THE ROLE OF FEDERALISM IN HEALTH SURVEILLANCE: A CASE STUDY OF THE NATIONAL HEALTH-SURVEILLANCE “INFOSTRUCTURE”

Kumanan Wilson

INTRODUCTION

Health surveillance is an often overlooked yet vital component of the Canadian health-care system. Health surveillance authorities are responsible for tracking and forecasting health events and examining the determinants of these conditions. These authorities may, for example, identify the development of an infectious disease outbreak or draw attention to gradually increasing rates of cancers and their association with an environmental risk factor. Surveillance information provides public health officials with the knowledge they require to intervene early and effectively to prevent or control emerging health problems.

Over the past several years concern has emerged among all orders of government that current standards of health surveillance are grossly inadequate. In 1995, federal, provincial, and territorial (F/P/T) officials, in conjunction with epidemiologists and public health authorities, began a coordinated effort to develop a new national approach to health surveillance. This initiative was primarily motivated by concerns over the existence of serious gaps in current surveillance activities. It was believed that if these gaps were not addressed a large-scale, public health crisis, similar to what the blood system had experienced
with HIV and hepatitis C, could occur. The overall approach, currently in the process of being developed, is referred to as the Network for Health Surveillance in Canada (the Network). The most advanced component of the Network is the National Health Surveillance Infostructure (NHSI), an Internet-based network/infrastructure, designed to build capacity to help coordinate health-surveillance activities across the country.

Beyond their impact on health, the development of the Network and the NHSI are important because they represent a fundamental change in the manner in which Ottawa and the provinces interacted in the field of health surveillance. A new collaborative approach replaced the previous relationship in which the two orders of government had acted relatively independently of each other. To this point, the collaborative approach has been considered a success, allowing for the emergence of a widely supported national plan in a relatively short period of time.

This case study will describe the design and development of the Network and the NHSI as well as Health Canada’s closely related Health Protection Branch (HPB) Surveillance Transition project. In order to give context to this case study, selective background information on public health and health-surveillance activities in Canada will be provided. The constitutional ambiguity surrounding jurisdictional responsibility for health surveillance in Canada is described as well as how this led to a highly fragmented health-surveillance regime throughout the country. The important contribution of the Krever Inquiry into the Canadian blood system crisis is offered as an example of the serious consequences that can emerge for governments and the public caused by the neglect of addressing structural problems in the management and delivery of this important health subsystem. The impact of different forms of federalism in the field of health surveillance will be evaluated and a comparison will be drawn between the experience in health surveillance and the experiences in environmental harmonization. The methodology and criteria for this assessment are provided in the introductory chapter of this volume.¹

The complete analysis of this case is limited because the programs being examined are not all in place as of yet. Therefore the focus will be on the impact of federalism on the development of these programs. The case study will attempt to determine why a collaborative form of federalism was chosen and its advantages and disadvantages compared to the previous disentangled model. Based on the analysis, an attempt will be made to determine what characteristics of a policy initiative make it best suited to a collaborative form of federalism.
BACKGROUND ON HEALTH SURVEILLANCE

The Canadian health-care system consists of three components: health care, health promotion, and health protection. Health surveillance falls under the category of health protection. Public health surveillance refers to the process of collecting, analyzing, and disseminating health data. Surveillance authorities collect data to monitor and investigate health events or determinants of health, analyze and interpret this data, and disseminate this information to those who require it. The objective of surveillance is to provide timely, accurate, and strategic information and analysis to assist the health system in areas of policy, planning, and evaluation. Health surveillance can deal with both communicable disease such as infections and non-communicable diseases such as diabetes, heart disease, and cancer. Communicable disease surveillance is particularly important since its implications transcend all geographic and jurisdictional boundaries.

Under the Constitution Act, 1867 the majority of health care falls under provincial jurisdiction. Provinces are responsible for “the establishment, maintenance and management of hospitals, asylums, charities and (charitable) institutions in and for the province, other than marine hospitals.” Responsibility for health protection is less clear with federal and provincial governments sharing responsibilities. Public health is considered primarily a provincial concern under section 92(13) of the Constitution Act, 1867 which gives the provinces responsibility for property and civil rights. Further provincial authority in this field is derived from the power they are given in section 92(16) over matters of a local or private nature in the province. Health surveillance falls into both of these categories and is therefore considered a provincial responsibility.

The federal authority in the field of health protection derives from a number of sources. Under section 91(27) of the Constitution Act, 1867 the federal Parliament is assigned power over criminal law allowing it to pass legislation to prevent transmission of a “public evil.” This permits it to pass legislation to control transmission of health risks. The residual power given to Parliament under the national concern section of the “peace, order and good government” power of the Constitution Act, 1867 also allows it to enact legislation to regulate matters of national health and welfare. These must be issues in which intra- and extra-provincial implications of the issues are linked, in which provinces are not able to regulate effectively on their own and in which failure of one province to regulate would affect the health of residents of other provinces. Health surveillance falls under this category. The federal government
also obtains authority over health protection by the power it is given to quarantine and to regulate trade and commerce of an interprovincial or international nature. Therefore, under the constitution, the provinces and the federal government share responsibility over issues of health surveillance. Both orders of government have used their authority in the area to pass legislation. The federal government, through the *Statistics Act* and the *Department of Health Act* has a mandate to collect information on public health risks of a Canada-wide nature. Provincial governments have also passed similar, but not complementary legislation to address intra-provincial health risks. Despite the existence of this legislation, there remains a lack of jurisdictional clarity in the area. Importantly, Ottawa lacks the constitutional authority to enforce legislation that compels provinces to transfer surveillance information to federal officials. Therefore, such transfers must occur voluntarily.

Federal public health functions are carried out by Health Canada and in particular its Health Protection Branch (HPB) (see Appendix B). Health-surveillance activities of the HPB are primarily the responsibility of the Laboratory Centre for Disease Control (LCDC). The LCDC collects information from the provinces and territories on these diseases, assists provinces in the diagnosis of communicable diseases and helps provinces, upon request, to react to health threats from these diseases. It monitors public health and emerging diseases nationally and internationally and provides an overall health surveillance function for the country. At the provincial level there is considerable variability in the organization, financing, and administration of public health activities.

