



CIHI

Health Data Ethics Framework

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Agenda

1. About CIHI
2. Why health data ethics?
3. Development of the Health Data Ethics Framework
4. Application of the framework
5. Outcomes so far
6. Questions



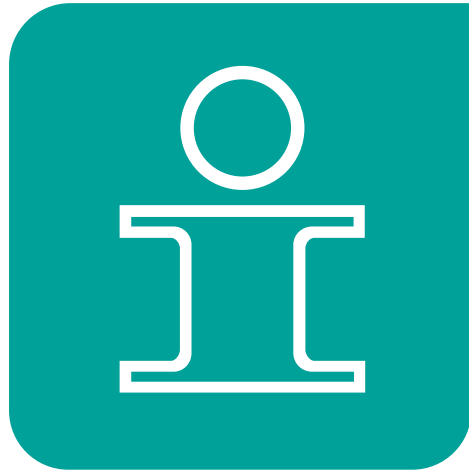
The world's best health systems are powered by data.

CIHI is a vital source of Canada-wide health data that Canadians rely on to inform health policy, care, management and research. It's our job to ensure that health data is trusted, connected, accessible, timely, contextualized, relevant and comprehensive.

We are building a future where every Canadian gets the care they need — when and where they need it.

Better data. Better decisions. Healthier Canadians.





The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential information on Canada's health systems and the health of Canadians.



CIHI hosts extensive linkable, pan-Canadian data across the health care continuum...



Types of care

- Hospital and emergency
- Mental health
- Home care
- Long-term care
- Rehabilitation
- Pharmaceuticals
- Clinical registries: organ transplant/renal, hip and knee replacements; trauma
- More



Patient-reported data

- Patient-reported outcome measures (PROMs)



Health spending

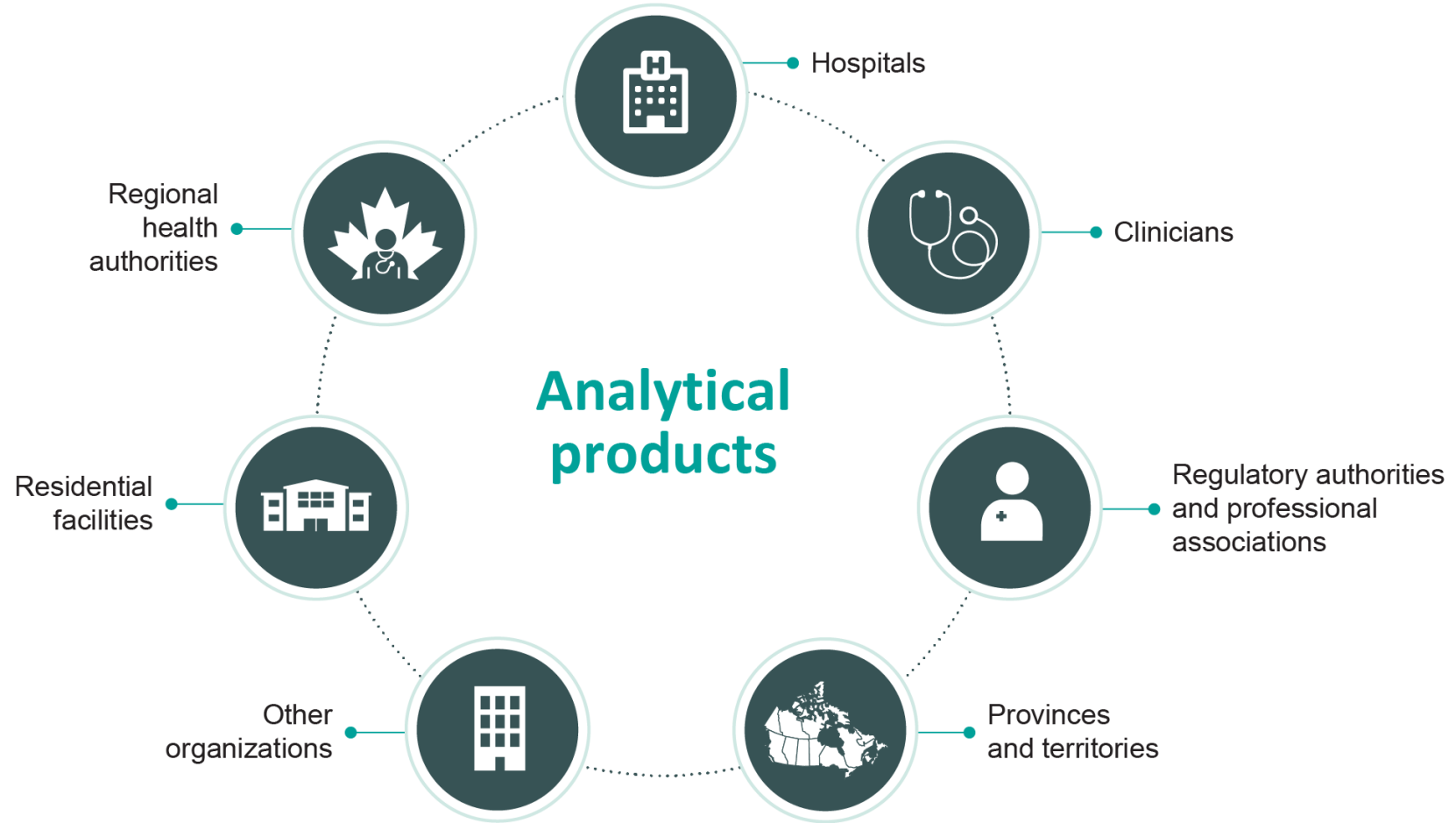
- Patient costing data
- Hospital and regional health authority financial accounts
- Physician billing
- System-wide health expenditures



