National Collaborating Centre for Infectious Diseases
Centre de collaboration nationale des maladies infectieuses

National Collaborating Centre for Determinants of Health
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Public Health Surveillance 2030
Report on Regional Consultations

July 2024, Revised

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GATHERING DIVERSE PERSPECTIVES
ON THE FUTURE OF PUBLIC HEALTH SURVEILLANCE IN CANADA

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Table of Contents

Introduction – Public Health Surveillance 2030

Surveillance is one of the six core functions of public health in Canada.[1] Public health surveillance has been defined as, "the continuous and systematic collection, orderly consolidation and evaluation of pertinent data with prompt dissemination of results to those who need to know, particularly those who are in a position to take action".[2] Surveillance is used to generate data and information needed to detect and understand health conditions, guide policy development, and take action in resource allocation and program planning.

The Public Health Agency of Canada (PHAC) is leading the Public Health Surveillance 2030 initiative to develop a vision for public health surveillance in Canada for 2025 to 2030. As part of its engagement process with public health experts to develop the Vision, PHAC partnered with the National Collaborating Centres for Infectious Diseases (NCCID) and Determinants of Health (NCCDH) to host consultations with regional experts across Canada. PHAC and the two NCCs agreed that it would be essential to hold the in-person events in large and smaller cities to hear a variety of perspectives. From the beginning of October 2023 to the end of January 2024, NCCID and NCCDH hosted a series of in-person and virtual engagements with public health personnel and allies at all levels of authority, to hear about any frustrations with current public health surveillance systems and to facilitate conversations about aspirations and expectations for a Vision for Public Health Surveillance 2030.

This report documents the approach, methods and results of the in-person and on-line engagement sessions. It is one part of the record of information PHAC is gathering to inform Public Health Surveillance 2030.

It is important to note that the word surveillance is not considered acceptable in many circles. As Janet Smylie notes, "*The word surveillance is associated with imposed, possibly involuntary or hidden close observation or inspection by external authority and hence can have negative connotations for Indigenous peoples*".[3] Furthermore, it is clear that members of the general population may confuse or conflate the purpose of public health surveillance with other forms of government oversight or monitoring and have related concerns about privacy, autonomy and the ethics of collecting and using public health data.[4]

[1] Canadian Public Health Association https://www.cpha.ca/sites/default/files/uploads/advocacy/strengthen/strengthening-ph-systems-brief-e.pdf
[2] World Health Organization https://www.emro.who.int/health-topics/public-health-surveillance/index.html
[3] Smylie, J, 2021. Assessment of and Response to First Nations, Inuit and Métis Well-being. ***In*** Visioning the Future of Public Health. National Collaborating Centre for Indigenous Health. https://www.nccih.ca/Publications/Lists/Publications/Attachments/10351/Visioning-the-Future_EN_Web_2021-12-14.pdf
[4] Klingler, C., Silva, D.S., Schuermann, C. *et al.* Ethical issues in public health surveillance: a systematic qualitative review. *BMC Public Health* **17**, 295 (2017). https://doi.org/10.1186/s12889-017-4200-4

With these cautions in mind, this document does use the word surveillance as a shorthand. However, NCCID and NCCDH recommend that the final Vision for Public Health Surveillance 2030 takes into account, and responds to, the confusion and the concerns about what is meant by surveillance for public health.

NCCID and NCCDH recommend that the final Vision for Public Health Surveillance 2030 takes into account, and responds to, the confusion and concerns about what is meant by the word "surveillance".

Public Health Surveillance in Canada

There is no single, coordinated public health surveillance system in Canada. Instead, surveillance is conducted through a range of independent data systems under the stewardship of numerous organizations in different jurisdictional levels and by different sectors of society. Public health professionals collaborate with partners across different settings and organizations to systematically collect, manage, analyze, and interpret data, and then communicate the resulting information to guide decisions and inform public health action. Surveillance systems are enabled by components such as laboratory capacity, informatics and IT, human resources, partnerships, and community trust.

PHAC notes that, "The context for surveillance has changed rapidly over the past two decades, including the emergence of new diseases and health threats, changes in data governance norms, and the increasing availability of new data and technologies. Consequently, the science and practice of surveillance have advanced considerably to address changing demands and adopt new approaches. For example, expansion of reporting to incorporate data on stimulant-related harms, hospitalizations and emergency medical service responses, funding to conduct research on the impact of the opioid crisis on Indigenous health, and dynamic modelling of substance-related deaths. Despite these advances in surveillance, the context for surveillance continues to evolve, and surveillance systems must continue to adapt, for example adjusting to the many effects of climate change and effectively making use of technologies such as genomics and artificial intelligence."

NCCID conducted an informal review of literature in June 2023, and the NCC for Methods and Tools conducted a rapid scoping review over the following months. The two exercises highlighted that while there was considerable innovation in surveillance during the COVID-19 pandemic, there are gaps in current public health surveillance systems such as heterogeneity in data collection and definitions, inconsistent guidance for confidentiality and data protection, lack of interoperability between multiple information systems, a lack of financial, human, and technological resources, and a lack of data disaggregation.[5] The context of public health surveillance has also changed rapidly over the past two decades. Trends driving the future of surveillance include new diseases and health threats, changes in

[5] National Collaborating Centre for Methods and Tools. (2023, September 15). *What are the latest innovations in public health surveillance*? https://nccmt.ca/pdfs/res/surveillance-innovations.

data governance norms, emergence of new data sources and publicly available sources, and new data mining and analytical technologies.

PHAC's initiative is intended to develop a renewed vision for public health surveillance in Canada that is informed by Canadians and public health stakeholders across jurisdictions. Ideally, the Vision will:

- Articulate the characteristics of a high-performing surveillance system in Canada;
- Describe how surveillance systems should provide insights to drive timely and effective public health action;
- Be based on science, evidence, and real-world examples; and
- Articulate an aspirational future state for all surveillance stakeholders to enable collective and coordinated action.

