Pan-Canadian Public Health Network
Partners in Public Health

Blueprint for a Federated System for Public Health Surveillance in Canada: Vision and Action Plan

"Public health is society's collective effort to put in place structures, processes and systems that protect everyone's health. Collaboration is at the heart of this effort: success in public health depends largely on our ability to work together across jurisdictions, disciplines and sectors."

2016

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Quebec will not participate in the **Blueprint for a Federated System for Public Health Surveillance in Canada**. However, based on its interests, it may participate in working groups for the protection of public health and to share information and best practices.

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EXECUTIVE SUMMARY

The Blueprint vision and action plan is a high level framework document that lays out the core infrastructure elements and collaborative context needed for the Federated System for Public Health Surveillance in Canada. It describes the formalization of an envisioned collaborative system of equal partners who demonstrate leadership and obligate themselves to act according to their capacity and resources in ways that are non-binding and resource neutral. This formalization aims to establish the necessary infrastructure to support enhanced responsiveness, and increased efficiency and effectiveness across Canada and across jurisdictional levels. The Federated System presents opportunities for sharing existing and emerging surveillance infrastructure, without imposing a rigid singular solution. It aligns surveillance activities, while recognizing the reality of both shared and autonomous surveillance activities.

Vision for the Federated System for Public Health Surveillance

The Blueprint Vision (Part 1) describes the core infrastructure elements of the Federated System for public health surveillance or the "what" of the Federated System. It presents a high-level view of a more responsive and integrated system for public health surveillance across Canada and across jurisdiction levels. However, what is intended is not a 'how to' manual for public health surveillance. It does not propose rebuilding public health surveillance "*from scratch*". Rather, it proposes a collaborative pathway to a more efficient and effective system, building on the excellent public health surveillance already being undertaken and the strong relationships among surveillance partners. The Blueprint recognizes past successes and previously identified gaps and, with its Action Plan, proposes a means of addressing these key gaps in public health surveillance in Canada using a federated approach.

Action plan for the formalization of infrastructure for federated public health surveillance

Part 2, the Action Plan to achieve a Federated System, concretely describes the high-level actions required to achieve this vision, which also can be called the "how".

Five priority action items have been identified as the core infrastructure building blocks of the Federated System. Each of these building blocks represents an area of collaborative development of surveillance infrastructure, where surveillance partners realize shared benefits as an outcome of working together in the Federated System.

While the Action Plan may point to areas where investment may be needed to achieve a federated approach to surveillance, the Blueprint does not focus on resources. A federated approach to public health surveillance aims to do the right collaborative surveillance in the most efficient way and aims to use our fiscal and human resources on shared objectives to maximize the benefits of surveillance for all Canadians.

Blueprint Overview – Frequently Ask Questions

A resource to help facilitate understanding of the Blueprint Vision and Action plan has been included in the form of Frequently Asked Questions, attached as Annex 1.

Action Plan Infrastructure Priorities and Strategic Objectives:

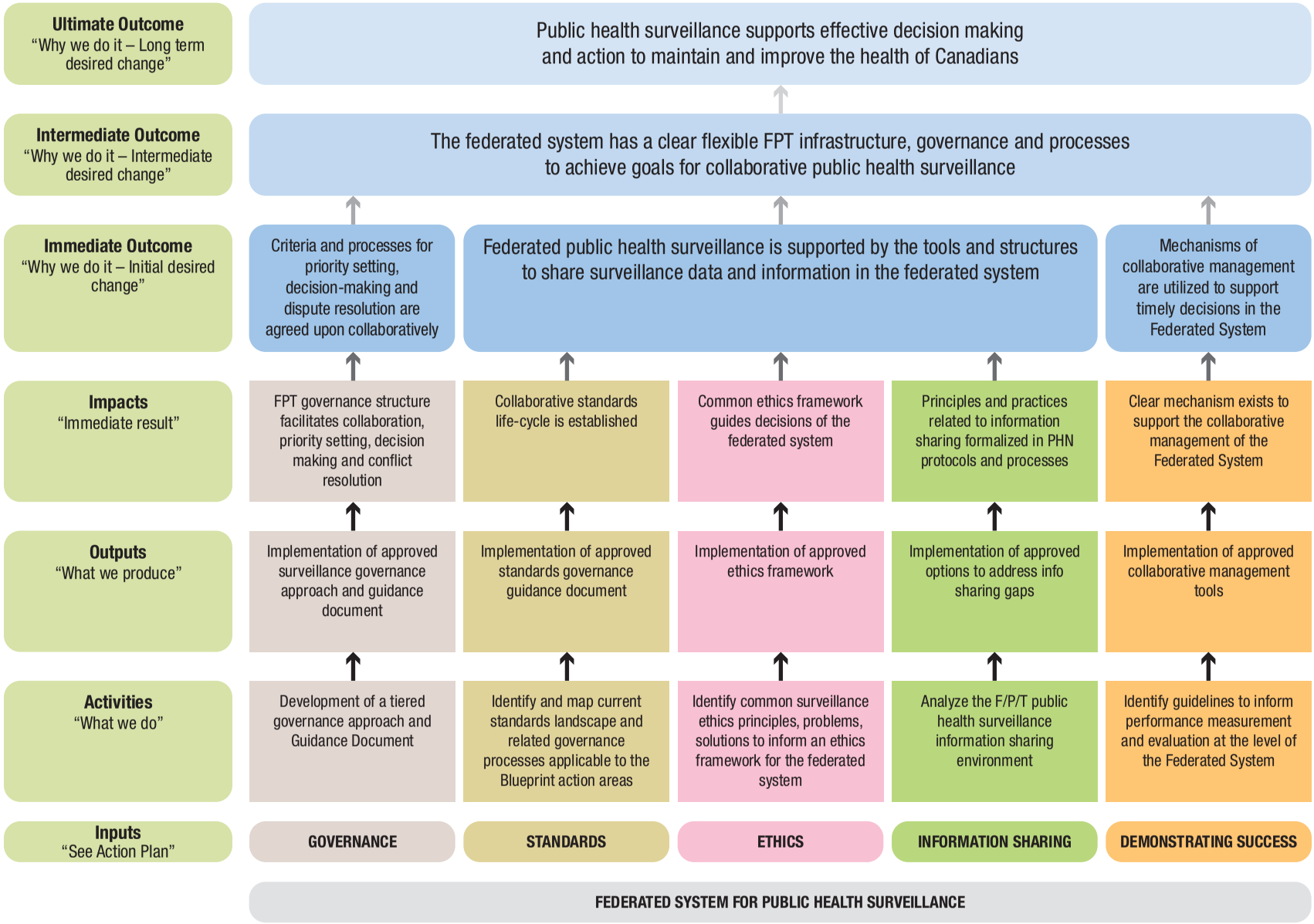
1. Governance of the Federated System – Structures and processes to guide collaborative development of infrastructure
    - To develop a tiered surveillance governance approach that utilizes existing Pan-Canadian Public Health Network structures and mechanisms, and identifies the most appropriate level of authority for the full range of surveillance discussions needed and decisions to be taken.

2. Standards in the Federated System – Supporting policy, data and information interoperability
    - To identify the key players and current environments that shape the development, implementation, and assessment of standards required for the Federated System for public health surveillance. This will lead to the identification and implementation of a collaborative process for standards development.
3. Ethics for the Federated System – From ethos to ethics, the identification of collaborative surveillance principles
    - To develop an integrated ethics approach and tools for public health surveillance based on many organizationally based and practice-based ethics guidelines and frameworks for public health. This approach and tools will identify shared values and principles as a resource supporting effective surveillance processes and structures spanning jurisdictional mandates in the Federated System for public health surveillance.
4. Information Sharing – Linking federated surveillance plans and priorities with information exchange
    - To identify and develop options for addressing barriers to timely and meaningful exchange of public health information in the Federated System
5. Demonstrating the success of the Federated System – Continuous quality improvement through performance measurement and evaluation
    - To develop and implement continuous improvement tools and guidelines that inform performance measurement and evaluation of the Federated System; and, to identify criteria supporting assessments of the infrastructure elements of the Federated System. This will support its governance by providing management with information on system functioning for decision making.

For each priority area in the Blueprint Action Plan (Part 2), context, gaps, strategic goals, strategic objectives, objectives, principles, criteria for success, measures of success, dependencies, risks and key tasks have been identified.

To provide an overview and aid discussion, a logic model (see Page 3) depicts the connection between the activities in each priority area and the strategic objectives of the Federated System.

Logic Model – Blueprint for the Federated System for Public Health Surveillance



PART 1 – VISION
PURPOSE AND STRUCTURE OF THE BLUEPRINT

The Blueprint for a Federated System for Public Health Surveillance in Canada is a two-part document outlining a vision for a more responsive system to support public health surveillance across Canada and articulating an action plan to achieve this vision.

Part 1, Vision for a Federated System for Public Health Surveillance in Canada, describes the Blueprint vision and core infrastructure elements of a Federated System for surveillance – the *'what'* – alongside considerations for putting those elements into place in Canada.

Part 2, Action Plan to achieve a Federated System for Public Health Surveillance in Canada, builds on the vision and elements described in Part 1, and concretely describes the key tasks needed to strengthen the system and implement the vision – the *'how'*.

The Blueprint describes a high-level view of a more responsive and integrated system for public health surveillance across Canada and across jurisdiction levels. However, what is intended is not a 'how to' manual for public health surveillance, nor does the Blueprint propose to rebuild public health surveillance *"from scratch"*. Rather, with a focus on surveillance infrastructure, it proposes a collaborative pathway to a more efficient and effective system, leveraging the excellent public health surveillance already being undertaken at various jurisdictional levels and the strong relationships among surveillance partners. The Blueprint recognizes past successes and previously identified gaps and, with its Action Plan, proposes a means of addressing these key gaps in public health surveillance infrastructure in Canada, using a federated approach.

While the Action Plan may point to areas where investment may be needed to strengthen the federated approach to surveillance, the Blueprint does not focus on resources. A federated approach to public health surveillance aims to support the right collaborative surveillance in the most efficient way, to establish shared objectives, and to use our fiscal and human resources, to maximize the benefits of surveillance for all Canadians.

1. WHAT IS A FEDERATED SYSTEM FOR PUBLIC HEALTH SURVEILLANCE?

Key points

- Public health surveillance provides timely intelligence on the health of the population and informs effective responses to emerging and ongoing issues, and other public health challenges.
- Currently, public health surveillance in Canada operates within a collection of interdependent systems, set up along jurisdictional lines to deal with specific diseases, injuries and risks to and determinants of health.
- In the Blueprint, **federated** refers to a collective activity, done for mutual benefit, in a consistent fashion, by equal partners who retain autonomy over their own activities.
- A Federated System for public health surveillance reflects the shared responsibility for health surveillance across jurisdictions and presents opportunities for sharing infrastructure, without imposing a rigid singular solution.
- While considerable progress has been made in the past decade, national surveillance does not yet fully reflect the repeated recommendations, from Naylor and others, to make systemic improvements.
- The Blueprint proposes an evolution of existing systems, practices and collaborations to achieve the vision of a Federated System for public health surveillance in Canada.

WHAT IS PUBLIC HEALTH SURVEILLANCE?

By 1968, the World Health Assembly had adopted the concept of population surveillance as an essential function of public health practice (Lucas, 1968). This function is often represented as a cycle that includes continuous improvement and, most importantly, a way to support public health decision making and other actions. An effective surveillance system includes the following activities:

- detection and notification of health events
- collection and consolidation of pertinent data
- investigation and confirmation of individual cases or injuries and outbreaks
- routine analysis and creation of reports
- feedback of information to those providing the data
- feed-forward (i.e., the forwarding of data to more central levels)

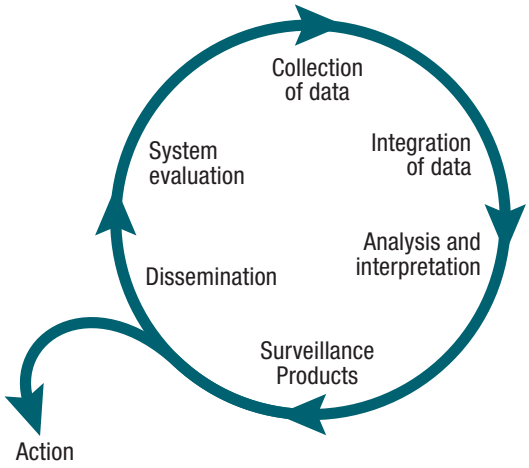


Figure 1: Public Health Surveillance Cycle

Given this definition and representation of the surveillance cycle, it could be summarized that:

> *"Health surveillance is … the starting point that leads to the production of accurate and timely public health intelligence on the health of the population and guides effective responses to emerging issues and public health challenges as well as facilitating public health planning and decision making. As such, health surveillance is also central to our relationships with public health partners and stakeholders from coast to coast to coast, and internationally."*
>
> *PHAC Surveillance Strategic Plan 2 (2013–2016)*

Therefore, as a core function of public health that provides essential information for action, surveillance is a cornerstone for decision making. It provides timely intelligence on the health of the population and informs effective responses to emerging and ongoing issues, and other public health challenges. Acting in the absence of such information can have immediate and disastrous consequences for individuals or whole populations.

