

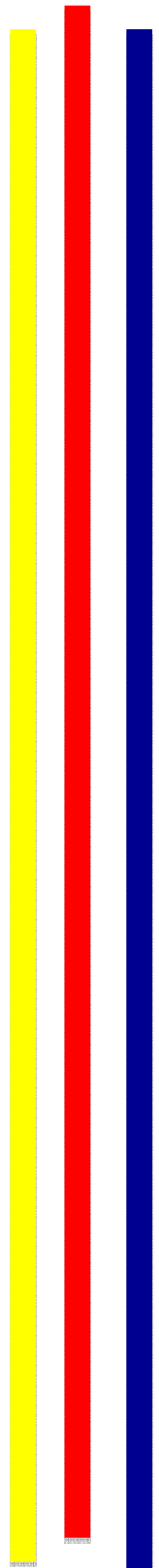
SPECIAL SERIES: THE ROLE OF FEDERALISM IN PROTECTING THE PUBLIC'S HEALTH

Still waiting for a comprehensive national epidemic surveillance system: A case study of how collaborative federalism has become a risk to public health.

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Abstract

This paper evaluates efforts to establish an integrated and functional countrywide epidemic detection and reporting system in Canada following the 2003 SARS outbreak. The purposes and products of epidemiologic surveillance are reviewed, as are the intersectoral and international dimensions of infectious disease control, and the ambiguity in Canadian law of related public health roles and responsibilities. An analysis of current networks, policies and programs, augmented by key-informant interviews, demonstrates that progress toward developing national real-time capacity in epidemic surveillance has been limited. Although a blend of disentangled and collaborative approaches to this issue was effective in developing consensus between levels of government on the need and agenda for coordinated changes in the pre-SARS era, as well as in the immediate aftermath of the crisis, the same intergovernmental strategy appears to have made little actual progress achieving such changes in subsequent years. Counterproductive respect for jurisdictional boundaries, limited resources at the Public Health Agency of Canada, and the use of weak policy instruments in pursuit of intergovernmental collaboration have done little to alter the reality that epidemic surveillance in Canada is characterized by duplication and competition, conducted within institutional “silos” that use incompatible information systems and produce incommensurable data, and shared through informal and voluntary rather than mandated and automatic mechanisms. The impact of federalism on surveillance policy effectiveness has thus not been positive, and in fact undermines the obligation to protect domestic and international health. A federal trust model, based on the combination of national guidelines and flexible ongoing federal funding, may present a politically feasible option for restructuring intergovernmental relations on this issue. [This approach will help](#) secure the transfer of epidemiological information during public health emergencies, the [importance](#) of which has been reinforced by more recent infectious disease outbreaks, notably the epidemic of listeriosis in 2008 and the global influenza H1N1 pandemic of 2009.

“Long before SARS, evidence of actual and potential harm to the health of Canadians from weaknesses in public health infrastructure had been mounting but had not catalyzed a comprehensive and multi-level governmental response... SARS is simply the latest in a series of recent bellwethers for the fragile state of Canada’s federal/provincial/municipal public health systems. The pattern is now familiar. Public health is taken for granted until disease outbreaks occur, whereupon a brief flurry of lip service leads to minimal investments and little real change in public health infrastructure or priorities. This cycle must end.” (National Advisory Committee on SARS and Public Health, 2003, 11+64)

1.0 INTRODUCTION

This chapter will review recent attempts to create a fully integrated and functional Pan-Canadian epidemic surveillance system, or what the National Advisory Committee on SARS and Public Health (the Naylor Report) referred to as “a seamless national network for detecting and managing emerging and existing infectious threats to public health” (2003, 91). The objective is to update the knowledge base on the impact and effectiveness of recent policies and intergovernmental strategies for achieving this public health goal. It is also to locate those strategies, and potential policy alternatives, within this book’s conceptual framework, thereby deepening its exploration of issues at the intersection of Canadian federalism, public health policy, and population health improvement.

These tasks are undertaken by describing and evaluating intergovernmental and interagency efforts to establish a countrywide epidemic detection and reporting system in Canada since the 2003 outbreak of severe acute respiratory syndrome (SARS). The findings, which clarify how the legal, technological, organizational, policy, and operational aspects of epidemic surveillance throughout the country are shaped and constrained by intergovernmental considerations, are based on a thorough review of policy-related documents and on the content of 21 semi-structured key-informant interviews with academics, public health authorities, and senior policy makers at multiple levels. Intergovernmental considerations, while encompassing the roles and relations among federal, provincial, and territorial (FPT) governments, are shown to be incomplete in the case of epidemic surveillance unless they also include those of municipal and international health authorities. Analysis of the multiplicity of agents, institutions, and processes involved in epidemic surveillance will reveal key insights into specific factors that promote or hinder timely and effective multilevel cooperation on epidemiological data collection, interpretation, and information sharing, both routinely and in emergency situations.

The post-SARS period (2003-2008) was early on characterized by a profusion of urgent calls for public health renewal, including national surveillance capacity development. Significant new public investments appeared to follow, as did reforms to improve the readiness of all levels of government to detect and respond to disease outbreaks. The analysis presented here, however, suggests that SARS has not brought about an end to the cycle of neglect and stagnation that has undermined public health in Canada, and that progress in developing national capacity to conduct infectious disease surveillance in Canada has been limited. Indeed, efforts expended retooling collaborative intergovernmental approaches have been ineffective in fostering significant change toward the creation of an integrated secure real-time national surveillance network that cuts across existing jurisdictional and institutional boundaries.

Such a conclusion points to the imperative to rethink the current reliance on high-level collaborative intergovernmental approaches to the issue of epidemic surveillance, perhaps in favour of a federal trust model based on the combination of national guidelines and flexible federal funding, as has been successful with immunization harmonization. This and other policy options will be reviewed in detail in the evaluation and concluding sections of this chapter. To set the stage for the description and evaluation of epidemic surveillance initiatives in Canada since SARS, a review will first be provided of the purposes and products of health surveillance as a core function of public health, the major intersectoral and international dimensions of infectious disease control, and the ambiguity in Canadian law of public roles and responsibilities for conducting and coordinating surveillance activities.

2.0 BACKGROUND

2.1 Public & Population health, Health Surveillance & Protection, and Data

Public health, surveillance, and health protection are related and overlapping concepts. All are concerned with the health of people in general rather than specific persons per se, and are thus distinguishable from the provision of health care services to individuals. If public health is the science and practice of ensuring the health of a community through collective action, then health protection is among its main tools, along with population health assessment, health surveillance, health promotion, and disease and injury prevention. Health protection, in turn, involves shielding the population from current and emerging health threats, and it depends heavily on specific types of information, or what a 1999 FPT National Health Surveillance Network Working Group called: “Health-related data collected and maintained for the aggregate good, for prevention of harm to others or for monitoring the health of the population.” (Health Canada, 1999, iv)

Population health approaches, which increasingly incorporate a concern for the social determinants of health, therefore demand a significant breadth and depth of information, some of which is likely to be considered sensitive on the grounds of personal or community concerns, and perhaps also for collective economic or political interests. Thus, while public and population health require an expanded scope of information-gathering activities to take into account the broad range of health determinants and strategies, as well as the principles of evidence-based decision making and accountability, there are countervailing values and trends that aim to constrain the scope of such activities. Personal privacy considerations, for example, as well as regional jurisdictional autonomy, seek to narrow, or at least regulate, the scope of health information availability and sharing. Consistent with the population health model, surveillance has been defined in Canada as “the tracking and forecasting of any health event or health determinant through the continuous collection of high-quality data, the integration, analysis and interpretation of those data into surveillance products (such as reports, advisories, warnings) and the dissemination of those surveillance products to those who need to know.” (Health Canada, 1999, 6)

Health (or epidemiological) surveillance, which both the World Health Organization and the World Bank consider to be an essential function of public health systems, is thus a convenient term under which a broad and complex series of cyclical tasks are grouped. These tasks include

activities ranging from detection, identification, and compulsory notification of certain diseases, to the maintenance of longitudinal disease-specific registries and the continuous or periodic population surveys, to the aggregation of data on consumption patterns and economic activity. The foremost objectives of health surveillance are similarly extensive, but, following the activities of the Public Health Agency of Canada's (PHAC), are in the main are to: monitor health trends; trigger interventions to prevent transmission or reduce the morbidity and mortality caused by disease outbreaks; identify threats to health and emerging diseases and high risk populations; improve understanding of health determinants and assess public health impacts; generate research for planning, resource allocation and service evaluation; and provide evidence for developing policies and empowering individuals.

As there is no single aim or model for health surveillance, systems must be fitted depending on the purposes they are designed to serve. Improving surveillance systems involves ensuring the use of methods with the appropriate sensitivity and specificity for the outputs desired. (e.g.: it is not an improvement to increase the specificity for an early-warning system if this introduces unacceptable delays in detecting, confirming, or reporting outbreaks). Accurate and timely facts about emerging patterns and trends of disease are vital not only for epidemic containment and pandemic control, but also for the formulation and evaluation of policies for the prevention and management of all types of communicable and chronic disease. (Teutsch & Churchill, 2000) The key point from the preceding is that surveillance is useful only to the extent that it is able to provide timely and accurate information that can guide interventions and underpin effective public health practice, planning, and evaluation at local, regional, national, and global levels.

2.2 Surveillance as an Inter-sectoral and International Responsibility

In the wake of the SARS epidemic, the importance of timely access to useful epidemiological data for effective public health action at all levels of jurisdiction was widely seized upon. It was also leveraged by a range of actors and institutions to seek the authority and resources to better coordinate their domestic and international activities with those in various other sectors, including trade, defense, transportation, food safety, and environmental protection. Canvassing the full array of subsequent proposals and connections is not appropriate here, but a brief review of three important linkages - in the areas of animal health, global public health governance, and emergency response - is needed to appreciate the extent of Canada's needs and obligations with regard to epidemic surveillance, and to set the stage for a more detailed evaluation in subsequent sections of this chapter.

As human and animal health are inextricably linked, and as agricultural practices and the global market for food products continue to contribute to the emergence of new infectious diseases at a rate of approximately one per year over the last three decades (Fauci, 2005; Morens et al, 2004), systems that integrate surveillance of disease in both human and animal populations are increasingly considered essential. The importance of effective surveillance for avian influenza, for example, has been well demonstrated in practice. A delayed response to an outbreak of an avian influenza virus of low pathogenicity in Mexico in 1992 led to its evolution into a highly pathogenic form that was not controlled until 1995. This delay resulted in a response at a considerably higher cost than would have been necessary if action had been taken when the outbreak first occurred (WHO, 2004). Delayed reporting, due in part to the limited capacity of

existing public health systems in affected countries to identify and confirm avian influenza in humans, is also widely considered to have contributed to the spread and scale of the currently expanding H5N1 influenza outbreak in both avian and human populations (FAO/OIE/WHO, 2004). Moreover, the World Bank warns that the degree of economic disruption caused by avian influenza viruses is directly related to how fast and how effectively control measures are implemented, and that detection and response delays can significantly multiply the health and economic impacts of an outbreak, particularly in developing countries (World Bank, 2004).

The main surveillance related development in the human-animal health link in Canada since SARS was the launching in October 2005 of the Canadian Animal Health Surveillance Network, a partnership between the Canadian Food Inspection Agency and the PHAC that is funded by the Federal Departments of National Defense and Public Safety. The Network's objective is to detect emerging animal disease threats in real time, with a focus particularly on animal disease with zoonotic potential, and on providing a rapid response to minimize the human health and economic risks to Canada. A combination of the laboratories of these two agencies perform expert microbiological reference testing and carry out research to improve Canada's capacity for identifying viruses and bacteria, often used to support surveillance and outbreak investigation. Much of this is done, under high-level biosafety containment, at the Canadian Science Centre for Human and Animal Health in Winnipeg, which houses both the National Microbiology Laboratory and the National Centre for Foreign Animal Disease. Testing for infectious diseases at the human, animal and environmental interface is also performed at PHAC's Laboratory for Foodborne Zoonoses in Guelph and at units in St. Hyacinthe, Quebec and Lethbridge, Alberta. The Network was designed to deliver a national early warning system, laboratory diagnosis, and information sharing on animal disease threats by the end of 2008. However, interviews (particularly those with provincial public health officials) revealed that such an achievement would be of limited practical value since the network currently relies on intermittent rather than regular testing, and passive rather than active surveillance. Moreover, the comprehensiveness and degree of integration of the Network with existing provincial agencies was questioned, since, for example, H5N1 testing occurs only in wild bird populations and not in industrial poultry stocks, and since major provincial actors such as the Ontario Ministries of Agriculture, Food, and Rural Affairs and of Health and Long Term Care, have yet to become partners on the project.

