Chapter Five: Surveillance

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Introduction

Public health surveillance has three basic component activities – data collection, data analysis, and disseminating information to those who plan and carry out public health programs. Effective surveillance has the capacity to isolate and identify early information that may signal an infectious disease outbreak, allowing for evidence-based decisions when responding to such outbreaks and helping mitigate their impact.

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West Nile Virus (WNV) offers one recent example of a successful surveillance initiative. In the case of WNV, detecting and testing dead birds and mosquito traps were used as a sentinel for the potential arrival and spread of this mosquito-borne disease. Ontario and other jurisdictions have used this information to tailor interventions, determine the rate of spread, and guide potential actions such as the use of larvicides.[1]

A different type of example is the role of surveillance in detecting and responding to potential bio-terrorism threats. In the wake of the US anthrax scares of October 2001, the New Jersey Department of Health and Senior Services, together with the Centers for Disease Control, began formal surveillance for the clinical signs and syndromes that were compatible with anthrax.[2] The objectives of this surveillance initiative were improved case findings, characterizing the population at risk, and determining the magnitude of the potential outbreak.

In Canada, both the National Advisory Committee on SARS and Public Health[3] and the Standing Senate Committee on Social Affairs, Science and Technology[4] have noted that surveillance efforts here in Canada lack the degree of investment and comprehensiveness demonstrated in the U.S. To some extent, this has been due to three distinct barriers: a lack of technological capacity, a lack of analytical capacity, and privacy and data use concerns.

However, coordinated work has been underway in Canada for several years on a range of surveillance projects, as part of the Canadian Integrated

Public Health Surveillance (CIPHS) collaborative. Specifically, CIPHS is charged with:

- Promoting a uniform public health information management concept, and ensuring consistency in new pan-Canadian initiatives.
- Providing overall strategic direction for developing shared public health applications and databases, and assisting in the definition of new requirements.
- Coordinating future development and ongoing maintenance of shared applications.
- Ensuring the security of data collected.
- Fostering collaboration between CIPHS members, and linking with government and non-government agencies.[5]

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This collaborative process, while regrettably slow, holds significant opportunities for improved national cooperation toward creating a comprehensive federal/provincial/territorial surveillance plan. This is an essential exercise, as any effective surveillance strategy should ideally be national in scope and allow for comparable analysis and deployment of data across jurisdictions.

In any effective surveillance strategy, technology plays an increasingly critical role. It is essential to have a well-developed system for real-time data sharing and reporting, and for the rapid dissemination of surveillance information. Information and information technology systems increasingly provide the spine for effective real-time data reporting and analysis.

The Panel heard that during SARS tremendous efforts were made to implement effective screening and surveillance. These efforts were hampered by a number of major pre-existing challenges quite apart from the outbreak, including an inadequate information technology system that allowed only limited data analysis in many areas.

Key Learnings

Surveillance capacity: SARS brought to light the lack of and need for a comprehensive infectious disease surveillance infrastructure in Ontario, with the capacity to link the acute and long-term care, community, and public health sectors. The Health Surveillance Working Group agreed in 2002 that such a health surveillance infrastructure must be developed.[6]

To-date, however, efforts have been largely episodic and disease-specific.

The purpose of the Health Surveillance Working Group is to advise on the development and coordinate the implementation of a national network approach that: integrates Canada's health surveillance networks; promotes the collection of data and its use for health surveillance purposes; builds capacity to undertake health surveillance; and, improves access to health information.

However, there has not been a rapid or comprehensive movement toward integrated and effective infectious disease surveillance either across the province or nationwide. The Standing Senate Committee on Social Affairs, Science and Technology recently stated in this regard that "the lack of surveillance activities is a matter of considerable urgency,"[7] echoing concerns previously raised by the National Auditor's report. These include the lack of financial capacity to maintain and establish chronic disease surveillance systems and the failure of Health Canada to achieve health surveillance activities established in 1999-2000.[8] In addition, the National Advisory Committee has called for:

- Investments to enhance disease surveillance and link public health and clinical information systems.
- Regional capacity for infectious disease surveillance, outbreak management, and related infection control activities.
- A new Network for Communicable Disease Control that would link Federal/Provincial/Territorial (F/P/T) activities in infectious disease surveillance, prevention, and management.
- A new Canadian Agency for Public Health that, in partnership with the Network for Communicable Disease Control, would give priority to infectious disease surveillance, including providing technical advice, funding, and programs to support training.
- Support for hospital-acquired infection control, including hospital surveillance as a priority program.