Approach to the Regional Engagements

The NCCID and NCCDH's approach to the regional engagements was to invite and involve as wide a range of public health personnel as possible in each of the sessions. This included an emphasis on hearing from First Nations, Métis and Inuit staff as well as public health employees who work for Indigenous public health organizations. The intent was to achieve diverse participation at every event from a range of:

- public health organizations (i.e., Indigenous, regional, provincial, and federal)
- roles (e.g., policy, planning, program delivery)
- professions (e.g., public health nurses, medical officers of health, veterinarians, pharmacists)
- public health issues (e.g., communicable and non-communicable diseases, oral health, mental health)

The NCCs used a template with these designations (organization level, role, etc.) to keep track of the invitations issued, and to help to fill gaps where there appeared to be an imbalance among registrants, as possible. There was capacity for as many as 35 guests at each site, and all the NCCs worked with PHAC staff and local personnel in each region to achieve the desired mix of participants.

The approach for virtual sessions, which began in December 2023, was slightly different. All people who had received an invitation to a regional meeting were sent invitations to the two "catch-up" virtual sessions (December 15, 2023, and January 29, 2024). They were encouraged to attend if they had missed being on-site locally and to forward the invitation to colleagues.

Additionally, five other sessions were held in January 2024. Two were with public health staff in New Brunswick and Newfoundland. The other three were specific to: a) members of the Canadian Public Health Laboratory Network; b) personnel who work in data management organizations; and c) agencies and individuals who are particularly interested in distinctions-based data (i.e., population-specific data disaggregation). Invitation lists for the virtual engagement sessions were drawn up by PHAC and the NCCs, with no limit on the potential number of participants.

Total Numbers of Guests Invited, Registered and Attended

Location	Invited	Registered	Attended
Manitoba - **Winnipeg**	44	37	32
BC - **Prince George**	48	25	18
BC- **Vancouver**	96	37	27
Nova Scotia - **Halifax**	56	44	28
Ontario - **Toronto**	84	36	30
Quebec - **Montreal**	85	26	15
Alberta - **Red Deer**	76	24	18
Saskatchewan - **Regina**	91	37	23
Ontario - **Thunder Bay**	71	30	30
Yukon - **Whitehorse**	39	14	6
Northwest Territories - **Yellowknife**	33	14	7
Nunavut - **Iqaluit**	29	12	11
Catch-up I		14	6
CPHLN	57	28	13
Data Authorities	24	11	9
Distinctions-Based	12	10	2
New Brunswick	28	31	29
Newfoundland & Labrador	91	31	29
Catch-up **II** (including PEI)		69	30
Totals	**964**	**530**	**363**

Ultimately, there was considerable variety across the events in terms of numbers of people who attended, their roles in public health and the communities they represent and work with. While some meetings were quite small, they appeared to provide safe spaces for conversations about surveillance.

In a number of cities and regions, we had very good representation from Indigenous organizations and in others it was lacking. Fortunately, the NCC for Indigenous Health is conducting a separate consultation with First Nations, Inuit and Métis-led organizations. Quebec was in the midst of a provincial teachers' strike and there were few attendees at the Montreal session as a result. Furthermore, we were not able to reach other francophone public health areas or experts in Canada, with the exception of one community-based 2SLGBTQI+ organization in Manitoba.

Meeting Facilitation

In-person events were held from 8:30 am until noon at each site. (In the afternoons, the engagement sessions shifted to the 2024 Core Competencies). The flow of the information shared with participants about Public Health Surveillance 2030 and the facilitated discussions was standardized to help ensure consistency in what participants heard, and in how their perspectives were recorded in discussions. Regardless of the location, the agenda was as follows:

- Whenever possible, the morning opened with a prayer or teaching from an Elder or Knowledge Keeper. Their words and teachings were inspiring and set the tone for the sessions in each region.
- Following opening words from NCCID and NCCDH staff and a summary of the agenda and the objectives for the meeting, a member of the PHAC team presented an overview of the Public Health Surveillance 2030 initiative, including the numerous means of engaging with experts.
- NCCID gave a short presentation to encourage further reflection of what is meant by public health surveillance, and to encourage participants to consider all aspects of surveillance relative to their jobs and knowledge over the course of the morning.
- Facilitated discussions began with two rounds of small-groups discussions: *Envisioning the Future and Elements of Success*. Discussion points raised in the two rounds were recorded on flip-chart paper (as well as by notetakers at some sites), and key points were shared with the larger group after each round.
- Participant groups were then reorganized and guests worked together to create lists of current Challenges and Solutions
- There was an opportunity for all to provide short notes on flip chart sheets on anything that had not been covered in their conversations so far, under the heading of *What are We Missing?*
- The final exercise was a gallery walk, *Here, There and Elsewhere*, in which small groups worked together to think about where they could already work towards a Vision for public health surveillance (*Here*), where they could enlist the support of colleagues (*There*), and what would involve other sectors or agencies (*Elsewhere*)
- Each morning concluded with time for reflection and any comments about the process and the discussions of the day.

The virtual sessions were held on Zoom and followed a similar engagement process, compressed to 90 minutes.

NCCID used Slido, an interactive platform, to have participants engage in three of the exercises during the virtual meetings. For the Envisioning the Future exercise, participants created a word cloud of the important points they wanted to see in the future. The Elements of Success exercise allowed

participants to type in more text, describing examples of successful surveillance partnerships and programs. The What are We Missing exercise, later in the session, also allowed participants to type as much as they chose.

For each of the exercises, *Challenges and Solutions*, and *Here, There and Elsewhere*, participants were placed in virtual break-out rooms which were facilitated to encourage more fulsome discussions of the issues that they faced in their particular place of employment and communities.

Documentation & Analysis

The information shared by participants was recorded in a number of ways, depending on the meeting format as noted above: flip chart notes, discussion notes recorded by notetakers, sticky notes and replies on Slido. All information was collated by NCCID staff into a single Excel workbook for each session. All notes, flipcharts, sticky notes, Slido content, and photographs (collectively considered the raw data) remain in their original form at NCCID.

