. Historical trends and available scientific knowledge have led health officials to predict that another pandemic is likely. New strains of influenza are appearing that threaten the health of Canadians. It is important, therefore, that formal plans and agreements be in place to deal with another pandemic.

14.44 Health Canada should finalize agreements and protocols with relevant organizations covering roles, responsibilities and procedures for handling threats to public health, such as controlling diseases at ports of entry, managing outbreaks of food-borne diseases and dealing with influenza pandemics.

Department's response: *Agreed. Health Canada is collaborating with the Canadian Food Inspection Agency (CFIA) and provincial and territorial governments to finalize a protocol specifically intended for managing food-borne illness outbreaks. The development of further such agreements with relevant organizations, including those for disease control at ports of entry, will ensue.*

A memorandum of understanding on a national response to an influenza pandemic is under intensive discussion with the provinces and territories at this time.

Need for Good-Quality, Comparable Health Surveillance Information

14.45 We would expect that all players in the health surveillance process would use common standards and protocols to classify, collect and report data on diseases and injuries. Common or uniform standards and protocols are critical to ensuring that surveillance information is comparable across the country. Information needs to be comparable if governments, decision makers and the public are to be properly informed about risk patterns and trends in the occurrence of diseases and injuries.

Lack of formal arrangements for reporting communicable disease data to LCDC

14.46 Health Canada has no formal arrangements with the provinces covering the procedures for collecting and exchanging data on communicable diseases. It drafted a memorandum of understanding covering the exchange of

data on these diseases some 10 years ago, but this was never finalized with the provinces and territories. Currently, provinces and territories report cases of nationally reportable communicable diseases to LCDC on a solely voluntary basis, and they submit the data according to different criteria. For example, information on tuberculosis that LCDC receives (and then presents) is based on the date of onset of illness in Ontario but the date of diagnosis in all other provinces. This makes it difficult to compile a national picture of how many people have tuberculosis and for how long they have been infected.

14.47 LCDC has developed forms for collecting data on tuberculosis and AIDS as well as for several other diseases. These forms provide a structure for the provinces and territories to follow when submitting their data on these diseases. We note that to encourage physicians to report their AIDS data, British Columbia has issued a "short form" version of LCDC's form. This means that, even though it has specified its requirements, LCDC is unable to collect all the data it needs. Nor have similar forms been developed for most diseases. As a result, provinces submit widely varying types of data to LCDC, depending largely on what data they have available or choose to send. LCDC receives large amounts of data, but much of the data received is of limited usefulness because they are not comparable or uniform. For example, we found that provinces submit case-by-case data on a total of 114 elements. However, of these elements, only eight are common to — that is, reported for — all cases. We also found that no common format exists for reporting data. LCDC receives some data in electronic format and other data in hard copy.

14.48 Co-ordinating these disparate reports at the federal level is a time-consuming undertaking. Non-comparable data and different reporting procedures make it difficult to produce timely reports that yield accurate national "snapshots" of individual communicable diseases.

14.49 The national Advisory Committee on Epidemiology (ACE), which includes representatives from the provinces and territories, has helped to compile definitions of communicable diseases and to classify certain ones as "notifiable". Notifiable diseases are those that are reported across Canada (see Exhibit 14.4). However, provincial and territorial health authorities are not obliged to use ACE's definitions and its list of notifiable (reportable) diseases. Furthermore, there is still a need for agreement on which of several emerging diseases should be added to the list of reportable diseases and how they are to be defined.

14.50 For example, chicken pox was reported nationally between 1924 and 1959, and then it was dropped from the list of reportable diseases. In 1986, it was put on the list again. Because new vaccines are available for chicken pox, surveillance information is important to help determine their efficacy. However, since 1986, reporting of chicken pox to LCDC by the provinces and territories has not been universal. Incidence data from 1998 are available for only eight provinces and territories, representing only about 55 percent of Canada's population. It is estimated that of the number of cases projected annually — approximately 380,000 — fewer than 20 percent are reported.

14.51 Clearly, comparable surveillance data are essential to estimate the size of a health problem and to determine its economic burden on society, to characterize trends, and to evaluate intervention and prevention programs. Deficiencies in our national health surveillance information also affect Health Canada's ability to provide valid information for use internationally to address global issues of disease control.

14.52 Health Canada should work with provinces and territories to establish common standards and protocols for classifying, collecting and reporting data on communicable diseases.