The animal origins of recent public health threats such as SARS and pandemic influenza also figured among the motivations for the revision in May 2005 of an agreement among all 192 members of the World Health Assembly called the International Health Regulations (IHR), the only binding international legal instrument for the control of infectious diseases. Canada played a significant role in negotiating the terms of the agreement, has championed its implementation, and is a signatory to the treaty without reservation.¹ The IHR are an attempt to modernize and standardize the ways that countries and key international agencies such as the WHO approach the prevention, protection against, and control of infectious diseases. (McDougall & Wilson, 2007) The revised regulations do so primarily by imposing on all countries the obligation to develop, strengthen, and maintain the capacity to detect, report, and respond to public health emergencies that have the potential to spread beyond their borders.

Under the new IHR, Member States must report to WHO in a timely way any cases within their borders of a list of specific diseases (including smallpox, polio caused by a wild-type poliovirus,

human influenza caused by a new subtype, and SARS) as well as any threat, accidental or deliberate, that qualifies as a “Public Health Emergency of International Concern” (PHEIC)—whether infectious, chemical, biological, or radiological. Once an event of concern is identified, the affected country must assess the public health risks of the event within 48 hours. If the event is determined to be notifiable under the IHR, the country must report the information to WHO within 24 hours.

To meet the requirements of the revised regulations, cooperation between FPT and local officials is evidently critical. Indeed, the IHR require not only that all countries identify the competent domestic authorities responsible for public health activities at community, sub-national, and national-levels, but also that they establish a single office at the national level with the capacity to disseminate information to, and consolidate input from, all relevant sectors across the administration and the country. This office is referred to in the IHR as a National Focal Point, and it is required to provide, on a 24-hour basis, support through specialized staff and logistical assistance, as well as serve as a direct operational link with senior health and other officials at all level, and to be accessible at all times for communications with WHO.

The PHAC Centre for Emergency Preparedness and Response (CEPR), originally formed in 2000 at Health Canada but now one of the ten core organizational units (Centres, Directorates, or Laboratories) within PHAC, has been identified as the Canadian National Focal Point for the IHR, and as “Canada's central coordinating point for public health security issues”. According to its website, the Centre’s responsibilities include developing and maintaining national emergency response plans for PHAC; monitoring outbreaks and global disease events; assessing public health risks during emergencies; contributing to keeping Canada's health and emergency policies in line with threats to public health security and general security for Canadians in collaboration with other federal and international health and security agencies; being responsible for the important federal public health rules governing laboratory safety and security, quarantine and similar issues; and being the health authority in the Government of Canada on bioterrorism, emergency health services and emergency response. Within CEPR, it is the Emergency Operations Centre, formed in 2003 and consisting of a national hub in Ottawa, a public health laboratory operations centre in Winnipeg and a back-up facility, that is responsible for central direction, control and coordination during emergencies.

According to recent submissions to the Treasury Board Secretariat, the Emergency Operations Centre has been undergoing since 2006 a three-phased “redesign and upgrade planning aimed at increasing the Centre's capacity to operate as a 24-7 information gathering, risk assessment and risk management hub”. A 2007-08 PHAC priority was to further connect the three units to provincial, territorial and international networks. In line with this priority have been pledges to develop the hemispheric reach of the Centre, notably those undertaken through the Security and Prosperity Partnership of North America (SPP), a trilateral cooperation, mutual assistance, and information sharing agreement between Canada, the USA, and Mexico launched in 2005. The most prominent public health related element of this partnership is the North American Plan for Avian and Pandemic Influenza, released in August 2007, under which the signatories have agreed to develop guidelines and share best practices in infection control, to test mechanisms for communication and epidemiological information exchange among federal level institutions, and to establish a trilateral Laboratory and Surveillance Technical Working Group to identify areas

of technical assistance needed to improve laboratory, surveillance, and outbreak response to pandemic influenza in border areas and at national levels.

2.3 Enhancing Surveillance on the Canadian Political Agenda

Although SARS clearly raised the public and political profile of infectious disease surveillance, multiple warnings had been issued prior to 2003, and the importance of national level health surveillance information had been recognized in Canada long before then. The necessity of such information for effective policy-making, for example, was noted at least as far back as the Lalonde report in 1974. The necessity of such information for health protection was highlighted by numerous governmental audits and reports beginning in the mid 1990's. Most notable among these, prior to SARS, are the reports of the Krever (1997) and Walkerton Commissions (2002), and the federal Auditor General reports of 1999 and 2002. Recommendations related to health surveillance were also found in two major federal reports on health care released in 2002, the Standing Senate Committee on Social Affairs, Science and Technology Study on the State of the Health Care System in Canada (the Kirby Report) and the Royal Commission on the Future of Health Care in Canada (the Romanow Report). Recommendations to improve population health infrastructure and strengthen public health capacity in order to facilitate the collection and analysis of accurate and comprehensive public health information for research, evaluation, and policy purposes were also made by the CIHR Institute of Population and Public Health (originally produced in 2002, revised and republished in 2004).

The place of epidemiological surveillance on the Canadian political agenda has also evolved in tandem with advances in information technology over the last 15-20 years. Such advances have played a significant part in encouraging and facilitating the drive for improved health information, often in conjunction with the assertion that health policy and program decisions should be based on the best available evidence. In particular, electronic technologies hold the promise of timely if not real-time access to more complete and standardized information sources, sources that over time may be able to provide the longitudinal data necessary to more effectively monitor and improve population health. Responding to the opportunities inherent in new technologies, Health Canada, PHAC, and provincial and territorial health ministries have been investing since the early 1990's in the development of new electronic systems for the secure flow of information among the various sectors involved in public health, and particularly in the development of standardized networks for electronic patient health records (EHR) so that health care providers can access patients' clinical records from multiple sources. A selective review of the initiatives and products of such investments related to infectious disease surveillance will be undertaken in the following section where current public health information and infrastructure networks will be presented in more detail.

The appearance of surveillance as a significant item on the Canadian intergovernmental agenda appears linked to the crisis in the safety of the Canadian blood supply system during the mid 1990's and, more generally, to perceived gaps in Health Canada's ability to conduct public health surveillance and protect the public from preventable disease and injury. The number and severity of transfusion-acquired infections between the mid 1980's and the mid-1990's led to recommendations for enhanced health information activities in both the 1997 Report of the Krever Commission on blood safety and the 1999 federal Auditor General's report (Wilson,

2003). The Krever Commission recommended “strengthened surveillance by public health authorities at both the federal and the provincial-territorial levels of infectious diseases, including those that are blood-borne” (volume 3, chapter 39, Recommendation #49, pg. 1073). The Auditor General recommended that Health Canada strengthen its ability to conduct timely health surveillance in collaboration with provinces and territories to better protect the health of Canadians from threats such as infectious and chronic diseases and unsafe consumer products (Chapter 14).

Three years later, a follow-up by the Auditor General of Canada noted that limited or no progress had been made in resolving most of the weaknesses identified in the 1999 report, and that national surveillance continued to be weak, untimely, and incomplete (Chapter 2). Noting the lack of FPT agreement on roles and responsibilities (particularly on data sharing and common standards), and the failure to formally establish surveillance priorities or provide adequate funding to support them, the 2002 report concluded that the federal capacity to “anticipate, prevent, respond to, monitor, and control diseases” was compromised (page 1). Continued collaboration and cooperation “among all the partners in health surveillance” was recommended, particularly with regard to the Canadian Integrated Public Health Surveillance (CIPHS) program, an integrated software and database application for the standardized reporting of clinical and laboratory generated infectious disease data that continues to this day to be managed by FPT representatives. Progress by the program in contributing to a pan-Canadian public health information management solution was deemed “regrettably slow” by Ontario provincial authorities examining the SARS crisis less two years later, in 2004, principally because the implementation of the lead component of the system, the Integrated Public Health Information System (iPHIS – see the following sections for details), did not create any actual cross-jurisdictional linkages, resulting in autonomous systems operated in provincial or territorial “silos”.ⁱⁱ No consideration of alternative or complimentary policy instruments or strategies was provided in the 2002 Auditor General of Canada report, which concluded that “an established approach to national health surveillance is still many years away” and expressed concern that new comprehensive approaches were being adopted without specific timelines and independent of existing surveillance activities rather than incrementally within current systems (6-7).

Similar concerns were found that same year, 2002, in two high-profile federally-commissioned reports on the financing, organization and delivery of health care in Canada, the Commission on the Future of Health Care in Canada (Romanow report), and the Standing Senate Committee Study on the State of the Health Care System in Canada (Kirby report), both of which discussed the importance of infectious disease surveillance. Whereas the Kirby Report discussed the importance of developing an integrated local infrastructure, the Romanow Report emphasized the importance of supporting international initiatives, including health surveillance in low-income countries, to reduce the risk of communicable diseases spreading to Canada. In fact, the Romanow report did not specifically discuss existing or potential national public health surveillance initiatives, instead recommending that Canada use its expertise to assist foreign governments and international agencies in the detection and prevention of the international spread of diseases, particularly by working “...with the World Health Organization to strengthen and renew the International Health Regulations on monitoring and containing communicable diseases” (240).

The Kirby Report found that efforts in Canada to create a nationwide integrated and effective infectious disease surveillance lacked the degree of investment and comprehensiveness demonstrated in the U.S, and that “the lack of surveillance activities is a matter of considerable urgency”. It recommended that the federal government make infectious disease surveillance a top priority and build capacity for a comprehensive, national disease surveillance system by allocating at least \$200 million in additional funding per year to “ensure strong leadership and provide additional funding to sustain, better coordinate and integrate the public health infrastructure in Canada.” More specifically, the report urged Health Canada to use a Communicable Disease Control fund to assist the provinces and territories in building up their disease surveillance and control capacity, and to begin work to immediately build up existing FPT infrastructure with the goal of establishing a comprehensive network that would link disease surveillance and control activities across all jurisdictions. The Kirby report also recommended the negotiation of memoranda of understanding between various levels of government on the processes and protocols that would allow for greater immediate collaboration, especially in creating a health alert system for the reporting of infectious disease outbreaks, as well as for the deployment of federally-employed field epidemiologists to every region in the country in sufficient numbers as may be needed in dealing with a health emergency. Such collaborative and non-legislative strategies were favoured by the Kirby Report, despite the fact that it noted that legislative renewal will be necessary in the longer term, in order to harmonize and improve federal and provincial health emergency legislation. In the short term, however, the Kirby Report argued that most of the major changes needed to develop a national surveillance system could be accomplished without resorting to new legislation. (Frank, DiRuggiero, & Moloughney, 2003). It is noteworthy that the Kirby Report, researched and written before SARS, nonetheless evaluated the surveillance situation in Canada to be dire enough that it suggested an implementation window of a mere 12-24 months for its public health and surveillance related recommendations to be completed or substantially underway.

Calls for better integration of surveillance systems, and better use of information and communication technologies, gained significant and public urgency and prominence in the aftermath of the SARS outbreak of 2003. This was due in no small measure to the forcefulness and similarity of the conclusions issued by the National Advisory Committee on SARS and Public Health (the Naylor Report, 2003), the Ontario Expert Panel on SARS and Infectious Disease Control (the Walker Report, 2004), and the Ontario SARS Commission (the Campbell Report, 2004). All three of these high-profile investigations concluded that the very organization of public health and health care in Ontario, and the lack of detailed real-time public health data sharing among orders of government, likely contributed to the spread of the pathogen [see quotes in textbox below]. All three reports also noted high levels of dissatisfaction and low levels of interoperability of existing information technology systems for infectious disease surveillance, and as a result recommended urgent development of more sophisticated and integrated IT platforms with compatible standards and communication technologies across Canada in order to ensure timely, appropriate, and secure access to public health information. The necessity of improved national surveillance was also framed in all three reports as essential to pandemic influenza preparedness.

“...there was an obvious breakdown of communication [during SARS], which is hardly surprising given the inherent difficulties of federal-provincial

cooperation and the complete lack of any preparedness or any existing system to ensure an effective flow of information during a crisis. ... There was a damaging combination of problems: lack of information systems, lack of preparedness, lack of any federal-provincial machinery of agreements and protocols to ensure cooperation, all possibly overlaid by a lack of cooperative, collaborative spirit in some aspects of the Ontario response. ... If a greater spirit of federal-provincial cooperation is not forthcoming in respect of public health protection, Ontario and the rest of Canada will be at greater risk from infectious disease and will look like fools in the international community” (Campbell, 2004, 67-68 + 16)

“Either memoranda of agreement or legislative arrangements should be developed among Health Canada and all P/T jurisdictions laying out protocols covering all aspects of the conduct of the management of significant outbreaks [including] adoption of highly flexible and interoperable data platforms that allow sharing of public health information.” (Naylor, 2003, 112)

“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... It is of paramount importance to develop and implement an effective surveillance framework... We understand that there are several activities occurring within the [Ontario] Ministry [of Health and Long Term Care] 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 lay out how all of these initiatives link together.” (Walker, 2003, 165 + 167)

The Naylor Report conclusions and recommendations merit particular attention for their comprehensiveness and for their explicit national policy prescriptiveness, even if an assessment of the subsequent policy impact of the report might well conclude that it has been limited. Like the Kirby Committee, the Naylor Committee recognized the urgency of the surveillance deficit, and recommended immediate improvement commitments to generate measurable results within a very short time, and notably no more than one year for many of its recommendations. The Naylor Report also similarly recommended that top priority be given to surveillance, for which the federal government should provide technical advice and funding to provincial and territorial jurisdictions, as well as programs to support training of personnel required to implement surveillance programs. This was to be achieved by the federal provision of \$100 million per year in support of provincial, territorial and regional capacity for surveillance, outbreak management, and related infection control activities, and by the initiation of a new Network for Communicable Disease Control that would link together these FPT activities and facilitate the longer-term development of a comprehensive and national surveillance system.

