

**KNOWLEDGE  
TO ACTION  
S E R I E S**

**WBS RESOURCES AND TOOLS**

# **HEALTH DATA GOVERNANCE AND ETHICS**

Health data governance is a component of information governance that refers to the overall management, collection and use of health data. It applies to what decisions about data must be made, how they are made and who makes them (Institute for Circumpolar Health Research, 2022). Values are critical to what population data gets collected, how this data is created and governed, and how this data informs actions that achieve equitable health outcomes for all.

Nowhere is the power and importance of control and oversight of health data more apparent than in the experience of Indigenous people and communities in Canada.

## Data Sovereignty and Indigenous Peoples

“First Nations governments are not wanting to operate with the Big Brother mentality that we’ve all been groomed into believing in relation to what data does to us—it’s more like we want to come from the grandmother perspective. We need to know because we care.”

Gwen Phillips, Ktunaxa Nation and Board Director, First Nations Information Governance Centre (FNIGC) (NCCIH, 2020, pg. 37)

The importance and power of the values selected to guide data governance can be seen in how perspectives are slowly shifting from a focus on data *about* Indigenous peoples to data that tells the stories *of* Indigenous peoples – who they are and where they feel they need to go. This way of framing population health data “actively disrupts the status quo, illuminates Indigenous peoples’ strengths, and honours distinct First Nations, Inuit and Métis populations” (NCCIH, 2020, pg. 37).

This requires a shift to the creation of an “ethical space” where population health data is developed as a partnership between the community and public health, and the data itself incorporates additional ways of knowing through stories and local community knowledge. It can also mean representing community data following kinship lines rather than following colonial definitions of Indigeneity (NCCIH, 2020). In this way, the governance of population health data is grounded in ethical practice and contributes to our lifelong journey toward reconciliation between Indigenous and non-Indigenous people in Canada.

## Principles of Data Sovereignty

The First Nations Principles of OCAP® provide a foundation for approaching the ethical governance of population health data. OCAP stands for Ownership, Control, Access and Possession (see Box 1). First Nations in Canada have been advocating for these rights for decades,

partly because of the improper use of their information witnessed over the years. The First Nations Information Governance Centre (FNIGC) provides training on these principles. It is working toward a vision that every First Nation will achieve data sovereignty in alignment with its distinct world view.

### Box 1: OCAP Principles (FNIGC, n/d)

#### OWNERSHIP

Refers to the relationship of First Nations to their cultural knowledge, data and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

#### CONTROL

Affirms that First Nations, their communities and representative bodies are within their rights to seek control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project—from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.

### Box 1 (continued): OCAP Principles (FNIGC, n/d)

#### ACCESS

Refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is held. The principle of access also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

#### POSSESSION

While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.

The FNIGC clearly states that OCAP® is not a doctrine or a prescription. It operates as a set of First Nation principles (i.e., it does not speak to the broader Indigenous community) and respects a community to make its own decisions regarding why, how, and by whom information is collected, used or shared. It expresses First Nations jurisdiction over information about their communities and community members.

Other data sovereignty and data governance principles include Manitoba Métis principles of OCAS (ownership, control, access, and stewardship) and Inuit Qaujimajatuqangit (translated to, “that which Inuit have always known to be true”) (Institute for Circumpolar Health Research, 2022).

# HEALTH DATA GOVERNANCE AND ETHICS

These principles can be supported using the 4-Ps approach: personal experiences, partnerships, policies and processes (see Figure 1). They represent a blend of Western and traditional Indigenous approaches, in alignment with “two-eyed seeing.” A two-eyed seeing approach looks at data through

both a traditional Indigenous lens and a Western lens. It considers Indigenous information to be owned by the local Indigenous community, and stewarded by provincial and other governments through their oversight role (Indigenous Primary Health Care Council, 2023).