Health workforce

- Physicians
- Nurses
- Occupational therapists
- Pharmacists
- Physiotherapists
- Allied health professionals
- More

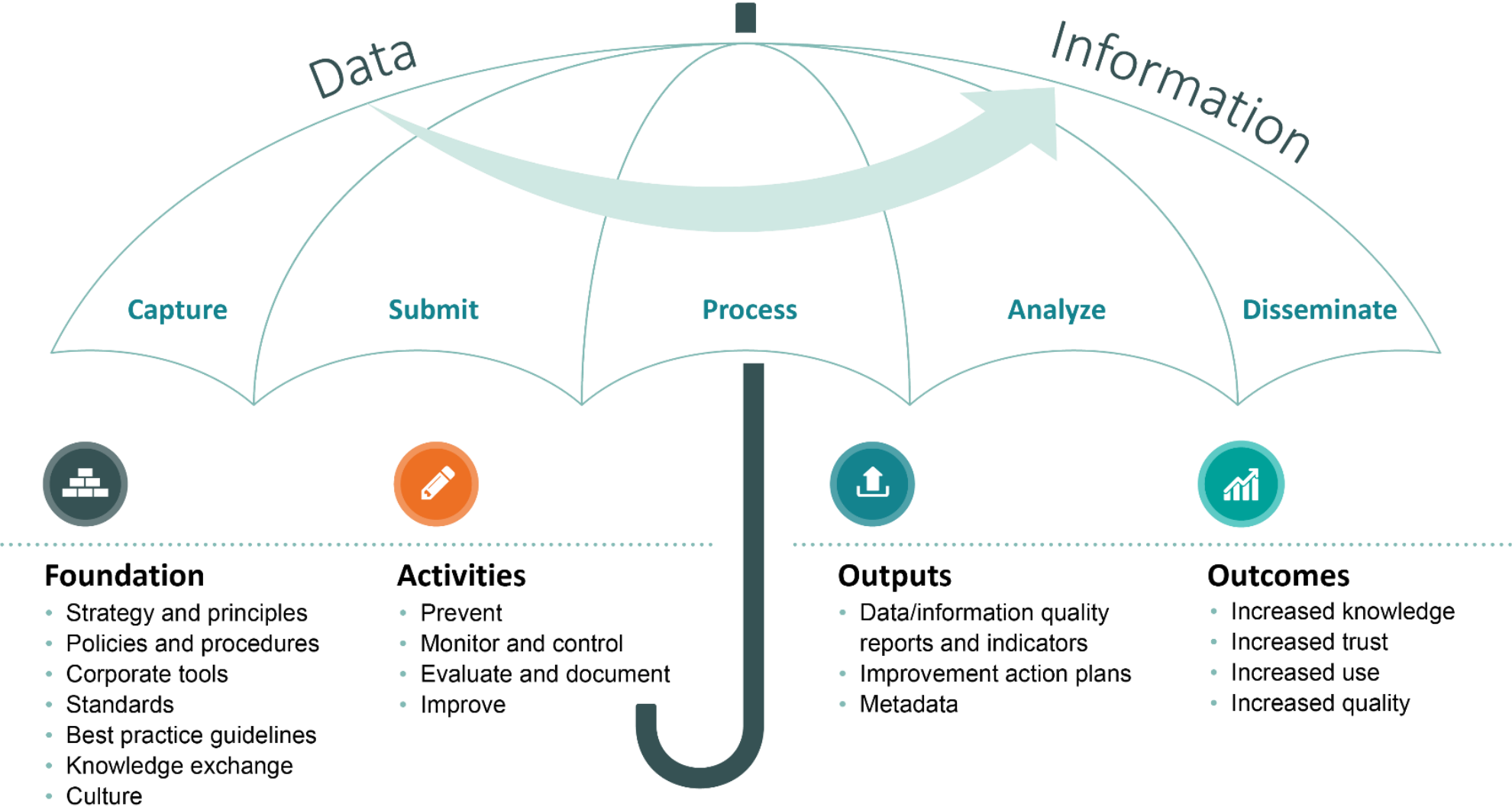