In light of how the SARS outbreaks occurred, the Naylor Report also recommended federal support for nosocomial infection control and real-time alert systems linking public health and clinical information systems, including hospital surveillance as a priority program, and the reclassification of specific infections as nationally notifiable, with surveillance for them supported by mechanisms for active and passive laboratory surveillance. The negotiation of intergovernmental agreements for the collaborative surveillance of infectious diseases and response to outbreaks and other public health emergencies, the establishment of a working group to assess the capacity of existing public health infrastructure to be transformed into a pan-Canadian system, and the development and funding of training programs and tools to support local public health agencies in systematically developing, implementing and evaluating crisis and emergency risk communication strategies, also featured among the key intergovernmental strategies put forward in the report. To complement surge capacities in all domestic jurisdictions as well as globally, the Naylor Commission advocated for the creation of an FPT Network for Emergency Preparedness and Response and of two fully-equipped and immediately deployable national epidemic response teams, as well as significant enhancement of the federal mechanisms for international technical liaison, particularly with the World Health Organization and the US Centers for Disease Control and Prevention.

Finally, and on the question of legislative renewal for public health, the Naylor Report advised the Government of Canada to embark on a time-limited intergovernmental initiative to review and renew the legislative framework for disease surveillance and outbreak management, and to harmonize emergency legislation governing the management of public health emergencies. It qualified this, however, by noting that if *“a coordinated system of rules for infectious disease surveillance and outbreak management cannot be established”* through existing FPT collaborations and the recommended intergovernmental legislative review, then the federal government *“should initiate the drafting of default legislation to set up such a system of rules, clarifying F/P/T interactions as regards public health matters with specific reference to infectious diseases.”* (Naylor, 2003, Recommendation 12B.6, 216) The Naylor Report also urged the launching both of a comprehensive review of the application of the Protection of Information and Privacy and Electronic Documents Acts and the Privacy Act with respect to their application to routine and emergency public health activities, and of a Public Health Ethics Working Group to develop an ethical framework to guide public health systems and organizations during emergency public health situations.

2.4 Overlapping & Uncertain Roles and Responsibilities

As the growing intergovernmental intricacy of the surveillance-related recommendations surveyed above suggest, the constitutional, statutory, and regulatory framework governing public health in Canada is complex and uncertain. It is also characterized both by a paucity of legal direction for a clear separation of powers and responsibilities on certain public health issues related to surveillance (including data ownership and information sharing), and the overlapping of different and rarely concordant law on others (including privacy of medical information, which is subject to widely varying standards by and under a variety of federal and provincial statutes and agreements). As “public health” is not an enumerated topic specifically assigned to one or another level of government in the Constitution, both orders are authorized to legislate

depending on “the nature and scope of the health problem in question” (Ries in Bailey, Caulfield & Ries 2008, 10). This has resulted in a very thick legislative and regulatory framework for surveillance related activities in Canada. For example, a legal inventory updated in 2005 of all relevant federal, provincial, and territorial statutes and regulations governing infectious disease control, (excluding case law, international regulations, and the internal policies of infectious disease agencies) runs to more than 600 pages. (Lacroix et al, 2003) Much of the following information is drawn from that comprehensive survey.

With regard to public health in general, the federal government can invoke its exclusive authority over “Quarantine and the establishment and Maintenance of Marine Hospitals” (s. 91 (11)) to regulate all aspects of infectious diseases (Attaran & Wilson 2007; Ries 2005). It can also invoke its exclusive authority over criminal matters (s. 91 (27)), the census and statistics (s. 91 (6)), Indians and lands reserved for the Indians (s. 91 (24)), naturalization and aliens (s. 91 (25)), and in matters of national defence (s. 91 (7)) should bioterrorism become a concern or if support from the Royal Canadian Mounted Police or Canadian Forces is deemed necessary. The federal government can as well “make laws for the Peace, Order, and good Government of Canada” (the POGG clause), in relation to all matters not constitutionally assigned to the provinces (s.91 (30)), although this last provision has largely slipped into disuse.

The provinces and territories can invoke their authority to legislate in matters pertaining to the establishment, maintenance and management of hospitals, asylums, charities and eleemosynary (philanthropic) institutions in and for the Province (s. 92 (7)) and to “property and civil rights in the Province” (s. 92 (13)). All provinces and territories have passed legislation to regulate public health in general, and several have regulations covering infectious diseases alone (Ries in Bailey, Caulfield & Ries 2008), and the courts have generally reinforced provincial jurisdiction over routine sanitation and disease control activities, even though the federal government has involved itself non-legislatively in public health by providing conditional funding for public health programs or by entering into legal contracts to develop public health initiatives (Braën 2002; Leeson 2002; Wilson, 2001).

The key federal acts governing public health surveillance activities are the Department of Health Act and the Quarantine Act. The former gives the Department of Health powers relating to disease surveillance and the “protection of the people of Canada against risks to health and the spreading of diseases” (s.4) and refers to this on several occasions not simply as a power, but as a duty. The latter provides general and emergency powers to the federal government to act to prevent the introduction and spread of disease through the country by inspecting and applying quarantine orders on goods and travelers arriving in Canada. [as the chapter by McClennen in this volume demonstrates?] It is indicative of the unworkability of existing federal emergency legislation, however, that the *Emergency Act* 1985 has never been invoked in Canada, perhaps in large part because it requires that an issue or event be publicly labeled as being beyond provincial abilities to manage (Ries, 2005).ⁱⁱⁱ

All provinces and territories have also passed legislation governing emergencies. These generally cover infectious disease epidemics and other situations presenting a serious threat to public health. For example, Ontario’s *Health Protection and Promotion Act* of 1990 and *Emergency Management and Civil Protection Act* of 2004 (and supporting legislation and regulations

relating to emergency management, occupational health and safety, personal health information protection, ambulances, hospitals, and regulated health professionals) together outline a broad range of infectious disease surveillance and reporting requirements. All provinces and territories have regulations establishing a list of reportable diseases requiring special attention and measures, which form the basis for implementation of the reporting systems.

As noted above, the reporting of infectious diseases to an authority for surveillance purposes will often necessarily involve the transfer of personal health information. Legal experts have signaled that there are three distinct stages in the reporting of infectious diseases, and that each raises distinct confidentiality issues: (1) reporting; (2) storage and sharing of reported information by public authorities; and (3) use of the information for infectious disease surveillance or management purposes, this last use itself split into two activities: (1) research and statistics and (2) medical management of communities and individuals infected by or exposed to communicable diseases. (Lacroix et al, 2003) These raise important privacy and consent considerations that will not be reviewed here (see Lacroix et al, 2004), except to reinforce the complexity of the shared responsibilities and overlapping laws and regulations that frame the collection of public health data for statistical purposes and for managing infectious diseases.

An additional indication of this complexity is found in the fact that although every province has a list of reportable diseases, there is significant variability from jurisdiction to jurisdiction on which diseases must be declared, which terms are used to describe certain infections, which individuals are responsible for reporting, how and when the report must be made, who is the recipient of the report, and what are the penalties, if any, for failure to report. Lacroix *et al* report that “in most cases, the information is received by the medical health officer (MHO) of the locality concerned, who then forwards it to the minister or ministry/department of public health ... [although] the information may pass through a number of links in the reporting chain before it reaches the highest authorities in the public health structure” (2005, 10). The reporting chain beyond the provincial level, however, is infrequently specified. Only three provinces (PEI, QC, MB) have provisions stating specifically that information pertaining to infectious disease reports may, at the request of national public health officials, be sent to or shared with the Government of Canada for national surveillance purposes. Only two provinces (QC, MB) have public health acts that explicitly acknowledge that the prevention of disease may require information sharing (including personal information) with the federal government, the government of another country, or with other provinces.

Jurisdictional authority for epidemic surveillance and data collection and investigation is thus mixed in Canada, characterized by unclear and overlapping responsibilities. Moreover, the presumption of primary provincial authority to gather, aggregate, and analyze surveillance data has been increasingly contested since SARS, a type of crisis which clearly showed how the spread of infectious diseases ignores regional and global boundaries and thus increasingly lends itself to the quarantine and criminal law clauses of the constitution, and perhaps even to the peace, order, and good governance provision, given the need for national preparedness coordination, which fall under the auspice of the federal government (Attaran & Wilson, 2007). Discussions about the creation of an explicit federal legislative framework for epidemic surveillance in Canada have gone on for more than a decade, yet movement in this direction has been painstakingly slow, and the authors of the compendium of legal provisions from which

much of the foregoing was drawn conclude that what is clearly not in place at present is a “*simple, clear and transparent legislative regime*” governing the intergovernmental management of infectious disease in this country (Lacroix et al, 2005, 40).

3.0 CURRENT SYSTEMS, DESIGNS & INITIATIVES

The *de facto* Canadian operational system for the detection of domestic outbreaks consists of five components: the clinical health care system, local/territorial/provincial health agencies, federal agencies, academic/professional organizations, and collaborating governmental and private organizations and service providers. All five components of the system participate in aggregating, analyzing, and sharing surveillance data. The current Canadian approach to detection of disease outbreaks in particular is complex and involves many organizations interacting in a loosely connected, informal but increasingly collaborative manner, although clinical health care providers, local public health units, and provincial health departments and ministries remain the key levels at which detection of domestic outbreaks occurs. A complete environmental scan of all relevant actors and networks lies beyond the scope of this project (but see NCCID Foresight Exercise, 2005), and thus only those directly involved in epidemic detection and outbreak response coordination across jurisdictions, with an unambiguously intergovernmental composition or mandate, or with an actual national or international scope of operation, will be reviewed here.

It is noteworthy that despite the importance of a national surveillance network and the repeated calls for its development, the current situation in Canada continues to be one that consists of a patchwork of health surveillance systems that continues to suffer from substantial gaps, both individually and as a whole. These gaps occur across the entire spectrum of surveillance functions (data collection, transmission, aggregation, analysis, interpretation, and dissemination) and organization, and are particularly acute when it comes to data sharing agreements, information technology and management infrastructure, uniform data quality and reporting standards, emergency response coordination, and the lack of a mandatory operational common list and coding nomenclature for notifiable diseases (despite the recent release of voluntary national standards to this effect), not to mention stable funding for the development of each of these priorities. Moreover, there are at present, despite numerous recommendations to set hard deadlines, few specific timelines for the implementation of a national surveillance network or the intermediate steps required to create such a system. Indeed, fixed functional objectives or chronological targets tend often to be conspicuously absent from the formal documents and proposals of Health Canada, PHAC, and other FPT bodies, perhaps because where they have appeared in the past, they have so rarely been met. Some progress, however, has recently been made in proposing health information and technology standards, as well as in creating, or recombining and reorienting, various coordinating mechanisms for FPT collaboration on this issue. Formal legal and policy harmonization or integration, however, despite the creation of a national public health agency post-SARS, remains largely unachieved, and most day to day operations are facilitated through a variety of informal professional contacts and networks rather than through the formal agencies and mechanisms of Canadian intergovernmental relations. Paradoxically, Canadian public health officials at the local level may, as a result of the informal professional networks and automated media-scanning services described below, have better

overall access to rapid and detailed information about outbreaks occurring in other countries than they do about those occurring in other provinces or territories.

3.1 Infrastructure networks

3.1.1 The Public Health Agency of Canada (PHAC)

The PHAC has primary federal responsibility for public health and health emergency management, and an explicitly collaborative mandate to lead federal efforts and mobilize Pan-Canadian action in preventing disease and promoting and protecting national and international public health. Formed in 2004 and organized into four branches that together employ nearly 2000 staff, the agency is charged with developing national plans and systems in conjunction with the provinces and territories, including for influenza pandemic and other infectious disease outbreaks. PHAC has also formed various Health Emergency Response Teams, and is ostensibly charged with acting as primary liaison with foreign and international public health organizations. Regulatory law enacted in 2006 provides the Agency with “clear authority to receive, manage and protect health information, ensuring that it will be able to obtain the information it needs to fulfill its mandate.” (PHAC, 2007, 103)

The Agency currently participates in health surveillance in conjunction with provincial and territorial ministries and agencies and in collaboration with the Canadian Institute for Health Information (CIHI). Much of this work is pursued through three key networks: the Network for Health Surveillance in Canada (NHSC), the National Collaborating Centre on Infectious Diseases (NCC-ID), and the Pan-Canadian Public Health Network (PHN).