Department's response: *Agreed; implementation is under way. In conjunction with the Communicable Diseases Subcommittee of its Advisory Committee on Epidemiology, which comprises representatives from all provincial and territorial ministries of health, the Laboratory Centre for Disease Control has concluded an agreement on which diseases are nationally notifiable and on definitions of surveillance. The next task, scheduled to commence in the fall of 1999, will be to develop common data standards for the reporting of nationally notifiable diseases.*

National Health Surveillance Systems Are Not Working as Intended

14.53 A critical component of health surveillance is information. To carry out its surveillance responsibilities, Health Canada needs health surveillance systems that allow it to monitor diseases and injuries effectively on a national level. These systems are central to collecting, analyzing and disseminating information on the incidence and prevalence of an injury or disease (the number of new cases and the total number of cases of a given disease, and who — age, gender, occupation, etc. — is most likely to suffer from it).

14.54 Good-quality and timely information is the critical element in anticipating, preventing and controlling health risks that affect the well-being of Canadians. The purpose of Health Canada's surveillance systems is to provide such information.

Exhibit 14.4

Nationally Notifiable Diseases[1]

Disease	Year First Reported[2]
AIDS	1986
Amoebiasis	1927
Botulism	1933
Brucellosis	1928
Campylobacter	1986
Chancroid	1979
Chlamydia, genital	1990
Chicken pox	1924-1959, 1986
Cholera	1974
Diphtheria	1924
Giardiasis	1983
Gonococcal infections	1924
Gonococcal ophthalmia neonatorum	1979
Heamophilus influenzae B	1979
Hepatitis A	1927-1958, 1969
Hepatitis B	1969
Hepatitis C	1991
Hepatitis non-A, non-B	1983
Legionellosis	1986
Leprosy	1925
Listeriosis	1990
Malaria	1929
Measles	1924
Meningitis, pneumococcal	1979
Meningitis, other	1979
Meningitis, viral	1952
Meningococcal infections	1924
Mumps	1924-1959, 1986
Paratyphoid	1924-1952, 1969
Pertussis	1924
Plague	1924[3]
Poliomyelitis	1924
Rabies	1927
Rubella	1924
Rubella, congenital	1979
Salmonellosis	1958
Shigellosis	1924
Syphilis. congenital	1992
Syphilis, early latent	1992
Syphilis, early symptomatic	1979
Syphilis, other	1924
Tetanus	1957
Tuberculosis	1924
Trichinosis	1929
Typhoid	1924-1952, 1969
Verotoxigenic *Escherichia coli*	1990
Yellow fever	1924[3]

[1] Provinces and territories are not required by legislation to report on this list of diseases to LCDC.

[2] Where reporting stopped, for whatever reason, the dates indicate for what period and then the year when reporting began again.

[3] Reportable since 1924, but no cases have been reported.

Source: Laboratory Centre for Disease Control

14.55 Key surveillance systems that we looked at were not working as intended. For a number of reasons, they were not enabling Health Canada to effectively monitor communicable diseases such as influenza, AIDS, tuberculosis and food-borne disease. The same is true of systems related to chronic diseases such as cancer, diabetes, and heart disease and stroke.

Taken together, the weaknesses that we observed have clear national implications for public health.

14.56 Taken together, the weaknesses that we observed have clear national implications for public health. First, they compromise Health Canada's ability to detect, anticipate, prevent and control health risks associated with outbreaks of communicable diseases. Second, they compromise its ability to plan, carry out and evaluate public health programs and other programs that deal with the causes and treatment of diseases.

Problems in collecting data on communicable diseases

14.57 The lack of common standards and agreed-upon procedures for reporting information at the provincial and territorial levels has a significant effect on systems at the national level.

14.58 We recognize that Health Canada does not have direct control over the quality and completeness of the data that others submit. Nevertheless, any deficiencies in these data severely impair the effectiveness of the Department's national health surveillance activities.

14.59 We found widespread delays in reporting cases of AIDS, tuberculosis, and other communicable diseases to Health Canada. The Department allows provinces and territories eight weeks after the end of each six-month period to report all AIDS cases. This timing permits it to publish a surveillance report within one month after receiving the data. However, we found that about half of the recorded AIDS cases were not reported until nine or more months after diagnosis. The longest delay in reporting was 16 years. Moreover, some physicians do not report all AIDS cases (the extent of this non-reporting is also unknown).