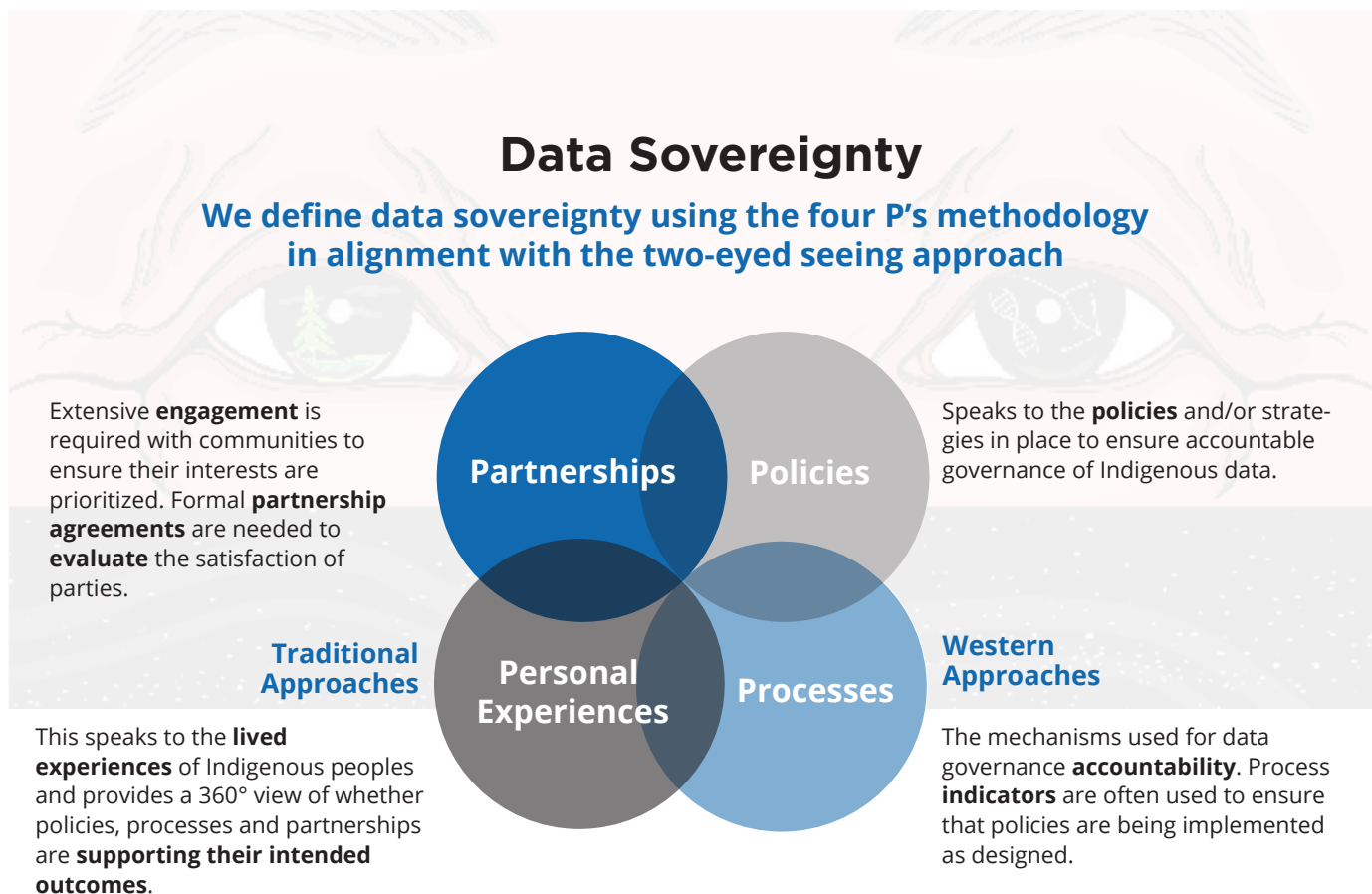


Figure 1: Data sovereignty (Indigenous Primary Health Care Council, 2023, pg. 15).

# WASTEWATER-BASED SURVEILLANCE (WBS) DATA AND ETHICS

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Ethics have been identified as an important aspect of WBS, in particular as they relate to expanding meaningful community engagement as part of institutionalizing WBS within public health surveillance systems (Korfmacher & Harris-Lovett, 2022) (see also, Part 1 – Overview).

The World Health Organization (WHO) released ethical guidelines on public health surveillance in 2017 (see Box 2) to identify key ethical considerations that may arise and reinforce the public health (and governmental) duty to conduct surveillance, share data and engage with communities in a transparent manner (WHO, 2017).

Hrudey and colleagues (Hrudey et al., 2021) applied these ethical guidelines to the rapidly evolving field of WBS. They recognized that the influx of environmental scientists, including analytical chemists/molecular biologists and environmental engineers, in this work during the COVID-19 pandemic meant that there was likely a lack of knowledge and experience applying environmental monitoring evidence to inform epidemic management by public health agencies. This meant a significant likelihood that ethical requirements associated with collecting and disseminating data related to human health outcomes were not well understood.