SURVEILLANCE AS AN INTERCONNECTED AND INTERDEPENDENT INTERGOVERNMENTAL ENTERPRISE

Surveillance has been a key activity of public health departments and local authorities for over a century in Canada. Over the last fifty years, vast quantities of health information have become available to support public health actions and decisions. Analytic methods have become more sophisticated. The global context of public health has become increasingly complex because of trade, travel and migration. Surveillance can no longer be considered primarily a local activity, but must be acknowledged as an interconnected and interdependent enterprise. National governments, including Canada's, are devoting considerable effort towards becoming more open with respect to data of value to consumers, the private sector, other governments, and academia and non-governmental organizations.[1]

Risks to health are not limited by political and geographic boundaries. Only in very rare instances will the tools and methods for surveillance be of use in just a single location. This suggests that efficiencies can be realized through collaboration. In most situations, some form of national coordination of information is required across levels of government; indeed, for some diseases, international coordination is mandated through the World Health Organization and the World Organisation for Animal Health (OIE).

> *In the Blueprint, the terms **surveillance**, **health surveillance** and **public health surveillance** are used interchangeably.*

Core Functions of Public Health[2]

- Public health surveillance
- Population health assessment
- Disease and injury prevention
- Health promotion
- Health protection
- Emergency preparedness and response

1 http://data.gc.ca in Canada, http://data.gov in the USA and http://data.gov.uk in the UK

2 This list may vary by jurisdiction, but these six will encompass the activities of a typical public health organization.

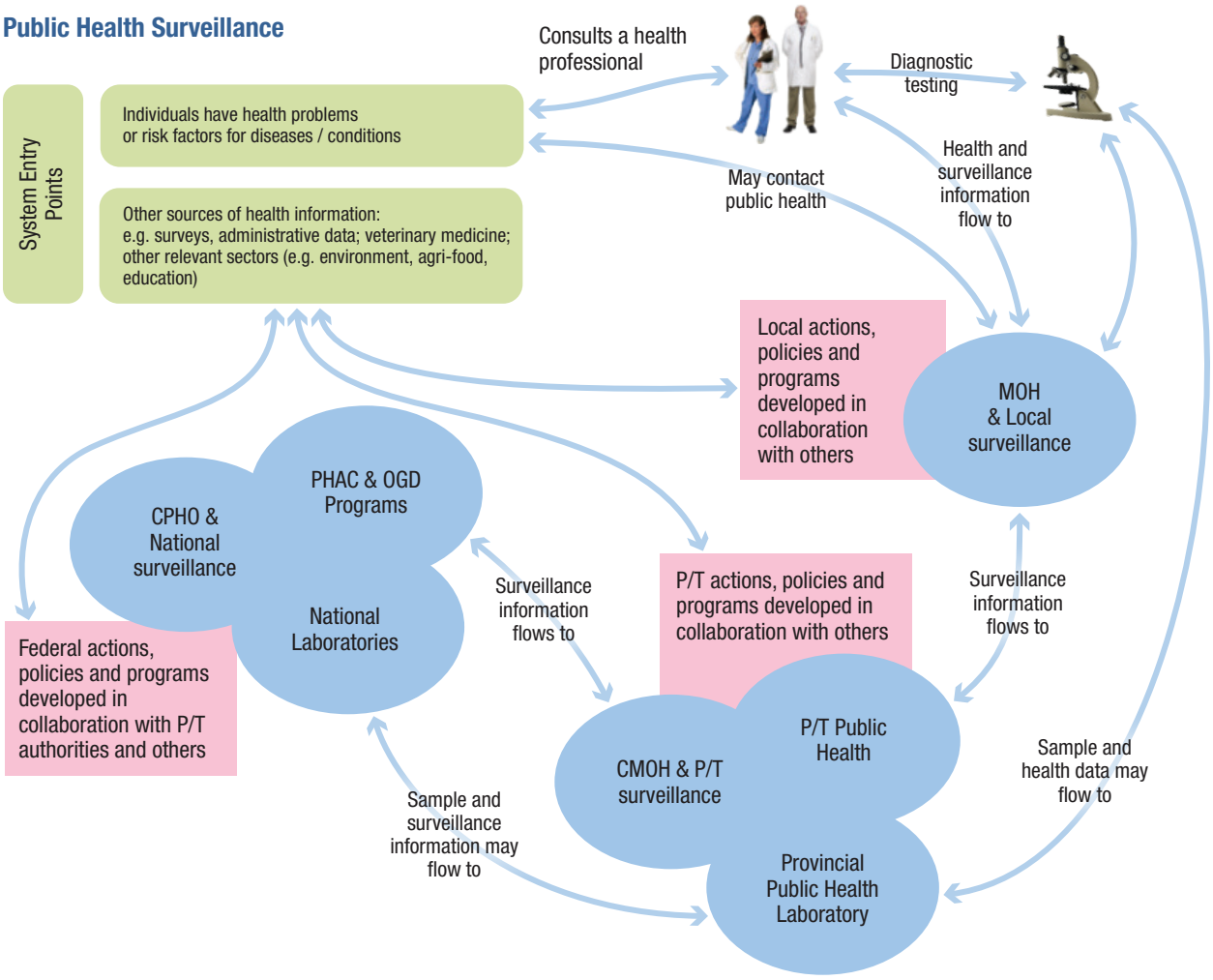


Figure 2: Public Health Surveillance – information for action

WHAT IS A 'FEDERATED APPROACH' TO PUBLIC HEALTH SURVEILLANCE?

Currently, public health surveillance in Canada operates within a collection of interdependent systems, set up along jurisdictional lines to deal with specific diseases, injuries and risks to health. If we consider **public health** as a collective activity serving all Canadians, then the *surveillance enterprise* can be described as a collective of surveillance systems with similar purposes, but varied in focus. A federated approach outlines that these systems should not operate in isolation, but should be (and are) connected in various ways. In the Blueprint, **federated** refers to a collective activity, done for mutual benefit, in a consistent fashion, by equal partners who retain autonomy over their own activities. It comes with obligations and requires leadership, which may be distributed across the partners.

A federated approach is not a new idea in public health surveillance in Canada, first being described in the proposal for a Network for Health Surveillance in Canada (1999) that sought to "improve the collection, access to, and use of health information, and thus facilitate timely evidence-based decisions that will protect and promote the health of Canadians." (Proposal to Develop a Network for Health Surveillance in Canada, 1999, p22–23)

> *In the information management world, federation is generally described as the ability to access information and communicate between disparate content silos.*
>
> *– Reed E. Irvin*
> *Getting From Point A to Point B:*
> *What it Means to Take a Federated Approach*

In the context of public health surveillance in Canada, the Federated System is envisioned as a national network of systems and activities that:

- is based on a commitment among the partners to work together in an organized manner for the collective benefit of Canadians;
- has explicit governance;
- respects jurisdictional legislation related to public health surveillance;
- does not depend on individual practitioners to function, but emphasizes the institutional linkages among organizations within the Federated System;
- protects individual privacy or meets the individual's expectation of their right to privacy;
- is purposeful, that purpose being to inform public health actions and policies;
- supports sharing of appropriate data to support that purpose;
- is accessible by public health programs at the federal, provincial/territorial, and local levels, as well as to partners and stakeholders;
- combines epidemiological and laboratory sciences wherever appropriate; and
- strategically links people, processes, and technologies.

Partners in a Federated System may choose to give up some autonomy for the common good and, in return, share in distributed leadership and shared benefits. For example, while the outputs of 'local' surveillance activities may be of limited use to other jurisdictions, a Federated System presents natural opportunities to share the experiences, practices and knowledge gained with other partners.

A Federated System presents opportunities for sharing and creating greater alignment of infrastructure, without imposing a rigid singular solution; aligning surveillance activities, while recognizing the multiple purposes of surveillance and the reality of both shared and autonomous surveillance activities (see Annex 2).

THE NEED TO WORK TOGETHER

A Federated System for public health surveillance reflects the shared responsibility for health surveillance across jurisdictions. Effective surveillance is often national in scope, not limited to a single jurisdiction or a single level of public health. Despite variation in the public health roles and responsibilities across jurisdictions, there is growing recognition that a federated model for public health surveillance in Canada is critical in this changing landscape.

> *"Governments will be judged on the accuracy, robustness and timeliness of the information they provide to their citizens, as well as by their actions to prevent and mitigate public health risks, particularly in times of stress (e.g., outbreaks, pandemics, serious emerging trends in chronic disease risk factors)."*
>
> *Surveillance Policy Framework Presentation to PHNC/CCMOH*
> *May 2012*

The Blueprint refers to infrastructure that supports surveillance activities. The illustration below shows the broad range of organizations and mandates engaged in public health; the importance of connecting data to action exists at all levels; and the supporting, core and foundational elements that are required to ensure effectiveness and efficiency.

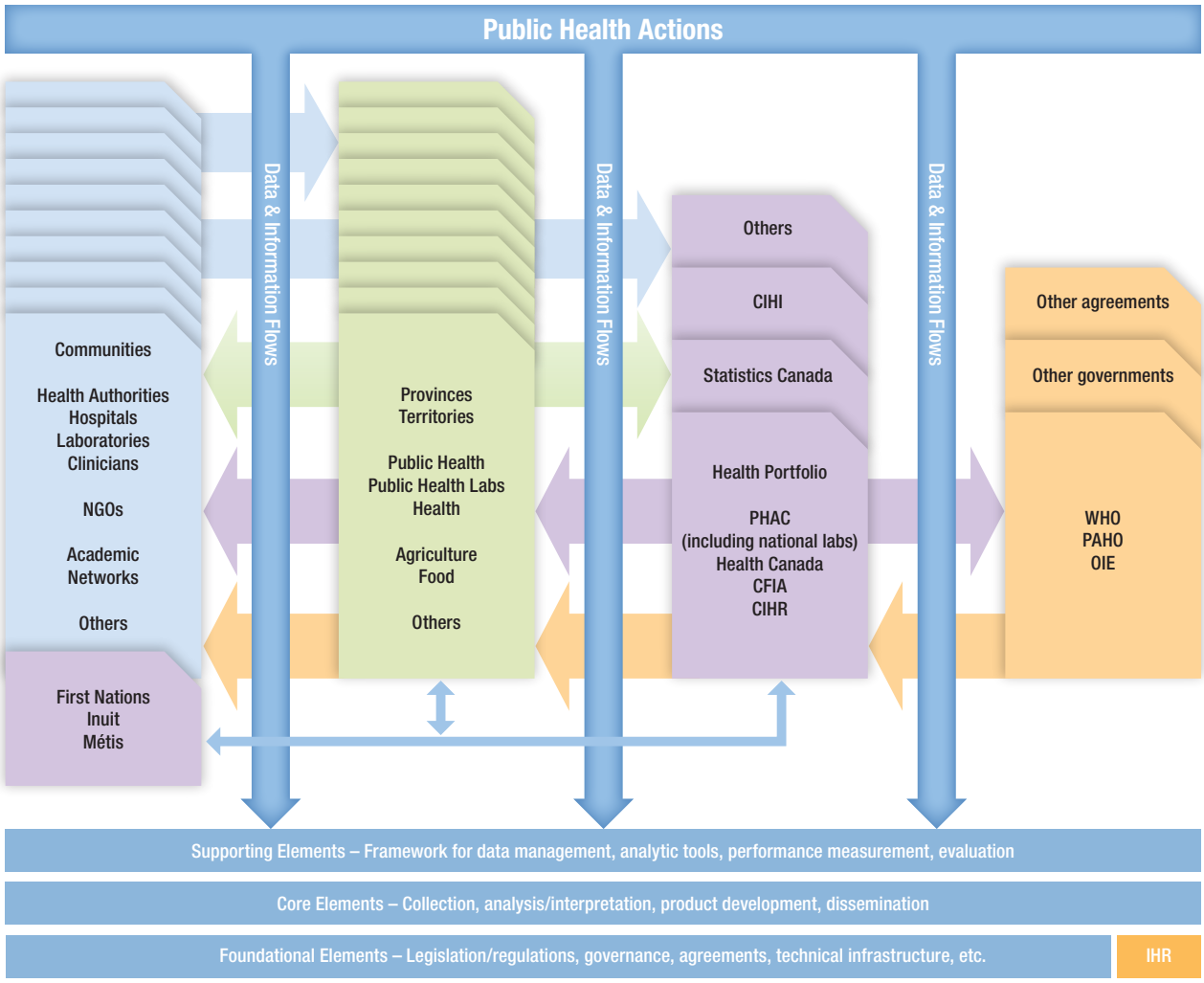


Figure 3: A federated model of health surveillance in Canada[3]

3 Data & Information flows are not unique to surveillance – e.g. provincial data flows to CIHI and back; nor are they monolithic as depicted. Also, the First Nations, Inuit and Métis channel is shown because of its unique character within the local – federal context.

WHY A BLUEPRINT FOR A FEDERATED SYSTEM FOR PUBLIC HEALTH SURVEILLANCE?

The Blueprint builds on extensive work begun in 1999 with the National Health Surveillance Initiative, which aimed to improve the way public health surveillance is undertaken in Canada. Public health has made considerable advances in surveillance in the past decade. However, there are limitations. National surveillance in Canada does not yet fully reflect the repeated recommendations, from Naylor and others, to make systemic improvements. In spite of improvements in surveillance, post-outbreak reviews have repeatedly called for recommendations to enhance public health surveillance (e.g., Walkerton, SARS, Listeria, pandemic influenza H1N1).

The Naylor report indicated the specific need for national cooperation.

> *"[A] more cohesive, comprehensive approach to public health must form the basis for a sustainable public health system. This means cooperation not only across governments but also within governments, and involves the private sector, non-governmental organizations, and the public. This is no easy task." (pg. 19)*
>
> *"Systems-based thinking and coordination of activity in a carefully-planned infrastructure are not just essential in a crisis; they are integral to core functions in public health because of its population-wide and preventive focus." (pg. 212)*
>
> *– Learning from SARS,*
> *Renewal of Public Health in Canada, 2003*

Among the significant challenges remaining is that information held locally cannot always be easily shared within or across jurisdictions.