14.60 Because of these delays in reporting and the unknown extent of non-reporting, the AIDS-related information that Health Canada produces does not accurately portray, for example, the number of people living with AIDS, or the number who have died from it. Such basic information is essential to developing effective national strategies and programs to deal with this disease. The Department has recognized these problems for a long time. Since 1993, it has attempted to apply statistical methods to adjust the number of AIDS cases in order to take reporting delays into account, and it has included the analysis in its surveillance reports as a regular feature. However, it now suspects that reporting patterns may have changed in the past year or two and that these changes may need to be incorporated in the statistical methods it uses to analyze reporting delays. The Department believes it is necessary to assess the reporting patterns and improve the methods before new adjustments are published. Therefore, it did not include this feature in its report for 1998. Nevertheless, AIDS cases diagnosed by physicians but never reported to LCDC cannot be estimated by this analysis.

14.61 We recognize that Health Canada has no authority to compel physicians to report communicable diseases. Non-reporting is largely beyond its control, since authority rests with the provinces. The 1997 report of the Krever Commission recommended that the governing bodies of physicians and surgeons in the provinces and territories require physicians to report communicable diseases. However, provincial and territorial practitioners continue to either underreport communicable diseases or not report them at all. This continues to be an important, long-standing problem.

14.62 We found weaknesses in the data being input to FluWatch, a system for both collecting "local" data on influenza and feeding the results back to the provinces and territories to provide them with national influenza-related information. Regional reporting varied widely, with some regions not reporting at all. In 1997–98, 191 physicians were recruited from across Canada to provide weekly reports on influenza cases over the reporting period. On average, only 115 physicians (60 percent) submitted a report each week, and only 100 (52 percent) submitted reports for at least 20 of the 27 weeks required. Moreover, the Department does not obtain timely and accurate data on hospitalizations and deaths from pneumonia and influenza for its FluWatch report. This information is essential for developing a strategy to ensure that the most vulnerable in the population (the elderly and children) will be vaccinated in the event of an influenza pandemic.

14.63 Health Canada should work with provinces and territories to explore ways to improve the reporting of communicable diseases by physicians.

Department's response: *Agreed. Health Canada will commence discussion of this important issue at the next meeting of the Council of Chief Medical Officers, to be held this fall.*

Weaknesses in the data on chronic diseases

14.64 As was true of data collection relating to communicable diseases, there are gaps in surveillance information on certain chronic diseases — for example, diabetes and heart disease and stroke. Some work is being done to correct this situation (see paragraphs 14.81 to 14.88), but further work is needed to generate surveillance information on these chronic diseases.

14.65 We reviewed two cancer surveillance systems: the Childhood Cancer Treatment and Outcome Surveillance System and the National Enhanced Cancer Surveillance System. We noted weaknesses similar to those we found in the data on communicable diseases. Here, too, deficiencies in the data have meant important gaps in information on cancer prevention, control and treatment outcomes at the national level.

14.66 The Childhood Cancer Treatment and Outcome Surveillance System is designed to provide information on access to treatment, outcomes, and regional differences in diagnosis and initial therapy. We found that Health Canada is able to obtain only partial data for 1995 and 1996 from Ontario, which accounts for a significant proportion of childhood cancer cases in Canada. We also noted that the system contains incomplete data on youths between 15 and 19 years of age. Individuals in this age group often receive treatment at general hospitals, which, unlike pediatric hospitals, do not typically supply data to the system.

14.67 The National Enhanced Cancer Surveillance System has the potential to provide comprehensive information on the linkages between cancer and environmental factors. However, the Department told us that there are gaps in environmental data because complete data are not available from most provinces. Some surveillance information has been produced, but gaps need to be filled if the system is to reach its full potential.

14.68 Health Canada, in collaboration with provinces and territories and with other organizations, should strengthen its Childhood Cancer Treatment and Outcome Surveillance System and National Enhanced Cancer Surveillance System to ensure that gaps in surveillance information are filled.

There are gaps in surveillance information on certain chronic diseases.

Department's response: *Agreed; implementation is under way. The Laboratory Centre for Disease Control's review of the sources of data used for all of its surveillance systems will be*

completed in September 1999. This will be followed by a systematic evaluation of the effectiveness of its surveillance activities, including a review of the quality of data sources. The Department is currently assessing its needs for cancer surveillance, particularly related to the environment. Subsequent improvements in data sources and enhancement of data quality where necessary will assist in filling gaps in surveillance information in all systems.

National surveillance information on childhood injuries does not yield a complete picture

14.69 In 1990, LCDC's Child Injury Division established the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP). This is a surveillance system for collecting data on the nature and circumstances of injury of persons seeking emergency medical care in Canadian hospitals. CHIRPP collects injury statistics from 16 hospitals, including 10 pediatric hospitals. Its focus is on children, and its objective is to reduce the incidence and severity of childhood injuries from all causes.