Information technology infrastructure: Similar to the National Advisory Committee, the Panel heard that poor systems and weak information dissemination capacity were two key impediments to the controlled response to the SARS outbreak. Failure to implement a "seamless and effective system prior to the SARS outbreak for communication of routine infectious disease alerts...may have contributed to...harming Canada's economy and reputation."[9] At the onset of SARS, Ontario did not have an adequate information technology (IT) network in place to address this kind of outbreak.

IT infrastructure and two-way communication capabilities varied between municipal, provincial, and federal governments, across health units and agencies, and among health service providers. For this reason, it was not possible to gather epidemiologic information from the field in a timely manner, centralize data input, and disseminate information to the health and public sectors. This inability appears to have been compounded by a series of perceived or real policy, administrative, and other barriers to information access experienced by both the OSSAC and the broader research community.

Existing networks: In addition to dealing with the evolving case definition for SARS, the province, Public Health Units, and healthcare providers had to draw on what already existed and attempt to create an infrastructure as the SARS crisis unfolded. As the National Advisory Committee and others have noted, a combination of technical, non-technical, and ad hoc data collection instruments were used at the outset of SARS. The lack of central resources and analytical capacity created tremendous challenges in formulating accurate, consistent, and reliable information. In 1997, the Provincial Auditor's Report observed that the Reportable Disease Information System (RDIS) contained limited information about the extent and results of contact tracing.[10] To help monitor the effectiveness of Public Health Division programs, the Auditor – after highlighting these concerns – went on to request further information from the Ministry. The Ministry response to the Auditor stated "a new information system for tracking reportable diseases is in early development" and "improved management of contacts by the local health departments and more complete data for monitoring the effectiveness of the Tuberculosis Control Program" would be achieved. The Auditor further recommended improvements be made to the effectiveness of contact tracing. To this the Ministry response was "it is expected that the enhanced information system [for tracking reportable diseases] will allow more in-depth monitoring of contact tracing."[11] To-date, six years later, the Ministry has still not developed a method for improved contact management by local health departments. No 'enhanced information system' was available to manage the reporting of SARS, six years after the Ministry responded to the Provincial Auditor's comments.

For instance, the RDIS would normally be used by the Public Health Units to report diseases. However, early on, the RDIS was found to be an unsuitable instrument for this type of reporting. RDIS was antiquated (developed in the late 1980s), and was originally created to be a case management tool for public health surveillance of reportable diseases.

Another data collection instrument that was used during SARS was a web-based application known as the Integrated Public Health Information System (iPHIS). Since 1996, the federal and provincial governments have been working to implement iPHIS across Canada for public health case management. During SARS, Public Health Units attempted to implement a SARS component for iPHIS that had been originally developed between Health Canada and the Ministry. However, the system could not be created overnight and proved to be both labour-intensive and unable to capture the necessary information. Attempts to combine iPHIS with a Microsoft Access database used for line listings, with support from Health Canada, were also discussed but never implemented.

Furthermore, iPHIS had never been designed to facilitate the management of quarantine or to assist with contact tracing. In the midst of SARS, Ontario desperately required effective quarantine management tools and inference-based systems for contact tracing, given the large numbers of people in quarantine and the complex patterns of transmission. Several systems were examined, including Powercase, used by the Ontario Provincial Police for case investigations, yet no solution has emerged to date to address this problem.

Ontario desperately required effective quarantine management tools and inference-based systems for contact tracing.

Ultimately, SARS data was primarily collected using line-lists, similar to spreadsheets, received from the Public Health Units. These lists didn't allow for a rigorous analysis of the data, thereby delaying the process and wasting valuable analytical time and resources.

The province also acutely felt the lack of a standardized electronic data collection instrument, which could have been tailored as the case definition for SARS gradually emerged. Without an electronic surveillance and data entry tool, Ontario a province with considerable resources, had to rely on paper-based systems and/or a number of locally crafted 'systems'. In certain cases, these systems lacked consistency and made the final compilation of data extremely challenging.