Thematic analysis was then used to organize and analyze data for each topic based on patterns revealed by the data and the consultation objectives. After reading the data several times, thematic codes were determined to organize and categorize the information, and a code was applied to each discussion point recorded.

NCCID created a short set of powerpoint slides for every session with the key points raised on that day. All analyses and the results shared in this report, however, reflect the greater depth and breadth of information recorded during the engagement sessions.

What We Heard

A. Envisioning the Future

The first question posed to participants was to consider, "In a perfect community/region/province/Canada, what will we have in place that will make public health surveillance effective and sustainable, in terms of…"

Responsibility to Community

Participants at all consultations expressed the need for greater community involvement in the surveillance process. The word “participatory” was frequently used to describe the nature of

engagement for people providing their information (data). The data collected should also be meaningful and intentional, and based on what the community has identified as important. Participants noted that community should be the frame of reference for context, and the context should be considered in data analysis and interpretation.

It was also widely suggested that there needs to be a method of reporting back to the community after data collection was complete, to "close the loop." Participants noted that surveillance information should be returned to the community and made accessible so it can be applied at the local level, by communities. Participants also commented that data should be disseminated to reach the right people involved in decision making.

Some participants mentioned they felt public trust was affected during the pandemic due to a lack of government transparency, which may make it difficult create trust now when collecting surveillance data and in thinking about how it will be presented. Communication should be understandable and jargon-free, regardless of the language spoken. Some attendees stated they felt that the public appreciated access to timely, straightforward public-facing data during the pandemic, and this approach led to better understanding by the general public than other reporting methods such as annual reports.

There were a number of references to roles and responsibilities for community engagement, with one suggestion that PHAC should support local data collection and use, and one suggestion that the particular city (i.e., the municipality) be involved. Data sovereignty and the matter of who owns data were also raised, with many participants indicating community ownership is critical when considering policy.

> At most of the consultations there was support for greater transparency about the reasons for collecting public health data, more timely reporting to communities, and greater respect for community rights and data ownership.

What This Means for the Vision

The foundation of surveillance should be built with the communities providing the data. The consistent references to full-cycle community involvement suggest that the consultation participants see a need for surveillance to be grounded in the communities in which data are collected. Surveillance should be a meaningful reflection of the people in the community and undertaken with the intent to give benefits back to the community.

The focus on community foundations also suggests ideal surveillance moves beyond data sets and is built on relationships. Establishing reciprocity with communities over their data can build trust and sustained engagement that surpasses the timeframe of data collection and more closely resembles a partnership. A commitment to community and relationships could also be a way to rebuild or forge trust.

Workforce Preparation and Availability

To our participants, workforce preparation and availability meant appropriate training and resourcing capacity to support surveillance. They felt it was important for workers to have surveillance-specific skills

and particular kinds of expertise, and noted areas – such as epidemiology, that were particularly valuable and appreciated during the pandemic, and thus a strength to build on. We also heard there were other areas of expertise that need to be developed more, such as information management and data science. Participants suggested there could be a stronger link between public health education programs and professional development. Some participants mentioned the health of the workforce needs attention, referencing burnout and fatigue. Building capacity in numerous areas of surveillance was also important to attendees, requiring more resources and ensuring they are distributed equitably. It was mentioned that there are some gaps in communication, in that the workforce does not always understand the purpose behind collecting data.

What we Heard: Workforce Preparation and Availability for Ideal Surveillance

Themes	Discussion content
Workforce capacity	• More workers are needed overall • Resourcing to support more types of surveillance or sites is required, such as sentinel sites and Northern or rural areas, as well as for more training • Surveillance processes can be used to decrease workloads and improve efficiency for workers, by reducing duplication and focusing human resources in areas with the greatest need. Artificial Intelligence may be a way to address this. • Resources should be aligned with levels of need, such as when disease prevalence increases staff allocation to the issue also increases accordingly
An informed and supported workforce	• Workers need to understand the "why" of collecting data • Closing the loop on communications through the collection process is important • There are gaps in communication to the workforce about staffing and human resource capacity • There are opportunities to improve diversity and equity practice in recruitment and retention, and ensuring the workforce – including those in decision-making roles – is representative of the populations they serve. This includes francophones outside of Quebec as well as sexual and gender minorities throughout the country.
Surveillance specialties and expertise	• The surveillance workforce needs to be resourced to understand all health issues, not just infectious diseases • Frontline staff need to understand surveillance's practical application to their work. Data entry into the system could be done by frontline workers. • The workforce needs more expertise in data science, complex systems, data collection, and investigation; and also in the unique needs of certain populations, such as gender and sexual minorities and francophones outside of Quebec

	• The workforce should reflect First Nations expertise and other ways of knowing • Transdisciplinary expertise should be considered in workforce planning to avoid silos • Surveillance workforce (i.e., not just front line public health) should be able to apply an intersectional lens to minimize discrimination and stigma across populations • There is some role confusion between public health staff and primary care providers • Concerted efforts to capture single or multiple events over longitudinal systems in the lab networks exist but they are not standardized. • Need to consider how those events and interventions are tracked for effective reporting and for policy makers and researchers to use
Surveillance training	• There is a lag between academic programs and workforce capacity in practice. Education and professional development should be better integrated. • Training programs should be based on Canadian contexts • Surveillance and data collection training should also teach students how it will influence their work • Training should empower knowledge to action

What This Means for the Vision

Workforce capacity needs to align with the specific skills and resources needed for surveillance. Workers need to be supported with training and resourcing that sets them up for success in meeting the objectives and demands of surveillance activity. The references across all consultations to specific skills suggest an opportunity for surveillance-specific training as part of formal academic programs and ongoing professional development. Capacity-building needs forethought and planning to ensure the particular roles, skills, and level of engagement needed to bring the surveillance vision to life are characteristics of an appropriately prepared and confident workforce.

B. Elements of Success

In small groups, participants next discussed what factors, conditions and resources are already in place and can be sustained or strengthened. Participants were encouraged to list these “elements of success” as part of the path towards the Vision.