14.70 CHIRPP is an important initiative that provides useful information. However, we noted two significant gaps. Three provinces are not represented in the system at all, and there is little coverage of injuries that occur in rural areas. For example, there is no coverage of farm injuries that occur in Saskatchewan.

14.71 Such incomplete data hamper CHIRPP's ability to generate an accurate national picture of where and to whom injuries are occurring, and the types of injuries involved. Without this kind of information, it is difficult for CHIRPP to fully achieve its stated objective of reducing the number and severity of injuries to children.

14.72 Health Canada should ensure that its Canadian Hospitals Injury Reporting and Prevention Program provides a complete national picture on childhood injuries from all causes.

Department's response: *Agreed. The Laboratory Centre for Disease Control's present review of data sources for all surveillance systems and its subsequent evaluation of the efficiency and effectiveness of its surveillance activities will provide the information needed to enhance all of its programs.*

Weaknesses in data collection lead to delays in dissemination of surveillance information

14.73 Dissemination of information represents the final stage of Health Canada's health surveillance activities. This is the point at which information is placed in the hands of those who need to have it — the organizations responsible for implementing plans and strategies to deal with public health problems. The effectiveness or value of Health Canada's health surveillance systems depends on the extent to which the information they produce is disseminated and used by other organizations and levels of government to improve the health of Canadians.

14.74 Each bureau of LCDC responds to specific requests for surveillance information and distributes data through various publications. For example, the Cancer Bureau prepares detailed summaries of cancer incidence in specific areas in response to external requests, produces various cancer updates and publishes articles in peer-reviewed journals. As well, LCDC has made an effort to disseminate its surveillance information more effectively. In 1996 its Document Dissemination Division was created with a mandate to strengthen dissemination activities. Its responsibilities include co-ordination of publications, editorial production, and electronic dissemination. Key publications include the *Canada Communicable Disease Report*, published twice monthly, and *Chronic Diseases in Canada*,

published quarterly. As well, LCDC posts information on the Internet.

14.75 However, the quality of this information depends on how well the other components of the system are working. Unless the "up front" weaknesses in data collection are dealt with, the availability of up-to-date and good-quality health surveillance information will be compromised. The problems of out-of-date and incomplete data have led to delays in publishing certain reports.

14.76 We noted that surveillance information on AIDS for the period up to 31 December 1998 was published within a reasonable time (in April 1999). However, the latest available information on tuberculosis and many other communicable diseases is for the period ended 31 December 1996, because Health Canada believes that more recent data are incomplete. The lack of up-to-date information on tuberculosis impairs Canada's ability to not only monitor this global disease but also evaluate the effectiveness of the criteria used and process in screening for and controlling the entry of tuberculosis into this country.

14.77 Similarly, while Health Canada has published some information on childhood cancer, it is based mostly on data from sources other than the Childhood Cancer Treatment and Outcome Surveillance System. Although this surveillance system has been collecting data since 1995, the first comprehensive report providing information on cases diagnosed in 1995 and 1996 is not expected until the fall of 1999.

14.78 While individual bureaus periodically solicit feedback on the value of their dissemination activities (through consensus conferences, for example), LCDC has not formally evaluated the effectiveness of its dissemination activities — who uses the information, how they use it, and whether they find it timely. Such evaluations are necessary to ensure that efforts to disseminate surveillance information are directed appropriately and that other organizations and levels of government are using the information to improve the health of Canadians.

14.79 Health Canada should ensure the timely dissemination of surveillance information to those who need to have it. The Department should identify who uses the information, how they use it, and whether they find it timely.

Department's response: *Agreed; implementation is under way. One of the goals in developing the National Health Surveillance Network is to improve the sharing and exchange of health information, and the analysis and dissemination of that information. As indicated above, this initiative is well advanced.*

In addition, the Laboratory Centre for Disease Control intends to expand the "Disease Surveillance On-Line" database in the next fiscal year to include data on additional diseases. This will allow data obtained from the provinces and territories, Statistics Canada or other sources to be posted much earlier than information is made available in print.

A readership survey of Chronic Diseases in Canada *will be conducted in the fall of 1999 to update information obtained from a 1992 client survey on the readership's profile, and to ascertain preferences regarding dissemination tools (print or Web) and the journal's content.*

A detailed, formal evaluation of the Web site is planned for FY 2000–2001. The Internet-based "Canadian Health Network", to be implemented in 2000, will provide the public with enhanced access to quality information about health promotion and disease prevention to facilitate better personal decisions about health.

The Laboratory Centre for Disease Control has not formally evaluated the effectiveness of its information dissemination activities.