In the end, data was reported simply as the daily total numbers of suspected and probable cases, as further analysis was not initially practical or feasible. However, some additional fields such as age and gender were added later. The Panel heard that a flexible and robust IT system to handle major outbreaks is urgently needed – such a system would link the various components of a communicable disease surveillance system. The province needs access to timely and accurate data sharing and integrated reporting – hospital emergency rooms, walk-in clinics, labs, physician

offices, etc. – to allow for direct data entry, linkages across jurisdictions, and to track contacts in quarantine and manage information.

Epidemiologic and analytical capacity: During the SARS crisis, it was impossible to perform anything but rudimentary analyses. No single, comprehensive means of data collection existed, so only small amounts of data useful for statistical analysis were available. Because of this, the Panel found that both Public Health Units and the Public Health Division of the Ministry could perform only limited analysis in a timely manner. In any event, relying on such findings from statistical analysis of a small number of data would have been problematic; statistically, it is an accepted principle that results from analyses of small numbers of data are not generalizable.

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The lack of trained staff compounded this problem. Analyzing surveillance data requires contributions from trained professionals such as epidemiologists, statisticians, and biostatisticians. The Panel found that epidemiological and biostatistical expertise at the provincial level during the SARS outbreak was clearly insufficient to meet the needs.

Inconsistent data: There was some consistency in the data collected by Public Health Units, although it was far from comprehensive. However, we heard that acute, long-term care and community-based facilities may or may not have collected similar information from suspect cases. Indeed, the failure to be able to electronically deploy a single measurement instrument encompassing comparable data, led to an inability to critically analyze and respond to 'signals' in health data.

'Signal' refers to useful information conveyed by some communications medium, and 'noise' refers to anything else on that medium. In an all-electronic surveillance system, collecting data from emergency departments, 911 calls, physicians, laboratories and even analyzing and recording medicine purchases from a local pharmacy chain poses one problem, the signal-to-noise ratio: there is an incredible array of information to analyze.[12] In general, this ratio refers to the amount of useful information (the signal) in relation to anything else (the noise).

Put simply, it is hard to know if the surveillance system has been worth the expense. For instance, it clearly identifies flu season but probably does not

prevent people from getting sick. "These systems are not for everyone; they're unproven. We're not sure they can pick up on something if it does happen. We're hoping they will."[13] We do not have collection devices at this point fast enough to be able to know what is going on. Indeed, the technology is there to do it, but the process is not. Therefore, the surveillance system needs to have a pre-determined way of evaluating its worth as disease definitions change and 'noise' is reduced.

Data sharing protocols: Individuals in the field and those associated with providing scientific advice on SARS to the Ministry, told the Panel of persistent data problems and the difficulty in obtaining timely data. The National Advisory Committee also noted the perception among some at the federal level that Ontario was providing insufficient data in a timely manner, or forwarding it inconsistently. Regardless of the accuracy of the perceptions, one thing seems apparent – either clear, consistent data use protocols and appropriate liaison protocols were not adequately in place during SARS, or, if they were, their content was not widely known to the participants.

While there may have been progress in this area, the Panel sees the need for an urgent review and reaffirmation of all appropriate data access and sharing protocols. This review should look at how these protocols may pertain to federal/provincial/municipal exchanges of information, in both emergency and non-emergency situations, as well as processes to allow disease research that is pertinent to identifying and containing an outbreak, and other research purposes.

Upon completing this review, the existing governing framework reflected in these agreements should be made public. This would provide a clear indication of the rules and limitations regarding data access should a future outbreak occur.

Legislative barriers: The Ministry should appropriately review actual or potential legal barriers to accessing and sharing surveillance and case information, since this posed yet another obstacle in analyzing data collected during the SARS crisis. Although this problem was emphasized during the outbreak, we recognize that there is an ongoing, systemic problem in sharing data for analytical purposes.
The Panel recognizes that proper safeguards are needed to ensure the privacy, confidentiality, and security of information-appropriate data. Yet this data must also be made available for analytical purposes in a timely fashion. The Panel recognizes the potential need for personal identifiers, for example, to contact the patient in certain circumstances. To achieve this,

there must be an encryption process designed within the surveillance system to provide for different levels of access to identifiable information, while protecting the privacy of the specific individual. Data management processes and policies must therefore be implemented to make effective and adequately protected use of the information collected.