The Network for Health Surveillance in Canada, in operation since 2001, manages a variety of programs, most notably the CIPHS, the Canadian Integrated Public Health Surveillance Program (comprised of two case based reporting platforms, one clinical, iPHIS and one laboratory, LDMS), the Geographic Information System (GIS), and, in conjunction with WHO, the Global Public Health Information Network (GPHIN). The iPHIS platform (or integrated Public Health Information System), the product of a decade long collaboration between public health authorities in British Columbia and at Health Canada beginning in 1993, provides a nearly real-time web-based provincially centralized repository for data collection, linking and sharing, with integrated statistical analysis and alerting functions (notably through the Canadian Integrated Outbreak Surveillance Centre). It had been implemented across 50% of the country’s local public health units by late 2005, and as such is the closest the country has ever come to having in place a standardized tool on which a national surveillance system could emerge, even if actual use of the platform, and cross-jurisdictional integration, was reported by many interviewees to be low.

The National Collaborating Centre on Infectious Diseases, established in 2005, is charged with building linkages and joint activities across Canada’s public health institutions and disciplines so as to better translate existing and new evidence into practice as well as identify knowledge gaps and the requirements needed to fill them. With regard specifically to infectious disease prevention and control, however, the Collaborating Centre has to date concluded little more than an initial scoping consultation, and is still in the planning phase of a “survey of current Canadian public health efforts in detection, identification and monitoring systems for emerging and re-emerging infectious diseases”. (www.nccid.ca/en/new-technologies, Feb 28, 2009)

The Pan-Canadian Public Health Network, also formed in 2005, is where FPT collaboration on the day-to-day business of public health in Canada is conducted by a number of Expert Groups. Initially promoted by an FPT Special Task Force on Public Health as “a new way for different levels of government across Canada to work together”, the Network provides “policy and technical advice to FPT Deputy Ministers of Health on public health matters” as well as support for jurisdictions “during emergencies and/or crises”. Governed by the provincial and territorial Chief Medical Officers and the Chief Public Health Officer for Canada, its objectives are to negotiate intergovernmental agreements on public health issues between jurisdictions, to delineate roles and responsibilities for how different levels of government will work together on public health issues, and to develop a common approach to public health legislation that will help ensure consistency in the public health laws across the country. The Pan-Canadian Public Health Network’s Surveillance and Information Expert Group (SIEG) provides coordination and leadership for public health surveillance, information collection, analysis and sharing across Canada, and was instrumental in drafting a Memorandum of Understanding on the timely sharing of information in preparing for and responding to a public health emergency, although this agreement has yet to be formally approved by FPT officials.

3.1.2 Canada Health Infoway Inc.

Created with a \$1.2B federal capitalization in 2001 and managed as a foundation through Health Canada by way of conditional grants, Canada Health Infoway (CHI, but hereafter “Infoway”) was designed to convert the consensus that IT must be a central role approach to renewing the healthcare system into the development and implementation of a national electronic health record (EHR) system. Infoway was created as an independent, shared-governance corporation, and is based on a collaborative approach since its members are the Deputy Health Ministers from the federal, provincial and territorial governments. Infoway’s mission is to develop and foster the adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis, and it aims to put into place an Interoperable electronic health record system across 50 per cent of Canada (by population) by the end of 2009. It does not collect, store, or analyze any public health data.

Although Infoway was not originally mandated to develop public health surveillance solutions, when SARS and the reports that analyzed the crisis showed a need for such systems, a further funding agreement between the Government of Canada and Infoway was signed March 2004, which provided \$100M for the development of health surveillance systems over a five-year investment timeframe, with a specific mandate to support the management of infectious diseases and immunization. The agreement stipulated specifically that Infoway construct a bilingual national health surveillance system consistent with EHR solution architecture and that the funds be invested in development & implementation of the solution (on an 80/20 Infoway/jurisdictions cost-sharing basis), not operation & maintenance. Interviewees reported that the move surprised many people at both PHAC and Infoway, since the expectation of many was that the former was the more logical choice to receive the new funding, since it was actively rolling out its own iPHIS platform across the country at the time. In the event, the terms of the agreement specifically excluded Infoway from investing in any existing federal public health programs or initiatives, effectively arresting the further development of iPHIS at a point in time when the platform was being touted by the PHAC as the new national standard, and seriously undermining

the Agency's leadership role in the development of further national outbreak surveillance plans and technologies.

An Infoway Steering Committee was quickly established to direct work on a national surveillance solution, comprising a senior public health decision-maker and a senior IT manager from each Canadian Province and Territory; federal representatives from PHAC (2), Health Canada, and Statistics Canada; as well as representatives from other stakeholder organizations such as the Canadian Public Health Association, the Canadian Institute for Health Information, the Canadian Medical Association, and the Council of Chief Medical Officers of Health. This group approved an investment strategy that prioritized integration of the proposed national health surveillance system (subsequently named Panorama) with the broader electronic health record project, which remains Infoway's primary mandate. The aim was to have this system, which was to include immunization management, infectious disease surveillance and reporting, infectious disease case and outbreak management, and health alerting) fully integrated with provincial health registries and laboratory repositories and fully implemented in all jurisdictions by early 2009.

3.1.3 Emerging Regional Collaborations

A handful of recent intra-provincial and border projects have recently emerged, driven primarily by a desire on behalf of bordering local public health units to improve communication and coordination of surveillance activities with their neighbours, in which the strategy appears to purposively exclude any operational role for the federal government (although some do receive federal funding support). These include an emergency management agreement in the Pacific-Northwest (involving Alaska, British Columbia, Idaho, Oregon, Washington, and Yukon), a Memorandum of Understanding on international emergency management on the Eastern Seaboard (among the States of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, and the Provinces of New Brunswick, Newfoundland, Nova Scotia, Prince Edward Island, and Quebec), a Cross Border Contingency Plan in the Erie-Niagara region (Municipality of Niagara, Province of Ontario, and the Counties of Erie and Niagara in the State of New York), and a Public Health Data Sharing Agreement among the members of the Great Lakes Border Health Initiative (the States of Michigan, Minnesota, New York, and Wisconsin, and the Province of Ontario). Interestingly, the converse of this trend is also true, as more substantial federal-to-federal linkages are also being pursued. Trilateral talks between Canada, the USA, and Mexico, for example, have been ongoing since 2001 in the context of the Global Health Security Initiative (GHSI), in which a group of senior public health officials from the three countries have agreed to enhance informal coordination and communication on emerging health threats such as pandemic influenza. Under the aegis of initiative's objectives, Canada and the US have exchanged full-time liaison officers between PHAC and CDC, and full-time trilateral exchange positions are to be established by the end of 2008.

3.2 Information networks:

Canadian epidemiologists and other public health practitioners directly involved with detecting and responding to infectious disease outbreaks, most of whom work within municipal public health units supported by regional or provincial laboratories, rely on a number of relatively

recent electronic sources of information, all of which provide some ability to communicate and share data, although with varying degrees of accessibility, formality and depth of detail. Although a full inventory of these tools cannot be provided here, a brief sketch of those most commonly consulted by Canadian professionals involved with epidemic surveillance is provided here, including the Global Public Health Intelligence Network (GPHIN), the Program for Monitoring Emerging Diseases (PMM), and the PHAC's main information management platform for collaboration, surveillance, alerting and response, the Canadian Network for Public Health Intelligence (CNPHI).

3.2.1 The Global Public Health Intelligence Network

Developed in the mid 1990's by Canadian Health officials and now maintained by PHAC in collaboration with the WHO, The Global Public Health Intelligence Network is a secure, internet-based early-warning system for detecting potential public health threats worldwide by continual monitoring of over 10,000 global media sources in nine languages. The Network gathers relevant information by monitoring media sources throughout the world and makes this information available to governments and non-governmental organizations. The post-SARS reports all noted that the Global Public Health Intelligence Network received a Chinese-language news report with an English header of a flu outbreak in mainland China on November 27, 2002, but that the full report was never translated. The result was that Health Canada officials did not become aware of the new disease until several months later, along with the rest of the world, in February 2003.

While interviews confirmed that this would not likely occur again at the federal or international level, they also revealed that the information generated by the Global Public Health Intelligence Network is not widely available by the practicing public health community at local or regional levels within the country. Although the network is available in near-real-time on a 24/7 basis, and can be accessed anywhere there is internet access, it is a fee-based subscriber service, with annual rates for single Canadian government or non-profit users beginning at \$30 000. Many local public health units, and even those in major urban centres like Toronto, Montréal, and Vancouver, thus do not have direct access because they cannot afford it. Respondents also confirmed the finding from the Naylor report that there are still too few formal coordinated communications systems within provinces, let alone across them, for dissemination of information from the Network to front-line institutions and workers, and that this is despite the fact that most of the larger provincial health ministries pay to access the Global Public Health Intelligence Network generated information.

3.2.2 The Program for Monitoring Emerging Diseases

Established in 1994 and operated by the nonprofit professional organization, the International Society for Infectious Diseases (ISED), Pro-Med Mail is an open registration multi-lingual Internet-based reporting system dedicated to rapid global dissemination of information on outbreaks of infectious diseases to 40,000 subscribers in 165 countries. Pro-Med Mail facilitates communication amongst the international infectious disease community, including scientists, physicians, epidemiologists, and public health professionals, who post reports, raise alerts,

participate in on-line discussions, respond to requests for information, and collaborate together in outbreak investigations and prevention efforts.

Because individual clinicians and public health officials often post unusual occurrences of infectious disease on Pro-Med Mail, the Naylor Report concluded that the initiative constitutes an informal and useful back-up system to more official channels (Naylor, 2003, 93), and interviewees confirmed that local public health officials and hospital infection control staff frequently consult Pro-Med Mail, and that most local public health units have at least one or more staff members who subscribe or monitor Pro-Med Mail alerts. Interestingly, and perhaps tellingly, this use within the Canadian public health community was regarded by numerous respondents as crucial to their being able to stay current not only with international outbreaks, but also with domestic public health events, and particularly those occurring outside the region or province in which they work. Several interviewees also noted that they rarely rely on any single source of near real-time national or international epidemiological information, and that they regularly consult all the sources to which they have access when seeking details on any particular outbreak.

3.2.3 The Canadian Network for Public Health Intelligence

The Canadian Network for Public Health Intelligence (CNPHI) is the PHAC's primary information management and technology platform for surveillance, alerting and response, and is Canada's de facto national public health information management system. A collaboration between federal, provincial, territorial, and regional health authorities across Canada that was generated by a \$3M Health Canada grant immediately following the end of the SARS outbreak, the Canadian Network for Public Health Intelligence is now used daily by more than 2900 registered users in every public health jurisdiction in the country to facilitate infectious disease management. Providing a secure, web-based collective of applications and resources designed to fill critical gaps in Canada's public health infostructure, the Network's goal is to enable real-time surveillance, alerting, intelligence exchange and response to critical public health events, while respecting jurisdictional responsibilities and privacy concern through a jurisdiction-specific sponsorship framework that regulates user's access to information. Information about infectious disease outbreak is available online through the Canadian Integrated Outbreak Surveillance Centre (CIOSC), a virtual office that facilitates the issuance of near real-time pan-Canadian public health alerts and timely exchange of information between local/regional, provincial/territorial and national public health officials.

In theory, the common architecture across the Canadian Network for Public Health Intelligence's more than 30 applications and resources supports multi-jurisdictional data sharing and inter-jurisdictional case-management and decision-making by integrating disparate laboratory and epidemiological surveillance data while respecting jurisdictional responsibilities and privacy concerns. Interviews revealed, however, that despite the project's commitment to integrating with extant information management systems and databases, it is regarded as having significant limitations and is most often employed as a secondary resource, parallel to existing information systems and interprovincial alert networks. For example, despite being compatible with and actually integrated within iPHIS in many jurisdictions, the Canadian Integrated Outbreak Surveillance Centre's alerts function is currently limited to enteric, respiratory, general, zoonotic

and adverse events following immunization components, which excludes such outbreak-prone pathogens such as nosocomial and sexually transmitted infections, and syndromic surveillance information. It also lacks, unlike many existing provincial alert systems, connections with public and private non-public health authorities such as law enforcement, military, industry, and transport agencies and firms, as well as more dynamic emerging resources for decision-making such as predictive modeling and mapping and outbreak simulation tools. Broader intergovernmental and cross-jurisdictional integration, as well as more advanced collection and processing of surveillance data, and dissemination of strategic information, is thus necessary if the Canadian Integrated Outbreak Surveillance Centre is to achieve the coordination of responses necessary to meaningfully address potential health threats, and this is indeed the long-term strategic plan and vision for the network.