Progress in Filling Surveillance Gaps

14.80 In 1995, as part of a commitment by Health Canada to strengthen its surveillance capacity, LCDC launched a public health intelligence reinvestment initiative. It was designed to enable LCDC to expand its surveillance networks in order to address certain gaps in the surveillance of diseases such as diabetes, cardio-respiratory diseases, tuberculosis, cancer, sexually transmitted diseases and perinatal diseases. We examined LCDC's progress in establishing surveillance systems in two of these areas, diabetes and heart disease and stroke.

Development of a national diabetes surveillance system has been slow

14.81 Diabetes is a major contributor to the burden of illness and health care costs in Canada. However, only limited national data on this disease are available. A national diabetes surveillance system would improve the situation, but its development has been slow.

14.82 As early as 1986, the National Diabetes Task Force identified the collection of reliable data on diabetes as a priority. In 1995, the Diabetes Division was formed within LCDC. The concept of a national surveillance system on diabetes was put forward in 1996. A risk assessment prepared in March 1998 identified significant gaps in surveillance information on diabetes, and suggested action to take.

14.83 It is important that LCDC begin work in this area, because existing data sources have significant limitations. For example, the National Population Health Survey and the Aboriginal Peoples Survey do not address this issue to the extent necessary and are limited by self-reporting and by sample size. As a result, reliable information on the extent of diabetes and its burden on health care is not available to assist in the development of prevention and control measures.

14.84 The 1999 federal Budget provided $55 million to develop a Canadian diabetes prevention and control strategy over the next three years. We noted that the Diabetes Division has begun to work with Statistics Canada, the Diabetes Council of Canada, the Canadian Diabetes Association, the Canadian Institute for Health Information and provincial/territorial governments to develop a national diabetes surveillance system. This system, which is not expected to be operational until 2000, represents another positive step toward closing the gap in diabetes surveillance.

A national surveillance system has not yet been developed for heart disease and stroke

14.85 Heart disease and stroke remain the major causes of death, disability and illness in Canada. The Department recognizes that a health problem of the magnitude and complexity of heart disease and stroke needs a strong information base to determine how the individual, the family, the community and government can best respond effectively and efficiently. The core functions of LCDC's Cardiovascular Disease Division, created in September 1995, include national heart disease and stroke surveillance, risk assessments of factors associated with heart disease and stroke, and national prevention and control activities.

14.86 LCDC has identified the need for up-to-date statistics on the number of people who suffer from heart disease and stroke and the deaths attributable to it. Such statistics are central to determining whether prevention and control efforts are working effectively. However, there is a time lag of approximately two to three years in the data, due mainly to data collection and refinement issues that need to be dealt with by the provinces and

territories, Statistics Canada and Health Canada.

14.87 There is also a lack of good-quality national surveillance information on health outcomes related to heart disease and stroke, the risks influencing heart disease and stroke, and efforts at prevention, treatment and rehabilitation. LCDC has only recently begun surveillance work on behavioural risk factors.

14.88 Health Canada is collaborating with other organizations, including the Canadian Institute for Health Information, Statistics Canada and non-government organizations, to develop an integrated surveillance system for heart disease and stroke. However, this is not expected to be fully operational until 2003.

14.89 Health Canada should, in collaboration with other organizations, take steps to fill surveillance gaps by ensuring the timely development of national surveillance systems on chronic diseases such as diabetes, and heart disease and stroke.

Department's response: *Agreed; implementation is under way. For several years, the Laboratory Centre for Disease Control has been working with stakeholders to develop national comprehensive chronic disease surveillance systems. The National Diabetes Surveillance System (NDSS), the most advanced initiative, will be operational by 2000 and will become a model for the surveillance of other chronic diseases.*

Current Efforts to Improve Health Surveillance

14.90 Change initiatives are not new at the Health Protection Branch (HPB). We reported in 1995 (Chapter 4) and in our 1998 follow-up (Chapter 28) that the Branch had undertaken change initiatives since 1993. We expected that the Branch would have taken appropriate action to find solutions to identified problems in surveillance and related areas. We found that many efforts to effect change, including the recent transition initiative, have been directed to the right areas.

14.91 The Health Protection Branch launched a three-year process of transition in August 1997. The purpose of the transition initiative is to help strengthen the Branch and its ability to better manage risks to the health of Canadians into the next century. The transition comprises five major components: legislative renewal, surveillance, science core, risk management framework and program development.