Federal health surveillance has traditionally focused on communicable diseases. Ottawa has collected information on these since 1924. It interacts with the provinces in this area via the LCDC, which in 1988 assumed full responsibility for collecting information on notifiable diseases from Statistics Canada. The LCDC assists the provincial health ministries in the diagnosis of communicable diseases and helps them identify and react to health threats. Provinces and territories supply information on notifiable diseases to the Bureau of Infectious Disease at the LCDC via the Canadian Communicable Disease Surveillance System. However, there is dissatisfaction at the national, provincial/territorial and local levels about existing relationships in this area.

An example of previous federal-provincial interaction in non-communicable disease surveillance is the now discontinued Sentinel Health Unit Surveillance System. In 1993 the LCDC launched this system in an attempt to improve the...
The Role of Federalism in Health Surveillance

scope of its surveillance activities beyond communicable diseases. Provincial epidemiologists identified key health units within their jurisdiction that would participate in this program. The LCDC dealt directly with these units and collected information that could be used for developing public health policy (demographic, incidence, risk factor data, etc.). Provincial ministries of health could be bypassed in this process. A current example of non-communicable disease surveillance is cancer surveillance. Provincial cancer registries send cancer incidence and mortality data to a national cancer registry at Statistics Canada. This process is, for the most part, voluntary. Voluntary agreements also exist for sharing data on hospital discharges. These are then sent to the Canadian Institute of Health Information (CIHI).

Several problems currently exist in health surveillance. Experts in the field see many “islands of activity” in health surveillance with a lack of coordination and standardization and provincial, interprovincial, and national links. They believe this results in an inefficient, fragmented system with duplication and, especially, important gaps. Their major concerns include a lack of integration of existing health-related databases, inadequate linkage between laboratory-based diagnostic data and public health data, and lack of information on determinants of health. There is also confusion over federal-provincial roles and responsibilities in health surveillance, which is largely a result of ambiguity in the constitutional division of powers.

At the federal level there are major difficulties with the considerable variation in the format of the information provinces send to the LCDC as well as the variety of computer programs used. The LCDC also recognizes it has significant resource and organizational limitations in carrying out effective surveillance. At the local level, public health officials support Health Canada’s assistance of provincial public health laboratories. There is satisfaction with communicable disease surveillance activities of Health Canada but non-communicable disease health surveillance is felt to be inadequate. There have been concerns with the fragmented approach to surveillance taken by the LCDC and its tendency to bypass provincial ministries when dealing directly with local health units. Some public health officials have found the organization of the LCDC difficult to understand and have had trouble communicating with this directorate. There is also a belief that communication between the various bureaus of LCDC is not optimal. However, more importantly, public health officials are looking for a greater federal role in coordinating surveillance activities across the country.
The Auditor General’s 1999 report highlighted many of the current deficiencies of the present state of health surveillance. It identified the need to coordinate current health-surveillance activities, address important gaps, clarify roles and responsibilities, have clear rules and procedures to deal with emerging health threats, improve levels of communication and have a mechanism to evaluate quality of surveillance. This report drew particular attention to the nationwide outbreak of a food-borne salmonella infection in spring of 1998 as an example of the consequences of an inadequate health-surveillance system in Canada. 12

PARALLELS WITH THE CANADIAN BLOOD SYSTEM

The experience of the Canadian blood system in addressing the problem of blood transmission of hepatitis C and human immune deficiency virus (HIV) provides further insights into the motivation of the current health-surveillance initiatives. The difficulties of the blood system have been described in detail by the Commission of Inquiry on the Blood System in Canada (Krever Commission). 13 To summarize the report of this commission, it was identified that the operator and regulator of the blood system, the Red Cross and Bureau of Biologics, had responded too slowly to the emerging evidence of blood transfusion of hepatitis C and HIV. This delay resulted in numerous potentially avoidable infections and it created a public health disaster. The commission attributed these delays to several systemic problems. Among these were a dysfunctional relationship between the major players in the blood system, problems in the method by which decision-making occurred and inadequate and inappropriate use of existing evidence of risk of transmission.

The state of the blood system prior to the HIV and hepatitis C crises and the current state of health surveillance share many features. The pre-Krever blood system was a low-profile field which allowed it to operate free of scrutiny despite the existence of serious governance and systemic problems. Only after the emergence of a public health crisis did the blood system draw public attention to its deficiencies and only then were the problems addressed. Health surveillance also does not receive much public attention and has developed several of the problems faced by the pre-Krever blood system. In describing the systemic problems of the blood system, the Krever Commission stated that:

"responsibility for the blood system is fragmented … the various functions integral to the supply of blood, such as regulation, funding and planning, are
undertaken by different stakeholders. The respective functions, authority and accountability of each party are not well defined ... This lack of definition may affect accountability within the system, and ultimately its safety.\textsuperscript{14}

The issues of fragmentation, unclear roles and responsibilities, and lack of accountability have been identified as some of the major deficiencies to be overcome as the health-surveillance system is being reformed.

The Krever Commission had a profound impact on decision-making at all levels of government, particularly in public health circles. It sent a strong message that inadequate information was not a justification for inappropriate decision-making. Officials in Health Canada recognized the risk of a repeat of the blood crisis in other public health sectors. The potential risk provided a strong motivation for the development of the new surveillance initiatives.

DEVELOPMENT OF THE NETWORK FOR HEALTH SURVEILLANCE IN CANADA AND THE NATIONAL HEALTH SURVEILLANCE INFOSTRUCTURE

The Network for Health Surveillance in Canada is an attempt by federal, provincial, and territorial partners to address the deficiencies in the field of health surveillance. The objective of this project is to build capacity at all levels (local, regional, provincial/territorial, and national) to acquire and share health-surveillance information so as to improve evidence-based decision-making in the public health sector. It is believed that the Network will deliver better quality surveillance information, easier access to this information, timely sharing of the information, and tools for the integration and analysis of this information. It will also provide standards for the collection of surveillance data and provide an adaptable system which can accommodate changing health-surveillance needs. However, it is \textit{not} intended to be a comprehensive plan for health surveillance. Individual partners can choose to operate outside the Network if they so desire and will still remain accountable for many surveillance functions.