... from many sources



Why health data ethics?

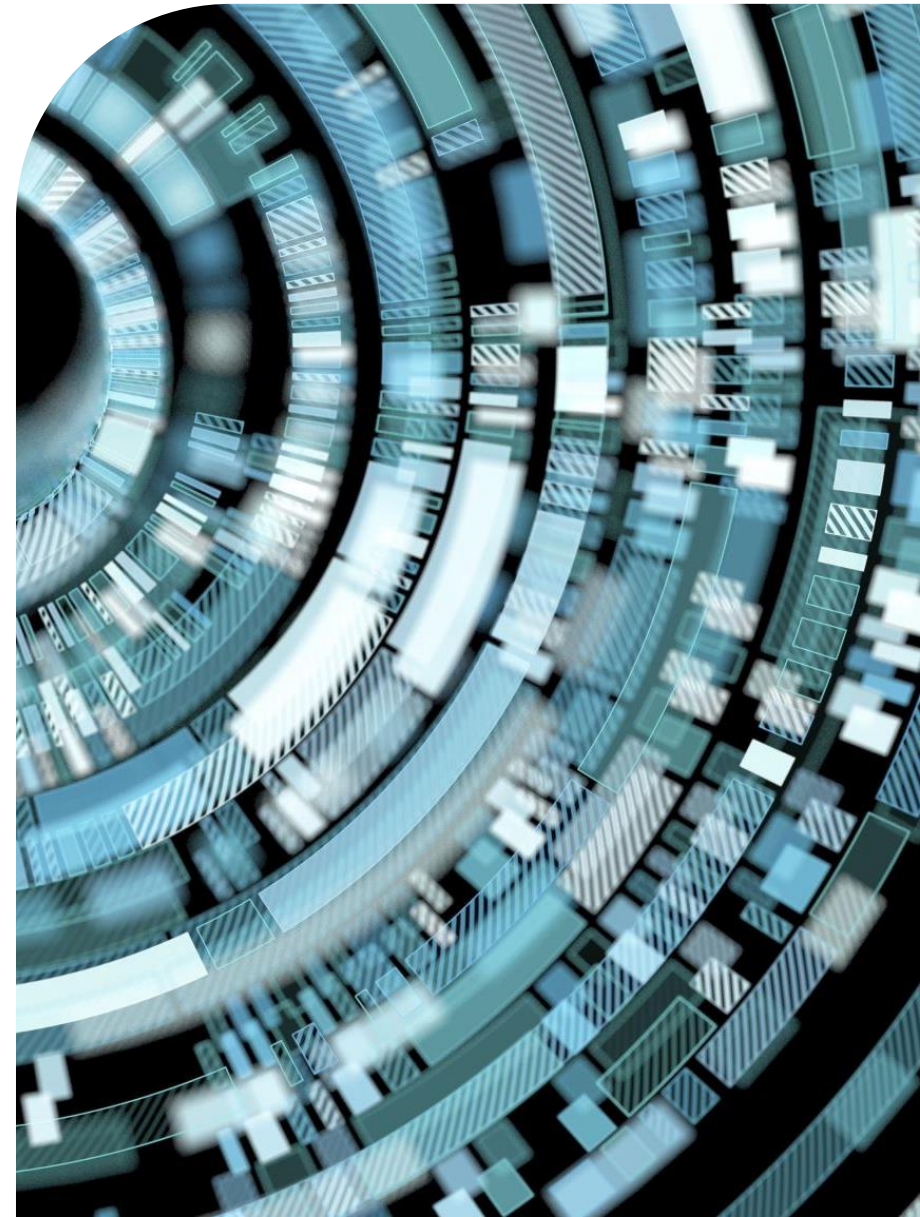
How it fits in CIHI's health data governance toolbox