Work has begun on strengthening Health Protection Branch's future surveillance capacity

14.92 An important step toward strengthening and expanding the Branch's surveillance capacity is its support of an integrated national surveillance network for public health information. Such a network would integrate information from sources ranging from local to global. As part of the surveillance transition, an Office of National Health Surveillance has been created within the Branch to provide secretariat support for federal/provincial/territorial working groups. These include the National Health Surveillance Network Working Group and the Surveillance Integration Design Team. The objective of the Office and the working groups is to create an integrated national health surveillance network that will enable Canada to produce accurate and timely information for all levels of the public health system. The national health surveillance network is intended to provide an infrastructure for surveillance, but not content.

14.93 Extensive consultations have been carried out with various stakeholders. In the fall of 1998, at the request of the federal/provincial/territorial deputy ministers of health, the Surveillance Integration Design Team

released a discussion paper on an integrated national health surveillance network for Canada. Consultations on the discussion paper were then held with provincial and territorial officials and non-government stakeholders across Canada, culminating in a national conference on the proposed national framework in March 1999.

Early concrete steps have been taken toward creating a national health surveillance network.

14.94 The results of these deliberations were released in April 1999 as a proposal to develop an integrated national health surveillance network for Canada. The proposal suggests roles that each partner in the health surveillance network can and should play. It also outlines some of the key policies and co-ordinating mechanisms that are needed to provide a solid foundation for building an integrated network to meet the needs of all of the players while better serving the health of Canadians.

14.95 Based on the proposal, the Department prepared a report and recommendations in June 1999 for consideration by federal, provincial and territorial deputy ministers of health. The proposal represents a significant step forward. An integrated network would do much to address a number of weaknesses that we have discussed in this chapter. For example, it would promote more complete, up-to-date and uniform data from which to produce health surveillance information on a number of diseases and injuries. We commend these efforts to improve national health surveillance. We also recognize that developing the network will present challenges to Health Canada in getting all players to work together. It is unclear when such an integrated national health surveillance network would be implemented, as there are no planned timeframes or action plans for implementation. It is paramount that all parties involved in this network remain committed to its implementation.

Pilot projects are under way to improve access to data

14.96 We noted that early concrete steps have been taken toward creating a national health surveillance network. A series of pilot projects is being carried out to improve access to existing databases and the linkages among them. The projects are also intended to provide tools for analyzing and presenting information, and to speed up access to the information. For example, the Spatial Public Health Information Exchange (SPHINX) demonstration pilot in Alberta is testing procedures for accessing information that already exists in digitized health-related databases. Improving access to this information will help to strengthen national public health surveillance.

Co-operation is essential to improving health surveillance

14.97 As we have noted, Health Canada shares responsibilities for surveillance with other jurisdictions. We recognize that this complicates its efforts to make the needed improvements in health surveillance. However, it is imperative that the Department impress upon the provinces and territories that improving surveillance is an urgent task, and it is in everyone's interest to resolve as quickly as possible the problems that are standing in the way of "getting on with the job".

Performance Measurement and Reporting of Results

14.98 There are several tools at LCDC's disposal to facilitate better management of surveillance activities. These include evaluation, performance measurement and risk assessment. Unlike other aspects of surveillance (which, to a large extent, rely on the work of outside organizations), applying these tools is within LCDC's control.

14.99 Taken together and properly used, these tools provide distinct benefits

for an organization's management. They tell management what has worked to produce desired results and what has not; whether individual systems are cost-effective; and, in the case of LCDC, whether the systems and the resources required to operate them are focussed on the areas that pose the greatest risks to Canadians' health. In addition, these tools yield information that allows an organization to report publicly on the effectiveness of its health surveillance work.

14.100 We expected that Health Canada would evaluate its surveillance systems to measure their effectiveness, including whether they are achieving their stated objectives. We also expected that it would have performance measures in place to help managers gauge the ongoing performance of surveillance systems, and that outcome measures as well as outputs would be emphasized. We expected that the Department would use evidence-based risk assessments to ensure that it concentrates its resources on the diseases and injuries that pose the greatest risk to public health. Finally, we expected public reporting on the effectiveness of surveillance activities.

Few systems have been evaluated and there are no plans to evaluate others

14.101 LCDC has no formal plans to evaluate its surveillance systems. No resources have been identified to complete evaluations and few have been done.

14.102 Only two of the seven established systems we examined had been evaluated — the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP) and the National Enhanced Cancer Surveillance System. The latter system was included in an evaluation of the Action Plan on Health and the Environment.