Indicators of the absence of a shared surveillance data sharing infrastructure

- varied jurisdictional legislative and regulatory contexts place competing demands on existing human resources, especially at the local level
- reliance on paper records
- incompatible electronic record-keeping systems
- lack of data standards
- lack of common objectives
- lack of knowledge of data holding amongst systems

NOT JUST A CANADIAN PROBLEM

Canada is not alone in facing these challenges. The United States Centers for Disease Control (CDC) has outlined at least six major concerns that must be addressed by the public health community as part of their vision for public health surveillance in the 21st century: a common lexicon, definitions, and conceptual framework for public health surveillance; global surveillance needs; informatics, including information technology; a skilled workforce; data access and use; and data management, storage and analysis.

The European Centre for Disease Control (ECDC) transformed more than 17 independent surveillance networks covering 27 countries speaking 23 official languages into an integrated surveillance system for infectious diseases. In a 5-year transformation period, The European Surveillance System (TESSy) was implemented.

While the European system is not without its challenges, significant success has been experienced and credited in part to legislation and regulations; agreements on objectives and standards; efforts to improve data quality; and increased buy-in as partners began to reap the benefits of enhanced cohesion.

In Canada, the Federated System for public health surveillance should not be confused with an integrated 'surveillance system', such as TESSy. Nevertheless, there are lessons to be learned from the ECDC experience, particularly in the areas of standards, data quality, and interoperability of systems.

FROM THE CURRENT STATE TO THE FEDERATED VISION OF SURVEILLANCE

CURRENT STATE	GAP	FEDERATED VISION
Incomplete implementation of repeated recommendations for public health surveillance in Canada	Progress has occurred, but is limited by lack of shared vision and action plan to achieve it	Canada has a Blueprint for a Federated System for Public Health Surveillance in Canada which includes an action plan to implement
Few standards and agreements for information sharing Delays in timely use of surveillance information for programs and policy	Barriers to timely and meaningful exchange of data Data not shared	Appropriate sharing and timely use of surveillance information to benefit the health of Canadians Clear expectations for timely analysis and reporting for national surveillance programs

AN EVOLUTIONARY APPROACH

The Blueprint proposes an evolution of existing systems, practices and collaborations to achieve a Federated System for public health surveillance.

FROM	TO
Disparate surveillance systems within and across jurisdictions	Integrated surveillance – an efficient national network of prioritized Public Health surveillance systems
Inconsistent data standards	Common standards and protocols for data gathering, custodianship, data definitions, sharing and dissemination
Informal and ad hoc agreements for data and information sharing	Formal agreements for the collection, use and dissemination of Public Health information
Policies and actions based on outdated or limited surveillance data	Timely surveillance products to support public health actions of policy-makers and decision-makers
Duplication of effort	Increased sharing of data and resources
Lack of a consistent approach to F/P/T surveillance priority setting	Effective governance for joint surveillance priority setting
Varied jurisdictional legislative and regulatory contexts poses challenges and barriers to information sharing	A common understanding of the various legal contexts that inform and guide public health information sharing and decision making that forms the basis to address and overcome barriers

The following chapters explore the infrastructure required to implement a federated approach to public health surveillance in Canada.

2. ETHICS, AUTHORITIES AND AGREEMENTS

Key points

- Public health surveillance activities are undertaken for the public good. Within a Federated System, there will be a common, explicit, ethics guidance framework for surveillance.
- Although effective sharing of public health information for defined and agreed upon purposes is fundamental to a successful 'systems approach' to surveillance, primarily informal mechanisms currently exist in public health for systematic data sharing across governments.
- The Federated System for surveillance must work within legislation and authorities to formalize data sharing agreements, building on work already underway in this context.
- A Federated System must be able to respond promptly during a public health event, based on agreements that are in place.

The primary motivation for public health surveillance is to ensure the health of populations (*Health for All*, WHO). The Canadian reality is that public health activities involve partnerships among local, provincial, territorial, federal and international jurisdictions, as well as non-governmental and private organizations. Partnerships for surveillance in a Federated System must have not only a legal foundation, but also require a basis in ethics to provide a common lens for articulating potential conflicts in values in the development and operation of surveillance systems across the legal boundaries of jurisdictions.

PUBLIC HEALTH ETHICS

Public health surveillance is undertaken for the common good; that is, public health uses the information gained to develop and deliver programs and policies aimed at protecting and improving the health of populations. To this end, professionals in public health subscribe to various professionally and jurisdictionally defined codes of ethics developed to inform their scope of practice.

Discussions of public health ethics in Canada are relatively recent and evolving.[4] However, it is recognized that ethics provides a principle-based guide or map that can be used to analyse the increasingly challenging issues that arise in public health. Public health initiatives, including surveillance, are often characterised by uncertainty regarding the best course of action. There have been relatively few publications on ethics and public health surveillance in Canada (For example Désy, M., Filiatrault, F., and Laporte, I. 2012). Internationally, in 2014 the World Health Organization (WHO) launched a project to develop WHO Guidelines on Ethical Issues in Public Health Surveillance[5] and the Public Health Agency of Canada is currently monitoring the development of this project for application in Canada and to help inform approaches relevant to the Federated System.

In general, ethics can contribute to enhanced decision making for surveillance by broadening the scope of analysis and highlighting additional elements that ought to be considered. The following principles demonstrate the practical application of ethics in public health surveillance and are considerations for the articulation of a common ethics framework for the Federated System.

4 See the National Collaborating Centre for Healthy Public Policy web site at www.ncchpp.ca/en/ for public health ethics resources.

5 www.who.int/ethics/topics/surveillance/en/

Practical Application of Ethics in Public Health Surveillance

- Public health surveillance data should be acquired, used, disclosed, and stored for legitimate public health purposes.
- Public health surveillance data acquired should be limited to that reasonably necessary to achieve the public health purpose.
- Public health surveillance data may be used only for the legitimate public health purposes for which it is acquired.
- Identifiable public health surveillance data may be disclosed only when justified, for public health purposes, and subject to strict privacy and confidentiality standards.
- Public health surveillance data should be stored and managed in a physically and technologically secure environment.

Ethics in public health surveillance,
adapted from *Principles and Practice of Public Health Surveillance*,
3rd ed. Oxford University Press, 2010

LEGAL BASIS FOR PUBLIC HEALTH SURVEILLANCE

The Constitution Act, 1867, outlines the division of responsibilities between provinces and the federal government. While the majority of health care responsibilities were given to the provinces, responsibility for public health was not as clearly allocated, with federal and provincial governments sharing responsibilities (Wilson, 2004). Federally, the *Department of Health Act and the Public Health Agency of Canada Act* primarily provide the mandate for national public health surveillance.

The authority for public health and public health surveillance in the provinces and territories is set out in public health legislation, particularly regulations governing infectious diseases (Wilson, 2004). They place obligations on local authorities, health practitioners, laboratories and others through regulations that establish a list of reportable diseases requiring specific measures. This list forms the basis for the implementation of reporting systems.

LEGISLATIVE FRAMEWORKS

While governments' use of data must respect legislation and be consistent with protecting individual rights, under current legislation there continue to be information sharing challenges associated with pursuing the public good.

Many provincial public health acts focus solely on health protection responsibilities and not the full range of core public health functions. Some, however, reflect the broader scope of core system functions (BC, SK, ON, QC, PE), although how these are expressed varies. Quebec's legislation most closely aligns with how core functions are described in key pan-Canadian reports. Nova Scotia has indicated an intention to develop comprehensive legislation. While the Acts in the Yukon and Northwest Territories (NT) have recently been updated, Nunavut's act was largely imported from NT and dates back to 1957. A new Act is in development there, and a more comprehensive perspective to public health is proposed. Some Provincial/Territorial legislation (e.g., Manitoba and Quebec) identifies the need for sharing information with the federal government, while others are silent on this issue.

SHARING OF PUBLIC HEALTH INFORMATION

Public health information sharing practices are determined by jurisdictional health legislation, and the provisions of privacy and access to information legislation. While privacy legislation seeks to protect individual privacy, access to information legislation provides a right of access to information in records under the control of a government institution.

Federal, provincial and territorial privacy laws define personal information and the conditions for sharing this information. Within this context, information sharing in the public health domain distinguishes administrative purposes (decision making about individuals) from non-administrative purposes (aggregate use: reporting, statistical, research, evaluation, epidemiological).[6] In addition, other sharing of public health information, such as that which may take place with various stakeholders under access to information legislation, must respect the rights of individuals to protect their personal information and the provisions that exempt the disclosure of personal information consistent with privacy laws.

Although effective sharing of public health information is fundamental to a successful 'systems approach' to surveillance, data sharing across governments primarily relies upon informal mechanisms. The current approach to information sharing is ad hoc, comprising informal historical processes, formal and informal arrangements between specific parties for specific purposes, sometimes through informal collegial relationships. In addition to information sharing among health ministries, Statistics Canada plays a significant role, and through the *Statistics Act* has considerable authority, to collect health information, as well as vital statistics. The Canadian Institute for Health Information has an important and growing repository of health data and is working with PTs on improving data quality. These organizations are critical partners that provide necessary data to support public health surveillance.

To begin to address some of the noted information sharing challenges, the Federal/Provincial/Territorial Multi-Lateral Information Sharing Agreement (MLISA), which came into force in October 2014, outlines when, what, and how infectious disease and emerging public health events information will be shared between and among jurisdictions, while continuing to respect the existing legislation within jurisdictions. The main body of the agreement includes Annexes on governance, data management and public health events of international concern. MLISA is based on a model that allows the addition of technical annexes over time, based on agreed-upon national surveillance priorities, when these are determined.

FROM THE CURRENT STATE TO THE FEDERATED VISION ON ETHICS, AUTHORITIES AND AGREEMENTS

CURRENT STATE	GAP	FEDERATED VISION
Informal agreements on purpose of and arrangements for information sharing Some formal disease-specific agreements and movement towards creating formalized information sharing technical annexes as part of MLISA for infectious diseases and public health events of international concern Few formal links to electronic health records	Agreements in place may not stand the test of law Approach to formalize data sharing agreements in the context of non-communicable diseases No basis for conflict resolution Piecemeal approach to data sharing	Partners in the Federated System agree to share data under appropriate conditions Clear expectations for timely analysis and reporting for national surveillance programs Appropriate standards to support information sharing Broad agreement on principles and practices related to data sharing across jurisdictions Data sharing agreements in place
No explicit public health code of ethics to guide professionals working in the area of health surveillance	Lack of a common articulation of public health ethics	An ethics framework for the federated surveillance system is in place

6 This distinction may vary across jurisdictions.

3. GOVERNANCE

Key points

- Currently in Canada, there are multiple fora for decisions on surveillance; priority setting and decision making on surveillance activities are not always undertaken collectively.
- One of the most important aspects of a Federated System for public health surveillance is a shared governance model for collective priority setting and decision making, where appropriate.
- Jurisdictions retain autonomy with respect to resource expenditures and the actual operation of surveillance for their own purposes.
- In the Blueprint vision, it is recommended that surveillance governance is undertaken through the existing public health governance structure: the Pan-Canadian Public Health Network.
- The articulation of a clear dispute resolution process, achieved through clarifying and refining existing mechanisms, will be essential for the effective operation of the Federated System.

Public health surveillance is a shared responsibility among Federal, Provincial, Territorial and local jurisdictions. This Chapter outlines the roles and responsibilities of people, positions, organizations and the jurisdictions involved in the proposed Federated System.

The principles and purposes of public health surveillance are similar across jurisdictions and levels (local, P/T, federal, international). It is beyond the scope of this document to elaborate on the differences beyond a brief discussion of surveillance roles. Suggested surveillance roles within the Federated System are outlined in Annex 2.

LOCAL ROLES

The local level (health unit in Ontario, health authority or region in other provinces) plays a key role in the delivery of the core programs in public health. The local level is usually the first line of detection of new or emerging diseases and other potential threats to public health, even when they are not designated as reportable. In fact, such surveillance may not involve public health authorities until a reportable situation is encountered. For example, routine hospital infection surveillance has its own purposes in that clinical setting and local public health would only be aware of reportable diseases or outbreaks.

The local medical officer of health (MOH) has authority to collect information under jurisdictional-specific public health legislation. The local medical officer of health, and her/his delegates, will be the first point of contact from the public or others reporting individual cases or concerns. The local health authority has a role to triage reports and often will make direct contact with individuals to gather more information. This case investigation role, for diseases deemed 'reportable' under legislation, is directly aligned to the traditional surveillance concept of vigilance, but is used also as a key point of surveillance data collection.

Similarly, local laboratories are the initial points of information gathering for surveillance programs that rely on the identification of pathogens or toxins in human or other samples.

Local public health authorities undertake all surveillance activities with a view to their own populations and 'close the loop' through reporting to practitioners and the public.

PROVINCIAL AND TERRITORIAL ROLES

Provinces and territories work collaboratively with a wide range of parties at the local level, including clinicians, public health staff, primary care providers, hospitals and emergency rooms, laboratories, schools, and other service providers and collectors of health-related data. Provincial and territorial legislation requires the reporting

of notifiable diseases to public health officials. While the reporting chain may vary across the provinces and territories, the office of the local medical officer of health will usually be the primary recipient of medical information, which is then forwarded to the provincial or territorial authority for public health. Provinces and territories are also custodians of health administrative data that is useful for surveillance, including clinical, laboratory and drug utilisation data. Thus, provinces and territories are the major contributors of surveillance data to the national level. Collaboration is needed to ensure that the legal obligations of the Government of Canada are met, nationally and internationally.