Information Quality Framework



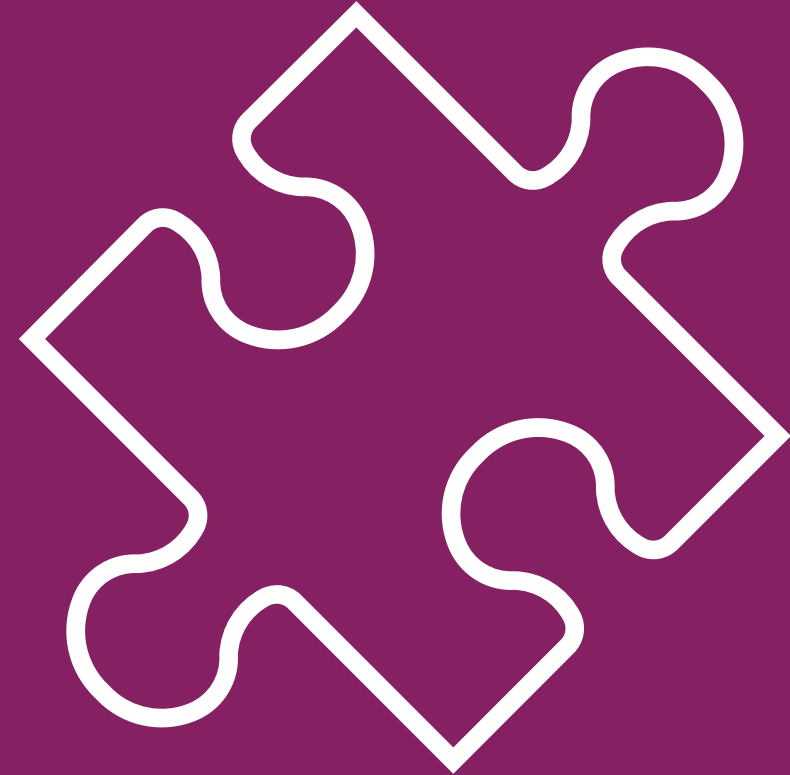
Privacy and security framework

- a coherent and comprehensive approach to enterprise privacy and information security management
- CIHI is a prescribed entity under Ontario's Personal Health Information Protection Act (PHIPA)



The role of health data ethics

- Our Information Quality Framework and Privacy and Security Framework provide guidance for if we **can or cannot** undertake an action.
- Health data ethics are designed to help us navigate the trickier **'should we'** or **'how should we'** situations.
- As we look ahead, health data ethics also informs how we prioritise and develop new initiatives.



Health research ethics vs. health data ethics

Health research ethics

- Guides the ethical acceptability of **health research**
- National approach: [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#)

Health data ethics

- Guides ethical acceptability of **health system use of data**
- No national approach

First Nations, Inuit & Métis governance practice & principles

[The First Nations principles of OCAP®](#)

[Inuit Qaujimajatuqangit](#)

[Métis OCAS](#)



Key ethical issues in health data

1. Balancing risks and benefits
2. Building and maintaining trust
3. Safeguarding and promoting individual and collective rights
4. Preventing exacerbation of inequities
5. Protecting privacy
6. Ensuring appropriate use



Why identify organizational ethics?

1. To enable a systematic method for identifying, articulating and addressing ethical issues along the entire health data life cycle
2. AI, and other technological advances, increases the need to proactively plan out approaches to ethical dilemmas
3. To be transparent about our approach so that everyone – patients, funders and other interest-holders - can engage with it and help us improve.
4. To clarify organizational ethics as distinct from the personal values and ethics we each hold as individuals



Evolution of the Health Data Ethics Framework

2019-2020: Health Ethics, Law, & Policy (HELP) Lab contracted to develop a data ethics framework for CIHI

2021 – 2024: Internal application and refinement. Further enhancement through additional internal and external review.