14.103 An external committee evaluated CHIRPP in 1991, two years after the program had begun. The review recommended that both the system's representativeness and the quality of information on the cases be improved. The program has not been evaluated since. Therefore, it is not apparent whether LCDC has acted on the recommendations, whether the program has improved, or whether any new problems have arisen over the past seven years. Our audit, however, noted a number of weaknesses in CHIRPP (see paragraphs 14.69 to 14.71) that suggest that Health Canada has not yet resolved all the problems identified in the 1991 review.

14.104 The 1997 evaluation of the Action Plan on Health and the Environment assessed LCDC's progress in establishing a national enhanced cancer surveillance system with a focus on environmental risks. The evaluation found that LCDC had made progress in constructing various components of the surveillance system, but that various tasks, such as initial data gathering, had not been completed.

14.105 In 1993, external consultants completed an evaluation of LCDC's activities. The evaluation focussed on issues such as LCDC's role and the relevance and quality of the expertise and services it provides to clients and partners. It found that most of LCDC's clients felt that its services and products were essential, but that there were delays in obtaining them. The findings indicated a lack of sufficient back-up expertise at LCDC during emergencies, and poor communication between LCDC and its clients. Significant changes have taken place at LCDC over the last six years, but no subsequent evaluation has been planned to determine whether and to what extent the weaknesses have been addressed.

Need to develop appropriate indicators for measuring performance

14.106 Whereas evaluation is review that is carried out periodically, performance measurement involves the ongoing

measurement of inputs, outputs, and outcomes. Performance measurement helps managers know whether a surveillance system is on track. Central to measuring performance are performance indicators, which specify the terms in which performance or success will be measured. Performance indicators may be output-focussed, such as the number of seminars held or brochures distributed. Or they may be outcome-focussed, such as surveillance information used in program or policy decisions that lead to the desired reduction in the occurrence of diseases or injuries.

14.107 LCDC has developed objectives for the surveillance systems that we reviewed. It has begun to develop a framework for better measurement of its performance, but it is not complete. LCDC has not yet finished developing indicators to measure performance that focus on outcomes as well as inputs. The performance indicators it has developed tend to be process- or output-oriented. For example, the Cancer Bureau lists items such as "client satisfaction" and "publication in scientific journals and other publications" as performance indicators of its childhood cancer program. As well, few indicators focus on specific surveillance systems.

14.108 Until LCDC finishes developing its performance measurement framework and includes in it outcome-oriented performance indicators, it will have some difficulty knowing what works and what does not, and when to take corrective action.

Only limited use of risk assessment

14.109 Risk assessment is an important tool that can be used to direct surveillance effort to best advantage — that is, commensurate with the risk to public health that a disease represents. Risk assessment techniques can be used, for example, to determine the risks that one disease poses to public health compared with another. By using the results of risk assessment, management at LCDC can focus surveillance activities and resources more sharply on the diseases and injuries that pose the highest risk. In essence, then, risk assessment can be used to help ensure that effort is spent where it will have the most impact.

14.110 We noted that the Advisory Committee on Epidemiology, working jointly with LCDC, uses a risk-based approach to select and prioritize communicable diseases that are to be reported nationally. As well, in 1995, after consultations and using criteria to rank the severity of surveillance gaps, the Department launched its public health intelligence reinvestment initiative. This included a greater focus on chronic disease surveillance.

14.111 However, in the specific surveillance systems we examined, we found few cases in which a thorough risk assessment of individual diseases (as a prelude to surveillance) had been done to assess their risks in comparison with others and to outline options for action. An exception was the health risk report and recommended control strategy completed for diabetes, which included an epidemiological assessment, analyses of knowledge gaps and jurisdictional considerations, and a control strategy.

14.112 Instead, most diseases considered to be candidates for surveillance are identified through formal and informal consultations rather than objective, evidence-based risk assessments. Through these consultations, the Department has identified major gaps in surveillance coverage (for example, chronic diseases such as musculoskeletal diseases, nervous system and mental disorders and skin and related diseases).

14.113 The Health Protection Branch has taken initial steps to improve the way it manages risk. As part of its transition initiative, the Branch has recognized the need to consider not only the risks associated with individual diseases but

also their relative importance. As well, the Branch has recognized the need to improve the way it communicates risk issues to its clients and other stakeholders.

Need for improved reporting of results to Parliament

14.114 LCDC reports to Parliament only limited information on the effectiveness of its surveillance systems and activities. We reviewed departmental Estimates/Plans and Priorities documents and Performance Reports for the last five years and found few references to either the rationale for the surveillance systems or their objectives and effectiveness. As well, the results of the 1993 LCDC evaluation were not reported to Parliament.

14.115 Health Canada should strengthen the evaluation, performance measurement and reporting of results of its health surveillance systems and activities.