Elements Already in Place

Strong relationships are enabling a shift from "clients" and "stakeholders" to "partners." Ongoing, sustained engagement with Indigenous partners was mentioned by some participants as a strength, noting that there is recognition of different ways of knowing.

Using existing infrastructure or repurpose technology in new ways was suggested as a way to leverage processes to new public health topics and populations. Innovative approaches, such as using wastewater data, were noted as positive expansions of surveillance.

Meeting participants clearly expressed the public health workforce is a current key strength. We heard there are committed, dedicated, knowledgeable staff who bring a positive attitude and willingness to share to support the common good of improving surveillance. There is expertise and experience in the workforce, and it was mentioned that access to multiple areas of public health expertise and epidemiologists is especially valued.

There were several references to notable improvements seen in response to pandemic management. Participants mentioned positive changes in areas such as timeliness in decision-making, red tape reduction, and resourcing to meet demand.

What We Heard: Elements of Success Already in Place

Theme	Discussion points
Relationships	• Partnerships with academia and research bodies support connections among research, public health practice, and communities • Intergovernmental and cross-jurisdiction collaboration through tables, working groups, and communities of practice can promote dialogue and unity in working toward a common goal • There are strong partnerships at the local level with community agencies and coalitions • Building trust with First Nations has encouraged data sharing
Technology features and tools	• Access to real-time dashboards, interactive data, and communication tools is meaningful • Moves to a single health record system and electronic health records are strengths • COVID accelerated integration of data systems • Acute care and diagnostics data can be made accessible and harnessed for secondary use in public health • Canadian Public Health Laboratories Network (CPHLN) has distributed sites across the country, with enough standardization to observe differences; do need to link to providers and public health policy makers

	• Genomics is a powerful tool, there are many surveillance systems segmented for the purpose; so far, we not making best use of those systems for insights
Dedicated, skilled workforce	• There are established professional networks and communities of practice that enable engagement with peers • Working remotely and digital collaboration tools has improved connections and reduced silos • It is widely recognized there is a range of expertise in public health that is valued an appreciated among the workforce
Improvements due to pandemic response	• Increased use of timely, public-facing data was seen as generating public awareness in trusted sources • Increased capacity at the local level improved collaboration and a broader understanding of surveillance • Attention was drawn to equity through COVID equity data

Summary – What Can be Strengthened?

Participants spoke of the need to improve collaboration within existing relationships. At the local level, there is opportunity for more community engagement in priority-setting, and for local approaches to inform provincial decisions. Building on relationships with other agencies outside of health and existing intergovernmental connections were suggested as starting points for breaking down silos and bridging fields of expertise. Participants are also interested in learning from each other, and suggested using existing tables and networks to share lessons learned and what is working well.

In terms of data and technology, there is recognition that there may be numerous data sets available, but participants mentioned there are barriers to retrieving and using the data. It was also noted that qualitative data should be considered evidence and is important to truly hear the population's voice. Participants felt a system with capacity for real-time data would improve clinical guidance and decision-making. Equity considerations were also raised, in that certain types of data are not available to report in some communities, putting those areas at a disadvantage by not being included in a dataset.

Participants mentioned they would appreciate more opportunity for training, professional development, and to connect with others. While the workforce has willingness and interest in improving surveillance, time and capacity can be barriers.

What We Heard: Elements That Can be Strengthened

Theme	Discussion points
Collaboration	• Role and scope clarity between provinces and PHAC would improve province's understanding of surveillance data requests

	• Documenting how parties have decided to work together would formalize the terms of the collaboration • Information should flow from the community, not top down, to help make public health decisions and address gaps
Data and technology	• Data are collected and available, but it also needs to be easily accessible • Timely data would improve in-the-moment decision making • Qualitative data needs to be included to better understand meaning and context • Smaller communities and areas that use a different information system are at a disadvantage for reporting data • Systems need to be integrated and interoperable; not a new concept but not yet achieved • Public health-specific lab testing (pathogen genomics (e.g.PulseNet), wastewater)is in place primarily to support public health work. The scope and resources required for provincial and national public health surveillance systems must be recognized, to ensure tools, infrastructures and capacities are supported as part of coordinated and integrated public health surveillance system in Canada. • COVID has done an incredible job standing up much-needed laboratory surveillance infrastructure in Canada. It is critical that this asset is maintained
Workforce capacity and training	• Use existing networks to increase opportunities to learn from each other • Expanding skill sets will build capacity • Public health staff need increased opportunity and time for surveillance training and data collection

What This Means for the Vision

Capitalize on existing building blocks. Some items mentioned as elements already in place and working well were also considered to be elements that could be strengthened. Using these components as bases from which to launch improvement could lead to quick wins without the disruptions of designing and implementing brand new initiatives. In a resource-strained sector, leveraging current capacity in a targeted manner may be a key strategy to optimize time, financial, and human resources.

Participants noted that the coordination and infrastructure developed during COVID-19 (cross-disciplinary work, lab systems and data sharing, community involvement in many aspects of decision-making) is a critical asset that must be maintained.

C. Gaps and Solutions

In new groups, participants worked together to list challenges – factors that can prevent achieving the Vision for public health surveillance – and their potential solutions.

Summary

Lack of integration, linkages, and coordination was seen as a significant gap in surveillance. It was spoken of in terms of data, information systems, standards, and roles. Participants felt that the many systems in place in different regions and the inability to link them (lack of interoperability) creates silos, redundancies in data entry, and differences in data across provinces and territories. The lack of standards was noted as hindering data comparability and actionability, as well as creating skewed data at the population level. Some participants noted a lack of clarity about roles and responsibilities among and between local, provincial, and federal bodies. Suggested solutions included provincial and national access to one common system, intersectoral contributions to system development, and mandating shared platforms.

The specifics of surveillance challenges varied across the country. In some locales political interference was an issue; in other places, rebuilding community trust was mentioned. Outside of the major cities, teams are coping with antiquated, often paper-based, systems or there are just too few staff to manage the data requirements.