FEDERAL ROLES

The legislative authority over health, including public health, under the constitution is a shared responsibility between federal and provincial/territorial jurisdictions.

The Government of Canada has unique responsibilities for certain federal populations–those populations for which the federal government either provides health care and benefits, goods and/or services, or reimburses the cost of providing health care and benefits. Surveillance activities are conducted among these populations under federal responsibility.

The federal government role in public health surveillance includes acting as the formal link between Canada and global and regional organisations (e.g., WHO, PAHO, ECDC) or other countries' organisations (e.g., CDC). For surveillance purposes, this includes collating and aggregating information from the Provinces and Territories to provide a national picture and also providing the international picture to P/Ts. The same surveillance products are of value to public health partners in Canada, especially since they can form the basis of comparisons that provide insight into population health status. The Federal role also includes coordinating surveillance activities across jurisdictions and playing a leadership role in the development, implementation, and evaluation of national surveillance programs.

INTERNATIONAL PARTNERS – WHO AND PAHO

The World Health Organization (WHO) is the directing and coordinating authority for health within the United Nations system. A central and historic responsibility for WHO is the management of the global regime for control of the international spread of disease. The Pan American Health Organization (PAHO) is the specialized health agency of the Inter-American System and serves as the WHO Regional Office. Canada's primary link to these organizations is through the Public Health Agency of Canada.

In 2005, WHO approved a revised version of the International Health Regulations (IHR). State Parties had until 15 June 2012 to meet their IHR core surveillance and response requirements. Canada has been fully compliant with the IHR requirements since this time. This international treaty provides a framework for the coordination of the management of events that may constitute a Public Health Emergency of International Concern (PHEIC). All countries are required to detect, assess, notify and respond to public health events and establish public health core capacities, including surveillance, as outlined in the IHR.

NETWORK GOVERNANCE AS A FOUNDATION FOR THE FEDERATED SYSTEM

Governance is about regulating or controlling how an organization is influenced or steered by establishing procedures to guide functioning and accountability. For example, joint priority setting and decision making are governance activities.

In a Federated System, decisions are made in collaboration with all partners. The Blueprint vision proposes that surveillance governance is undertaken through defined processes using the existing public health governance mechanism: the Pan-Canadian Public Health Network. The governance approach most suited to the Federated System for public health surveillance in Canada is that of a network governance approach. Canada is fortunate to have the foundations of network governance in the Pan-Canadian Public Health Network (PHN).

Network governance also is not a new approach, as it reflects the core of how public health is conducted and is relevant to all aspects of public health. This is true for both routine collaborative actions ("peacetime" actions) as well as for collaborative actions addressing urgent public health events ("wartime" actions); both modes of collaboration require public health practitioners to work with and through networks to accomplish their objectives, but with the latter form of collaboration requiring a greater degree of centralization among multiple organizations that are not part of a traditional hierarchy (Rocan, 2012).

Given the complexity of many current problems and the involvement of a diverse range of interested parties, network-based strategies are foundational. A network governance approach provides the following advantages:

- Increased opportunities to learn from each other and increase knowledge on complex issues;
- Increased opportunities for innovation;
- Increased opportunities to harness resources (financial and non-financial) of other actors;
- Facilitated exchange of information through the development of a common frame of reference; and
- Increased trust, thereby increasing willingness for co-operation on the development and implementation of common strategies and enhanced social cohesion within the network.

The essential governance challenge is to bridge our varied hierarchical organizations with the negotiating, coordinating, linking, adjusting, and joint problem solving required for our collaborative work to ensure that a "greater good" can be achieved than could be achieved by any single hierarchy acting alone. Also, a collaborative initiative doesn't mean that all parties need to be involved.

While agreement on a common agenda, goal or mission is required, the establishment of a common collaborative aim doesn't mean a uniformity of opinion, but rather implies a shared understanding of common goals and objectives. In undertaking collaborative initiatives, network members are free to participate based on a willingness to make investments without the requirement for all network members to participate.

A tiered governance approach is an initial step toward network governance by identifying the distribution of federated surveillance roles and responsibilities across the hierarchical oriented layers of the Pan-Canadian Public Health Network. Network governance practices for the Federated System will be developed through process models and piloting, and will be reflected in an overall federated surveillance governance guidance document.

EVOLUTION OF GOVERNANCE BASED ON THE PAN-CANADIAN PUBLIC HEALTH NETWORK

In a Federated System, decisions are made in collaboration with all partners. The Blueprint vision proposes that surveillance governance is undertaken through the existing public health governance structure: the Pan-Canadian Public Health Network.

The Pan-Canadian Public Health Network (PHN), established by Canada's Federal, Provincial and Territorial Health Ministers in 2005, is a network of public health jurisdictional representatives from across Canada, who work together to strengthen public health in Canada. The Network brings F/P/T governments together to manage public health emergencies and to work on the day-to-day business of public health. This approach can provide efficiencies and collective expertise and experience to deal with common public health issues, such as obesity, and other chronic and communicable diseases. (See Figure 4)

The PHN Council is accountable to the Conference of Deputy Ministers of Health. Deputy Ministers of Health provide direction and approve public health policy priorities for Canada. Some public health issues may be brought to the Conference of Ministers of Health.

The work of the PHN is managed by three steering committees, including the Public Health Infrastructure Steering Committee, which has a mandate to advance the development of public health infrastructure processes and intergovernmental structures required to enable core public health functions, including, but not limited to public health surveillance.

The PHN (Council, Steering Committees, and Task Groups) also receives guidance on technical issues from the Council of Chief Medical Officers of Health (CCMOH), which includes the Chief Medical Officers of Health from each provincial and territorial jurisdiction, a representative from the Public Health Agency of Canada, the Chief Public Health Officer, and the most senior Public Health Physician of the First Nations and Inuit Health Branch of Health Canada.

THE ROLE OF THE PUBLIC HEALTH NETWORK

The Blueprint vision outlines an approach such that governance of a Federated System for surveillance is based on the current structure of the Pan-Canadian Public Health Network.

The mandate of the **PHN Council** is to serve as the senior and central governance body of the Pan-Canadian Public Health Network. The PHN Council is responsible for taking a strategic, coordinated view of the ongoing conduct and operation of the PHN.

PHN COUNCIL MANDATE	IMPLICATIONS FOR A FEDERATED SYSTEM
Providing advice to the Conference of Deputy Ministers of Health (CDMH) on public health matters	Recommend approval of the Blueprint for a Federated System of Public Health Surveillance
Promoting cohesion and coordination among public health groups, to reduce duplication of activities	Promote the Blueprint vision and the Action Plan in all jurisdictions and to other Network partners
Serving as the governance forum for developing and monitoring the key deliverables of the PHN	Provide a focus for dispute resolution – the Terms of References across Council and Steering Committees will require review and revision as necessary for alignment to support dispute resolution mechanisms
Guiding the development of collaborative public health strategies	Oversee the implementation of the Blueprint Action Plan
Preparing, negotiating, implementing and adapting public health agreements as required	Approve data sharing agreements and other collaborative projects and recommend for the approval of CDMH when appropriate

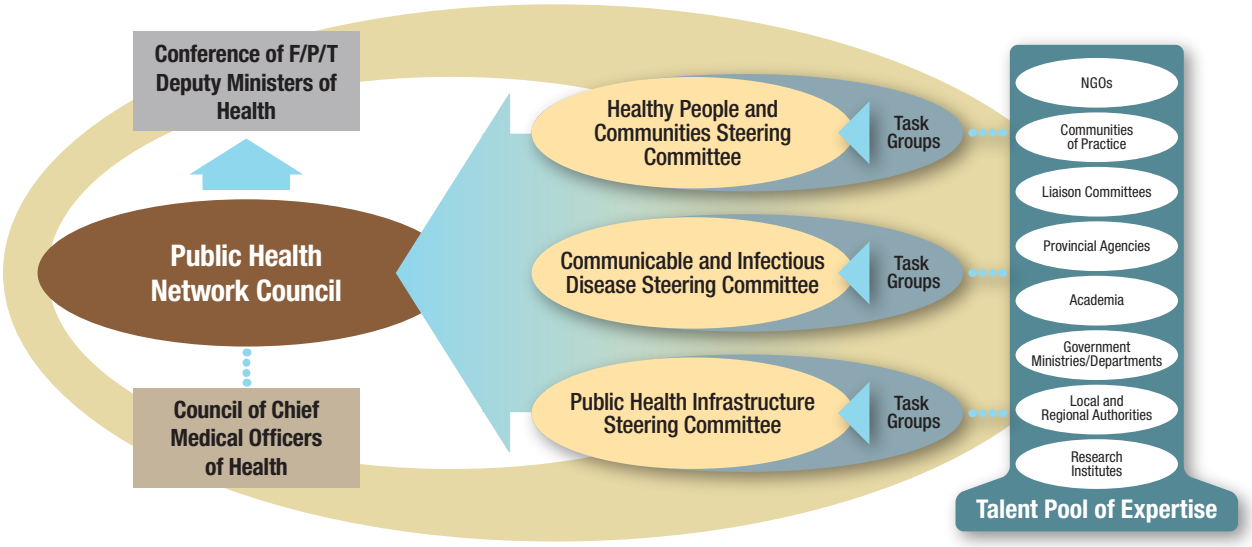


Figure 4: Pan-Canadian Public Health Network Governance Structure

FROM THE CURRENT STATE TO THE FEDERATED VISION ON GOVERNANCE

CURRENT STATE	GAP	FEDERATED VISION
Multiple fora for decisions on surveillance Room to improve in appropriate utilization of the Public Health Network Priority setting and decision making on surveillance activities not always undertaken collectively Surveillance roles are shared	Decision making is not always inclusive of relevant partners Decision making process is cumbersome No agreed-upon set of surveillance priorities National surveillance out of step with local and P/T realities	Clear, appropriate, governance structure for public health surveillance, including priority setting and decision making Forum for conflict resolution Decisions are taken at the appropriate level Clear surveillance roles that derive from legislation, signed agreements where appropriate, or other tools Shared leadership

4. STANDARDS FOR SURVEILLANCE

Key points

- Agreement on standards for surveillance does not mean that surveillance programs must be identical across Canada. Standards define the 'what' and, not necessarily, the 'how' of surveillance. Standards allow diversity of purpose and implementation while ensuring that the meaning of data is consistent when it must be.
- Variation from standards may be acceptable, provided that surveillance programs that require a coherent national picture are able to adjust for or clearly explain provincial and territorial differences.
- For practical reasons, a core set of surveillance data should be standardized, as these data elements will be used in multiple surveillance systems and across all jurisdictions, recognizing that the core data set may differ for infectious and chronic disease surveillance.
- The core set of variables should be extended to include the concept of severity of disease and elements typically used in case definitions.
- Governance of the Federated System for surveillance will allow for technical groups to establish case definitions, core data sets and most other standards, with escalation to a higher level of decision making only when agreements cannot be reached or when proposed standards from different groups are at odds with each other.

This Chapter deals with the standards that ensure that data can be collected, shared, analysed, and acted upon in a mutually comprehensible way.

> *In the Blueprint,* ***standard*** *is used in the broadest sense: a uniform method, process, or consistent set of values and definitions, which are used to achieve a common understanding between parties.*

SCOPE

In a Federated System for surveillance, adherence to standards for surveillance support the meaningful exchange of information, provide for economies of scale and simplified system development, and ensure that agreements and policies are respected.

Standards will be discussed in the context of *foundational elements* that support a Federated System for surveillance. Each of the foundational elements may have roles that go beyond surveillance in the public health system, or even within the health system as a whole. The Blueprint will not consider other uses, but the Action Plan should be implemented in a way to make the best use of existing standards, especially when these are in use elsewhere. The Action Plan establishes a governance process by which surveillance standards can be fully elaborated and agreements reached.

In this Chapter, we describe the standards that are required to ensure a common understanding for efficient exchange and use of information.

CONCEPTUAL ELEMENTS	CONCRETE ELEMENTS
Agreement on what conditions, diseases, risk factors, determinants, and protective factors are under surveillance	Laboratories
Agreed purposes of surveillance	Information technology and computing capability
Scope of information that must be collected to meet the purpose	Modeling and analytics capabilities
Design and planning for collecting and distributing the information/ data to be shared, and management of that information/data	Information dissemination and knowledge translation
Appropriate uses and interpretation of the outputs of surveillance	Communication between different infrastructure elements
	Human resources
	Data sources

Surveillance standards should not be interpreted as being prescriptive and inflexible, but instead as tools to create interoperable systems, taking into account existing infrastructure in different organizations within a Federated System. Clearly, there will be situations, such as emerging pathogens or disasters, when standards must be adapted.

CONCEPTUAL FOUNDATIONAL ELEMENTS

Conditions, diseases, risk factors under surveillance

Resources at all levels are never sufficient to allow for surveillance of everything of interest, and therefore there must be prioritization. To properly undertake surveillance in a Federated System, all those who are expected to be participants must agree, and must agree to the level of effort applied. Having appropriate governance systems in place that will create the forum for discussion and consensus is essential to achieving this agreement.

Agreed purposes of the system

The purposes of surveillance will drive the design of any surveillance. Some diseases or conditions may require more than one approach to meet all of the purposes considered.

Purposes should include a time frame, which may be ongoing. The point at which the purpose has been served could be defined arbitrarily or though criteria such as a threshold incidence rate or absence from a specified population or geographical area. The criteria for “sun-setting” or changing a system should match the purpose for which the system was created.