# HEALTH DATA GOVERNANCE AND ETHICS

Key challenges for ethical WBS include:

- Ensuring public trust, which is necessary for public health interventions to be effective.
- The potential for WBS to identify groups of individuals, making the data potentially sensitive as human health-related information that may require privacy.
- The potential of competing interests between individual rights and freedoms and population interests, making data collection and reporting choices difficult to balance.
- Information needs to be timely and of sufficient quality (i.e. validated) to achieve public health goals, including providing early warning of localized outbreaks.
- Data collection and reporting need to align with community values and concerns, especially the mitigation of risks of harm for marginalized communities who are likely to experience increased stigma (e.g. First Nation, Inuit and Métis communities, LGBTQ2S+ people, visible minorities). Data also needs to be effectively shared with the communities from which it has been collected.

## Foundational Elements

Hrudey and colleagues focused on four foundational premises from the WHO guidelines (WHO, 2017) as the basis for consideration of ethical approaches in WBS (Hrudey et al., 2021, pg. 8486):

1. **COMMON GOOD:** Surveillance is acknowledged as a common good, and its benefits are fundamentally shared and cannot be subdivided into individual private benefits.
2. **EQUITY:** This is about ensuring the just distribution of socioeconomic benefits and burdens across a group or population, often in accordance with need and merit. Equity is a central concern for public health ethics, recognizing that social inequality adversely affects health.

3. **RESPECT FOR PERSONS:** Sometimes referred to as “dignity,” this is the recognition of the inherent worth of all persons by virtue of being a person. This consideration recognizes that the rights, liberties and other interests of individuals are important, in addition to overall population wellbeing. Individuals should be involved in decisions that affect them whenever possible
4. **GOOD GOVERNANCE:** Not specifically an ethical principle, good governance is a sound political aspiration subject to several ethical considerations. This includes accountability, transparency and community engagement.

Hrudey and colleagues point to the 2017 WHO guidelines for public health surveillance (WHO, 2017) as the best source for guiding ethical practice by environmental scientists and engineers (see Box 2). They also make the point that simplistic rules for planning and implementation of WBS strategies will not suffice due to the number of ethical factors to consider, some of which may seem to conflict with other guidance.

*“[T]here is a need for an open dialogue that will reveal valid concerns for individual interests potentially in conflict with surveillance that is intended to serve the well-being of the population ... the point is to carefully consider the full range of issues raised and to make informed decisions that balance these issues in a rational manner.”*

(Hrudey et al., 2021, pg. 8489-8490).



# HEALTH DATA GOVERNANCE AND ETHICS

## Box 2: WHO guidelines on ethical issues in public health surveillance (WHO, 2017)

**Guideline 1.** Countries have an obligation to develop appropriate, feasible, sustainable public health surveillance systems. Surveillance systems should have a clear purpose and a plan for data collection, analysis, use and dissemination based on relevant public health priorities.

**Guideline 2\*.** Countries have an obligation to develop appropriate, effective mechanisms to ensure ethical surveillance.

**Guideline 3.** Surveillance data should be collected only for a legitimate public health purpose.

**Guideline 4.** Countries have an obligation to ensure that the data collected are of sufficient quality, including being timely, reliable and valid, to achieve public health goals.

**Guideline 5\*.** Planning for public health surveillance should be guided by transparent governmental priority-setting.

**Guideline 6\*.** The global community has an obligation to support countries that lack adequate resources to undertake surveillance.

**Guideline 7.** The values and concerns of communities should be taken into account in planning, implementing and using data from surveillance.

**Guideline 8.** Those responsible for surveillance should identify, evaluate, minimize and disclose risks for harm before surveillance is conducted. Monitoring for harm should be continuous, and, when any is identified, appropriate action should be taken to mitigate it.

**Guideline 9.** Surveillance of individuals or groups who are particularly susceptible to disease, harm or injustice is critical and demands careful scrutiny to avoid the imposition of unnecessary additional burdens.

**Guideline 10.** Governments and others who hold surveillance data must ensure that identifiable data are appropriately secured.

**Guideline 11.** Under certain circumstances, the collection of names or identifiable data is justified.

**Guideline 12\*.** Individuals have an obligation to contribute to surveillance when reliable, valid, complete data sets are required and relevant protection is in place. Under these circumstances, informed consent is not ethically required.

**Guideline 13.** Results of surveillance must be effectively communicated to relevant target audiences.

**Guideline 14.** With appropriate safeguards and justification, those responsible for public health surveillance have an obligation to share data with other national and international public health agencies.

**Guideline 15.** During a public health emergency, it is imperative that all parties involved in surveillance share data in a timely fashion.

**Guideline 16.** With appropriate justification and safeguards, public health agencies may use or share surveillance data for research purposes.