Many participants noted that the way different teams came together during COVID-19 and the autonomy and authority they had to do whatever was needed, is a model they would like to have continue.

The capacity of the workforce was noted as a gap and frequently expressed in terms of lacking resources—time, financial, expertise, and staff. This lack of resources has often led to reactive instead of proactive responses, training needs, relying on volunteers, and pressures managing federal-level reporting and information requests. Certain surveillance-specific skills such as epidemiology and data analysis were seen as areas for capacity-building. Some attendees representing smaller centres noted teams become responsible for many public health functions, not just surveillance, and that the public health workforce can be transient with a lot of turnover due to difficulties recruiting and retaining staff. Participants also noted that access to certain skills and expertise can be different for smaller and larger centres. Leadership changes, political change and priority shifts, and staff turnover without organizational knowledge transfer were also noted as challenges. Solutions to close these gaps included ongoing training, sustainable and predictable funding, and providing time and resources dedicated to surveillance functions.

Trust was also a common concept that came up. Some participants felt public trust in public health and surveillance has eroded, as well as trust between public health workers and organizational or government leadership. There is also seen to be mistrust generated by the gap between the information governments want to collect and what the community is willing to share, as well as hesitancy about how the data will be used or interpreted and if it may be stigmatizing. Participants also mentioned that there needs to be more trust in the data; not collecting data that is truly reflective of the population affects

perceptions of data quality and accuracy. Suggested solutions to these issues included strengthening community involvement, focusing on relationship-building, and tackling the spread of misinformation.

What We Heard: Gaps and Suggested Solutions

Themes	Discussion points—Suggested solutions
Lack of integration, linkages, and coordination	• Increased automation and interoperability • Intersectoral contribution to system development • Standards for processes, data collection, methods, data compilation, case definitions, and methods • PHAC employees could be embedded in local public health areas as a bridge • Universities help sustain surveillance systems • Incentivize participation in surveillance with funding • Surveillance systems are integrated with electronic health records • System connects clients' care that may be received in multiple locations • Adopt a coherent perspective on surveillance to break down artificial barriers between types of population, administrative, public health data • Address "human interoperability" • AMR is very challenging, involving farms, abattoirs, retail, environment, etc. While work on AMRNet has continued, there is much to be done, especially to share back to provinces and territories • Genomics can be part of the story; surveillance is multi-disciplinary
Workforce capacity	• Provide opportunities for surveillance training early on in the workforce's career path • Consider how to have local capacity that is rolled-up through provincial and federal systems • Streamline processes and improve tools to reduce collection and reporting burdens • Standardize training • Build interdisciplinary teams with different sets of expertise; CPHLN has demonstrated this across the country • Need workforce modernization around genomics
Trust	• Use participatory engagement to build systems and surveillance from the ground up • Provide more information on how the collected data will be used • Invest in relationships

	• Bring information back to communities • System is non-partisan and arms-length • Advocate for underrepresented populations • Include building trust in training programs and curriculum • Establish data protections to ensure confidentiality • Reduce time between event recognition and ability for public health to act • Support public health staff if they experience ethical or moral distress

What This Means for the Vision

This is no doubt public health personnel across a range of roles and authority levels have frustrations and challenges with public health surveillance related to data collection, managing data sets, adapting outdated systems to new requirements, personnel shortages, and the need to reply to myriad questions and policy requests. In some parts of Canada, public health staff are managing more than 10 different data entry forms, entered in data sets that are not set up to streamline data retrieval. In the majority of meetings, participants also worried about the inability to report back to community in a timely fashion, and that includes sharing national-level data routinely. In some regions, frustrations had to do with limited interest from leaders in ensuring public health surveillance is effective. and in some cases with the long-term effects of political interference.

The long list of solutions participants generated points to the knowledge they have about what is needed locally to streamline data collection, analysis and reporting, with respectful engagement with communities. In many places, we heard that guidance on standardized and streamlined data collection and analysis processes would be invaluable. The potential for "human interoperability", meaning having a skilled workforce who can easily move between data sets, was raised. Improved software and linked data sets would certainly be preferable to what some regions are working with, but interestingly, artificial intelligence and new data sets only came up among academics at the events. Otherwise, participants spoke of the basic need to have reliable electronic data sets and the ability to integrate social data such as vital statistics.

D. What Are We Missing?

In plenary discussions, participants were invited to raise any topics falling under a few broad categories that had not been discussed to that point.

Summary

Comments regarding the workforce included the importance of considering staff health, safety, and well-being, especially in the context of staff shortages. Some participants mentioned the need for the public health workforce to be a better reflection of population diversity. Specific areas of training needs were also noted, such as community engagement, political acumen, and policy evaluation. Ongoing

professional development and education was seen as important to ensure the workforce's continuing renewal.

Discussion about technology included using AI as a support, not replacement, for public health workers, and that it should move public health forward through new tools and efficiencies. Using technology solutions from outside of healthcare was suggested as a way to simplify work and learn from other fields. Updating technology and IT systems in current budgets was noted as a challenge.

Sustainability was raised in the context of political environments, as some participants felt that political will is a factor if there are "data gate-keepers" and sustainable funding and systems need to last after leadership or government changes. Other comments about improving sustainability referred to longer funding cycles, establishing long-term science strategies and priorities, retaining the workforce long-term, and sharing successes of public health surveillance.

Regarding ethics and equity, there were calls for a defined surveillance ethics framework, and consideration of the ethics and accountability of not including small populations or those facing structural disadvantage in data collection. There were concerns about certain types of data collection, such as race-based, reinforcing stigmatization, while some participants held the view that this type of information is important to inclusivity. Use of data and findings was also framed by some participants as an ethical issue, in that data should be used for improvement and to benefit the community.

Participants reiterated their wishes to see qualitative and social determinants of health data incorporated into surveillance, with some specific suggestions of climate change, education, and homeless encampments as potential indicators. The quality of data input was also mentioned, with consistent training on data entry and automated processes seen as ways to reduce the amount of time spent on cleaning data.