The NHSI operationalizes many of the concepts put forth by the Network project. The NHSI is a federal-provincial collaborative effort to develop Internet-based tools that will allow for national and international surveillance of disease and other potential risks to health. Its objective is to develop an electronic infrastructure that will improve coordination of the presently fragmented health surveillance activities occurring throughout the country. Some of its key elements include\textsuperscript{15}: 
Integrated national public health architecture. The NHSI will link key public health nodes such as public health laboratories, hospitals, and physicians’ offices.

Global surveillance and early-warning networks. The NHSI will coordinate with international health-surveillance systems to provide early information on emerging global health risks.

Policy and program decision support systems. The NHSI will assist in the analysis and interpretation of surveillance data. This will facilitate the tracking of risk factors and diseases as well as health expenditures, the economic burden of disease, and the effectiveness of health programs and policies.

Integration of human health-surveillance information with other determinants of health information. The NHSI will collect information on factors such as socio-economic status and level of education and assess their impact on health (although this is not an immediate priority).

Development of a comprehensive Internet-based health information resource. The NHSI will link health-surveillance data across the country via the Internet.

The NHSI is intended to develop on the basis of an implementation strategy of successful local pilot projects which are then voluntarily generalized across the country. Local public health officials who identify gaps in current health-surveillance activities are encouraged to approach federal officials for assistance. The federal government, through its HPB Surveillance Transition office, will provide supportive funding to build the electronic infrastructure to address the surveillance needs for that particular site. These initial pilot projects will be tested and evaluated at the local level and, if found to be successful, will be offered to other sites across Canada. In this way the NHSI will provide ongoing needs-based investment in infrastructure which is intended to be function specific (i.e., building information-collection capacity) as opposed to disease specific. Some of the components and support systems which are in the process of being developed are described in Appendix C.

The development of the Network and NHSI initiatives has involved a complex interaction of several federal, federal/provincial/territorial, provincial, and non-governmental organizations (some of these organizations and their contributions are outlined in Appendix D). A bottom-up pressure from local epidemiologists and public health officials to change the current system of health surveillance coincided with recognition at the federal and provincial levels that an improved system was necessary. Also critical to the development
process was the presence of new information technology that made a national surveillance system possible.

Over the 1990s Ottawa reduced cash transfers to the provinces for health care. The provinces also constrained or reduced funding to regional and local health organizations. The reduction in funding to the regional level was accompanied by a devolution of power, the objective of which was to contain costs and improve health outcomes. Local public health units, as a result, came under increasing pressure to improve the efficiency of their activities. However, achieving these efficiencies required improved methods of data collection at local levels and the facilitation of information-sharing between provinces. Traditional health-surveillance activities could not adequately carry this out. This explains the grass-roots pressure from local epidemiologists and public health officials to improve health-surveillance systems.

At the same time, at the federal and provincial levels, there was a growing recognition that a more coordinated approach to surveillance was necessary. In March 1995, the deputy ministers of health, in an effort to improve communication between levels of government, established an F/P/T working group to examine the health roles and responsibilities of each level of government. The main focus of this F/P/T collaborative effort was to search for overlap and duplication. The task force noted that there were few areas of overlap and duplication in health protection. Instead, large gaps were found, especially in health surveillance.

Pressure also began to emerge from other sources for improved health surveillance. In September 1995, the Information Highway Advisory Council (IHAC) called for a federal leadership role in developing a unifying health information infrastructure. This was followed by a report in September 1996 by the Canadian Network for the Advancement of Research, Industry and Education (CANARIE) which called for Health Canada to work with the provinces and territories to develop a national strategy for the institution of an integrated health information network. In February 1997, the federally commissioned National Forum on Health recommended the development of an evidence-based health system based on a nationwide information system.

In response to these reports, particularly the National Forum on Health, the February 1997 federal budget committed $50 million over three years to develop a Canadian Health Information System (CHIS — now referred to as the Canadian Health Infostructure), an electronic “network of networks,” to support evidence-based decision-making. In April 1997, the Advisory Council on Health Infostructure was created to advise the minister of health on
developing a long-term strategy to establish a Canadian Health Information System. This strategy included a call for the development of several pilot projects as well as the launch of a three-pronged Health Canada initiative to accelerate the development of an information system. The initiatives called for were a Population Health Clearing House, a First Nations Health Information System and a National Health Surveillance System. The health-surveillance system eventually developed into the NHSI. The responsibility for designing and developing the system was given to the HPB. The assistant deputy minister (ADM) of this bureau brought in surveillance and epidemiology experts from the LCDC to design such a system.18

**Surveillance Transition**

At the same time that the CHIS initiatives were being launched by Health Canada, the HPB was going through a process called “Transition.” During the Transition, HPB reviewed several of its responsibilities through in-depth consultations and made appropriate adjustments to adapt to changing health-protection demands. Surveillance is one component of Transition. The original objective of Surveillance Transition was to coordinate the surveillance activities of all HPB directorates as well as develop a surveillance framework for Canada and a coordinated national approach to surveillance activities. The Surveillance Transition initiative would eventually produce the Network for Health Surveillance. The NHSI operationalizes many of the concepts embodied in the Surveillance Transition initiative and the two projects share several key personnel.19

The federal government approached Surveillance Transition as a collaborative process from the outset, working closely with the provinces and territories. The deputy ministers of health supervised the overall project. Initial work on the Surveillance Transition project was conducted by an Integration Design Team. This team built on the work of the previous F/P/T working group on roles and responsibilities. (The working group had preliminarily assigned to federal, provincial, and territorial governments specific responsibilities in health surveillance.) The Integration Design Team, also F/P/T in nature, expanded on this work by determining who is to be responsible for what aspects of a national health-surveillance system. It recommended functional roles and responsibilities of the main partners involved in national health surveillance and recommended processes whereby the F/P/T partners can, in a collaborative manner, establish, review, and amend — when necessary —
national surveillance priorities. The Integration Design Team presented a draft report to the deputy ministers of health in June 1998 which led to the publication of a discussion paper on an Integrated National Health Surveillance Network for Canada in September 1998. These reports initiated a broad series of consultations across the country.\textsuperscript{20}

Work on the development of the Network was assumed by the Health Surveillance Working Group, another F/P/T organization, from August 1998 onwards. This F/P/T working group is to advise on development and coordinate the implementation of the surveillance network. This includes strategic planning and priority setting as well as determining evaluation strategies. It will be responsible to the Advisory Committee on Health Infrastructure, which will report to the Conference of Deputy Ministers. Currently the Network has received F/P/T approval by the Conference of Deputy Ministers of Health. All provinces including Quebec have endorsed the project in its current form. The NHSI component of the Network is in the process of developing and implementing several pilot projects and has received approval for funding for the next three years.\textsuperscript{21}