**Guideline 17.** Personally identifiable surveillance data should not be shared with agencies that are likely to use them to take action against individuals or for uses unrelated to public health.

\*Identified by Hruddy et al. (2021) as less directly relevant to WBS related to SARS-CoV-2.

Although there is recognition in the field that ‘simple rules’ are not helpful, there have been recent efforts to create a structured ethical review template for wastewater-based testing in public health. Bowes and colleagues have proposed a consolidated framework of 11 categories of questions with three assessment levels: minimal review required, review suggested, and review strongly suggested.

This structured ethical review approach is recommended to guide the necessary

contextual discussions that guide the work in research, surveillance and other settings where wastewater-based testing is used. The authors make the point that this approach will be particularly important as wastewater-based testing expands into applications that transcend multiple disciplines, such as opioid detection, where campaigns will need to be reassessed for each new application, community and location (Bowes et al., 2023).

## Strategies to Address Equity Issues

Ethical and socially equitable WBS requires effective community engagement strategies that bring researchers, public health practitioners, people with lived experience and community leaders together around the following questions (adapted from Halden et al., 2022):

- Why are we monitoring wastewater, and who will benefit from it?
- What are the histories, beliefs, religion and cultural practices of the communities in which monitoring is envisioned and how can their interests and concerns be acknowledged and addressed?
- What information will be collected (and what can be considered optional)?
- Who will have access to the data?
- Who will be included and excluded in the monitoring given the local infrastructure?

- Can the information collected potentially lead to marginalization or stigmatization of individuals, groups or geographic settings?
- Who are the appropriate entities, diverse communities, and their spokespersons to engage with? How can a true partnership of equals be created that honours the needs and concerns of all?
- How will the information be communicated? Can it be delivered in the preferred methods and channels of communication of community members?

## IMPLICATIONS FOR PUBLIC HEALTH COMMUNICATION

WBS needs to be adapted to the local context by ensuring potential partners (e.g., municipalities/local governments, researchers) and the wider community (i.e., community leaders, people with lived experience of marginalization, the general public, etc.) are engaged in the planning, implementation and reporting processes. This requires public health practitioners to attend to communication as a key dimension of the work to ensure:

- Adequate communication of the intents and purposes of the surveillance activities.
- An open and transparent process for selecting monitoring sites.
- Explicit consent from partners and community members when expanding or increasing the surveillance focus.
- Regular and sufficient communication about the program over time.
- Clear protocols for sharing data beyond the partners and community leaders when there is the potential to impact marginalized groups (e.g., law enforcement).
- Reasonable statements about the informational value of the data collected (i.e., not overstating).

- Translation of information into culturally acceptable and accessible formats.
- Strategies and funding should be provided to respond to related health challenges so that communities are not left with concerning information and no way to address related issues.
- (Adapted from: Halden et al., 2022)

See **Part 2 – BC Centre for Disease Control**, **Part 2 – Ottawa Public Health**, and **Part 2 - Nunavik Board of Health and Social Services** for more on the experience of applying data governance principles and ethics.



# QUESTIONS FOR REFLECTION

Thinking of your work/studies, community, and priorities for wastewater-based surveillance (WBS):

- How might you use the **principles** described here to assess your current community engagement approach for WBS?
- What **questions**, if any, would you add to the list provided to guide your community engagement activities?
- What resources are available in your community to integrate **reconciliation actions** into your WBS program? How might you attract more resources and build community capacity?
- How can you ensure your WBS **communication plan** does not create stigma for either individuals or specific communities in your region?

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## OTHER TOPICS IN THIS SERIES

### PART 1: OVERVIEW

### PART 2: CASE EXAMPLES

The case examples in this Knowledge-to-Action Series are stories told from the perspective of the Public Health practitioners most closely involved in the development and implementation of the WBS program in their region. They are intended to provide a deeper understanding of the organizational and community context, and key learnings related to interpretation and communication of information related to wastewater-based surveillance.

- BC Centre for Disease Control.
- Ottawa Public Health.
- Nunavik Board of Health and Social Services.

### PART 3: WBS RESOURCES AND TOOLS

The resources and tools in this Knowledge-to-Action Series are intended to provide a summary of key information and communication topics for public health practitioners related to WBS. Each document includes core concepts with references and links to additional materials. There is also a set of reflection questions at the end for individuals and teams to consider when applying the concepts to the development and implementation of WBS programs.

- Data Governance and Ethics.
- Dashboards for Communication and Decision Making.

## **Wastewater-Based Surveillance for Public Health: The Knowledge-to-Action Series. Part 3: WBS Resources and Tools. Health Data Governance and Ethics**

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