What We Heard: Additional Topics Raised by Participants

Theme	Discussion points
Workforce	• Need to consider if we can stop doing things to make room for surveillance activity, given burnout and staffing shortages • Staffing levels are inadequate to address root causes of problems • Workforce should be equitable and not based on population size • More training of individuals from a wider range of backgrounds (including racialized communities) to increase workforce diversity is needed • Workforce diversity also means a range of knowledge and skills • Ensure MPH and post-secondary education programs are including curriculum in skills needed in the workplace, such as data collection, population health assessment, and evaluation • Training is needed in both what is required currently, and what we anticipate will be required in the future

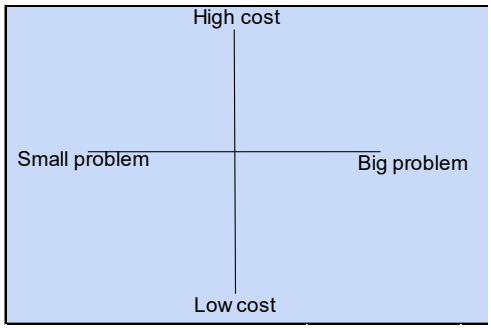
Technology	• Public health can better leverage modern data management approaches • There is opportunity to be more forward-thinking regarding technology so it is not already outdated by the time of implementation • There will be workforce training implications with increased AI use • Auto-generated reporting and documentation would increase efficiency
Data	• Ensure systems include a range of public health initiatives and interventions, not just current "fires" • Surveillance should be based on a wellbeing and strength-based approach instead of a deficit-based approach • Increase automation processes for data entry • Prepare for partnerships with private labs • Ensure data ownership and governance agreements are developed with populations facing structural and systemic discrimination
Sustainability	• Technology and systems need to be more adaptable to keep up with changing needs over time • The trend is to include more data, and automation can help the workforce manage increases in the future • Consider environmental impacts of increasing digitization as part of sustainability • Ensure continuity in surveillance management during any restructuring with a vision and targets any leader can follow • Labs are now starting to question surveillance activities and looking for duplications. Where are the roadmaps for this process? • An Epi-equivalent to the Laboratory Liaison Technical Office program may help to alleviate the pressure on provinces
Ethics	• Surveillance needs a clear ethics framework • Not having data to identify populations at risk of inequity is an ethical issue • Data collection from populations at risk and experiencing structural disadvantage could reinforce stigmatization or tokenize their participation

E. Final Engagement Exercises

The final exercise in every engagement session was intended to gauge participants' interest and capacity to help move towards a renewed vision for public health surveillance within their own spheres (*Here*), with colleagues and partners (*There*) and what requires involvement from other sectors or public health authority level (*Elsewhere*). The final exercise was tested in a few different ways before the final format and process were determined by the 5th session (note that there was not enough time for a final exercise with the participants in Vancouver).

Problems and Costs – Prince George and Halifax

For the first four sessions, participants were asked to consider where changes could be made within quadrants.



What We Heard: Problems and Costs

High cost, Big problem (Upper right quadrant)	**Low cost, Big problem (Lower right quadrant)**	**High cost, Small problem (Upper left quadrant)**	**Low cost, Small problem (Lower left quadrant)**
Data systems and infrastructure (cost, time, capacity, effort; functionality (high importance)	Elimination of duplicated work (as a result of one system) --> time and resource savings	Engaging public health practice	Partnerships
Consistency of language/ Recruitment and retention definitions	National data flows internationally (e.g., reporting on SDGs, etc.)	Team development	Relationship building/maintenance
Meeting the community where they are	Relationship building and maintenance industry - reasons for meaningful	Specialized knowledge within communities	Local access to data

	engagement with public health initiatives		
Incentives for staffing	Revamping documentation standards so that it is not cumbersome (mentioned twice)		
Having one data system (provincial or national) that works for everyone	Understanding, learning, embracing data governance - WHY		
Staff retention and expert professionals	IPT engagement and public health initiatives		
Investing in specialized knowledge within communities/teams	Revisiting and learning about data governance		
The four-year cycle of decision-making	Incorporating primary care data into public health		
Integration with social determinants systems	Workforce development: understanding, entry, interpretation		
Enabling legislation			

Here, There, Elsewhere:

The final exercise in the remaining engagement sessions was conducted as a gallery walk in-person, or in breakout rooms in the virtual sessions.

Summary

Engagement in the final activities in the consultations was high. Participants were happy to take ownership for some of the ways they could take steps towards a renewed vision of public health surveillance within their own circles of influence. And not surprisingly, they saw opportunities for others to contribute also.

The themes of commitments to community continued to be strong in all of the regions. In some cases, that was specific to First Nations and Inuit values, and in other centres it was somewhat more generalizable. In some cases, participant groups returned to the successes and solutions that are already

available – often during the pandemic – as mechanisms to move forward. Role clarity, professional development and authority to act were also considered key.

Further afield, participants commented on the need for leaders (political and within organizations) to understand what public health surveillance is, how data are used, and to serve as champions for sustained funding and resources.

Lastly, participants commented (elsewhere) on reassessing the unspoken values and tenets, to be more wholistic (well-being), integrating information and knowledge on the social determinants of health.