4.0 DESCRIPTIVE ANALYSIS: FEDERALISM'S IMPACT ON SURVEILLANCE IN CANADA

The forms of federalism operating in epidemic surveillance, despite being somewhat less than a simple fit with this book's analytical framework for public health federalism, are described in Table 1. The federal/provincial relationship is largely interdependent, even if characterized by islands of independence, and is at present largely non-hierarchical. Thus the form of federalism that best describes national epidemic surveillance in Canada is a complex of mix disentangled and collaborative relations, which fluctuates according to events and to shifting priorities, and is muddled by latent and as yet unexploited potential coercive capacities. The relationship of supranational governments, specifically the World Health Organization, with the federal government is primarily collaborative with an element of coerciveness/hierarchy, particularly when it comes to standards and information dissemination. In day-to-day practice, health surveillance of infectious disease outbreaks has also recently come to be characterized by a certain degree of innovative local-local and inter-regional collaboration, in recognition of the need for functional interdependence, although these relationships are very deliberately voluntary and non-hierarchical. The distinction between routine activities and crisis response is also relevant since the degree of coordination required is far greater when responding to a public health emergency. As a result, each order tends to work relatively independently and within its formal legal jurisdiction when work is unexceptional, but tends to engage in less formalized and more interdependent behavior during a crisis, which may be regarded by lower orders as creating more coercive conditions under which a stricter hierarchy is imposed.

Table 1. Form of Intergovernmental Relationships in epidemic surveillance

	Interdependent?	Hierarchical?	Relationship
Supranational-Federal	Y, but some new international coercive powers constrain national sovereignty	N, although WHO has limited capacity to impose policy obligations on F	International collaborative, with potential for some limited int'l unilateral
Federal-Prov/Terr.	Y, but weakly, since little F interest in forcing important PT changes	N, but F likely has capacity, even if chooses not to use effectively against PT	F-P/T concurrent (both disentangled and collaborative elements)
Prov/Terr.-Local	Y, strongly	Y, although completely within PT constitutional competence	P/T-Local unilateral
Federal-Local	N, although some F requirements may encourage modest policy adjustments	N	F-Local disentangled
Local-Local	Y, but weakly	N	interregional collaborative

It is interesting that despite the potential constitutional authority of the federal government to exercise power over national epidemic surveillance coordination, the case for which has been enhanced by the entry into force of the revised IHR in 2007, the regulation and implementation of surveillance activities post-SARS have remained largely disentangled in Canada, characterized principally by unilateral provincial authority. As Table 2 shows, collaborative elements have continued to emerge or evolve in the post-SARS era, particularly with regard to agenda setting, standards development, and funding for new integrated surveillance information technology systems. However, because formal legislative or regulatory requirements mandating the transfer of epidemiological information during outbreaks have yet to be adopted, no hierarchical relationship exists between the federal and provincial orders of government, and they continue to act relatively independently of each other. (This is especially evident when domestic and international activities related to infectious disease monitoring and control are contrasted.)

Once again however, the distinction between routine activities and crisis response complicates this picture, since service delivery and information sharing, which are largely disentangled responsibilities during routine operations, are transformed during a public health emergency into far more interdependent processes, necessitating collaborative decision-making and supportive measures. A similar observation applies to the distinction between strategic decision-making

(including policy making, standard setting, and program development), which often has of necessity a more collaborative intergovernmental character, and policy implementation and practice, which are more disentangled activities that may take place with minimal oversight from higher governmental orders.

Table 2. Roles and Responsibilities of different orders of government in epidemic surveillance (excluding special populations)

	Federal	Prov/Terr	Local	Supranational
Agenda/standards setting	Y (with supranational direction)	Y	potential; standards often defined by de facto local capacities or procedures	Y
Legislation authorities	Y, but constrained	Y	N	Y, but enforcement limited
Funding responsibilities	Y, but indirect	Y	variable	N, but mandated to coordinate international assistance
Delivery of service	Y, but constrained	Y	Y	Y, but largely consultative/supportive
Mandated upwards information transfer	Y	voluntary	Y	Y, WHO authorized to share all relevant information

The federal government has thus far exercised little coercion (or intrusiveness) in the area of national epidemic surveillance harmonization, which it appears to be pursuing instead through a blend of three policy instruments: (1) a third-party arms-length non-profit information technology systems development and implementation agency, Canada Health Infoway; (2) an informal voluntary information sharing network, the Canadian Network for Public Health Intelligence; and (3) a patchwork of efforts, at different levels and on different timelines, towards intergovernmental agreements and memoranda of understanding (MOUs) on key public health issues, including surveillance activities and standards, few of which have actually been concluded and publicly announced as of the time of this writing.

Indeed, numerous interviewees at both federal and provincial levels noted that that MOUs (which are also on occasion referred to as Letters of Agreement, although there is no clear distinction between these with regard to legal status) appear to be the new primary approach in Canada toward ensuring intergovernmental collaboration in public health generally, and in epidemic detection and response specifically. For example, an MOU on mutual aid during emergencies, including outbreaks of infectious disease and other risks to health, was signed by provincial Deputy Ministers of Health in late 2006 and finalized the next year. That agreement, however, revolves principally around the issue of accreditation, and represents a mutual pact among provinces to recognize the professional qualifications of health professionals such that they can work outside of the jurisdictions in which they are normally employed. In contrast to the more far-reaching US Emergency Management Assistance Compact, however, the MOU on Mutual Assistance has not been accompanied by the development of a dedicated communications network to facilitate alerting, data sharing, response, and accounting activities does, and does not include any agreements relating to cost-recovery and cost-sharing. (See: www.emacweb.org Feb 28, 2009) The EMAC is also decidedly more comprehensive than the Canadian agreement in that it delineates formal duties and responsibilities, provides operational and training resources, and offers model legislation as well as emergency contract templates.

Moreover, both federal and provincial interviewees revealed that FPT officials began with the most achievable MOU, and that there is no guarantee that more complex agreements will emerge in the future. Although a pan-Canadian MOU on information sharing during a public health emergency, for example, has been rumored to be on the federal agenda at least since the SARS crisis, it has yet to be concluded. Provincial interviewees, as well as several local front-line local public health practitioners, also signaled that although FPT officials are commonly heard to suggest that the principal hindrance to information sharing agreements in Canada lies in the difficulty of reconciling statutory privacy protections at various levels, the real impediment is more likely to be that timely quality data transfer and ownership is more complex and politically contentious than recognizing accreditation.

The key point here is that even the strongest most comprehensive MOU's are weak policy instruments, and that, as they appear to be emerging in Canada with regard to public health, they tend to be designed more for the ends of mutually beneficial publicity than for public health operations. This is so because such agreements are outputs that various stakeholders at multiple orders of government can point to in order to justify their efforts and claim an increasing level of intergovernmental collaboration without actually committing to investments in the mechanisms or infrastructure needed for genuine integration. MOU's are also more likely to be ignored during an actual crisis because they have no legally binding force and thus leave the choice to comply or not with the terms of the agreement largely with provincial or territorial decision-makers and on an ad-hoc basis.

A more coercive/intrusive strategy than relying on voluntary MOU's appears to be in the works, however, given the inclusion among PHAC priorities in the 2007-2008 fiscal year the goal of exercising its regulatory power to develop and adopt national surveillance standards. Such regulations would presumably compel provinces and territories to collect and transfer certain health information in a standardized format within prescribed timeframes, presumably to bring the country into compliance with international requirements.

This raises an interesting departure from the conceptual model of public health federalism employed in this book, however, since it suggests that the impetus and justification for resolving an impasse in terms of domestic intergovernmental collaboration on epidemic surveillance is at least in part due to the coercive nature of the relationship between supranational and federal authorities. Indeed, the WHO now clearly constrains the scope of national sovereignty with regard to potential health emergencies (Heymann, 2006), and the obligations and operations of the revised IHR now clearly compel the government of Canada to formulate policy in an area over which it has formerly held only partial and uncertain jurisdiction. This suggests that there is now some degree of concurrent responsibility for health surveillance that spans not just the orders of domestic government, but externally to other foreign governments and agencies, as well as to international authorities. This additional level of concurrency was of course in an important sense self-imposed, given that federal negotiators and representatives at the World Health Assembly participated in the formulation and adoption of the new rules and requirements, apparently with at least tacit provincial and territorial approval, since official letters of support were said by federal officials to have been sent by a majority of the provinces and territories to the then federal minister of health, although these have not been released to the public. But it remains the case that the domestic availability of policy options is being determined at least in part by the parameters of emerging international law.

Those parameters, moreover, run directly against the character of FPT activities in this area both pre and post-SARS. Indeed, two conflicting forces currently constrain federal policy discretion and instrument choice for the creation of an integrated national epidemic surveillance system: provincial/territorial rejection of unilateral federal authority on the issue, and international regulatory law compelling the enhancement and centralization of just such authority. Enhanced supranational authority in epidemic surveillance and response thus creates a serious accountability trap for the Government of Canada, the result of which has been a policy stasis in the area of epidemic surveillance: federal inaction to comply with international requirements will be politically damaging to the country, and potentially to global and domestic public health protection efforts, but determined federal legislative action to rapidly maximize interoperability and information exchange with provincial and territorial systems continues to be regarded as too politically contentious and/or costly to pursue.

5.0 EVALUATIVE ANALYSIS

How effective have the existing forms of federalism been in the area of epidemic surveillance in Canada? Overall, as suggested above, it appears that policy effectiveness, in both health and economic terms, as well as respect for democratic principles, have become casualties of a high but counterproductive respect for the principles and practicalities of federalism. Put another way, intergovernmental activities since 2003 appear to have had as their priority the preservation of existing jurisdictional divisions of roles and responsibilities, rather than the creation of an integrated real time national epidemic surveillance network of networks. The continued absence of such a system may well be putting Canadian citizens at unnecessary risk and certainly puts into question the usefulness of large past and present public investments in creating the necessary information and communication technologies, common standards, and advisory and coordination committees and networks.

The bottom line is that while there are now a few common models for epidemic surveillance activities across the country and within the PHAC, the practice of such in Canada is characterized by program duplication and competition, and by provincial and territorial silos that feature very different and often incompatible infrastructures, each of which is collecting data of variable quality, and the majority of which still cannot be aggregated at the national level. One key consequence of this is that very little public health data analysis, interpretation or forecasting is actually performed at the national level. The most troubling implication of this, in turn, is that it may be a form of self-protection on behalf of the PHAC. Although such responsibilities would normally be a key function of any national public health agency, perhaps the most convenient way to avoid revealing the agency's weaknesses in being able to conduct them is simply to not even attempt to do so. Interviews with several senior officials with longstanding surveillance experience, for example, spoke of recent pilot projects designed to explore how public health data is reported and used at regional, provincial/territorial, and federal levels (by tracking a sampling of notifiable diseases from source up through various aggregation pools). These projects found so little commensurability between datasets once they arrive at the federal level that not a single case could conclusively be said to have occurred where surveillance information affected a federal response, program, or policy. These reports have not been made publicly available. Moreover, although "health surveillance" is defined in detail in the Chief Public Health Officer's first ever Report on the State of Public Health in Canada, released in June 2008, no mention is made at all of any need for or efforts to improve epidemic surveillance in Canada, and a separate report on progress at the Agency since SARS promised for later in that same year has yet to materialize. (<http://www.phac-aspc.gc.ca/publicat/2008/cphorsphc-respcacsp/index-eng.php>, Feb 28, 2009)

The federal government also continues to appear reluctant to provide the PHAC with the human and financial resources it needs to overcome such weaknesses. Despite the various recommendations noted above for an independent arms length agency with a protected budget over which it exerts relatively autonomous control, the PHAC is not such an agency, and the majority of respondents regarded it as unlikely that it will ever become one. Provincial respondents were the most pessimistic about this possibility, while actual agency staff, perhaps understandably, were more guarded with their prognostications. Both groups of interviewees, however, were of the view that the choice to create the PHAC by order in council, as opposed to as a legislated service agency as recommended in the Naylor report, hobbled the agency's autonomy from day one. This decision has also left federal public health authorities in the nearly impossible position of seeking to establish the legitimacy and scope of operation of a new national agency, comprising some 2000 full time employees, in the absence of substantial control over the management, budget, or mandate of that agency.^{iv} Several academics and managers interviewed suggested that the lack of organization within the PHAC is the result of many years of medical management, and that federal public health capacity is no more developed or effective than it was when it was housed at Health Canada prior to SARS, since the agency continues to lack a long-term strategic plan including targets, a detailed inventory of employee expertise and skills, a human resources strategy linked to program priorities, and detailed information technology and management plans. Public health experts for their part tended to point out that the PHAC lacks institutional independence and apolitical professional integrity because it has no guaranteed protected budget, and because the post of Chief Public Health

Officer, in addition to not protected from dismissal without cause, has no clear authority to report autonomously and directly to the public or to parliament, both of which subject the practice of public health in Canada to what many interviewees (and nearly all of those not in the employ of the agency) regard as unacceptable as well as potentially de-legitimizing levels of political interference.