The NHSI, at this point, is considered a successful F/P/T initiative. While primarily federally conceived, its ongoing development and implementation has been an F/P/T collaborative process. In a comparatively brief period, Ottawa and the provinces have been able to work together to develop a design and proceed with implementation of pilots. There are several reasons for the success of this project. All levels of government recognized the need for a coordinated approach to surveillance, the information technology was available and the individuals involved in the development of the project shared a common vision. Also key was the collaborative way in which Ottawa and the provinces have worked. Ottawa has approached the NHSI as a national, joint federal/provincial/territorial initiative. This appears to have been essential to ensuring provincial cooperation. During the F/P/T meetings on roles and responsibilities significant levels of disagreement existed between Ottawa and the provinces, especially in areas where the federal government had taken a \textit{de jure} unilateral approach, as in the case of interpreting the \textit{Canada Health Act}. Provinces, having already experienced sizable cutbacks to their health-care transfer payments with the introduction of the Canada Health and Social Transfer (CHST), reacted negatively toward further federal initiatives in health. In the area of health surveillance, however, there was recognition by both Ottawa and the provinces that progress could be made and there was a willingness to work together to bring about a national plan. At the federal level there was also
recognition that, in general, a more evidence-based and program-rational approach to decision-making in health was necessary. Health surveillance, as one of the least contentious federal/provincial areas, was believed to be the area in which progress could be made relatively quickly.

Some concerns have been expressed regarding the development of the NHSI. The initial development excluded the provinces to a large extent. Partly as a result of this, the scope of the project may have been too large with too many pilots. The intent of the project subsequently changed from emphasizing the creation of an overall system to emphasizing the development of infrastructure on a project-to-project basis. This satisfied some provinces (Ontario and Quebec) which felt that the previous attempt to create a national system was too much of an infringement on their jurisdiction and too ambitious. Other provinces (Saskatchewan and Manitoba), however, had been more supportive of the development of an overall national system with national goals and objectives.

While F/P/T relationships in the development of the NHSI have to this point been generally positive, concerns have been expressed that the relationship among federal agencies may itself threaten the project. Specifically, concerns have been expressed that the directorates, particularly the LCDC, had been left out of the initial NHSI decision-making processes resulting in duplication of surveillance efforts in the HPB. Changes in the approach to the NHSI have, for the moment, addressed these concerns. The NHSI, however, currently remains separate and independent from the other HPB directorates.

Problems which may develop between the federal government and the provinces relate to the following issues: funding of surveillance activities, standards related to data collection, and ownership of information. With respect to the issue of funding, currently the federal government has been responsible for financing the coordination of the process while information-collection costs are being borne by the provinces. The continued development of the NHSI will require further investments in infrastructure at the local level, such as the expansion of current surveillance activities and training of personnel. Financing for this has not been finalized, although it will likely be obtained from a combination of federal, provincial, and private sources. However, it is expected that overall costs will be modest as the NHSI makes use of existing surveillance systems.

The issues of data quality and data ownership are also currently being worked out. Data quality is important to ensure a minimum standard of data collecting and processing. This will likely require strategic investments by national agencies such
as the Canadian Institute for Health Information. Data ownership is a more contentious issue. Provinces have expressed resistance to surrendering their data to federal officials due to concerns about how the data may be analyzed and for what purposes. The use of legislation to mandate transfer of provincial surveillance information to the federal level is considered unconstitutional. Conditional cost-sharing could be introduced to obtain this objective. However, the current commitment is to arrive at an agreement through cooperative means.

ROLE OF FEDERALISM IN THE DEVELOPMENT OF THE NHSI

The form of intergovernmental regime that best represents the historic relationships surrounding the health-surveillance activity is “disentanglement” or classic federalism with some collaborative components. With the exception of communicable disease surveillance both orders of government act relatively independently of each other and the relationship is non-hierarchical.

The development of the Network and the NHSI represents a move toward a more collaborative approach to federalism. While the initial development of the NHSI was primarily a federal initiative with little consultation with the provinces, Ottawa has subsequently worked closely with the provinces in developing pilot projects and planning for implementation. The NHSI can move ahead initially with federal funding. However, it will eventually require provincial funding at the level of specific projects. The Network, on the other hand, has been a collaborative process from the outset with Ottawa working closely with the provinces to develop a coordinated approach to national health surveillance. Its development has been supervised by the deputy ministers of health. Both levels of government must approve funding for the project in their respective budgets. The federal/provincial/territorial nature of the Design Team and Network working group as well as the cooperative approach to determine roles and responsibilities in the field of health surveillance highlights the essentially collaborative nature of this relationship. The federal government, to this point, has not relied upon any coercive measures to gain provincial cooperation for either the Network or the NHSI. Overall, the relationship has been mutually interdependent, non-hierarchical, and professionally respectful.

The collaborative relationship for the Network and the NHSI developed out of recognition by both provincial/territorial and federal levels that they would not be successful in achieving surveillance reform independently. Moreover, all levels of government shared a concern to reduce health risks and
improve public safety. Of the areas of jurisdicational dispute in health, health surveillance was viewed by both Ottawa and the provinces as the one in which progress was most likely to be made. The impact of federal reductions in transfer payments on provincial attitudes also contributed to the development of a collaborative relationship. After the federal reduction in transfer payments in the mid-1990s, the provinces were hesitant to enter into further shared-cost programs with Ottawa, particularly if there were conditions attached to funding. The collaborative approach adopted toward health surveillance is likely the only relationship the provinces would have agreed to because, after the initial roles and responsibilities were established, each level of government then funds what it sees as a responsibility of its own jurisdiction.

Several issues, such as developing a national standard of data collection and sharing, remain unresolved. There is a potential for Ottawa to take unilateral action in order to resolve this issue. In this approach, Ottawa would apply conditions to any federal funding for local surveillance activities. This might allow the federal government to set the standard of data quality and help to ensure that provinces supply data to federal agencies. This approach, however, would also represent a more hierarchical relationship between Ottawa and the provinces. Therefore, it is unlikely that provinces would agree to this form of arrangement due to concerns about how federal officials might use surveillance data. Provincial concern in this respect surrounds the federal government using surveillance information to “audit” provincial health-care systems.