What We Heard: Here, There and Elsewhere

Here	There	Elsewhere
Actively reach out to engage partners / improve communication and knowledge translation	Transparency in data use/collection/action	Relevant and timely SDOH data
Be creative in finding ways to work collaboratively / build networks and participation in communities of practice	Role clarity, particularly at federal and provincial levels	Commitment to a common goal
Data and resource sharing	Identify champions / Surveillance champions tell its story	Long-term investment in financial and human capital
Training and professional development	Long term leadership stability and funding / advocacy for public health resourcing	Political leadership, partnership, shared priorities and will
Engage communities to build trust /	Advocacy for integration – systems, data sharing, skills/training	Private and other sectors contribute/collaborate
Timely and publicly transparent data to show accountability	Leadership demonstrates appreciation for public health	Connect surveillance with research
Enable paths to influence up with advice on what is working and not working / leverage existing resources	Encourage collaboration and sharing / set up structures to enable collaboration	Data access and comparability / standardization across the country to learn from others
Expand lab and epidemiology partnerships	Consistency and standardization	Shared priorities and will / Break silos and be clear on what we can do together

Be aware of reporting demands	Training in culturally appropriate and trauma-informed care and data literacy	Build public awareness on public health to generate positivity
Get beyond regions and concentrate on patients/populations	We do not need to start from scratch	Listen to communities and follow through with action
Clearly state our needs to succeed	Culture change from no (problem focused) to yes (solution focused)	Look to lean principles for efficiency and resource allocation
If people have responsibility, they need to be given authority to carry out their job (culture/org issue)	Encourage a culture of the importance / use of data	Integrate community and Inuit perspective on health information / partner with Indigenous peoples
Change the term “surveillance”	Focus on the goal of impacting public health outcomes	Integrate youth perspectives
Clarify roles / desegregate teams	Meaningful First Nations empowerment to use data	Focus on well-being
Look to successes in zones (health authorities) for tools that can be used in other areas	Incentivize permanent workforce	
	Establish formal partnership with the National Collaborating Centres	

What This Means for the Vision

Despite coping with numerous frustrations with current public health surveillance collection methods, analyses and opportunities to work with communities to present and use data, participants in the regional engagement sessions were largely optimistic about the future. Working in small groups and, because of the nature of the exercise, building upon each other’s ideas, participants could see ways to move forward for themselves and their immediate colleagues. However, there are important opportunities for governments to strengthen public health surveillance units, and for PHAC to provide leadership as well as additional supports in some locations. These would be in the form of guides for standardizing data collection, data sets, contextualizing data reports and working with communities. Upgrading software and making new data sets available may be enticing, but without the dedicated, skilled workforce needed, the vision for public health surveillance cannot be realized.

Cross-cutting Themes and Links to Surveillance Processes

The information and perspectives gathered from participants across Canada revealed a number of cross-cutting themes relating to public health surveillance processes and the use of resulting data.

To participants, the ideal surveillance system:

- Is patient-, community-, and people- centred;
- Is grounded in relationships that are intentional and built on trust;
- Is enabled by a workforce that is supported with sustainable funding and training opportunities that foster surveillance-specific expertise, engagement, and continuous professional development;
- Includes holistic, well-being, qualitative, traditional and other ways of knowing, and social determinants of health data;
- Includes mechanisms for reciprocity of data and actionable insights that are applicable and appropriate to supporting improving the source community's health outcomes;
- Generates datasets and insights that are trusted as an accurate and representative reflection of the community, including using technology that enables inclusive population and community participation;
- Produces an accessible, reliable evidence base for timely decisions both upstream and downstream;
- Strikes a balance between privacy and access, using policy instruments that are appropriate for the type of data, intention of use, and community wishes;
- Uses technology infrastructure, programs, lab networks, and services that are integrated and supported by streamlined processes and workflows that minimize duplication, data entry, reporting burdens, and are accessible across jurisdictions.

Data Collection

Consider changing the terminology and redefine the scope of surveillance. The word "surveillance" itself was noted as problematic, and there have already been shifts in terminology to use "assessment" interchangeably with "surveillance" [6]. Across regions and discussion topics, it was strongly felt that data should go beyond infectious disease and pathogens to include social determinants of health, non-medical data, and qualitative data.

This means a shift from identifying and tracking disease or pathogen occurrence and rates to an operationalized acknowledgment and recognition of the factors contributing to health, wellness, and disease. Lived experience, stories, traditional knowledge, and social data would be valued alongside epidemiological and laboratory data.

[6] Public Health Agency of Canada. 2023. https://www.canada.ca/en/public-health/programs/consultation-vision-public-health-assessment-canada-future/document-technical.html

Surveillance would also mean including all members of the population to generate accurate and reliable data that is trusted as high-quality and a true reflection of the community. Gaps in information need to be filled by identifying populations that are currently underrepresented in surveillance or experiencing structural disadvantage.

Surveillance is dependent on relationships. Systems and processes are built with the communities providing the data. We heard that data collection is underpinned by social and contextual factors, such as trust, respect, and perceived transparency. There needs to be a bridge between data and relationships. Full-cycle community involvement grounds surveillance in the communities about which data is collected. Reciprocity with communities over their data builds trust and sustained engagement that surpasses the timeframe of data collection and more closely resembles a partnership. Demonstrated commitments to giving the benefits of surveillance activity to improve health back to the community can rebuild or forge trust.

Workforce capacity needs to align with the specific skills and resources needed for surveillance. We heard that workers need to be supported with training and resourcing that sets them up for success in meeting the objectives and demands of surveillance activity. There may be opportunity to explore a greater role for surveillance-specific training as a part of formal academic programs and ongoing professional development. Capacity-building could be approached with forethought and planning to ensure the particular roles, skills, and level of engagement needed to bring the surveillance vision to life are characteristics of an appropriately prepared and confident workforce.

Data Management

Put the pieces together. Interoperability is required for both systems and people. We heard calls for one national, federated technology system, but also caution that a one-approach-fits-all approach may lose sight of or not be suitable for local or regional needs. In a resource-strained sector, leveraging current capacity in a targeted manner may be a key strategy to optimize time, financial, and human resources.

Capitalize on existing building blocks. Using components as bases from which to launch improvement could lead to quick wins without the disruptions of designing and implementing brand new initiatives. There are examples of what is working well that could be leveraged across regions and help bridge context-specific gaps. This could extend beyond technology and systems, to professional tables and networks, community engagement strategies, lab networks, and relationships with research/academia.

Analysis and Interpretation

Surveillance needs to give back. A concern expressed frequently was that surveillance is currently seen as monitoring people, and something that is done to people's information; it is one-way. Insights

gleaned from the data ideally should be returned to the community with knowledge translation and implementation support. People providing data should not see the surveillance process as ending once their information is in a dataset, but appreciate it as a full circle, with their well-being at the core.