If a system is proposed and there is no existing purpose statement included in the standard that meets the need, it is reasonable to add a purpose, according to a governance mechanism of the Federated System for adding or revising the list of purposes.

Scope of information that must be collected to meet the purpose

While there is always a perceived benefit in knowing more and in having more data for analysis, information superfluous to the purpose of the surveillance should not be part of the system. If, in time, more or less in-depth information is required, it may be necessary to design a different system with a different approach more suited to the new purpose. These standards go one level deeper than described under *purpose*, above.

Design and planning for collecting, distributing and managing information/data to be shared

Different mechanisms are more appropriate to different purposes, and the effort of collection balanced against the gain in knowledge must be considered as systems are designed. Appropriate management of the data, in terms of flows, translation, security, storage, and other factors must also be considered.

It will be important to ensure that data collected for one purpose (for example administrative or billing) and used for another truly capture the concepts that are required by surveillance, or, if used as a proxy, that some analysis is undertaken to explain how they differ, and the impact on interpretation. Modern electronic systems such as the integrated Public Health Information System (iPHIS) and all medical records systems are designed for case management, yet surveillance data may be an output. Surveillance standards should be informed by existing electronic health records standards, and, conversely, surveillance requirements should be used to influence standards for such systems.

Clear definitions of the types of surveillance designs are critical. Different designs are appropriate for different purposes.

Appropriate uses and interpretation of the outputs of surveillance

These should respect jurisdictional roles and responsibilities, and should reflect the purpose of the system

CONCRETE FOUNDATIONAL ELEMENTS

Laboratories

Laboratories have traditionally been used for the diagnosis and confirmation of surveillance cases, including novel and emerging pathogen identification and characterization. However, their role in surveillance has expanded considerably to include surveillance of circulating strains of bacteria and viruses through the use of molecular characterization and genotyping techniques. Information obtained through the analysis of strain surveillance data provides more in-depth knowledge regarding patterns of disease transmission, enables outbreak source identification, supports monitoring of anti-microbial resistance, and is used to inform immunization strategies. At the local level, laboratory data are often transactional (specimen-associated) and require transformation using established and accepted business rules for case-based data.

Required IT and computing capability

Surveillance is now rarely a paper and pencil activity, with cases reported via paper forms. It is almost entirely electronic in most if not all of the phases of the surveillance cycle. With the increase in tools for manipulating and visualising large datasets, this is only going to increase, and the possibilities for getting greater use out of the data collected will expand.

Modeling and analytics capabilities

Though traditionally incidence or prevalence rates were the measure reported, there is a greater acknowledgement of a need for more robust analysis, and for modelling to plan for the future. For example, routine surveillance captures only diagnosed, reported cases. Models can be built to estimate the true incidence or prevalence of disease in a population.

Information dissemination/Knowledge translation

Surveillance is an activity that ends in action. Without using the data collected to contribute to some sort of intervention or action to reduce illness or risk of illness, the collection is an empty exercise. Although surveillance data can be used profitably entirely within the public health system, it is far more effective to extend its use to inform the public or other stakeholders, to increase knowledge and give people the opportunity to use the information to reduce their own risks.

Communication systems between different infrastructure elements

The different infrastructure elements work most effectively when they can communicate to better set up systems to meet all of the needs, and to provide enrichment to their mutual contributions. For example, a lab-based surveillance system would benefit from knowing epidemiological characteristics of the individuals from whom samples have been obtained.

Human resources

No systems can function without sufficient staff, and staff with the appropriate skills and knowledge. As surveillance is undergoing a transition into being a more technologically driven practice, there may be a need for a change in the skill profile or retraining. At the same time, current surveillance practices lag behind the capabilities of new graduates with respect to information technologies. Considerations of human resources should not be limited to epidemiological skills, but also consider the skills necessary in information management/technology to make use of newer information management practices and technological tools.

Appropriate data sources and analysis

Surveillance is defined as routine collection, analysis, and dissemination of information on disease/health states/risk factors. Therefore, for the activity to be routine, there must be data sources either in existence, or the ability to create a data source that can meet the need of the routine nature of the activity. The quality of data used and the appropriate analysis have direct impact on the quality of the dissemination of information.

FROM THE CURRENT STATE TO THE FEDERATED VISION ON STANDARDS

CURRENT STATE	GAP	FEDERATED VISION
No agreement of data transmission protocols	Haphazard data exchange, especially in emergencies	Standards in place for transmission and exchange of data
Multiple means of exchanging data between jurisdictions	Unmanageable protocols	Ability for systems to 'talk' to each other (interoperability) is simplified by adoption of standards
Limited uptake of joint solutions	Delayed national reporting of surveillance data	Reduction of standards setting activities within jurisdictions or subject-area silos by sharing and adopting shared standards
Provinces, territories use software and processes of their own or collaborate on joint solutions	Collegial agreements on methods break down when systems or personnel change	Process for establishing and maintaining standards for all conditions of national interest
Inconsistent use of case definitions for communicable and non-communicable diseases	Sharing of metadata lags behind sharing of data as systems change	Standards for all core data elements
Variability in the definition of the minimal data set for communicable and non-communicable diseases and immunization	Risk of failure to meet WHO requirements (IHR)	

5. DEMONSTRATING THE SUCCESS OF THE FEDERATED SYSTEM

Key points

- Demonstrating success is about instituting a results-oriented approach to the core governance function of the Federated System.
- Demonstration of success of the Federated System will require ongoing performance management implemented through performance measurement and periodic program evaluation.
- To build a multilateral approach, current, evolving, and best practices for assessing the performance of the surveillance function across jurisdictions will be explored.

Demonstrating success is about instituting a results oriented approach to the core governance function of the Federated System, which will shape the development, implementation, review, and ongoing governance of the Federated System for public health surveillance.

Any results-oriented assessment of our collective success will need to reflect the web of accountability relationships that link Federal, Provincial, and Territorial government surveillance stakeholders, as success is defined within this larger context.

Demonstration of success of the Federated System will require ongoing performance management implemented through performance measurement and periodic program evaluation.

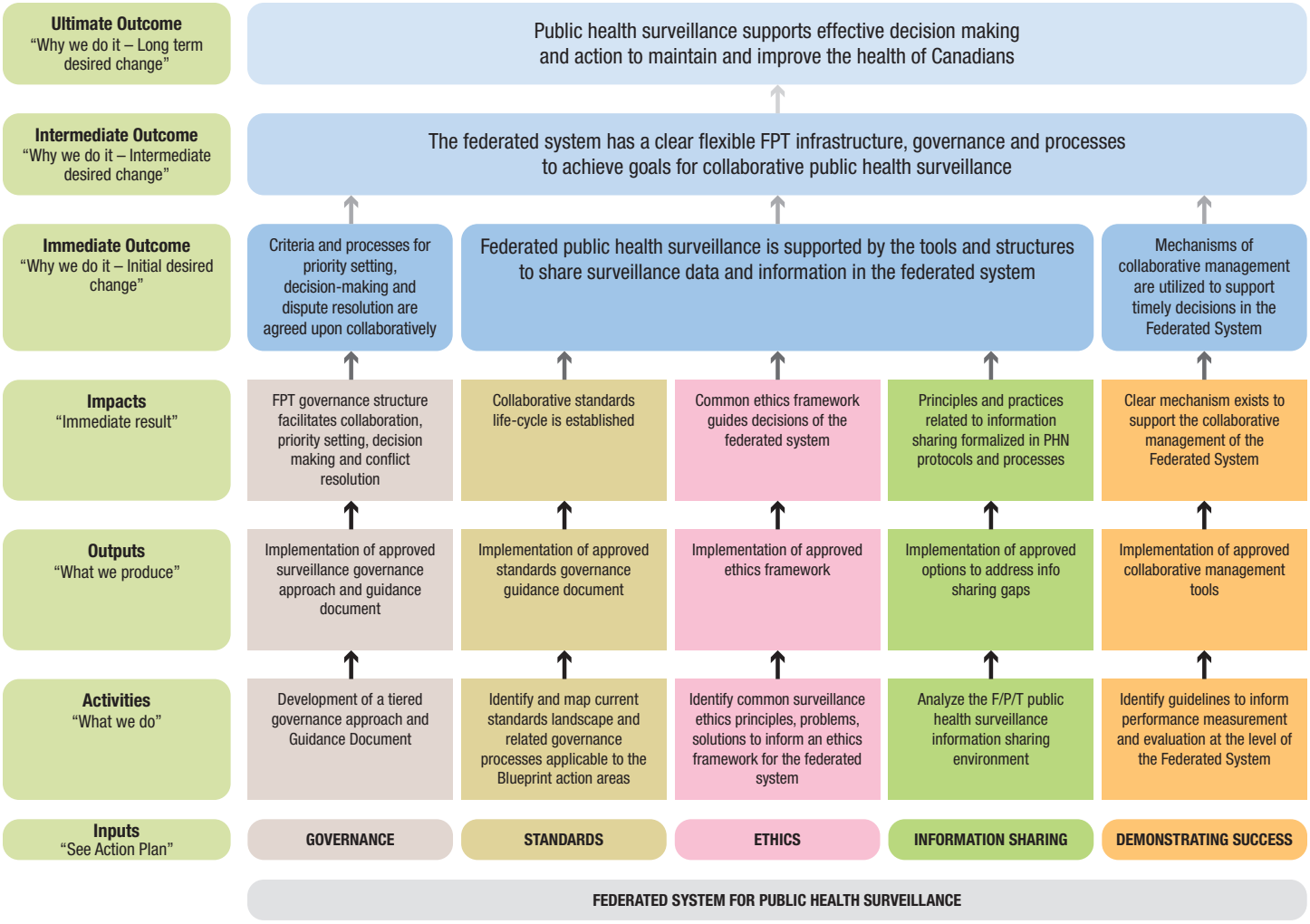
DEMONSTRATING SUCCESS OF THE FEDERATED SYSTEM

An essential tool for guiding the development of performance measures is the logic model for the Federated System (see next page), which will be used to develop performance measures for each infrastructure element across the levels of activities, outputs, and impacts. The logic model will also establish the foundational logic for a program evaluation framework of the Federated System, which will assess the linkages activities, products, impacts, and outcomes.

PROGRAM EVALUATION APPROACHES

Evaluation is the systematic and objective assessment of the relevance, adequacy, progress, efficiency, effectiveness and impact of a course of actions, in relation to objectives and taking into account the resources and facilities that have been deployed (World Health Organization, 1998). Several standard frameworks have evolved over the years for the evaluation of public health surveillance, including the CDC Guidelines (German et al., 2001; Klaucke et al., 1988), which consider ten aspects for assessment: simplicity, flexibility, data quality, acceptability, sensitivity, positive predictive value, representativeness, timeliness, stability and usefulness. However, this is context only for performance measurement at the Federated System level, for which few, if any, models exist.

Logic Model – Blueprint for the Federated System for Public Health Surveillance



INDIVIDUAL SURVEILLANCE SYSTEMS WITHIN THE FEDERATED SYSTEM

The surveillance evaluation literature is focused largely at the level of individual surveillance systems. Some of the principles, language, and terminology of this literature will apply directly to a Federated System, given that individual components also require evaluation. However, some of the existing principles will require translation when applied to the 'systems components' at the higher 'federated' level in order to support continuous quality improvement for the Federated System as a whole.

ASSESSING PERFORMANCE WITHIN THE FEDERATED SYSTEM

As with all government programs, performance measurement and evaluation are expected, and, given the scope of public health surveillance, this activity is too complex to be without a plan for both ongoing high-level performance measurement and periodic detailed evaluations.

The federated model is highly dependent on inter-organizational relationships. This suggests that performance measurement and evaluation may follow multiple tracks, including: the surveillance system, partnerships, methods, processes, and impacts or outcomes.

Performance measurement and evaluation will support management decision making about specific systems in the F/P/T domain or components of the Federated System as part of a life-cycle approach to providing evidence of the effectiveness of the operation of the Federated System.

GUIDING QUESTIONS FOR DEMONSTRATING SUCCESS

For each component of the Blueprint a starting point for guiding questions will inform both ongoing performance measurement and periodic program evaluation.

Governance

By governance we mean the structures and processes of the Federated System that guide engagement and decision making of the system, which, by consensus, provides the authority necessary for collaborative priority setting and decision making. The federated model for surveillance is characterized by collaborative leadership and shared governance with tiered decision making that identifies the most appropriate level of authority for various types of decisions. Some of the possible guiding questions for assessing performance include:

- How does the federated approach leverage existing assets and abilities?
- How will the governance model address agreement on the criteria used to assess gaps, areas of strength; what is included or excluded from the Federated System and the application of these criteria?
- What is the current scope of surveillance in Canada (across diseases, conditions, health events, and risk factors, jurisdictions, current/planned surveillance data sources, and gaps)?
- Does a federated approach increase efficiency and effectiveness of surveillance in Canada?
- How will the Federated System impact on surveillance system resource considerations, cost-effectiveness, data security, standardization across jurisdictions, and adaptability to meet local, provincial/territorial, and federal needs?
- Can the Federated System demonstrate contributions to public health decision making?

Ethics

A key tool for the sharing of surveillance data and information within the Federated System are the guiding values and principles that establish surveillance as a public good and provide the criteria for the ethical use, limitations of use, and dissemination of shared data and public health information. The feasibility of developing a common ethics framework to guide the decisions of the Federated System will be explored. Some of the possible guiding questions for assessing performance include:

- How does the ethics framework for the Federated System reflect the ethics frameworks of other large institutions, and inform and link to existing ethics frameworks guiding surveillance among the partners of the Federated System?
- How has the ethics framework of the Federated System been linked to the governance structures and management processes of decision making in the Federated System?