March 2025: Framework approved by Board of Directors

Fall 2025: Consideration of priorities for 2026-2027

June 2021: Initial version receives support from Board of Directors

January 2025: Public consultation brings praise from federal & provincial partners, PCHOs and other interest-holders

June 2025: Public launch of Health Data Ethics Framework and related content



8 ethical principles guide decision making



Public benefit



Equity



Protection from harm



Privacy and confidentiality



Social acceptability



Transparency and accountability



Respect for individual and collective rights and dignity



Data and information quality



Public Benefit

Making efforts to maximize the benefits to and well-being of individuals, groups, communities, society at large and health systems.

Examples

Canadian Institute for Health Information. [Deadly Impact: The Rise of E-Scooter Injuries](#). Accessed August 19, 2025.

Canadian Institute for Health Information. [Potentially Inappropriate Use of Antipsychotics in Long-Term Care](#). Accessed August 19, 2025.

Questions you can ask yourself

- Will taking this course of action enhance public discourse on this topic?
- Will this action widely benefit individuals, groups, communities, society at large, and/or health systems?

Protection from harm

Making efforts to prevent or minimize risks or burdens to individuals, groups, communities, society at large and health systems.

Discussion piece

Folkenflik D. [The New York Times' coverage of transgender people sparks newsroom divide.](#)
NPR. February 25, 2023.

Question you can ask yourself

- How likely is it that this course of action will cause harm? Harm could be to:
 - physical, mental or spiritual health
 - social or economic circumstances
- Are there steps we can take to safeguard against this harm occurring?



Social acceptability

Ensuring health data activities align with society's collective view of what is appropriate and suitable. Can sometimes be referred to as “social licence”.

Further information

Health Data Research Network (HDRN)'s, [*Social Licence for Uses of Health Data: A Report on Public Perspectives*](#), [Internet] Sept 2022.

Questions you can ask yourself

- Is there anything about this action which may not be socially acceptable?
- Thinking about our social and political landscape, is there anything that makes me think the social acceptability of this course of action may have changed recently?
- Does undertaking this action align with our organization's mandate?



Respect for individual & collective rights & dignity

Promoting the ability of individuals and communities to shape the basic course of their lives in a manner consistent with their values and independent of the control of others

Examples

Government of BC. [In plain sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care. 2020.](#)

Indremo M. et al. [Association of Media Coverage on Transgender Health With Referrals to Child and Adolescent Gender Identity Clinics in Sweden](#)
Jama Network Open. 2022.

Questions you can ask yourself

- Does the planned use shed light on past or current discrimination in a way that could be important to affected individuals or groups?
- Does the course of action potentially limit the choices of individuals or groups?



8 ethical principles guide decision making



Public benefit



Equity



Protection from harm



Privacy and confidentiality



Social acceptability



Transparency and accountability



Respect for individual and collective rights and dignity



Data and information quality

Application

How our ethical principles are being applied to enhance our health data stewardship



Governance and decision-making

Maturing approach to:

- Embedding in committee decision-making processes
- Informing corporate strategies and frameworks
- Applying the ethical principles in the development of new standards and information products.