If the federal government fails to continue to provide leadership in the area of national surveillance, provinces may choose to proceed on their own, resulting in the emergence of interprovincial collaboration. However, such an initiative would likely be difficult in the absence of federal coordination given the scope of the project and the initial investment needed for infrastructure. This suggests that a genuinely collaborative federal-provincial arrangement would be the most effective.

Policy Goals and Outcomes

The Network and the NHSI, unlike most health “care” initiatives, do not impact directly, but rather indirectly, upon individuals. The major impact of the collaborative approach in this area is to have allowed for the development of a coordinated national plan and the advantages and disadvantages that go along with this. However, collaboration has not, as of yet, resulted in the development of national health-surveillance standards as some provinces were resistant
to this approach. Instead, with respect to the NHSI in particular, issues surrounding standards and sharing of data will take place on a project by project basis. Overall, in the area of policy goals and outcomes, collaboration has been an improvement over the previous disentangled regime by allowing for a Canada-wide system with improved economies of scale and identification of gaps and duplication.

Efficiency. There are important efficiency advantages of a coordinated program in health surveillance insofar as there are massive costs and duplicated efforts in collecting this data separately across the nation. The major advantages are the coordination of governmental efforts allowing for clarification of roles and responsibilities and the identification of critical gaps and the elimination of duplicated efforts among governments. These potential benefits prompted the push for cooperation in the first place. A coordinated program will also allow for benefits due to economies of scale. The one-time investment by the federal government to develop projects for the NHSI will provide for an infostructure that can be shared by all provinces. The federal investment should be less than the combined expenditures of the individual provinces attempting to improve their current state of surveillance. Under a coordinated program, improving the sharing of information and building common infrastructures will improve health outcomes.

A theoretical disadvantage of a coordinated program compared to 13 provincial/territorial ones is a lack of responsiveness and delays in reaction time in an emergency. The NHSI likely will not incur these problems as there will be a reliance upon local surveillance infrastructure. Coordination of surveillance activities could also potentially lead to a loss of local experimentation. However, significant experimentation has not occurred to any large extent under the regime of disentangled provincial systems. It is expected that the NHSI should actually encourage experimentation by funding new surveillance initiatives at the local level.

Overall, collaborative federalism, by allowing for the development of a national plan, has a clear efficiency advantage over the more disentangled model of federalism due to the particular importance of coordination in this field.

Human Development. The NHSI is not explicitly designed to provide for human development in the sense that, for instance, an employment training program would. However, the existence and easy access to this improved health information may well contribute extensively to new research and intellectual development. In addition, a national approach to surveillance should result in
improved health outcomes by reducing morbidity and mortality and, conse-
quently, prevent loss of human capital. The coordinated approach will also
allow for the development of an overall vision and long-term surveillance stra-
tegy for the country. Eventually, investments will be made in the area of the
determinants of health which should further contribute to human development.
The new system will address the emerging public demand for monitoring
changes in health status, although it will be difficult to determine if better
measurement is a result of the new health-surveillance system or of other
changes being made in the health system at the same time.

The collaborative approach, by allowing for the existence of a voluntar-
ily coordinated national program, is expected to yield improved health outcomes
for Canadians and thus result in less loss of human capital than the current
state of surveillance under disentangled federalism. The degree of benefit in
this area cannot be determined at this time and is dependent on the success of
the implemented program.

Social Equity. Under disentangled federalism, there exists considerable vari-
ability from province to province in levels of health surveillance and
consequently the potential for variability in health. The Network and the NHSI
will attempt to reduce the regional discrepancies by promoting sharing of sur-
veilance infrastructure. Establishing national standards could further reduce
variability. Under collaborative federalism, standards will be determined by
discussion on a case-by-case basis. The ability to establish and ensure that
national standards are maintained would be more effective with a more unilat-
eral federal approach if that were possible to achieve jurisdictionally, which it
probably is not.

The move to collaborative federalism will not have a great impact on social
equity except by reducing discrepancies in levels of surveillance across provinces.

Democratic Principles

The low profile and technical nature of the field of health surveillance along
with the form of federalism influence the relationship between the NHSI, the
Network, and principles of democracy. Collaborative federalism appears to be
an improvement over disentangled federalism in addressing these principles.

Citizen Participation. Due to its technical aspect, and generally a lack of pub-
lic information about the prevalence and risks to Canadians of the diseases
being monitored, health surveillance currently has a low public profile.
Consequently, the major impetus for the development of improved health surveillance has not been public pressure but rather pressure from experts within the field. It is widely accepted by experts that the current situation is inadequate and could possibly lead to adverse health consequences. Political fear of another Krever inquiry has also acted as a motivator for change. The majority of the consultation that led to the development of the NHSI has occurred between non-elected officials and content experts in the field. There has, to now, been little public involvement in the process.

Collaborative federalism, in theory, may further contribute to the lack of public involvement by forcing each level of government to focus first on satisfying the other levels of government, with the Canadian public interest coming second in priority attention. However, there was little public involvement in health surveillance under the previous disentangled model, suggesting that it is the low-profile, technical nature of this issue that is the major factor. Ultimately collaborative federalism may actually increase public involvement by allowing the development of a national plan and thereby raising the profile of the field. In addition, by developing a coordinated approach to health surveillance, health information should be more readily available to the public. An argument could be made that the current low-profile nature of the field may actually benefit a collaborative regime to advance a common policy settlement by allowing for a consultative process that has not had to answer to the public.

Legislative Role. There has been a limited role for the legislature in matters pertaining to health surveillance. The federal government and the provinces have passed legislation to allow for tracking of public health risks as well as vital statistics. The legislatures have also been needed to approve funding for surveillance activities through federal and provincial/territorial budgets. Importantly, any potential federal legislation to compel provinces to share data with federal officials is considered unconstitutional. This has necessitated the development of a collaborative process to achieve agreements regarding this issue. The legislature’s main role in the development of the NHSI will be to approve funding for the program. The low public profile of surveillance is, again, an important contributor to the limited role of the legislature in the area.