Information Sharing

A framework or guideline for information sharing in the Federated System will guide the identification and amelioration of information sharing barriers that may be encountered as part of a federated approach to surveillance. The framework or guideline will be the result of a strategic analysis of the Federal, Provincial, Territorial public health information sharing environment to identify priorities for action, based on previous works and existing literature. Some of the possible guiding questions for assessing performance include:

- How do we work together (legally)?
- Does the federated approach to information sharing facilitate timely and effective arrangements for sharing surveillance data/information within the Federated System?
- Does the federated approach to information sharing provide the mechanisms and processes required to support the development of MLISA technical annexes?

Standards

Within the Federated System, a federated approach to standards development will identify a standards strategy, governance structure, and an operational plan. Key partnerships with Canada Health Infoway, Canadian Standards Association, and other organizations involved in public health informatics will be essential for outlining existing roles and responsibilities and closing any gaps between technology-based standards and broader surveillance standards. Some of the guiding questions for assessing performance include:

- How do we work together (operationally)?
- Do standards provide the infrastructure to pool data in the Federated System?
- How do standards promote a common understanding?

Management

In order to demonstrate success, results-based management principles and practices for governing the Federated System will need to be established to guide the development of performance measurement criteria and an evaluation framework. Some of the possible guiding questions for assessing performance include:

- How well is surveillance data translated into information useful for public health action?
- Are surveillance data used for planning, implementing and evaluating public health programs/interventions?
- Are surveillance data provided to decision makers/used for decision making?
- Do surveillance data lead to improved public health policy, practice or control measures?
- How effectively are surveillance outputs disseminated (via websites, visualization tools, and social media)?

FROM THE CURRENT STATE TO THE FEDERATED VISION FOR DEMONSTRATING SUCCESS

CURRENT STATE	GAP	FEDERATED VISION
Evaluations of individual surveillance systems 10-year-old gap analysis (End-to-End Surveillance)	No clear mechanism for understanding how well we are doing with respect to working together on this core function of public health	Continuous quality improvement of surveillance, including the Federated System for surveillance

PART 2 – ACTION PLAN
BUILDING INFRASTRUCTURE FOR FEDERATED SURVEILLANCE

The aim of a federated approach is to establish the necessary infrastructure to support enhanced responsiveness and increased efficiency and effectiveness across Canada and across jurisdictional levels. To that end, the Blueprint addresses the need for a common understanding of the needed system infrastructure and enhanced collaboration on public health surveillance among public health jurisdictions and institutional stakeholders. Foundational to establishing this common understanding will be the vision (Part 1) and action plan (Part 2) of the *Blueprint for a Federated System for Public Health Surveillance in Canada*.

Public health surveillance in Canada has advanced considerably in the past decade. Based on this solid foundation of practice, formalizing an approach to the alignment of surveillance infrastructure development across jurisdictions holds the potential to better coordinate and utilize surveillance resources and infrastructure, and ensure that timely and appropriate surveillance information informs public health action for the benefit of Canadians.

The vision and action plan of the *Blueprint for Federated Public Health Surveillance in Canada* represents formalizing an infrastructure between jurisdictions opting to collaborate with other jurisdictions to accomplish their shared objectives. The policy mechanisms required to establish this collaboration will initially make current practices governed by the Pan-Canadian Public Health Network more consistent and formalized. As the Federated System matures, an incremental F/P/T policy development approach, including a range of policy instruments of increasing formality (from protocols, to processes, to letters of support, to MOUs, to binding agreements) could be explored.

The *Blueprint for a Federated System for Public Health Surveillance in Canada* represents a starting place for establishing a common understanding of the infrastructure needed to support a system of integrated public health surveillance. Part 2 of this document, the Action Plan, builds on the federated surveillance vision set out in Part 1 and describes the actions necessary to achieve this vision for Canada, through high level descriptions and the identification of objectives, deliverables, and timelines for each priority infrastructure area. The focus of this part of the document is about building the foundations for collaboration on federated surveillance.

PRIORITIES FOR ACTION

The National Surveillance Infrastructure Task Group identified five priority areas, where infrastructure development is fundamental to establishing the vision for federated surveillance in Canada. These areas represent trust brokering mechanisms between jurisdictions, as a foundation for the Federated System. The priorities identified included governance, ethics, information sharing, standards, and demonstrating success.

Each priority area will be described in the Action Plan below.

1. GOVERNANCE FOR THE FEDERATED SYSTEM – STRUCTURES AND PROCESSES TO GUIDE COLLABORATIVE INFRASTRUCTURE DEVELOPMENT

Context for the development of surveillance governance infrastructure:

The Blueprint is intended to provide a common vision, framework and implementation plan for the Federated System for public health surveillance in Canada. Foundational to this is the shared governance approach for collective issue management, priority setting, and decision making at the federated level.

While jurisdictions retain autonomy in terms of resource expenditures and actual operation of the surveillance function within their jurisdictions, the federated governance approach represents the processes and mechanisms needed to establish agreement on the infrastructure to support collaborative surveillance in the Federated System.

The strategic objective of the governance priority is to develop a tiered approach that, for public health surveillance, defines, clarifies and formalizes existing Public Health Network (PHN) mechanisms. This will identify the most appropriate level of authority (or "tier") for the full range of surveillance discussions needed and decisions to be taken. Surveillance roles and responsibilities will be specified for each "tier", which will guide the development of clear, appropriate processes to facilitate collaboration, issue management, joint priority setting, decision making and conflict resolution in the Federated System. A diagram has been drafted to help illustrate the approach and facilitate conversation among F/P/T partners (see Figure 5).

Gap being addressed:

Currently, surveillance priority setting and decision making processes for collaborative F/P/T surveillance are undefined and ad hoc and there is a lack of clarity in surveillance roles, responsibilities, and mechanisms, including Indigenous peoples participation.

The governance approach for the Federated System for public health surveillance formalizes the mechanisms and processes of the PHN to better enable the collaborative surveillance function in Canada to be more responsive and resilient.

Strategic Goal: A formal governance mechanism is in place to facilitate collaboration, priority setting, decision making and conflict resolution, in order to support clear, appropriate and aligned F/P/T surveillance. This governance will effectively guide the growth and development of the Federated System infrastructure for public health surveillance.

Strategic Objective: To develop a tiered surveillance governance approach that utilizes existing Pan-Canadian Public Health Network structures and mechanisms, and identifies the most appropriate level of authority for the full range of surveillance discussions needed and decisions to be taken.

Objectives:

1. To develop the tiered governance approach.
2. To develop protocols and processes (based on examples) to guide the flow of decision making and project management in the Federated System.
3. To consolidate governance and protocol/process models into a single integrated document that could act as a guide for the Federated System.
4. To implement the governance approach of the Federated System.

Key foundational principles:

- Governance of the Federated System serves Canadians across the country through assuring enhanced coordination and responsiveness.
- There is an equality of parties and distributed leadership in the Federated System.
- Focusing on coordination will leverage common resources across Canada to achieve better alignment.
- Governance reflects the current mechanisms of the Pan-Canadian Public Health Network.
- Jurisdictions retain autonomy in the operation of their surveillance functions.
- Evolutionary change is intended through normal institutional planning cycles.

Criteria for success:

- Clarity in direction of appropriate action and timely decision making.
- Establishment of clear roles and responsibilities among participants.
- Identification of shared interests, concerns and values.
- Definition of common purposes, objectives, concepts and terminology.
- Promotion of rigorous deliberation of issues.
- Authority and responsibility linked to performance and review.
- Policy decision making balanced with delivery.
- Creation of a dispute resolution process.

Measurement of success:

- For the Federated System, a logic model, performance measures and evaluation framework will guide the assessment of success of the governance of the Federated System.
- Success will be demonstrated by identifying and assessing:
  - The level of commitment to the governance approach resulting in uptake of governance processes;
  - The perceived legitimacy, trustworthiness and credibility of the governance approach; and
  - The degree of mutual understanding generated.

Key dependencies:

- Each party has sufficient capacity for taking joint action, based on procedural and institutional arrangements, including explicit structures and protocols to sustain collaborative engagement over time. MLISA is one example of this kind of arrangement.
- All jurisdictions share a common vision of the Federated System.
- Surveillance roles and responsibilities derive from a broad range of guidance documents, signed agreements, legislation and regulations. Federated surveillance will require a broad networked interpretation across many authoritative sources.
- Ideally, jurisdictions will reflect the practices of the Federated System within their jurisdictions to ensure linkages with Indigenous, regional and local public health organizations that are among the first points of integration of public health surveillance information.

Risks:

- The Federated System does not have an explicit basis in legislation, and will need to implement a range of binding (e.g. MLISA) and non-binding agreements (such as MOUs) as a general mitigation to ensure operational effectiveness of the governance approach.[7]
- The federated governance approach may be at risk if there isn't sufficient motivation and the commitment of time by F/P/T jurisdictions to move beyond the status quo.

Key tasks:

	ACTIVITY	RESOURCES/SKILLS	LEAD	KEY PARTNERS	MILESTONES (DELIVERABLE DATE)
1.1	Develop a tiered governance approach	Policy Analyst, PH Decision Makers	PHAC	PHN	Model (TBD)
1.2	Develop governance processes – based on examples	Policy Analyst, Business Process Analyst	PHAC	PHN	Processes (TBD)
1.3	Develop integrated federated surveillance guidance document	Policy Analyst, Writer, Editor, PH Decision Maker	PHAC	PHN	Guidance document (TBD)
1.4	Support for review and approval of federated surveillance guidance document	Policy Analyst, Project Officer	PHAC	PHN	Launch of federated surveillance governance approach (TBD)

7 Note: The F/P/T report "Partners in Public Health" (2005) identified a range of arrangements considered essential for effectiveness.

PROPOSED FEDERATED SURVEILLANCE TIERED GOVERNANCE

TIER 1 – INTERGOVERNMENTAL LAYER

- CDMH Endorse major changes to surveillance policy direction
- CDMH receive MLISA Table of Representatives Annual Report

CDMH updates CMH as appropriate

TIER 2 – STRATEGIC LAYER

PHN Council

- Endorse the federated surveillance vision/surveillance policy direction
- Promote a common vision of a federated system
- Provide policy integration between federated system and jurisdictional systems
- Coordinates the integrated operations of the federated system for surveillance
- Decision making on direction, priorities, new, changes or sun setting of surveillance infrastructure or functioning of the federated system
- Dispute resolution process between strategic (Tier 2) and program (Tier 3)

CCMOH

- Technical advice

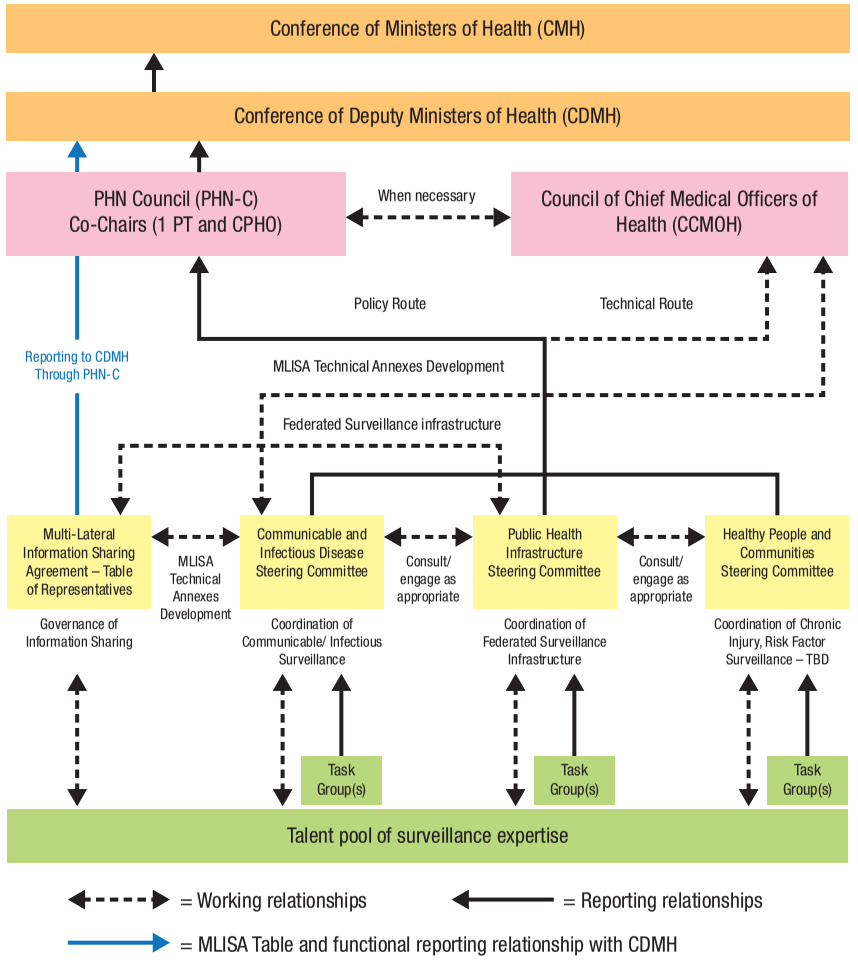
TIER 3 – PROGRAM LAYER – ISSUE MANAGEMENT, JOINT PRIORITY SETTING & DECISION MAKING

- CID SC – Collaborative integration of Communicable/infectious Disease surveillance
- PHI SC – Collaborative integration of Federated Surveillance Infrastructure, including recommendations on surveillance direction, priorities changes and performance measurement and evaluation of the Federated System
- HPC SC – Collaborative integration of chronic, injury, risk factor surveillance
- MLISA Table – Governance of information sharing and liaison with SCs to establish the coherent and formalized information sharing across jurisdictions

TIER 4 – EXPERT LAYER

- Provides expertise from PHN Task Groups and expertise outside the PHN
- Identification of initial technical and policy issues in the federated system
- Development and implementation of surveillance infrastructure projects
- Operational groups of federated surveillance system

FEDERATED SURVEILLANCE REPORTING / WORKING RELATIONSHIPS – BASED ON THE PHN



Linkage with other sectors and governance structures

Figure 5: A tiered governance approach for Federated Surveillance based on the PHN

2. STANDARDS IN THE FEDERATED SYSTEM – SUPPORTING POLICY, DATA AND INFORMATION INTEROPERABILITY

Gap being addressed:

The lack of a mechanism to align surveillance standards across Canada is a missing pillar of surveillance infrastructure that holds the potential to delay the early detection of outbreaks and is a barrier to better understanding chronic diseases and injuries, resulting in negative consequences for the health of Canadians. The Federated System for public health surveillance seeks to establish, where appropriate, uniform definitions, methods and processes to achieve a common understanding between parties.