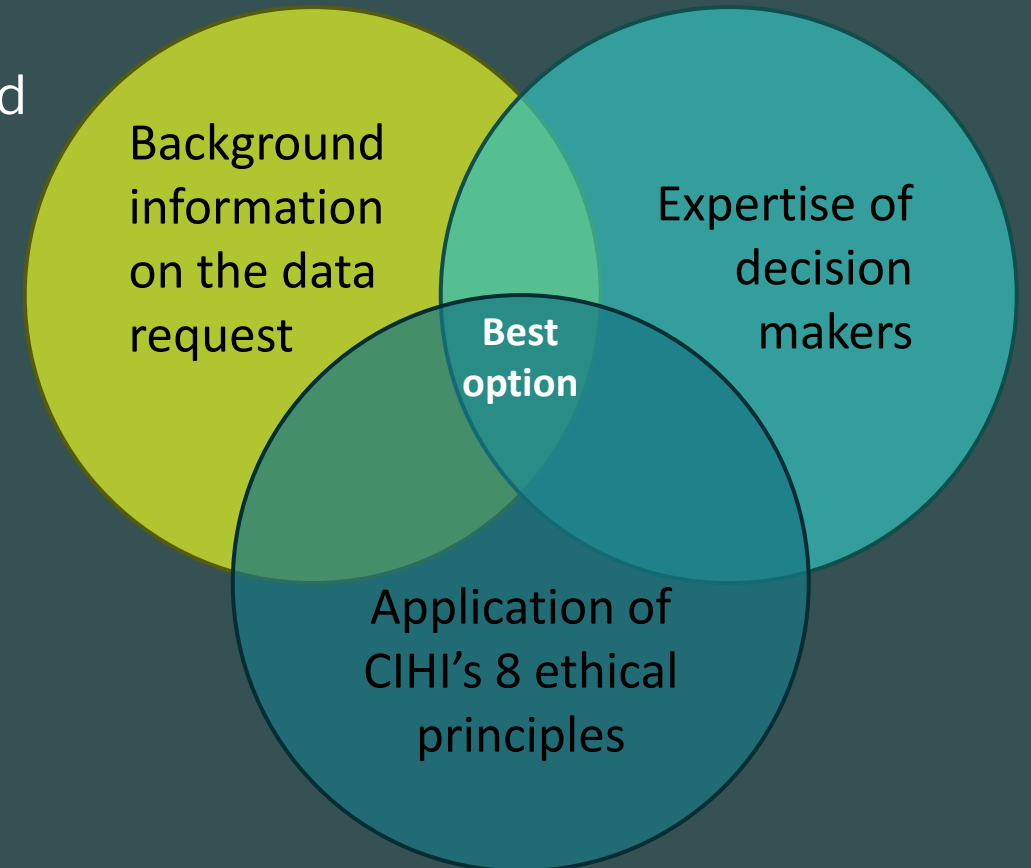
Processes and tools

- Incorporated in our Code of Business Conduct, renewed annually by all staff
- Reflected in updated policy guidance
- Integration of process specific tools
- Beginning to look at self-service tools



Example: Ethical consideration of data requests

- All 3rd party data and media requests are considered for ethical sensitivities .
- May escalate to ethical screening and full ethical assessment.
- Depending on sensitivity, CIHI may work with requestor to modify the request to reduce ethical sensitivity and / or provide additional context to avoid misinterpretation or misuse.



Internal education on data ethics

- Small group format
- Focus on encouraging curiosity
- Problem based learning
- Open-ended questions
- Tailored to process or group



The health data ethics principles support people to carry out their work



- Provides a common language to identify, discuss and address ethical sensitivities
- Clarifies organizational ethics as distinct from the personal values and ethics we each hold as individuals
- Having a standard approach – and common tools – empowers and supports more people to apply their own expertise to ethical dilemmas in the workplace

Health data ethics is a valuable tool in delivering health data stewardship



The [Health Data Ethics Framework](#) aids consistent recognition, comprehension, appraisal and resolution of ethical questions and challenges. It can support

- navigation of ethical dilemmas, and
- early identification of ethical sensitivities when developing new initiatives, ensuring sufficient time to undertake corrective action.

Lessons learned



Integration and culture change take time



Messaging must emphasize ethical principles enable *navigation*, not *calculation*



This framework needs to be a living document that will evolve as we gain more experience, new ethical issues arise and in response to interest-holders



Next steps

- Our engagement with health data ethics will continue to evolve in relation to changes in priorities, the needs of our organization and interest-holders, and ethical best practices
- We will continue to mature our application of the Health Data Ethics Framework
- We would like to grow Canada's community of practice around health data ethics
- We will continue to share resources



Additional resources

About Health Data Ethics at CIHI

- [Health data ethics](#) on cihi.ca
- CIHI's full [Health Data Ethics Framework](#)
- Queries: ethics@cihi.ca

If you are interested in **health data stewardship**, you may also wish to explore our approach to the following topics:

- [Health data stewardship](#)
- [First Nations, Inuit and Métis health](#)
- [Privacy and security](#)
- [Data and information quality](#)
- [Working with patients and families](#)

Questions





Thank you

For more information, visit

cihi.ca