Transparency and Accountability. In theory, collaborative federalism can potentially confuse issues of accountability allowing governments to blame each other for failures and reducing the pressure on governments to consult citizens. However, accountability for health surveillance under the previous system
was not clear. This was due to a combination of ambiguous constitutional division of powers and disentangled federalism which has not forced the issue to be addressed. The collaborative approach has resulted in an assignment of roles and responsibilities for health surveillance and therefore should make accountability more clear.

Under both disentangled federalism and collaborative federalism there has been a problem with transparency. There, in particular, appears to be a transparency issue with the process that led to the NHSI. This is partly a consequence of the numerous levels of government, government agencies, and stakeholders involved in the development process as well as its relatively complicated nature. Individuals in the HPB have expressed uncertainty over who is responsible for decision-making and how some of the decisions were arrived at. These concerns have contributed to a change in the focus of the project from initially providing a comprehensive information system to developing infrastructure for the ongoing collection of information on a project-by-project basis. The development of the Network initiative has been more transparent with a clear definition of individuals, organizations, and levels of government involved at each point of the development process.

The move to collaborative federalism has improved accountability by clarifying roles and responsibilities. The complexity of the discussions associated with the collaborative model may have contributed to poor transparency.

Protection of Public Interest. In theory, provincial and federal elected officials involved in the NHSI should be representing the interests of their respective electoral majorities. However, the technical nature of the NHSI has required reliance upon non-elected content experts who are not as accountable to the public. This combined with the lack of public awareness of the project and problems with transparency of the process increases the possibility of ignoring specific stakeholder concerns.

The parallels between the regulation and management of the blood industry and health surveillance demonstrate the potential negative implications for society of not addressing known concerns about the Canadian governments’ oversight of health surveillance. The regulation of blood products is a federal matter, while the management of the blood system was an interprovincial arrangement. Like health surveillance it had been a low-profile, technical field with a lack of public involvement in the process. The management board of the blood agency, composed extensively of provincial representatives, did not have
the authority of provincial/territorial treasuries to commit unbudgeted provincial money to repair emergency problems. This created a structural environment where the best interest of neither the F/P/T governments nor the Canadian public could be met on a timely basis and resulted in the failure to introduce appropriate HIV and hepatitis C tests when essential. Like the current state of surveillance, the blood industry had fragmentation of responsibility with a lack of clear accountability and poor transparency, as well as an ineffective intergovernmental management structure. The reformed blood system involves the public, is more transparent, and has made accountability clearer.

Health surveillance in its present state could be considered to be at risk for the same problems that the blood industry experienced. In an attempt to avoid a health crisis due to inadequate surveillance, experts in the field have pushed for reform. The reform, however, has not involved the public and thus is still susceptible to not addressing their concerns. Decisions may be made for financial reasons that limit certain surveillance activities or prevent action on early surveillance results that would not be made if the public were more aware of the process.

Collaborative federalism is an improvement over the previous disentangled system in protecting public interest by improving accountability. However, the overall lack of public involvement in the current surveillance projects leaves them susceptible to not addressing the concerns of important stakeholders.

**Federalism Principles**

The collaborative model was adopted to reform the health-surveillance system partly due to the fact that provinces were reluctant to allow further federal involvement in their jurisdictions after the introduction of the CHST. One of the primary goals of the collaborative process is to ensure that there is respect for jurisdictional boundaries.

*Respect for the Jurisdictional and Political Sovereignty of both Levels of Government.* The responsibilities for health surveillance are not clearly defined in the constitution. Both levels of governments have some responsibility for the function. Due to the lack of clarity of roles the potential for the federal government infringing on provincial jurisdiction exists. For example, the LCDC deals directly with local health units, often bypassing the provincial government. However, there does not appear to have been much provincial objection
to possible federal involvement in these technical matters. Rather, the greater concern was with the lack of a federal presence in providing leadership to develop Canada-wide coordinated surveillance activities.

The lack of jurisdictional clarity necessitated a collaborative approach to surveillance reform. The F/P/T Working Group on Roles and Responsibilities was an example of federal-provincial cooperation and the Network and NHSI have continued this collaborative style. In order for the NHSI and other Network initiatives to be fully implemented they must receive approval at both federal and provincial levels. The development process also undergoes F/P/T reviews at several stages.

The issue of national standards in the field of health surveillance has created some jurisdictional sovereignty concerns among some provinces. Related to this issue is the concern over ownership of surveillance information and how it is to be used. A federal-unilateral approach, if used to enforce sharing of surveillance data, could potentially infringe upon provincial sovereignty. The NHSI project, at present, will address these issues on a project-by-project basis. In general the approach taken by the NHSI to develop projects on a pilot basis in one region and then offer them to other interested regions appears to have reduced concerns over jurisdictional sovereignty violation.

The move to collaborative federalism has resulted in greater attention being paid to issues of jurisdictional sovereignty in this field of health. It is one of its most important features in contributing to health-surveillance reform.

A Commitment to Intergovernmental Processes for Conflict Resolution. At present neither the Network nor the NHSI have any formal mechanism outlined to deal with conflict resolution. Instead, issues will attempt to be addressed by discussion and through the achievement of a consensus on a case-by-case basis. Essentially, this requires unanimity on any major decision and will likely slow the development of the overall system. It has contributed to a decision not to proceed with national standards. This remains a potentially important problem for the establishment of an effective Canada-wide program.

A collaborative form of federalism is superior to the previous disentangled model in managing intergovernmental conflict. Surveillance under the disentangled form of federalism did not have any mechanism to address intergovernmental conflict other than the court system. A federal-unilateral approach would likely rely upon decisions at the federal level to withhold funding if standards were not being met.
PARALLELS WITH ENVIRONMENTAL HARMONIZATION LEGISLATION

A further understanding of the collaborative process, its strengths and its weaknesses, can be gained by reviewing the experience in the field of environmental harmonization. Two major F/P/T initiatives have occurred in recent years in environmental harmonization; the ambitious but failed Environmental Management Framework Agreement (EMFA) and the less ambitious Canada-Wide Accord on Environmental Harmonization (EHA). Both of these were attempts to address issues surrounding lack of coordination of governmental efforts in this area and concerns about overlap and duplication.22

As with health surveillance, the roles of federal and provincial governments in relation to environmental harmonization are not laid out neatly in the constitution. The initiative to harmonize environmental policy between F/P/T governments was partially borne out of concerns regarding this constitutional ambiguity. At both levels of government a spirit of cooperation marked the initial stages of the policy process. The collaborative process eventually led to the development of a draft version of the EMFA in 1994. This agreement was a detailed document which recast F/P/T roles in the area of environmental protection.