We heard that problems and a lack of clarity existed on both sides of the spectrum. For example, a number of submissions referred to the difficulty accessing data, while others pointed out that personal information was being transmitted or accessed by the Ministry, federal government, and outside researchers at certain times, without a clear understanding on the part of some health units of the authority to access such data.

In this regard, the Panel urges a thorough and detailed review of the provisions of *Health Protection and Promotion Act* (R.S.O. 1990, c. H.7), the *Freedom of Information and Protection of Privacy Act* (FIPPA) (R.S.O. 1990, c. F.31) and its municipal equivalent, *the Municipal Freedom of Information and Protection of Privacy Act* (MFIPPA), R.S.O. 1990, c. M.56. This review should examine any areas of actual or perceived lack of clarity regarding the appropriate legal authority to collect, use, or disclose personal information for research purposes (potentially including identifiers) in the context of an outbreak. This review should be balanced with a clear set of publicly available rules regarding who is or is not authorized to access identifiable information.

In addition, the Panel heard that the inability of some healthcare providers (such as Emergency Health Services (EHS)) to access an effective single identifier (potentially all health card numbers), such as a Unique Patient Identifier, impeded the ability to cross-link data for appropriate infectious disease tracking and research. For example, this issue arose within EHS given the significant role that the Provincial Transfer Authorization Centre played in managing patient transfers during SARS. The fact that infectious disease surveillance initiatives were unable to use a patient's Ontario Health Insurance Plan number as a verification and potential surveillance tool should be examined.

Towards a Comprehensive Surveillance System in Ontario

The Panel strongly supports the recommendations of the National Advisory Committee on SARS and Public Health and the Standing Senate Committee

on Social Affairs, Science and Technology regarding the urgent need to establish a national surveillance system. Many of the barriers that impeded the deployment of timely and effective surveillance during SARS are long-standing systemic issues. Left unresolved, they will impair the ability to both detect and respond effectively to a future outbreak. A robust real-time surveillance and early warning system, using global, national, and local epidemiology was lacking.

While the Panel heard that progress has been made in a number of key areas post-SARS – such as the establishment of a centralized epidemiologic unit (Epi-Centre) at the Ministry – there is clearly still a long way to go. Most pressing in this regard are the continued absence of an operational information technology system across all Public Health Units, and the need for rapid implementation of an effective operational laboratory information system to which Public Health could be linked.

Ontario has the basis to begin to build an effective surveillance infrastructure. Firstly, there is broad recognition from those outside of public health of the need for this infrastructure and of its relevance to the day-to-day activities of all healthcare providers.

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Secondly, the National Advisory Committee and the Senate Committee have suggested that Canada Health Infoway should support the renewal of the public health infostructure. Canada Health Infoway offers an opportunity for a potential infusion of resources, and an ideal vehicle for ongoing national collaboration.

Infoway's mission is to foster the development and adoption of electronic health information systems with compatible standards and communication technologies across Canada, so that Canadians and their healthcare providers will have timely, appropriate, and secure access to the information they need, whenever and wherever they enter the healthcare system.

The Panel also heard that Ontario possesses a range of resources that could potentially be used to craft a more robust surveillance framework. This includes formal surveillance programs (for example, for West Nile Virus, communicable diseases, and pandemic influenza), and a number of informal partnerships for surveillance, such as between Central West Ontario Health Units and Central West Ontario Health Planning Information Network (CWHPIN).

For example, CWHPIN is one of five Health Intelligence Units established by the Ministry. It is made up of seven Public Health Units and four district health councils, in the districts of Brant, Haldimand-Norfolk, Halton, Hamilton-Wentworth, Niagara, Waterloo, and Wellington-Dufferin, as well as McMaster University Faculty of Health Sciences. The mandate of this partnership includes identifying community needs; disseminating information; providing health intelligence; supporting professional and skills development; and, conducting evaluation and research.[14]

There are also opportunities to broaden the information collection capacity of Telehealth as a syndromic surveillance tool. This provincial health advisory line was established in November 1998 to provide health advice by telephone.

The Patient Transfer Authorization Centre (PTAC) and e-Physician Project (ePP) may also hold opportunities worth examining. PTAC, the centralized coordination of inter-facility patient transfers, was established during SARS to control the inter-facility spread of SARS. It is a potentially useful adjunct to an infectious disease surveillance plan. The central repository may provide an early warning system for any unusual types and levels of activity that had not yet been identified locally due to the dispersed nature of the local presentation.

ePP is jointly sponsored by the Ministry, the Ontario Medical Association, and the Ontario Family Health Network. Its goal is to implement high quality, integrated, and standardized IT solutions to automate physician practices. This too may provide comprehensiveness to a provincial surveillance plan.