To be fair, some of this lack of overarching corporate strategy within the PHAC may be due to the impetus under which the agency was created: a series of high profile health crises (including the tainted blood scandal, numerous water and food-borne disease outbreaks, and the SARS epidemic), each of which sparked high-profile investigations. Although the conclusions of the reports generated by such investigations contributed to the federal government decision to create PHAC, the weakness of such reports is that their very comprehensiveness generates a long list of deficiencies and a complicated, often overlapping, set of recommendations designed to be implemented as a whole. Given the lack of financial and strategic clout at the PHAC, however, as well as the need to demonstrate competency through the rapid production of deliverables, the agency was somewhat predictably forced to select a small number of narrow key issues for priority focus, to the detriment of much system-level thinking or systematic reform planning. Moreover, because most policy change is incremental, but even incremental change in public health in Canada is largely in the hands of provincial and territorial deputy ministers of health, the ability of PHAC to search for common problems and propose comprehensive solutions is further constrained. The concentration of public health policy power in the hands of non-federal political leaders operating under very little public scrutiny is thus itself a key obstacle to the achievement of anything other than minor incremental changes to the key public health policies, practices, and institutions.

5.1 Policy & Economic Effectiveness

It thus remains the case that, in practice, few significant improvements have been made to the epidemic surveillance gaps that existed before the SARS crisis, except perhaps in the area of influenza and influenza-like infections, where more comprehensive national data appears to be available through FluWatch, a national surveillance system developed in the late 1990's that provides weekly summaries of provincial and territorial influenza monitoring. (www.phac-aspc.gc.ca/fluwatch Feb 28, 2009) Similar conclusions hold with regard to the coordination of public health emergency intervention activities, which while somewhat improved, has still been identified as being problematic by nearly all of those interviewed, many of who expressed deep concerns for the flexibility and responsiveness of epidemic surveillance and response in Canada. The Emergency Operations Centre within the PHAC, for example, although it has been named the National Focal Point for the International Health Regulations, exists at the end of 2008 largely on paper only, since it has no formally defined functions or responsibilities and is activated and operates only once a potential public health emergency of international concern has been detected, and not continuously as required by the regulations. The Centre also has no full time staff as of writing, although a business plan is apparently being drafted to remedy these failings. Interviewees suggested, however, that even if such plans become reality, it is unlikely that the Emergency Operations Centre or the Chief Public health Officer of Canada will wield

much real operational authority, since nearly all sensitive international communications continues to occur through Health Canada's International Affairs Unit rather than at PHAC. On a related note, the only public indication that work has commenced on an assessment of national ability to comply with the new international regulations, due by June 2009, was made available in a summary of the "Surveillance Strategy Framework 2007-2012" (itself not made public). The summary, which appears to be a point by point response to the scathing 2008 report by the federal Office of the Auditor General, announces the anticipated release of an "Action Plan" on "how Canada plans on meeting its international obligations under the IHR" in December 2009. (PHAC 2008) Interviews confirmed that PHAC quietly began a review of the agency's readiness, as well as provincial, territorial, and major international points of entry capacities to comply with the new surveillance requirements, in 2008. Interviews also however revealed evidence that the federal government has been and remains aware of the gap between its new international commitments and its ability to comply with them, since it actively limited communication and consultation between the International Affairs unit of Health Canada and the PHAC when it came to Canadian representation at the World Health Assembly meetings in 2007, at which the entry into force of the revised IHR was discussed. In fact, the federal Ministerial decision was initially to send a very small team to Geneva for those meetings, one that excluded even the Chief Public Health Officer of Canada and all of the provincial and territorial Chief Medical Officers of Health, although the former did in the end get invited to be part of the Canadian delegation. This suggests a considerable awareness at the federal level of the extent of the lack of policy effectiveness in the area of outbreak surveillance, as well as a deep reluctance to include high profile or non-federal authorities within traveling negotiating delegations, presumably since they may be more likely to mention existing weaknesses in the Canadian network to an international audience. The disconnect between the domestic reality and the projection of Canadian image internationally is further demonstrated by PHAC's collaboration with WHO in developing a tool for assessing legal capacities to comply with the IHR, and the agency's involvement in applying the tool in various Caribbean region countries, all while glossing over the weaknesses of Canada's own legal infrastructure to meet the new global epidemic surveillance standards.

Another stark illustration of the lack of policy effectiveness in the area of epidemic surveillance is demonstrated by the fact that the Pan-Canadian Public Health Network, despite being in operation for nearly four years, is still meeting principally about updates and work plans. Several interviewees revealed that the PHN's Expert Groups have achieved little substantive work in the area of legal or operational standardization of infectious disease response or reporting, for example, and that key issues around data sharing, ownership, and decision-making authority remain unresolved. The Expert Groups in fact appear to have little ability to make progress on these recurring agenda items, so much so that several key observers also predicted that the PHN's lifespan is unlikely to exceed another 2-3 years. Thus, although the Network was designed to overcome the fate of former public-health related FPT councils and working groups, it appears to be falling prey to much the same forces: the recurring pattern is that provincial and territorial ministers of health grow weary of such structures due to the lack of results, and gradually withdraw. Evidence of this process is again available in the form of missed deadlines and a failure to reach FPT accords. In the summary for the Surveillance Strategic Framework mentioned above, for example, the Pan-Canadian Public Health Network was to have concluded

by March 2009 a privacy framework, a data sharing agreement for emerging diseases, and national surveillance principles. This deadline was not met.

Although it is very difficult to disaggregate from the operating budgets of various agencies and offices of intergovernmental affairs the amount of public money that has been spent on national epidemic surveillance coordination activities since 2003, interviewees' estimates were most often in the range of \$20-30 million (all direct FPT sources combined, but excluding exclusively provincial or territorial capacity or information technology development, as well as at least \$135 million in Canada Health Infoway grants). What level of economic effectiveness best describes this spending? The answer at this point is uncertain but appears to be low, since, despite the mild reduction of some overlap in a few narrowly-defined health surveillance activities, program duplication and competition across FPT levels is still significant when it comes to epidemic surveillance, and authority for data aggregation and analysis, as well as for timely and coordinated public health response, is also still minimal and heavily fragmented. Multiple federal level interviews also confirmed that even if the focus is restricted to federal agencies involved in epidemic surveillance, the low degree of coordination between them noted post-SARS (see eg: Vermaas, 2004) remains effectively unchanged today.

Moreover, although there appears to be some potential room for the improvement of economic efficiency through economies of scale related to the development of common information and communications platforms, software, and training modules, these have been as yet unrealized. On the contrary, rather than focusing on incremental additions to existing provincial and territorial IT and reporting systems and activities, the lion's share of total federal resources spent on national epidemic surveillance development has gone to creating a comprehensive new platform, Canada Health Infoway's Panorama, which was supposed to be completed and available to all jurisdictions by the spring of 2008. This has not happened however, and the substantial federal investment now appears to have come with very little guarantee of a solid return. This is because a recurring obstacle, as one interviewee noted, to intergovernmental collaboration on this matter is "*competition between programs with similar or related goals, approaches, or tools, with the most recent example of this being how Infoway undercut the platforms and approaches that have been in development at Health Canada the PHAC for many years.*"

Indeed, there is a compelling illustration of ineffective duplication and competition when a more detailed look at the history, features, and development of different recent surveillance programs is explored. For example, the Western Health Information Collaborative (WHIC) is "a process initiated by the Western Premiers and Deputy Ministers of Health to explore collaborative opportunities with respect to health infostructure initiatives". It lists Canada Health Infoway as being among its partners^v, despite the fact that the WHIC and Infoway approaches are somewhat at odds, since the former is leading with a chronic disease and injury focus, whereas Infoway is leading with infectious disease.

More significant, however, is the perception among several interviewees that federal Ministry of Health officials deliberately orphaned existing PHAC projects, as well as undermined that

agency's fledgling autonomy and authority, by shifting the mandate for developing a national infectious disease surveillance IT solution to Infoway. Whatever the merits of the iPHIS and Panorama systems as they currently exist, it was clear in 2004 that the former had many advances and advantages (not the least that it was the product of former FPT collaborations, and that the intellectual property rights for the system were and remain owned by the PHAC), and that the latter would have to start from scratch and duplicate much of the iPHIS work on standards and platform development, which would subsequently become the property of a commercial contractor, IBM.

A further demonstration of the extent to which PHAC was marginalized by Infoway, and was unable to defend itself, is the fact that when it became clear that Panorama would be lacking an alert functionality by the end of the 2007 commercial contract deadline, work on developing the alert module was halted altogether, and negotiations began between IBM and PHAC on integrating Panorama with CIOSC, the existing national alert system. The intellectual property rights to CIOSC, however, were held by PHAC, which sought to open a discussion of the royalties such integration might generate. Talks stalled almost immediately, and coordination with Infoway faltered. To resolve the impasse, Infoway unilaterally (that is, without consulting with PHAC) negotiated with IBM approximately \$3 million worth of concessions on behalf of PHAC.

Moreover, Infoway appears to have imposed further costs on the PHAC given how it is structured. Since it is composed largely as an informatics group, and as such possesses little in the way of population health knowledge or of the means and ends of surveillance, it quickly became apparent that the formation of advisory committees, staffed by substantial numbers of federal and provincial agency employees available to consult with Infoway managers and programmers, would be necessary. However, it was those agencies and ministries, rather than Infoway itself, that were required to absorb the costs related to such consultations, and the PHAC is estimated to have provided human resources support to Infoway equivalent to \$1M per year from 2003 onwards.^{vi}

Finally, all of this occurred simultaneously with significant reductions in federal Treasury Board funding for existing PHAC program support, and notably the drop in funding for iPHIS from \$5 million per year (2001-04) to \$500 000 (2005-7), and for CIOSC from \$1 million per year to zero in 2005. These cuts necessitated multiple mid-year appeals for supplementary funding in the form of repeated one-time \$500 000 allocations to maintain support for these initiatives, over a time period when many jurisdictions were still in the process of implementing both iPHIS and CIOSC.

Ontario was most notably in such position, having already spent \$25 million adopting iPHIS, which became fully operational across all 36 Ontario Health Units in late 2005. It now provides immediate, essential information for public health care providers, and access to near real-time reporting data for 75 Reportable and Communicable diseases in one centralized system. The Outbreak Management module, currently only in operation across Ontario, also tracks exposures to infectious diseases and manages quarantines. Ontario did, however, publicly announce in late 2007 that it will adopt one element of Panorama province-wide, the Materials & Vaccine Inventory Management module (a supply chain distribution and tracking database, although one that does not capture any clinical information about immunization coverage or adverse events

reporting), which is the only module the province was directly involved in developing and pilot testing. It is highly unlikely that Ontario will choose to adopt any other modules any time soon^{vii}, and many other jurisdictions appear to be similarly reticent, or committed to adopt only the modules most suited to the gaps in their existing system. Nova Scotia, for example, even suspended its plans for a scoping project to estimate and fix the costs for implementing Panorama, for what appears to be at least three years, by removing in mid-2007 the requirement for these from a Request for Proposals that it had made public earlier that year. In fact, at the time of writing, Newfoundland & Labrador is the only jurisdiction that is preparing to adopt both the Communicable Disease Case Management and the Outbreak Management modules, which were the functional areas that served as the very *raison d'être* for development of Panorama. That province is not yet, however, preparing to adopt the Notifications module, which means that even if the two modules prove to be a success within that province, the information captured will not be automatically available to any other jurisdictions, and will thus have to be transferred manually at the discretion of provincial officials. This is precisely the same situation that existed when SARS struck, and exactly the weakness that Infoway was supposed to overcome.^{viii} The fundamental point here is that Infoway has generated a product, but a product that may or may not meet public health needs and thus leaves very uncertain provincial and territorial uptake and national readiness, as well as the policy and economic effectiveness of the substantial investments required for its development and implementation.^{ix} In this regard, it is particularly revealing that Infoway's initial mandate was to have its infectious disease surveillance solution implemented and fully functional in 50% of the country by the beginning of 2009, despite the fact that iPHIS had achieved that mark by the end of 2005, when Ontario implemented the system province-wide.^x Instead of building on an existing system that had taken a decade to put into place across half the country, with a reasonable goal of achieving implementation or at least interoperability in the coming years for the other half, Infoway's decision to start from scratch on a new platform thus essentially set back the clock, perhaps by yet another decade, due to the disincentives to being an early adopter of such technologies. Indeed, each jurisdiction is free to choose which, if any, of Panorama's modules it wants to pilot or implement, on any timeframe it chooses. As a software application package only, but one that was designed expressly to be state of the art, Panorama requires advanced information technology and communications hardware (including broadband connections, a major issue for remote and northern public health units) and is as yet not backward compatible with an estimated 75% of the computer systems and databases currently in use in local public health units around the country. The following Naylor Report conclusion is thus just as valid, but far more ominous, five years post-SARS: "*Public Health is still struggling to catch up to the potential for effective surveillance afforded by new technologies. The problems have been not only the cost of implementing these systems...but also the very slow progress in gaining consensus across jurisdictions.... Progress has been too slow, and "stovepipe" systems persist everywhere.*" (Naylor, 2003, 92)