However, several concerns appeared regarding the development of the EMFA. A perception emerged that the consultation process that produced this agreement was not inclusive enough and it consequently came under criticism from several non-governmental environmental organizations. There were also concerns regarding the content of the agreement. It was viewed as being overly ambitious in attempting to assign a comprehensive set of roles and responsibilities a priori, before problems arose. Further, it did not outline an effective decision rule for resolving disputes and was believed to create a system that would exclude the public from decision-making. These problems with process and content ultimately resulted in the failure of the EMFA to be ratified.

F/P/T officials then embarked on another attempt to achieve environmental harmonization eventually leading to the EHA, which came into effect in 1998. The EHA primarily outlined general objectives that all parties agreed should govern policy-making. Issues of assigning roles and responsibilities are to be handled on an issue-by-issue basis. The effectiveness of the EHA in achieving agreements has yet to be determined.23

Further insight into the nature of the collaborative process can be gained by comparing the experiences in health surveillance and environmental
harmonization. In both areas there was unclear jurisdictional responsibility and a mutual recognition of the need for improved coordination. These features, combined with concerns over jurisdictional boundaries, made both fields well suited to collaborative federalism. However, in each area the collaborative process encountered difficulties for similar reasons. One of the primary reasons for the failure of the EMFA was its attempt to address too many issues at once. Similarly, the NHSI ran into problems in its initial stages due to concerns that it was too broad in scope. The ambitious nature of both projects appears to have heightened the concerns of stakeholders who believe they have been excluded from the development process. This led to the adoption of an incremental, case-by-case, approach in both fields. This approach has also been beneficial in reducing concerns over jurisdictional sovereignty and may represent the most effective method of implementing policies developed by a collaborative process.

OVERALL ASSESSMENT

Health surveillance is a shared federal-provincial responsibility. The present intergovernmental relationship which exists in this area would best be characterized as disentangled federalism with some collaborative components. Partly as a result of this relationship, there have emerged problems in health surveillance, such as large gaps in the F/P/T surveillance program activities as well as duplication. At local, provincial, and federal levels it was recognized that change was necessary. This mutual recognition encouraged the development of a more collaborative relationship between Ottawa and the provinces. To this point, the relationship has been successful. Compared to other health initiatives, there have been substantial levels of agreement between Ottawa and the provinces. An example of this has been the development of the Network and the NHSI.

The failure of disentangled federalism in this area can be attributed to several factors. There is a lack of clear constitutional jurisdiction in health surveillance resulting in uncertainty of roles and responsibilities. This uncertainty has in turn contributed to important program gaps. Under a disentangled regime, coordination of efforts across provinces, which is of particular importance in health surveillance, could not be accomplished. Also under disentangled federalism, the efficiency benefits of a national program could not be realized. There do not appear to be any major advantages of disentangled federalism over collaborative federalism in this particular area.
In many ways health surveillance is the ideal arena for collaborative federalism. Its success in this area is due to several factors: (i) the nature of health surveillance which requires a national plan and coordinated approach to improve efficiency and effectiveness; (ii) the recognition at all levels of government that surveillance improvements require intergovernmental collaboration on a developmental and ongoing basis; (iii) the lack of jurisdictional clarity in this field, requiring a cooperative approach to determine roles and responsibilities; and finally, the provinces are opposed to Ottawa introducing federal, unilateral initiatives to address the surveillance concerns.

The main disadvantage of the collaborative style of federalism is the lack of public involvement as well as the lack of transparency in the developmental process, problems that also existed under the previous disentangled regime. These are primarily issues related to the low profile and technical nature of health surveillance, as well as the lack of public information, but these may have been reinforced by the federalism regime adopted. If unresolved, these issues could place the new surveillance system in danger of not addressing the public’s concerns about their specific health risks. In addition, collaborative federalism appears to have produced a more incremental approach than would have occurred under a federal, unilateral system. This is partly a consequence of the importance of respecting issues of jurisdictional sovereignty under this form of federalism. Nevertheless, incremental progress is better than a total impasse precipitated by a jurisdictional dispute.

It is important to recognize that the development of the NHSI has only recently been completed and several issues surrounding implementation need to be addressed. Some of these, such as funding and standards, may result in intergovernmental conflict leading the federal government to take a more unilateral approach with respect to national standards of health surveillance. The main disadvantage of any such unilateral action — infringements on jurisdictional sovereignty — could threaten the entire national program as well as destroy the effective working relationship that now exists between the levels of government to address this public safety issue.

If the current collaborative approach fails, it is possible that some form of interprovincial collaboration may emerge. This will likely be regional and have some advantages of efficiency over the traditional arrangement while also preserving some degree of competition. However, provincial and territorial officials believe that a Canada-wide system is essential and this would require a greater federal role than would exist under interprovincial collaboration.
CONCLUSION

The development of the Network for Health Surveillance in Canada and the National Health Surveillance Infostructure provide valuable insights into the nature of collaborative federalism. Based on this case study, collaborative federalism appears to be effective in developing a rapid degree of consensus between levels of government. It is best suited for policy areas that involve some of the following characteristics:

- a recognition at both levels of government of the need for policy or program change in a field of shared jurisdiction;
- a need for a Canada-wide capability to coordinate activities at both levels of government to achieve effective policy and program implementation; and
- an area where provinces are hesitant to allow further federal unilateral involvement.

Also, based on this case study, it appears as if a pilot approach to collaborative federalism initiatives may be an effective way to reduce concerns over jurisdictional violation as well as reduce the concern of stakeholders who feel they may be left out of the decision-making process. This approach, however, does slow program implementation.