Action. Some participants expressed that surveillance activities felt like collecting data just for collection's sake. Determining and communicating the steps that will be taken once data is collected and analyzed is important for communities, data collectors, and data users in terms of trust and transparency. This may be particularly important when dealing with populations experiencing structural disadvantage or for which there may concerns regarding data sharing leading to stigma.

Apply multiple lenses. The lenses of social determinants of health, equity, and appropriate representation was an important component of data use for participants. This includes explicitly presenting context for data about populations experiencing disproportionate burdens or who may be disproportionately affected by decisions arising from data analysis.

Disaggregate the data. To support appropriate actions and equity, data needs to be available in disaggregated formats. The capacity to analyze data based on distinction can close gaps in understanding the status and unmet needs of populations and inform decisions on action, intervention, and risk reduction. It can also contribute to trust and transparency through people seeing themselves in analysis, interpretation, and decisions.

Information Dissemination

Trusted messages by trusted messengers. Trust may have eroded between the public and surveillance, between jurisdictions, and between the workforce and the data. Surveillance activities need to reach source communities and the public amidst concurrent waves of health information and be relatable. Audience analysis to determine who is trusted can enable knowledge translation that is targeted and relevant. Real-time information and improving timeliness of data is a key aspect of improving decision-making upstream and downstream and seeing surveillance data as an important decision-making tool. Surveillance also often seems to be viewed as hierarchical, with requests, requirements, and decisions being made top-down; a commitment to transparent communication and authentic collaboration with follow-through could forge trusting relationships across jurisdictions.

Reach a consensus-based approach to data sharing. The views on data sharing ranged the spectrum from making sharing mandated, expanding data sharing agreements and MOUs, to minimizing sharing to protect against stigmatization and preserve individual rights. Striking the balance between access, privacy, and use will need to be achieved through collaboration. The role of ethics and the potential of

building a surveillance ethical framework, as suggested by some participants, could be a foundation for data sharing, as well as other process components.

Knowledge translation is part of the surveillance process. Strategic, systematic knowledge mobilization and brokering would close the loops and enable data and insights to be used to their intended and optimal uses. KT would support the data returning to its source at the community level to enable transparency and/or actional, and enable uptake downstream, upstream, and at point-of-care.

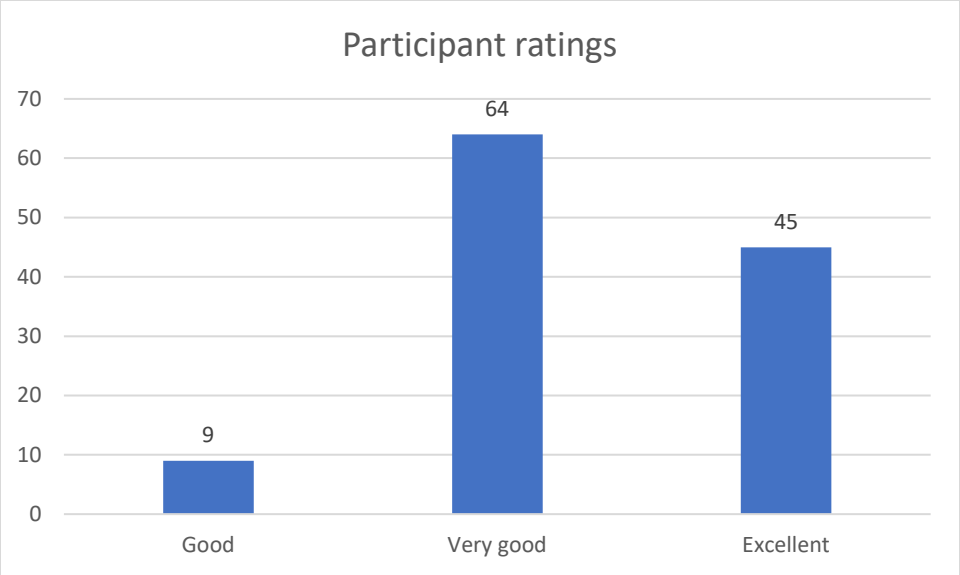
Appendix A – Evaluations

There were 118 responses to the survey received across all consultations, with over 92% of participants rating the session very good or excellent.

Feedback included comments about what worked well for the attendees, and suggestions for improvement. Many attendees appreciated the opportunity to be engaged, enjoyed meeting colleagues from different disciplines and hear a range of perspectives, and liked the facilitation and format. Some participants would have liked to receive materials in advance, felt the session needed to be a bit longer to best capture perspectives, and would have appreciated more diversity in expertise and public health roles represented. Selected quotes from participants are provided below.

What We Heard: Evaluation Results

What worked well	Suggestions for improvement
"Extremely well organized activities, flow, good time keeping (not an easy job with a passionate group!)"	"More representation at these tables from various levels, populations and communities. Also, more frontline staff should have been included"
"Small group sessions worked well and I liked that some different approaches were used for the small groups"	"I think a small exercise prior to would have helped me think through where my pieces fit into the overall picture"
"the quality of the facilitators and the invited guests in the consultation"	"perhaps pre-reading so we could be better prepared in our responses?"
"opportunity to contribute--represent my domain"	"would like to have heard more about what type of initiatives are in the works. How the provinces communicate with PHAC"
"I enjoyed the small breakout group sessions and carousel activities. I appreciated that every voice was valued."	"deliberate seating/organization groups for more representation in responses"
"I liked that on top of meeting the consultation objectives, it helped our local community identify what we can do better. "	"discussion seemed to veer from surveillance topic. Would have been good to formulate questions in surveillance context."
"Really enjoyed the diverse skills and education of everyone present. Different perspectives were great to hear"	"Better articulation of were we looking for solutions in province or national"


Participant ratings
70
60
50
40
30
20
10
0
64
45
9
Good
Very good
Excellent