Strategic Goal: Standards are used by F/P/T partners to enhance communication, interoperability and effectiveness within the Federated System. Where standards cannot be applied, the impact, implication and consequences of the absence of a standard will be assessed.

Strategic Objective: To identify the key players and current environments that shape the development, implementation, and assessment of standards required for the Federated System for public health surveillance. This will lead to the identification and implementation of a collaborative process for standards development.

Objectives:

1. Summarize and communicate a short working definition of standards as articulated in the Blueprint.
2. Identify and map current standards applicable to the Blueprint action areas and the interrelationships among these standards.
3. Establish criteria and a governance process for prioritizing standards for adoption, adaptation, or development within the Federated System.
4. Identify and implement a process for a collaborative standards development life-cycle (development, implementation, and audit):
    a. Develop common definitions related to surveillance standards and draft surveillance practice standards;
    b. Develop a standards repository, with linkages of other standards repositories and organizations; and
    c. Ongoing development of MLISA technical annexes.

Criteria for success:

- Prioritized standards will be identified for the full cycle of surveillance.
- Processes for collaborative agreement on how standards will be developed, implemented and audited will be identified and implemented.

Measurement of success:

- Prioritized standards are used across the full cycle of surveillance in the Federated System.
- Partners in the Federated System comply with the development, implementation and audit processes related to standards.

Key dependencies:

- Agreement by 14 jurisdictions that there should be a dispute resolution process for surveillance standards development, implementation, and audit for the Federated System.
- Agreements that the standards developed both serve national requirements and are feasible to implement at a local and provincial/territorial level.
- Where standards cannot be implemented due to lack of capacity or other challenges, an analysis of the impact on federated surveillance would be conducted and shared.
- Federated surveillance standards are dependent on the standards that exist at each layer of information integration.
- To understand the context in which federated surveillance standards operate, the considerable existing surveillance infrastructure will need to be identified, integrated and leveraged in order to support the effectiveness of federated surveillance standards.
- The governance of standards for federated surveillance will need to be situated within the formal standards governance structures for health and public health information in Canada.
- Given the importance of technical groups to establish case definitions, core data sets, and most other standards, the identification of "upstream" policy prerequisites is required to support "downstream" operations on standards development.
- The strength and acceptance of the infrastructure and governance structures of the Federated System will have a direct impact on the utilization of federated surveillance standards.

Risks:

- The governance dispute resolution mechanism will need to be robust enough to address the standards development, implementation, and audit aspects of the surveillance standards life-cycle.
- With the lack of alignment of the structures, mechanisms and processes being utilized by Canada Health Infoway and the Pan-Canadian Public Health Network to collaborate on standards infrastructure development, there is a risk that technology drivers will not align with F/P/T governance engagement on surveillance standards guiding federated surveillance.
- Varying F/P/T capacities may affect the ability of jurisdictions to implement proposed standards.

Key tasks:

	ACTIVITY	RESOURCES/SKILLS	LEAD	KEY PARTNERS	MILESTONES (DELIVERABLE DATE)
1.1	Establish a working definition of standards for the Federated System	Surveillance Epidemiologist, IM Specialist, Policy Analyst	TBD	PHN	Standards FAQ sheet (TBD)
1.2	Identify and map current surveillance standards landscape	Policy Analyst, Business Analyst, Project Officer	TBD	PHN	Standards environment scan (TBD)
1.3	Establish criteria and a governance process for prioritizing standards	Surveillance Epidemiologist, IM Specialist, Policy Analyst, PH Decision Makers	TBD	PHN	Governance process document (TBD)
1.4	Identify and implement a process for a collaborative standards development life-cycle	Surveillance Epidemiologist, IM Specialist, Policy Analyst, PH Decision Makers	TBD	PHN	Collaborative standards governance guidance document (TBD)

3. ETHICS FOR THE FEDERATED SYSTEM – FROM ETHOS TO ETHICS, THE IDENTIFICATION OF COLLABORATIVE SURVEILLANCE PRINCIPLES

Gap being addressed:

As there are many organizationally based and practice-based ethics guidelines and frameworks for public health, some common principles are required to span jurisdictional mandates in the Federated System for public health surveillance.

Strategic Goal: A common framework is in place to support ethical decision making in the Federated System. Ideally, the framework will enable a decision making environment where applying ethics is reflexive and deliberative. The framework and related tools will: a) provide a guide to support ethical analyses in an increasingly complex multi-lateral environment; b) help identify options for decision making that utilize common values and principles; and c) establish the appropriate scope of issues involved in decision making.

Strategic Objective: To develop an integrated ethics approach and tools for public health surveillance on many organizationally based and practice-based ethics guidelines and frameworks for public health. This approach and tools will identify shared values and principles as a resource supporting effective surveillance processes and structures spanning jurisdictional mandates in the Federated System for public health surveillance.

Objectives:

1. Identify the frameworks, principles and tools that currently support ethical decision making in public health surveillance in Canada.
2. Identify common surveillance ethics principles, problems and solutions for the complete surveillance cycle that are grounded in a larger public health decision making context.
3. Build tools to support ethical decision making in the Federated System for public health surveillance:
    a. Build an ethics decision making support tool to integrate with the governance model of the Federated System, perhaps based on a tool in use in Quebec (Desy et al., 2010); and
    b. A surveillance ethics case book will provide worked examples of the application of the ethics framework as a resource for building ethics competency in the Federated System.

Criteria for success:

- Identification of common ethics principles relevant for public health surveillance.
- Clarity in direction of appropriate action and decision making.
- Identification of shared interests, concerns and values.
- Definition of common purposes, objectives, concepts and terminology.
- Promotion of rigorous deliberation of issues beyond a mere common aggregation of interests.

Measurement of success:

- Ethics principles relevant for federated public health surveillance are used to guide decision making.
- A common ethics tool for the analysis of surveillance will be adopted/adapted within jurisdictions to support their engagement.
- A federated surveillance ethics case book is developed as a training and management competencies development resource.

Key dependencies:

- All jurisdictions share a common vision of the Federated System.
- Population and public health ethics emphasis and values will need to be clearly distinguished from the emphasis and values of bioethics.
- Some form of national population and public health ethics resource may be needed to help ground the development of a population and public health ethics appropriate for the Federated System of public health in general and surveillance in particular.

Risks:

- The sheer diversity of "siloed" ethics frameworks across institutions, reflecting a broad range of legal and professional practice-based requirements, may impact on the ability of collaborating jurisdictions to come to agreement on a common set of principles to support ethical decision making in the Federated System.

Key tasks:

	ACTIVITY	RESOURCES/SKILLS	LEAD	KEY PARTNERS	MILESTONES (DELIVERABLE DATE)
1.1	Surveillance ethics environmental scan	Public Health Ethicist, Policy Analyst, Project Officer	TBD	PHN	Summary Report (TBD)
1.2	Identify common surveillance ethics principles, problems and solutions	Public Health Ethicist, Surveillance Epidemiologist, Policy Analyst, PH Decision Maker	TBD	PHN	Synthesis Report (TBD)
1.3	Adopt, adapt or develop ethics review tools for surveillance in the Federated System	Public Health Ethicist, Surveillance Epidemiologist, Policy Analyst, PH Decision Maker	TBD	PHN	Decision making guide and ethics case book supporting ethics decision making in federated surveillance (TBD)

4. INFORMATION SHARING – LINKING FEDERATED SURVEILLANCE PLANS AND PRIORITIES WITH INFORMATION EXCHANGE

Gap being addressed:

The existence of barriers to timely and meaningful exchange of public health surveillance information (e.g. data and surveillance products) and absence of or informal/ad hoc information sharing agreements across Canada.

Strategic Goal: Information sharing agreements at the federated level reflect consensus on principles and practices related to data sharing across jurisdictions.

Strategic Objective: To identify and develop options for addressing barriers to timely and meaningful exchange of public health information in the Federated System.

Objectives:

1. Analyze the F/P/T public health surveillance information sharing environment to identify gaps and options to address them:
    a. Conduct an environmental scan of communicable and non-communicable disease, injury and other public health related information sharing agreements and other arrangements in place in Canada;
    b. Identify gaps and overlaps;
    c. Identify options to address gaps and overlaps; and
    d. Present recommendations to PHN governance bodies.
2. Develop and implement an approach, processes, and mechanisms for the development of MLISA Technical Annexes:
    a. Establish the approach to MLISA Technical Annex development;
    b. Establish a critical path for the development and approval of MLISA Technical Annexes; and
    c. Ongoing development and management of MLISA Technical Annexes.

Criteria for success:

- Information is available to support timely decision making.
- Agreements are informed by federated surveillance plans and priorities.

Measurement of success:

The proportion of flow of information in the Federated System governed by formal agreements compared to the proportion of information flow through less formal arrangements.

Key dependencies:

- Formal agreements are more effective in supporting the Federated System if they are aligned with plans and priorities outside of it.
- Formal agreements can only be implemented if they are informed by appropriate information and data standards infrastructure.
- Formal information sharing agreements have a range of drivers, such as globalization, technology, complexity and organizational change. The impact of any one of these drivers or some combination of these drivers will necessitate different forms of arrangements at various levels of formality.
- Formal information sharing agreements reflect one element in a structured approach to information sharing arrangements, which includes a spectrum of legislative authorities and mandates; agreements/ memoranda of understanding; protocols and guidelines. For formal arrangements to be effective they must be supported by the other elements of the spectrum of information sharing arrangements.

Risks:

- In the transition between informal and more formalized arrangements, there may be an impact on the flow of information available for public health decision making in the short-term.

Key tasks:

	ACTIVITY	RESOURCES/SKILLS	LEAD	KEY PARTNERS	MILESTONES (DELIVERABLE DATE)
1.1	Analyze the F/P/T public health surveillance information sharing environment[8]	Surveillance Epidemiologist, IM Specialist, Policy Analyst, PH Decision Maker	TBD	PHN	Summary Report (TBD)
1.2	Develop and implement an approach, processes, and mechanisms for the development of MLISA Technical Annexes	Surveillance Epidemiologist, IM Specialist, Policy Analyst, PH Decision Maker	TBD	PHN	PHN protocols and processes formalized to support the PHN Communicable and Infectious Diseases Steering Committee and the MLISA Table of Representatives (TBD)

8 Including communicable and non-communicable disease, injury and other public health related information sharing contexts

5. DEMONSTRATING THE SUCCESS OF THE FEDERATED SYSTEM – CONTINUOUS QUALITY IMPROVEMENT THROUGH PERFORMANCE MEASUREMENT AND EVALUATION

Gap being addressed:

There is currently no clear mechanism for understanding how well we are doing with respect to working together on surveillance as a core function of public health.

Strategic Goal: The Federated System for public health surveillance in Canada has the tools required to support its continuous improvement.

Strategic Objective: To develop and implement continuous improvement tools and guidelines that inform performance measurement and evaluation of the Federated System; and to identify criteria supporting assessments of the infrastructure elements of the Federated System. This will support its governance by providing management with information on system functioning for decision making.

Objectives:

1. Development of a logic model for the Federated System for public health surveillance.
2. Develop and implement a performance measurement framework.
3. Develop an evaluation framework as a planning and assessment tool.
4. Conduct periodic evaluations on areas of performance identified by performance measures and other criteria.

Criteria for success:

- Surveillance data is translated into information useful for public health action in a timely manner.
- Surveillance data is used for planning, implementation and evaluating public health programs/interventions.
- Surveillance data is provided to decision makers and used in decision making.
- Surveillance data leads to improved public health policy, practice or control measures.
- Surveillance outputs reach target audiences.

Measurement of success:

- The use of performance information from the Federated System in governance decisions that follow a 'plan-do-check-act' cycle.

Key Dependencies:

- An overall performance management framework for the Federated System will include both ongoing performance measurement and periodic program evaluation to support the vision of continuous quality improvement.
- To build a multilateral approach, current, evolving, and best practices for assessing the performance of the surveillance function across jurisdictions will need to be explored.

Risks:

- To demonstrate success through the adoption of performance management practices in the Federated System, there will have to be sufficient trust built up in the other four action areas of surveillance infrastructure. It will be critical to gain acceptance of some form of collaborative 'plan-do-check-act' cycle.