It is important to note that the full impact of collaborative federalism on realizing policy goals could not be fully assessed by this case study as the projects are still being developed.
APPENDIX A
INDIVIDUALS INTERVIEWED

1. Susan Tessier (9/7/98). Executive Secretary to Alexa Brewer.
2. Jane Welden (13/7/98). Strategic Planner HPB Transition.
3. Dr. David Butler-Jones (17/7/98). Chief Medical Officer for Saskatchewan.
4. Dr. Rick Mathias (15/7/98). Professor, Division of Public Health and Epidemiology, University of British Columbia. Consultant to Office of National Health Surveillance.
5. Dr. Paul Gully (22/7/98). Director, Bureau of Surveillance and Filed Epidemiology, LCDC.
6. Alexa Brewer (23/7/98). Former Director, Surveillance Transition. Former Project Manager for NHSI. Currently Director of Program Analysis in First Nations/ Inuit Health Program.
10. Dr. Joe Losos (14/9/98). Assistant Deputy Minister HPB.
12. Dr. John Spika (5/10/98). Director of Bureau of Infectious Diseases, LCDC. Integration Design Team Member
13. Deborah Jordan (29/7/99). Executive Secretary for Surveillance Transition.
14. Dr. David Mowatt (9/11/99). Project Manager for NHSI.
15. Dr. Harvey Lerer. (7/10/99) Director General at Canadian Environmental Protection Act office.
APPENDIX B

Important Individuals in the Development of the NHSI

Alan Nymark – Associate Deputy Minister (responsible for CHI Initiatives)
Dr. Joe Losos – Assistant Deputy Minister HPB
Alexa Brewer and – Project Managers for NHSI, Directors of Surveillance
Dr. David Mowatt – Transition
Dr. Rick Mathias – Co-designer of NHSI
Dr. Greg Sherman – Co-designer of NHSI
Ian Shugart – Visiting Assistant Deputy Minister in charge of HPB
Transition
APPENDIX C
DESCRIPTION OF THE NHSI

At present the core components to the NHSI are the Canadian Integrated Public Health System (CIPHS), the Local Public Health Infrastructure Development (LoPHID), and the Spatial Public Health Information Exchange (SPHINX). These are supported by the NHSI infrastructure which is composed of the Public Health Intelligence Database (PHIDB) and the Geomatic Information System Infrastructure (GIS). These are described in more detail below.

Core Components

*Canadian Integrated Public Health System (CIPHS):* A computer-based system designed to capture, integrate, and report surveillance data. This will link, in a standardized manner, data from a variety of health units across Canada.

*Local Public Health Infrastructure Development (LoPHID):* This component is designed to strengthen the local public health capacity to conduct surveillance, with attention to information on determinants of health. It will also generate and use local information for decision-making.

*Spatial Public Health Information Exchange (SPHINX):* This component is designed to access information already residing in health-related databases.

NHSI Infrastructure

*Public Health Intelligence Database (PHIDB):* A repository of information from NHSI and Health Protection Bureau (HPB) surveillance activities.

*Geomatic Information System Infrastructure (GIS):* This infrastructure will allow for the development of the spatial information needs of the NHSI project.

*Global Public Health Intelligence (GPHIN):* A global early warning system designed to monitor international sources of information to allow for early detection and validation of health risks.
APPENDIX D
SOME KEY ORGANIZATIONS INVOLVED IN THE DEVELOPMENT OF THE NHSI AND NETWORK

Federal Organizations

Information Highway Advisory Council: Created by the federal government to provide advice on how to develop the Canadian Information Highway. It also required a federal leadership role in developing a unifying health information infrastructure.

National Forum on Health: An initiative launched by the federal government in 1994 whose objective was to consult with the public and advise the government on ways to improve the health of Canadians. It proposed the development of an evidence-based approach to health decision-making which led to the introduction of the Canadian Health Infostructure.

Advisory Council on Health Infostructure: A group of key individuals in health care who advise the federal minister of health on the development of a national strategy for a Canadian health information system.

Canadian Health Infostructure: Created following recommendations from IHAC and CANARIE and in direct response to the National Forum on Health report. The NHSI is one component of the CHI.

Surveillance Transition Team: Individuals assigned with the responsibility of strengthening and expanding the HPB’s overall surveillance capacity. This team was responsible for the development and management of the NHSI. In coordination with the provinces it developed the Network.

Federal Provincial Territorial Organizations

Conference of Deputy Ministers of Health: This consists of federal, provincial, and territorial deputy ministers. Responsible for final approval of national surveillance initiatives prior to implementation. It initiated development of the Network in response to recognition that important gaps existed in health surveillance due to lack of coordination between levels of government.

Working Group on Roles and Responsibilities/ Overlap and Duplication: An F/P/T group originally designed to examine areas of overlap and duplication
The Role of Federalism in Health Surveillance

in health between levels of government and clarify roles and responsibilities. This group reported to the Council of Deputy Ministers and identified that large gaps existed in health surveillance.

*Integration Design Team:* Evolved from the Working Group on Overlap and Duplication. Comprised of health-surveillance experts from across the country, this Design Team was established to create an integrated national health-surveillance network. It reported to the Surveillance Transition Team and the Council of Deputy Ministers.

*Network for Health Surveillance in Canada Health Surveillance Working Group:* An F/P/T working group which built on the work of the Integration Design Team. This group is to be responsible for advising on the development and implementation of the surveillance network. It will report to an F/P/T Advisory Committee on Health Infostructure.

*Other Advisory and FPT Committees Involved in Surveillance Initiatives*

- Committee on Environmental and Occupational Health
- Council of Chief Medical Officers of Health
- Public Health Working Group Subcommittee of the Advisory Committee on Population Health
- Advisory Committee on Epidemiology
- Technical Advisory Committee on Public Health Laboratories

*Other Key Stakeholders*

*Industry:* CANARIE (the Canadian Network for the Advancement of Research, Industry and Education), a private, not-for-profit organization working to assist in the development of a Canadian Internet infrastructure. It is supported by Industry Canada. CANARIE called for Health Canada to work with the provinces and territories to develop a national strategy for the institution of an integrated health information network.

*Community epidemiologists and local public health officials:* created a bottom-up pressure to develop a coordinated approach to health surveillance to address major gaps in health surveillance.
NOTES

1 See Duane Adams, “Introduction and Overview,” in this volume.
4 Canada, Department of Health Act, 1996, c. 8; Statistics Act, 1970-71-72, c.15, s. 1.
5 C.P. Shah, An Introduction to Canadian Health and Health Care System, 2d ed. (Toronto: Department of Preventative Medicine and Biostatistics, University of Toronto, 1987).
8 Partnership for Quality, Timely Surveillance Leading to Action for Better Health, proposal to Develop a Network for Health Surveillance in Canada (Ottawa: Minister of Public Works and Government Services, 1999).
14 Ibid.