5.2 Respect for Principles of Democracy & Impact on Federalism

Given that the protection of all citizens is at risk by the ineffectiveness of existing surveillance systems and projects, it is arguable that the rights to health and to security of both a majority of Canadians, and even more so of the country's many minorities, are being undermined if not directly threatened by ongoing intergovernmental commitment to an unproductive form of

collaborative federalism as the dominant approach to the matter. Unfortunately, since there is only a very sporadic and diffuse public interest in this sphere, transparency on the matter is also very low, with no public interest groups coalescing around the need for improved epidemic surveillance, and low general awareness of the gaps, needs, and quality of recent policy responses. Moreover, what public concern does exist related to epidemic surveillance appears to be much more focused on the protection of the privacy of personal health information rather than on the effectiveness of national capacities.^{xi}

Policy making for effective national epidemic surveillance may thus be a species of “policies without publics”, which are characterized as being both “particularly problematical for democratic governance”, and as having a high potential to “fall flat due to lack of momentum” (May, 1991, 196 & 198), both of which are substantiated by this research. This is further exacerbated by the muddled legal roles and responsibilities for conducting health surveillance and sharing information, which disperses accountability among government orders for the ongoing failures and structural weaknesses described above. Indeed, although in principle most lines of formal political accountability within the federal government point to the PHAC (and, by virtue of the status of that agency within the government of Canada, to the federal minister of health), such lines are at law and in surveillance practice rather unclear. Democratic accountability for the failure to specify roles and responsibilities, and for the state of national epidemic surveillance capacity, thus remains overall very low, and may result, in the event of another emergency or crisis such as SARS, in the same sort of confusion and lack of cooperation that led to the type of suboptimal response, at all levels of government, to that situation in 2003.

The form of intergovernmental relations that was thus such a failure during SARS – a largely disentangled type of collaborative federalism showing high respect for formal jurisdictional divisions and provincial unilateralism – remains the strategy today when it comes to public health reform generally and the development of a national epidemic surveillance system specifically. The federal government appears intent to avoid taking any measures that may be perceived as an invasion of provincial public health sovereignty, and provinces at present retain ownership of all information captured by health professionals in their employ, subject to non-compulsory requests from federal authorities. Moreover, the manner in which provinces have been able to band together to impose constraints on the use of federal spending to develop and implement new public health initiatives raises questions about the effectiveness and equity of such investments. Indeed, although such projects are generally subject to ongoing ad-hoc cost-sharing negotiations, most end up with some form or another of a per capita disbursement formula. This sort of equal targeting of funds may be the most politically palatable, but it is far from ideal from a public-health perspective, since surveillance is a weakest-link type of public good, which means that investment in capacity building should reflect system needs by being concentrated in the areas and regions where there are the greatest deficiencies or risks, rather than dispersed equally across the provinces and territories regardless of their current capacities.

Experts questioned about potential future intergovernmental progress on epidemic surveillance were in the main pessimistic that much will change, despite their own convictions that the magnitude of the infectious disease threat and the urgency of the task of creating a national system justify an alteration of the form of federalism operating in the area public health reform. Much of this pessimism seems related to the current venues for ongoing intergovernmental

communication and coordination, which have subjected epidemic surveillance to the unhelpful competitive forces at play under the umbrella of general FPT health policy negotiations, and to the questionable decision by the federal government to make the country-wide integration of infectious disease surveillance (and indeed all public health surveillance activities) contingent on the development and deployment of a national electronic health record (EHR) system.

The promise of fully functional electronic health record systems is that they will improve clinical care, observance of guidelines, reduce medication and treatment errors, and generate accurate population level health information as a byproduct of case management. This promise, however, has yet to be fulfilled, despite a decade of major public and private investments, notably through Canada Health Infoway. A recent study, for example, failed to find that implementation of electronic health record systems is associated with improvements in the quality of ambulatory care (Linder et al, 2007). Similarly, although several systematic reviews of EHR systems have found some evidence for improved diagnostic performance and chronic disease management, they also found that only a small minority of implementation sites (7/52 or 13%) tend to show improved patient outcomes (Garg et al, 2005), and that these improvements are in turn largely seen only in major urban teaching hospitals involved in the development of the systems being evaluated (Chaudry et al, 2006). These findings cast important doubts on both the generalizability of the positive findings, and thus of the near-term benefits of introducing expensive new information technology platforms into already complex health care and public health work environments.^{xii} They also signal the difference between ‘buy-in’ and ‘force-in’ strategies, and the importance noted above of “interface, usability, and integration into normal workflow” (Joffe, 2007), because when such considerations are overlooked, the introduction of new health information systems can fail dismally, as was recently found in two out of three Canadian hospital settings (Lapointe & Rivard, 2006).

The tithing of a national epidemic surveillance system to an as-yet unavailable platform for nationally interoperable electronic health records thus evidently runs the risk of significantly complicating and delaying the deployment and operations of such a system, and introduces many of the weaknesses of an approach dubbed “legislation through technology”, which is to say a neglect of complicated democratic and contextual considerations (Roy, 2007, 91). It may be helpful to consider the question of standard setting in public health practice to illustrate this point: estimates of the number of policies or guidelines per local public health unit, which often regroup upwards of 20-30 different professionally accredited staff, range between 15 000 and 25 000. These vary according to unit, however, and thereby generate a staggeringly high variability across the country in terms of operating standards and coding schemes.^{xiii} This is not to suggest that there is no way to understand such information or make it useful, but rather that that it is no simple matter to resolve where to start the process of moving towards commensurability^{xiv}, even if this now appears to lie with a fully functional national EHR system. It is also to reinforce the point that the approach as it is currently operating often pits different surveillance activities and programs against one another, as was shown with regard to iPHIS and Panorama, in that they tend to have to compete for the same limited funding made available for surveillance. Thus it is that attention to surveillance systems itself is at risk of following political interests more often than historically or empirically established population health priorities or needs.^{xv}

6.0 CONCLUSIONS

“Provinces and territories are deeply suspicious of the feds, and the feds are deeply contemptuous of the provinces and territories. They both have a case.”

The politicization of surveillance improvement since SARS, and the elevation of public health capacity development more generally from out of the realm of specialized technical expert debate and exchange into formal intergovernmental affairs, appear to have created the conditions for a version of what is known in the federalism literature as a joint-decision trap (Scharpf, 1998). A joint-decision trap refers to the gridlock effects of inclusive agreement processes whereby a federal government, unable to act alone as a result of jurisdictional considerations and the need for formal agreement from all governments for new policies, is effectively blocked from addressing collective actions problems, or else held captive to the lowest common denominator of agreement among the regions (Painter, 1991). An unwillingness to agree by any single region thus results in a default decision that both maintains the policy status quo, and often leads to frozen institutional arrangements, a type of self-reinforcing inertia in the mechanisms of intergovernmental relations.

Such a trap tends to be sprung, and to stymie possible national programs in federal political systems, when even a single regional actor feels that the current situation is more advantageous to its interests than would be the newly proposed policy. The trap also seems to be particularly acute when a central government cannot credibly threaten to abandon an initiative by withdrawing its participation in a particular forum and seeking similar policy goals in another manner (Blom-Hansen, 1999), as appears to hold for the Canadian federal government given its goals as stated with the creation of the PHAC and with its international commitments. Joint-decision traps generate sub-optimal policy outcomes due to the inability to obtain consensus between all players, and they leave disproportionate power in the hands of last-in or hold-out regions, particularly when national uniformity is sought in order to prevent the spill-over effects of activities which cannot be confined by provincial boundaries (Painter, 1991).

The fact that surveillance now appears on the political agenda of Canadian executive federalism has thus created a de facto situation of concurrent powers with provincial paramountcy in the policy field of epidemic surveillance, and this has in turn lead to policy inertia and an increasingly constrained space for joint action based on collaboration through shared mutual interests. Despite the pervasive rhetoric, intergovernmental relations on epidemic surveillance since SARS have been rife with competitive and adversarial FPT tensions, and key issues perpetually reappear on the policy agendas of constantly shifting intergovernmental mechanisms because of debilitating deadlocks on the paths to their resolution. Indeed, there is some reason to question whether any genuinely collaborative forms of durable intergovernmental relations actually emerged beyond the level of rhetoric, either pre or post SARS, since the regions have resisted giving up any significant concessions in exchange for federal investments in surveillance solutions, and the federal government has resisted the necessity to act, on its legal and security prerogative, in a more coercive and unilateral manner to ensure a functional timely system of epidemic detection and response.

Thus the response to the SARS crisis is considered by many to be the “wake-up call that was never answered” (Foresight, 2005, 21), since if ever the necessary reforms and renewals were going to happen, they stood the best chance of emerging and being consolidated during the 2003-2008 time period that was the focus of this research. That disentangled collaborative intergovernmental relations have not lead to a functional and integrated national epidemic surveillance system, despite the fact that there are now national standards for notifiable diseases surveillance and reporting, and despite the priority accorded by nearly all FPT players to integrating such activities and data across the country and with other national public health agencies and with international bodies, is more than ample evidence that a new approach is required.

The irony of such a conclusion is unfortunately rich, since the decade preceding the SARS crisis (1992-2002) was characterized by relatively cooperative FPT relations which made of it a relatively productive period for public health innovation and diffusion of policy, practice, and technology. As one expert interviewed pointed out: “*There had been much less fed bashing during the 1990’s, and as a result, people just quietly went ahead and did it and shared it [conducted health surveillance, informally transferred data, and contributed expertise to the development of health surveillance information systems platforms such as GPHIN and iPHIS]*”. The window of opportunity to implement the fruits of this period of collaboration, however, may be closing, and the opportunity to achieve national surveillance integration wasted, despite the fact that Canada has made important contributions to global public health surveillance and has witnessed important sub-national innovation (particularly in BC, Alberta, Ontario and Quebec).

Moreover, the policy trends that bring with them a few minor promising indications, notably the allocation from the 2006 federal budget for pandemic preparedness of resources necessary to fund approximately 30 new public health positions within provincial ministries/agencies (most of whom are supposed to be epidemiologists charged with forming the foundation for surge capacity and pandemic influenza response, including surveillance and communication duties), are largely more of the same sort of time-limited ersatz collaboration that this chapter has demonstrated have failed to achieve their stated goals. The same can be said of the 2007 announcement of an additional \$35M (out of another \$400M for pandemic preparedness provided to Infoway from the federal budget) to be dedicated to Panorama implementation in the provinces and territories, since this amount is clearly insufficient relative to the task at hand.¹⁶

More damning still is that few jurisdictions appear to be currently interested in adopting the Panorama modules that are crucial to the creation of a truly national capacity to detect, monitoring, and respond to outbreaks of epidemic prone diseases. Overall then, little progress has been made towards the creation of an effective national epidemic surveillance system since SARS. Worse still, there may be sufficient evidence to predict that organizational shifts and investments since 2003 are likely to further delay the implementation of an integrated operational countrywide solution, not implausibly for as long as another decade.

Whether the ripples from increasing academic, public, and public health community scrutiny of the effectiveness of public health reforms post SARS, and from the voluntary imposition of demanding new international regulations for national surveillance activities, become waves of change further down the domestic orders of government will depend in large measure on the

federal government's choice of policy strategies over the next few years.¹⁷ The potential strategies range, in order of increasing policy coerciveness, from issuing guidelines (an option that is the least intrusive on provincial jurisdiction), to seeking intergovernmental agreements, to providing conditional funding, to adopting new regulations or legislation (Wilson et al, 2008). The evidence presented in this chapter suggests that a combination of the first three strategies has been pursued in the post-SARS period, and will continue to be pursued, but that that combination has been of only limited effectiveness. Resorting to new federal statutory law appears unlikely for the foreseeable future, particularly given the demonstrated preference of the Harper government for decentralized approaches that eschew a strong federal role for national social or health policy programs.¹⁸

Another possible federal unilateral approach could seek to exercise administrative control over certain elements of surveillance policy implementation through its own network of PHAC field offices across the country (the six existing but very low profile regional stations), in combination with the agency's regulatory powers. Indeed, the groundwork for passing new federal regulatory law, under the PHAC authorities contained in Bill C-5 passed in 2006, is currently being explored, but little additional information is currently available about the scope and content of the project. Moreover, this would be a significant about-face for the agency, which thus far in its history seems hampered both by provincial reluctance (and de facto ultimately beholden to the Provincial Assistant Deputy Ministers of Health, since the Pan-Canadian Public Health Network is not ultimately a decision-making body, but an advisory one) as well as by bureaucratic politics within the federal government, and notably by its lack of independence from Health Canada and the federal Minister of Health.