It is clear that Ontario is capable of creating a highly effective surveillance system. This was demonstrated in July 2002, during World Youth Day in Toronto. Toronto Public Health implemented the most comprehensive example of infectious disease surveillance seen in Ontario, making a clearly articulated syndrome definition available at the event sites, in four Toronto emergency rooms, in pharmacies, through 911 services, and through the coroner for the City of Toronto. These measures demonstrated that even without a fully electronic platform,

Toronto Public Health implemented the most comprehensive example of infectious disease surveillance seen in Ontario [at World Youth Day in July 2002].

robust disease surveillance activities can occur and have multi-sectoral involvement.[15]

Clearly, it will require significant work, time, and resources to achieve a comprehensive surveillance framework for infectious diseases (and beyond). The Panel has heard much about SARS surveillance, the proposed

approaches, and some of the challenges faced during SARS. The Panel agrees that it is of paramount importance to develop and implement an effective surveillance framework, given the fears of an imminent return of a respiratory infectious disease outbreak.

We understand that there are several activities occurring within the Ministry and at a national level, both shorter-term and longer-term, related to surveillance activities for SARS and other infectious diseases. However, it is not clear how all of these pieces fit together. To assist healthcare providers in understanding the overall picture, the Ministry should codify, formalize, and coordinate activities, and clearly laying out how all of these initiatives link together.

Therefore, we urge the Ministry to establish a clear process to examine future infectious disease surveillance needs and opportunities, as well as mechanisms for broad scientific and health sector involvement. Any infectious disease surveillance plan should, at a minimum, include local Public Health Units, community agencies, and acute and long-term care facilities. Over time, this data plan may expand to the private and not-for-profit sectors and community settings.

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A comprehensive infectious disease surveillance plan province-wide requires a sophisticated information technology (IT) infrastructure to ensure common standards across the province, and to enable rapid access to comprehensive surveillance plans. The IT systems used by health service professionals need to be developed urgently. The Panel recognizes that contact tracing and case management of infectious disease require an integrated IT infrastructure to better support evidence-based decision making.

Recommendations

36. The Ministry should build on work undertaken to-date and develop a comprehensive, provincial infectious disease surveillance plan by June 30, 2004. This work should:

    a. be carried out by a multi-disciplinary group, which includes scientific, government, information technology and healthcare partners, and which is accountable to the Minister of Health and Long-Term Care
    b. involve aligning and clarifying the roles of all post-SARS provincial advisory committees with working groups examining the issue of disease surveillance
    c. examine any opportunities or barriers to using existing tools such as Telehealth and Telemedicine
    d. include province-wide surveillance for facility-acquired infections.

37. The Ministry must ensure that an appropriate information technology infrastructure is in place to fully support the provincial infectious disease surveillance plan by June 30, 2004.

38. The Ministry should expedite the full implementation of the Integrated Public Health Information System (iPHIS), together with any required design modifications, across all Public Health Units in the province by June 30, 2004.

39. The Ministry must move rapidly to fully implement the necessary information technology supports to allow for contact tracing and quarantine management by Public Health Units by June 30, 2004. If this cannot be accomplished through design modifications to iPHIS, other suitable information technology platforms must be used.

40. The Ministry should establish a working group with representation from healthcare stakeholders, researchers, and the Ministry to review on an urgent basis all data access and data sharing protocols between Public Health Units, the Ministry, municipalities, and the federal government. This review should identify how and to whom identifiable personal information is authorized to flow in the event of an outbreak. The working group should submit a report to the Minister by March 31, 2004 outlining the common data sharing structure, reporting relationships, and other common requirements of the data access and sharing protocols.

41. The Ministry should undertake a detailed legislative review of the *Freedom of Information and Protection of Privacy Act* and the *Municipal Freedom of Information and Protection of Privacy Act* in the context of:

   a. the reporting requirements set out under the *Health Protection and Promotion Act*
   b. identifying potential barriers to the sharing of information in appropriate and timely manner
   c. ensuring appropriate protections for personal information.

   This review should be completed by March 31, 2004.

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