Department's response: *Agreed. Steps are being taken now to implement this recommendation.*

Conclusion

14.116 The success of national health surveillance depends largely on the ability of federal, provincial, territorial and local health departments and organizations to develop partnerships, to collaborate and to understand clearly what needs to be done to prevent and manage disease outbreaks, who should do it, and when and how it should be done.

14.117 Health Canada has no formal arrangements with the provinces and territories covering the common standards and procedures for collecting and exchanging data on communicable diseases. In addition, there are few formal agreements or protocols for dealing with the entry into Canada of serious communicable diseases, disease outbreaks and threats to public health.

14.118 We found weaknesses in the key surveillance systems that we looked at. The systems were not enabling Health Canada to effectively monitor communicable diseases such as influenza, AIDS, tuberculosis and food-borne diseases. There are significant gaps in surveillance information on certain chronic diseases such as cancer, diabetes, and heart disease and stroke. National surveillance information on childhood injuries does not yield a complete picture. In some cases, weaknesses in data collection lead to delays in the dissemination of surveillance information.

14.119 Health Canada needs to strengthen its procedures to measure performance and report results. It also needs to make better use of risk assessment in its health surveillance activities.

14.120 Work has begun on strengthening the Health Protection Branch's future surveillance capacity, including the proposal for an integrated national health surveillance network. Such a network would do much to address some of the weaknesses that we observed.

14.121 We recognize that LCDC is not solely responsible for a number of these weaknesses. Nonetheless, the weaknesses need to be fixed, and LCDC needs to champion change by ensuring that all players work together to improve the surveillance on which Canadians rely to protect their health.

Department's comments: *The federal government has launched an ambitious initiative to develop a National Health Surveillance Network. This is a complex undertaking that entails a significant collaboration between Health Canada and its provincial and territorial partners. The full impact of the initiative will not be realized until the entire Network is operational, but improvements are being made annually as components of the network are put in place.*

About the Audit

Objectives

The objectives of the audit were to determine whether:

- there are common standards and protocols to facilitate collaboration and sharing of information among all players in the health surveillance process;
- required surveillance systems are in place to provide timely and relevant information to anticipate, prevent and respond to health threats and emerging health risks;
- procedures to measure performance and report results are adequate;
- there is a rational basis for determining where and how health surveillance should be undertaken; and
- progress has been made in establishing solutions to identified problems.

Scope

The audit examined Health Canada's surveillance activities relating to diseases, both communicable and non-communicable, and associated behaviour risk factors, as well as injuries. We examined surveillance systems designed to collect, analyze and disseminate information in order to anticipate, prevent and respond to health threats and emerging health risks. This included a detailed review of 10 of the approximately 40 functioning surveillance systems the Department maintains in the areas of communicable and non-communicable diseases and injuries. Taken together, the surveillance systems we reviewed covered diseases and injuries that pose significant threats to health and represent a significant economic burden to society. In addition, we examined Health Protection Branch transition initiatives relating to surveillance, risk management and legislative renewal.

We had extensive discussions with departmental staff, selected provincial and local health officials, other agencies and selected foreign national institutions involved in health surveillance activities. As well, we had discussions with representatives of the Canadian Food Inspection Agency. We reviewed various studies and reports published by Health Canada, provincial and local health agencies and other national health bodies, and other documentation.

The audit did not examine the management of risks to health relating to consumer goods, medical devices and therapeutic products. The audit did not cover diseases relating to animals.

The quantitative information in this chapter that has been drawn from government and non-government sources or departmental databases has been checked for reasonableness but has not been audited.

Criteria

We expected that:

- all players in health surveillance would clearly understand Health Canada's role and responsibilities in the national health surveillance process;
- a full range of documented protocols and procedures would exist that indicate clearly what each player should do when a disease outbreak or health threat occurs;

- all players in the health surveillance process would use common standards and protocols for classifying, collecting and reporting data on diseases and injuries to ensure that all information is comparable across the country;
- Health Canada's surveillance systems for monitoring diseases and injuries would enable it to collect, analyze and disseminate all information necessary to help anticipate, prevent and respond to existing and emerging health risks;
- there would be procedures to measure the effectiveness of health surveillance activities and report results;
- Health Canada's health surveillance activities would be based on a sound risk-benefit approach and a rational priority setting framework; and
- appropriate action would be taken by Health Canada in establishing solutions to identified problems.

Audit Team

Assistant Auditor General: Maria Barrados
Principal: Ronnie Campbell
Director: Gerry Chu

Julie Charron
Anil Risbud
Glenn Wheeler

For information, please contact Ronnie Campbell.