In the short term then, and with the objective of securing the transfer of epidemiological information relevant to the confirmation and control of public health emergencies, and beyond the insufficient implementation monies already committed by Infoway, the federal government should consider more aggressive and creative strategies for restructuring intergovernmental relations so as to improve the protection of the public's health. As noted in the aftermath of SARS: "*A federally-imposed system might instead be viewed as a necessary last resort if collaborative and consensus-building mechanisms fail.*" (Naylor, 2003, 165)

The current low level of federal leadership, using weak policy instruments and a non-coercive approach to intergovernmental relationships, has failed to create an effective national system of public health surveillance. Given the overlapping constitutional jurisdictions over this area of public health practice, and the fact that national effectiveness ultimately depends on robust local and PT capacities, the Government of Canada may want to consider a federal trust model. Such an approach could combine guidelines with unconditional funding (at a minimum level of the \$100-200 million per year recommended in the Kirby and Naylor Reports, and separate from both other block grant programs or equalization envelopes), in order to apply the maximal political pressure on provinces and territories to use that money to integrate their health surveillance systems with federal authorities. A matching grants format could also be fruitfully adopted over the medium to long term, in order to limit the provincial and territorial temptation to reduce or eliminate their own surveillance development expenditures over time.

Whether a federal trust model will be sufficient to overcome the deterioration of Canada's public health systems as a result of chronic under-resourcing over the last several decades, and to accelerate development of an effective nation-wide epidemic surveillance network, remains at present an open question, and one that cannot be adequately answered in the absence of more contemplation and research on the details of such a policy. Based on the findings here, however, a trust model stacks up well against collaborative federalism, the limits of which appear to have been reached when it comes to epidemic surveillance integration. Although the history of a blend of disentangled and collaborative approaches to the issue was effective in developing consensus between levels of government on the need and agenda for coordinated changes in the pre-SARS era (Wilson, 2001) as well as in the immediate aftermath of the crisis, the same intergovernmental strategy appears to have made little actual progress in the years since 2003.

Moreover, the emergence of regional and cross-border relationships between local public health units in different provinces and in various US states, as well as the failure to secure full provincial/territorial buy-in for the most recent federally-sponsored information technology application for capturing and reporting surveillance data (Canada Health Infoway's Panorama system), and the success of a network of a user-developed platform for voluntary multi-jurisdictional data sharing and collaboration based on existing public health information systems (the Canadian Network for Public Health Intelligence), indicate that dramatically scaling up shared targeted financing for bottom-up innovations built upon current public health practices and information systems rather than comprehensively from scratch, may offer the most promise for the development of national surveillance capacity.

Addendum

More recent public health crises have shed additional light on the research and analysis offered here. The outbreak of food borne listeriosis in Ontario in the spring of 2008, and the global influenza A (H1N1) outbreak that was initially detected in Mexico in the spring of 2009, have been the most visible tests of intergovernmental relations in the field of health protection since the creation of the Public Health Agency of Canada. Some regard listeria as the first major test for the public health system's emergency readiness, as well as a better test than H1N1 since an influenza pandemic is anticipated and numerous protocols exist for its management. (Wilson & Keelan 2008) The listeria outbreak, on the other hand, not only originated within Canadian borders and thus challenged current surveillance and response mechanisms, but was also an unexpected event and thus a better indicator of the effectiveness and flexibility of the current set of FPT arrangements in public health.

Although it is too soon at the time of writing to conclude with much certainty about whether FPT cooperation in the face of H1N1 will be effective, there are indications that health protection activities at the federal and provincial levels have been both relatively well coordinated as well as transparent, albeit as a result of the informal mechanisms for communication and exchange described above. Unfortunately, the listeria outbreak demonstrated the opposite, and illustrates that the core conclusion presented above is valid: confusion over roles and responsibilities during a public health crisis, and especially information sharing, continue to be major obstacles to health

protection and timely response. What is particular about the listeria outbreak, or in other words where the findings of the Ontario report depart from the analysis presented in this chapter, is that the problem with information flow on this occasion was from Ottawa to the province rather than the other way around. According to the report, the federal food inspection agency, despite requests from the Ontario Ministry of Health, withheld and delayed information sharing that may have allowed a wider distribution of contaminated products and thus a greater exposure among the general public. (Ontario 2009) This suggests that any MOU or other agreements or arrangements for data sharing not only need to be urgently completed, as recommended above, but also that that must be bi-directional, in the sense that the federal government (and its agencies) must be held to the same obligation to the provinces/territories that it is asking them to make, which is to transfer all necessary data for evaluating and responding to a public health crisis in as timely a fashion as possible.

Moreover, although the federal Health Emergency Plan was activated in response to H5N1, and CEPR ran 24/7 for a month early in that outbreak, that plan was not engaged during the listeria outbreak, and neither the PHAC nor the Chief Public Health Officer of Canada took a lead role in publicly responding to the outbreak. Listeria was thus a prototypical example of why a strong federal public health presence is needed, and why the weaknesses of that agency as it currently operates puts Canadian lives at risk. The listeria outbreak, in addition to causing illness and deaths, crossed over multiple concurrent policy fields (food safety, agriculture and public health), had important economic consequences, and engaged political interests at both provincial and federal levels. There were therefore many reasons for, and opportunities to, subordinate the role of the public health agency and, consequently the importance of public health concerns, during the management of the outbreak. Although the Naylor report recommended that the PHAC and the CPHO should be “a leading national voice for public health, particularly in outbreaks and other health emergencies, and a highly visible symbol of a federal commitment to protecting and improving Canadians’ health”, the lack of leadership shown by the agency and its head is evidence of the claims above about its lack of autonomy and its susceptibility to political interference.

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End Notes

¹ In anticipation of potential jurisdictional complications in complying with the new requirements in light of its national legal and constitutional system, the USA (alone among countries with federated systems of government) issued a reservation that it will implement the IHR in a manner consistent with American principles of federalism (meaning that the federal government will not necessarily be able to ensure that state legislation and administrative arrangements will or can be fully adjusted to the IHR by June 2007), as well as under the understanding that the agreement does not create a private right to legal action against the federal government.

² By 2006, iPHIS had been implemented in whole or in part in many jurisdictions, notably throughout Ontario, British Columbia, Saskatchewan, Newfoundland and Labrador, the Yukon, and the Northwest Territories, in one region of Manitoba (Winnipeg Regional Health Authority), in one region and at the provincial level in Alberta (David Thompson Health District and Alberta Health and Wellness), as well as in the Bahamas.

³The more recent federal *Emergency Management Act (EMA)*, which came into force in August 2007, is unlikely to be any more frequently invoked, despite containing provisions for financial assistance to provinces when requested, because it retains the provision that the federal government may not respond to a provincial emergency unless the affected province requests assistance. The EMA is more accurately a framework for coordination among federal ministers and ministries and other government institutions, under the leadership of the Minister of Public Safety.

⁴A telling indication of the severity of these constraints lies in the discrepancy between the estimated 2006-07 budget requested by PHAC from the Treasury Board Secretariat (\$19 million) and the actual allocation for that fiscal year (\$8.6 million).

⁵ Curiously, the PHAC is not among the partners of WHIC; interviews revealed that this may have to do with a lack of confidence, if not a mistrust of, the PHAC at senior provincial levels in the lead funding provinces on the project.

⁶ Interviews also revealed that while these standards advisory groups have been generally tolerated within Infoway, they have by most accounts had minimal impact on the direction of Panorama development. In the view of several interviewees, the dominance of an informatics perspective at Infoway is a major disadvantage, and renders questionable the decision to hand over to it the development of a national epidemic surveillance system. Illustrating this point is the fact that Panorama has been built around two cutting edge programming languages, the SNOWMED CT medical terminology standard, and the HL7v3 messaging standard. Being the latest, most advanced and most detailed information standards of their ilk currently available, these were assumed by the IT experts within Infoway to be the best, despite the fact that neither is widely implemented by any health system anywhere else in the world, and despite the fact that there are currently no bridge technologies able to make them interoperable with the data capture fields and messaging protocols currently in use across Canadian public health units and agencies. Moreover, unlike its main competitor, the freely available ICD-9-CM (the most widely used

international statistical classification for disease and clinical codes, including at WHO, Health Canada, and PHAC), the SNOWMED CT nomenclature is proprietary (which means that a license must be purchased in perpetuity in order to continue to use it) and is not yet fully available in French. The HL7v3 messaging standard, furthermore, has been associated with such high implementation costs that plans to convert to the new standard in the UK, USA, Netherlands, and France have all been shelved over the 2005-2008 time period.

⁷ Particularly since experts interviewed noted that iPHIS was brought into operation in Ontario only in response to SARS; there had no plans before the crisis to adopt the system.

⁸ In fairness to the provinces and territories, it should be recalled that infectious disease control is only one facet of public health at the local level, and by a wide margin not the most important, at least by volume. One expert estimated that only about 20% of the staff and activities of most local public health units is devoted to communicable disease control. This also means that Panorama is also far from being the end of the process of building a fully functional pan-Canadian surveillance network, but would be rather more aptly understood as the beginning of such a process.

⁹ Moreover, although most provinces and territories are exploring possibilities for integrating Panorama into their own systems, design priorities have thus far shown a low focus on usability for practitioners. This is a crucial issue however, since implementation relies on such use. The early and ongoing lack of uptake of iPHIS within many local public health units because of practitioner unfamiliarity and resistance is instructive in this regard: iPHIS still does not capture half the Canadian population, and many local public health units still do not use it as their primary data entry point, but instead run it in parallel to their own systems, keying in their data and uploading to provincial or territorial ministries of health only once a week or once a month depending on the information.

¹⁰ Experts interviewed signaled that this is not strictly speaking accurate: although Ontario publicly announced that the system was in operation across the province entirely, this remains untrue in practice since iPHIS has not been put into place in any of the approximately 245 First Nations communities across the province, and since the fact that it has been installed and available in all 36 public health regions says little about whether it is actually used by practitioners. The 2007 Ontario Auditor General report in fact indicated that acceptance of the system was low in many public health units, and that the system's poor user interface, and the fact that it is not linked to laboratory information, has led to significant front line resistance to regular use of iPHIS, resulting in sporadic data entry at best. A 2-3 week delay between initial case reports received in local public health units and the time these are entered in iPHIS is apparently not uncommon, and has resulted in inconsistent and incomplete data at the provincial ministry level. Interestingly, First Nations and Inuit Branch is now working to negotiate implementation of Panorama within all aboriginal communities.

¹¹ This being the case, and public disinterest and distrust being so clearly an obstacle to the development of a functional national epidemic surveillance system, respect for the principles of democratic governance at a minimum seem to require efforts to involve a broader public and

stakeholder involvement in current and future epidemic surveillance policy development, as well as efforts to reinforce public awareness that the specific nature and purpose of access to personal information by public health officials during an outbreak or other emergency is to protect the health of the public, without abandoning all safeguards on individual rights, privacy being just one of these.

¹² Electronic health record systems also raise important questions with regard to database storage and management, data access and ownership, and secondary use of such information.

¹³ It is this lack of uniformity that explains the point made earlier that it is currently very difficult to take surveillance data out of the context in which it was collected and aggregate it in relevant ways, since measurement and reporting variability severely restricts the ability to pool and interpret data into any sort of useful national picture of public health trends.

¹⁴ It is revealing in this regard to recall, as one expert put it, that it took 15 years to put into place country-wide in principle standards for infectious disease definitions and notifications accepted, even though, because the federal government does not consider that it has the authority to mandate such standards, they remain voluntary, and variability among the lists of notifiable diseases thus persists across provinces and territories.

¹⁵ Apart for outbreak surveillance, one need only consider the conspicuous absence of federal or provincial government support for any proposals for surveillance of mental illness, musculoskeletal disease, or dental disease, in order to appreciate the full extent of this point.

¹⁶ Interviewees suggested that the real Panorama implementation costs for entire country are likely closer to \$500-750 million, if the estimates and actual costs in BC and Ontario of bringing iPHIS online are any indication, although provinces and territories may still balk since this does not include recurring annual operations and maintenance costs.

¹⁷ Another motivating factor could be the potential exposure of government to civil liability suits if the next public health crisis is fumbled, particularly given the common critical refrain of three federal and one provincial Auditor General reports instructing public authorities to remedy their deficiencies in epidemic surveillance and response. (See, e.g.: Ries, 2005) It is of note that one of the three elements of the US reservation to the revised International Health Regulations was the explicit statement that they are not considered to give rise to public liability. This effectively insulates the US federal government from civil litigation on the basis of negligence to comply with the regulations, a move that the Government of Canada chose not to make.

¹⁸ Although a slightly more plausible and optimistic take on this possibility was voiced by several experts, who felt that the mere threat of resort to federal legislation might be effective in moving provincial and territorial governments closer to consensus, even without in the end having to legally establish federal paramountcy in surveillance standard setting and mandating data formats and transfers.