Key tasks:

	ACTIVITY	RESOURCES/SKILLS	LEAD	KEY PARTNERS	MILESTONES (DELIVERABLE DATE)
1.1	Develop a logic model for the Federated System	Policy Analyst, PH Decision Makers	TBD	PHN	Federated surveillance program logic model (Drafted)
1.2	Develop and implement a performance measurement framework for the Federated System	Policy Analyst, Performance Management Specialist, PH Decisions Makers	TBD	PHN	Federated surveillance performance measurement framework and reporting template (TBD)
1.3	Develop an evaluation framework for the Federated System	Program Evaluation Specialist, Policy Analyst, Project Officer PH Decision Makers	TBD	PHN	Federated surveillance system evaluation framework (TBD)
1.4	Conduct formative and summative evaluations of Federated System to guide decision making	Program Evaluation Specialist, Policy Analyst, Project Officer PH Decision Makers	TBD	PHN	Initial and ongoing evaluation reports (TBD)

CONCLUSION

The Blueprint vision and action plan represent the development of a high level framework that lays out the infrastructure and collaborative context for the Federated System for Public Health Surveillance in Canada.

Overall, the Blueprint describes a plan for formalizing a collaborative system of equal partners who demonstrate cooperative leadership and obligate themselves to act according to their capacity and resources in ways that are non-binding and resource neutral.

Five priority action items have been identified as the infrastructure building blocks of the Federated System. Each of these building blocks represents an area of collaborative development of surveillance infrastructure, where surveillance partners realize shared benefits as an outcome of co-leadership.

It is envisioned that implementation of the Blueprint Action Plan will continue to reside with the PHN Public Health Infrastructure Steering Committee. The Committee will engage jurisdictions through its members to determine roles and responsibilities in bringing the vision of the Blueprint to fruition, to ensure that the Federated System is founded upon a solid and sustainable infrastructure.

LIST OF ACRONYMS

CCHS	Canadian Community Health Survey
CCMOH	Council of Chief Medical Officers of Health
CDC	Centers for Disease Control and Prevention
CDMH	Conference of F/P/T Deputy Ministers of Health
CIHI	Canadian Institute for Health Information
ECDC	European Centre for Disease Control
F/P/T	Federal, Provincial and Territorial
IHR	International Health Regulations
iPHIS	integrated Public Health Information System
L/P/T	Local, Provincial and Territorial
MLISA	Multi-Lateral Information Sharing Agreement
MOH	Medical Officer of Health
OIE	World Organisation for Animal Health
PAHO	Pan American Health Organization
PHAC	Public Health Agency of Canada
PHN	Pan-Canadian Public Health Network
PHNC	Public Health Network Council
P/T	Provincial and Territorial
SARS	Severe Acute Respiratory Syndrome
TESSy	The European Surveillance System
WHO	World Health Organization

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ANNEX 1: FREQUENTLY ASKED QUESTIONS (FAQS) – OVERVIEW OF THE BLUEPRINT FOR A FEDERATED SYSTEM FOR PUBLIC HEALTH SURVEILLANCE IN CANADA

What is the Blueprint?

The Blueprint is a comprehensive policy guidance document consisting of a vision for a Federated System for public health surveillance in Canada and an action plan for enabling the development and implementation of an infrastructure for more effective collaboration.

The Blueprint vision (Part 1), broadly outlines the aspirations and core infrastructure elements of a Federated System for public health surveillance in Canada. The second part, the Action Plan (Part 2), describes, in concrete terms, the actions to be taken to achieve the vision for the development of foundational infrastructure.

What is in-scope for the Blueprint?

The Blueprint proposes an evolution of existing systems, practices and collaborations to achieve the vision of a Federated System for public health surveillance in Canada which is based on a shared commitment among partners, with explicit governance and links institutions rather than just individual practitioners, respects jurisdictional roles and legislative requirements (such as privacy) and informal/formal arrangements to inform public health actions and policies.

What is out-of-scope for the Blueprint?

The Federated System is not intended to be a surveillance system or replace existing surveillance systems, but rather support the integration of F/P/T surveillance infrastructure. It will be dynamic in nature given that it is not a comprehensive plan for surveillance activities and therefore will not change existing accountabilities.

What is a federated approach?

In the Blueprint, federated refers to a collective activity, done for mutual benefit, in a consistent fashion, by equal partners who retain autonomy over their own activities. A federated approach outlines that parts of the system should not operate in isolation, but should be (and are) connected in various ways. It comes with obligations and requires leadership, which may be distributed across the partners.

What are the potential advantages of a Federated System?

A Federated System presents opportunities for sharing infrastructure, without imposing a rigid singular solution. It aligns surveillance activities, while recognizing the multiple purposes of surveillance and the reality of varied jurisdictional capacities and circumstances.

Is the Blueprint something new?

As a policy guidance document, the Blueprint builds on extensive F/P/T work begun in 1999 with the National Health Surveillance Initiative and the need for a "...'seamless' public health system that will allow public health professionals to coordinate activities in a carefully planned infrastructure." (Learning from SARS, 2003). The Blueprint particularly addresses the lack of a shared articulated vision and action plan to achieve a planned public health surveillance infrastructure in Canada.

What are the action priorities to achieve the vision of a Federated System?

The five priority surveillance infrastructure areas identified in the Action Plan include: Governance, Ethics, Information Sharing, Standards and Demonstrating Success.

What is the relationship between Blueprint and MLISA?

The integrated Blueprint is an overarching policy framework for a Federated System for public health surveillance in Canada. MLISA is a legal agreement that articulates how and what data on infectious diseases and urgent public health events will be shared between participating jurisdictions. MLISA is an example of a formal arrangement supporting infectious disease surveillance within the Federated System that is aligned with the broader information sharing priority of the Blueprint.

ANNEX 2: SURVEILLANCE ROLES

This Annex has been developed based on **Appendix 1** of the 1999 document *Proposal for a Network for Health Surveillance in Canada* as an exploration of distributed jurisdictional roles.

GOVERNANCE ROLES

ESTABLISH JOINT MECHANISMS FOR FEDERATED SYSTEM PRIORITY SETTING AND DECISION MAKING	
L/P/T* roles	Provision of expertise to support consensus development
Federal roles	Coordination and provision of expertise to support consensus development
Collaborative roles	Develop consensus on: • System governance model and mechanisms for joint priority setting and decision making • Surveillance priorities in the Federated System • Strategies for integration of health surveillance programs across different jurisdictions e.g. linking to other provincial/territorial agencies responsible for health information/data (Vital Statistics, hospital utilization etc.) • A mechanism for dispute resolution

SYSTEM CAPACITY ROLES

SUPPORT THE CAPACITY OF THE SYSTEM TO UNDERTAKE HEALTH SURVEILLANCE	
L/P/T roles	Ensure capacity at the local and P/T levels to collect, analyze, and integrate health surveillance data and disseminate findings
Federal roles	Ensure capacity at the national level to collect, analyze, and integrate health surveillance data and disseminate findings Provide support to provinces/territories to augment their capacity to undertake health surveillance, where appropriate
Collaborative roles	Establish and maintain a strategy which both supports the joint priorities of health surveillance and mitigates gaps in surveillance capacity in the Federated System
COORDINATE HEALTH SURVEILLANCE ACTIVITIES AT ALL LEVELS OF THE SYSTEM TO MAXIMIZE THE BENEFIT OF THE SYSTEM AS A WHOLE	
Collaborative roles	Ensure that processes are in place for the appropriate reporting of health surveillance activities to other departments/agencies, and for issues that impact on human health to be brought forward from other departments, as appropriate for action and response

*L/P/T: Local/Provincial/Territorial

OPERATIONAL ROLES

SYSTEMATICALLY MONITOR AND PREDICT PUBLIC HEALTH AND HEALTH DETERMINANT TRENDS	
L/P/T roles	Collect data, analyze, interpret health and health determinant trends over time at the provincial and sub-provincial levels Provide secure access to data for the Federated System (includes data from non-traditional health sources (e.g. laboratories) Support for provincial based sentinel health surveillance systems Sharing, reporting, analyzing, and disseminating health surveillance findings to appropriate partners for action and response for: • health impact assessment and action, disease control, injury prevention and health promotion planning • health policy development, implementation, evaluation, change and sustainability • support to clinical practice • support to clinical practice guideline development
Federal roles	Collation to the national level and interpretation of health and health determinant trends over time, interprovincial comparisons, national trends, review of international trends National health data collection through the Canadian Community Health Survey (CCHS), the Canadian Health Measures Survey (CMHS), and other surveys International health surveillance, liaison, action, response and sharing of information with international partners and provinces/territories and support for international agencies, e.g., reporting to PAHO, WHO. Strategic support for national surveillance including nationally notifiable diseases laboratory and epidemiologic surveillance, and notification of other orders of government of planned strategies Sharing, reporting, analyzing, and disseminating health surveillance findings to appropriate partners for action and response: • for health impact assessment and action, disease control, injury prevention and health promotion planning • for health policy development, implementation, evaluation, change and sustainability • for support to clinical practice • for support to clinical practice guideline development • to contribute to the development of national and international guidelines and standards
Collaborative roles	Track and forecast health and health determinant trends over time (including laboratory based, medical reporting, etc.) Development of indicators and national reports on the health of Canadians Identify and assess system needs for sentinel health surveillance Sharing, reporting, analyzing, and disseminating health surveillance findings to appropriate partners for action and response for: • health impact assessment and action, disease control, injury prevention and health promotion planning • health policy development, implementation, evaluation, change and sustainability • support to clinical practice • support to clinical practice guideline development

OPERATIONAL ROLES (cont'd)

DEVELOP SYSTEM STANDARDS/DEFINITIONS	
L/P/T roles	Contribute to the development of system standards/definitions for: • data collection, management and secure transmission; and integration of health surveillance information • data elements • case definitions and disease and injury reporting registries • definitions relating to health status and socio-economic characteristics • surveillance and laboratory methods; algorithms for surveillance purposes, analysis and interpretation and implementation of standards within provinces and territories
Federal roles	Contribute to the development of system standards/definitions for: • data collection, management and secure transmission; and integration of health surveillance information • data elements • case definitions and disease and injury reporting registries • definitions relating to health status and socio-economic characteristics • surveillance and laboratory methods; algorithms for surveillance purposes, analysis and interpretation and implementation of standards at the federal level, to ensure high quality data for comparison at P/T, national and international levels
Collaborative roles	Develop system standards/definitions for: • data collection, management and secure transmission; and integration of health surveillance information • data elements • case definitions and disease and injury reporting registries • definitions relating to health status and socio-economic characteristics • surveillance and laboratory methods; algorithms for surveillance purposes, analysis and interpretation
Others' roles	Partner in the development of standards/definitions particularly related to health services, indicators, health service encounter data capture (CIHI)
DEVELOP HEALTH SURVEILLANCE METHODOLOGY	
L/P/T roles	Support the development of standard techniques, models, analytical tools, definitions and implement them within provincial and territorial systems
Federal roles	Coordinate and support standard techniques, analytical tools, models, definitions Implement within federal systems Integrate with international agencies
Collaborative roles	Develop standard techniques, analytical tools, models, definitions
Others' roles	Provide data from various data holdings (CIHI, Statistics Canada)
PROVISION OF SPECIALIZED ANALYSES, EXPERTISE AND TECHNICAL SERVICES AND SUPPORTS	
L/P/T roles	Technical support and expert advice, reference laboratories, collaborative research, education and training
Federal roles	Technical support and expert advice, specialized analyses, reference laboratories, education and training Sharing of expertise at the international level
Collaborative roles	Provision of collaborative expertise within, and to support the benefit of, the system as a whole
Others' roles	Work with partners in the Federated System on standards for data collection, needs/protocols, etc. (CIHI)

OPERATIONAL ROLES (cont'd)

DESIGN AND IMPLEMENT INTEGRATED HEALTH SURVEILLANCE ACTIVITIES AND INFORMATION MANAGEMENT STRATEGIES	
L/P/T roles	Support the establishment of system frameworks, strategies and data/information exchange protocols Design integrated health surveillance systems within the provinces/territories, including strategies for integration of diverse health surveillance programs, and design of information infrastructure within a Federated System Implement improved information and data management strategies to support timely, accurate, valid, collection, processing and analysis of data within the provinces/territories and to share within the Federated System Implement strategies to protect personal privacy
Federal roles	Support the establishment of system frameworks, strategies and data/information exchange protocols Design integrated federal health surveillance systems consistent with joint priority setting International health surveillance, liaison and support for international agencies e.g. reporting to PAHO, WHO Implement improved information and data management strategies to support timely, accurate, valid, collection, processing and analysis of data within the Public Health Agency of Canada and the Federated
Collaborative roles	Support the operationalization of a Federated System for public health surveillance Develop national frameworks and strategies for the integration of diverse data/information holdings and infrastructures and data/information exchange protocols Endorse frameworks and strategies
Others' roles	Collaborate in specialized analyses; provide technical support in areas of particular competence (CIHI, Statistics Canada)
FUND, MAINTAIN AND EVALUATE THE EFFECTIVENESS OF HEALTH SURVEILLANCE ACTIVITIES AND THE NETWORK	
L/P/T roles	Fund, maintain and evaluate the effectiveness of health surveillance systems within the provinces and territories, including strategies for integration of health surveillance programs, design of information infrastructure and its fit within the Federated System Evaluate provincial/territorial health surveillance systems Identify gaps within the scope of the federated surveillance for public health surveillance
Federal roles	Fund, maintain and evaluate the effectiveness of federal health surveillance systems and their fit within the Federated System Strategic investment in national health surveillance infrastructure
Collaborative roles	Jointly fund, maintain and evaluate the Federated System Develop consensus on an evaluation framework for the Federated System Develop consensus on processes to efficiently act on issues identified by the evaluation of the Federated System