

# Dialogue on Data Phase 2

## PHIPA Consultation

Ministry of Health  
2022 - 2023



# PHIPA Listening: The Ministry of Health needs to hear from you

- Since Ontario's *Personal Health Information Protection Act* (PHIPA) came into force in 2004, Ontario's health system has shifted and continues to shift dramatically, incorporating changes in technology, information flows, health system organizational structures and operations, and models of care.
- PHIPA has been and continues to be updated.
- We need to hear from you about your needs and pain points for PHIPA implementation.

# Ontario's health system is modernizing

- Modernization will improve data flows within the system, integrate digital health technologies, support integrated care, and enable preventative programs and personalized medicine.

## The goals of modernization



Foster **research, innovation and economic development** in Ontario's health system.



Improve the **provider experience and coordination** across transitions of care.



Improve the **experience of patients, families and caregivers**.



**Patients and families** can participate more in care decisions.



**Ontario Health Teams** can share information to plan more effective care models for their communities.



**Ontario Health and the MOH** can support providers and planners more effectively.



**Researchers and innovators** can support the health system with new insights and solutions

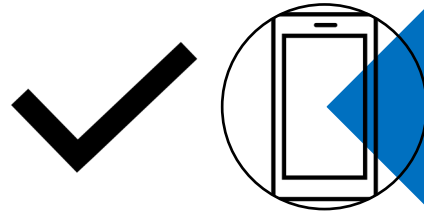


**Health care providers** have data to address health inequities.

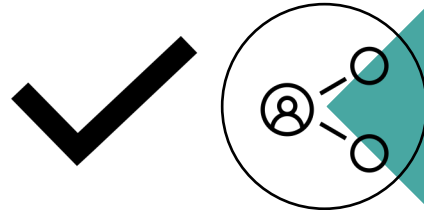
## The outcomes of modernization

# To support health system modernization, PHIPA is continuously amended

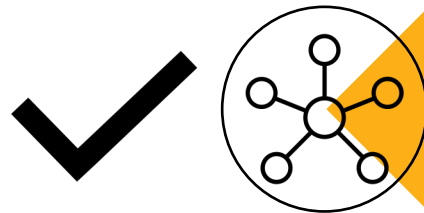
- Recent amendments to PHIPA have responded to the changes in technology, care delivery, and information flows in Ontario's health system
- Continued modernization efforts will be guided by your input



Enabling better access to PHI for patients, including through consumer electronic service providers (CESPs)



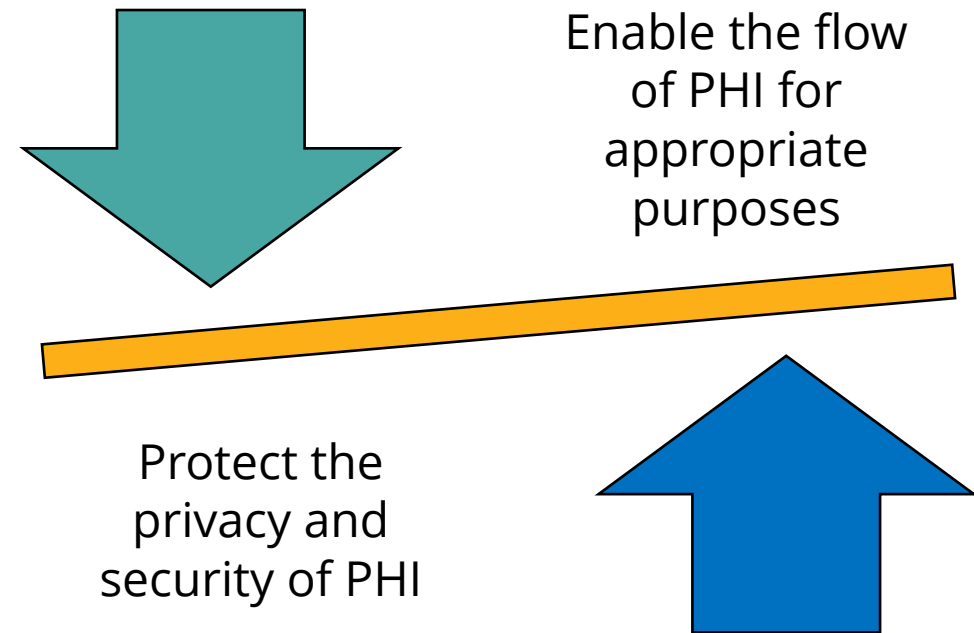
Improving the timely and secured sharing of PHI between providers, by including home and community care providers as HICs



Improving access to de-identified health data for health system planners and researchers across the system

# Future PHIPA amendments will continue to support the goals of health system modernization, in line with PHIPA's purposes

- Future amendments to PHIPA will continue to support Ontario's health system by continuing to balance PHIPA's dual key purposes.



# Future PHIPA modernization relies on your input for its success

- As part of Dialogue on Data, the Ministry of Health is engaging key health system stakeholders on health data policy challenges they experience, beginning with a focus on PHIPA.



**Built on insights  
from previous  
consultations**



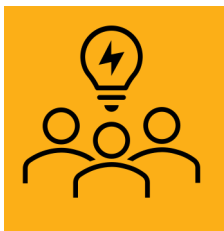
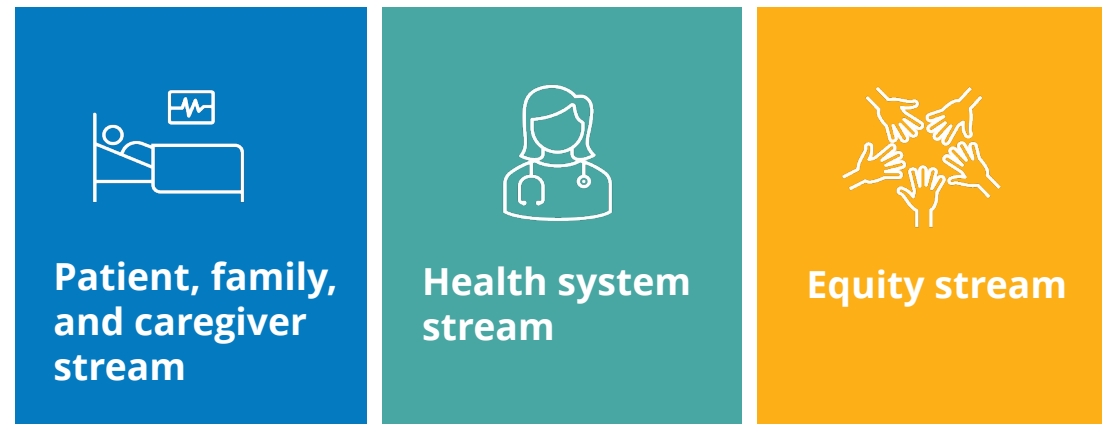
**Driven by  
stakeholders**



**A strong  
foundation for  
policy  
modernization**

# Dialogue on Data Phase 1 identified problems

- Phase 1 of Dialogue on Data sought to identify the needs and values, as well as the challenges, that patients, caregivers, health system professionals experience across Ontario's health system.
- Consultations unfolded across three streams between June 2021 and March 2022:

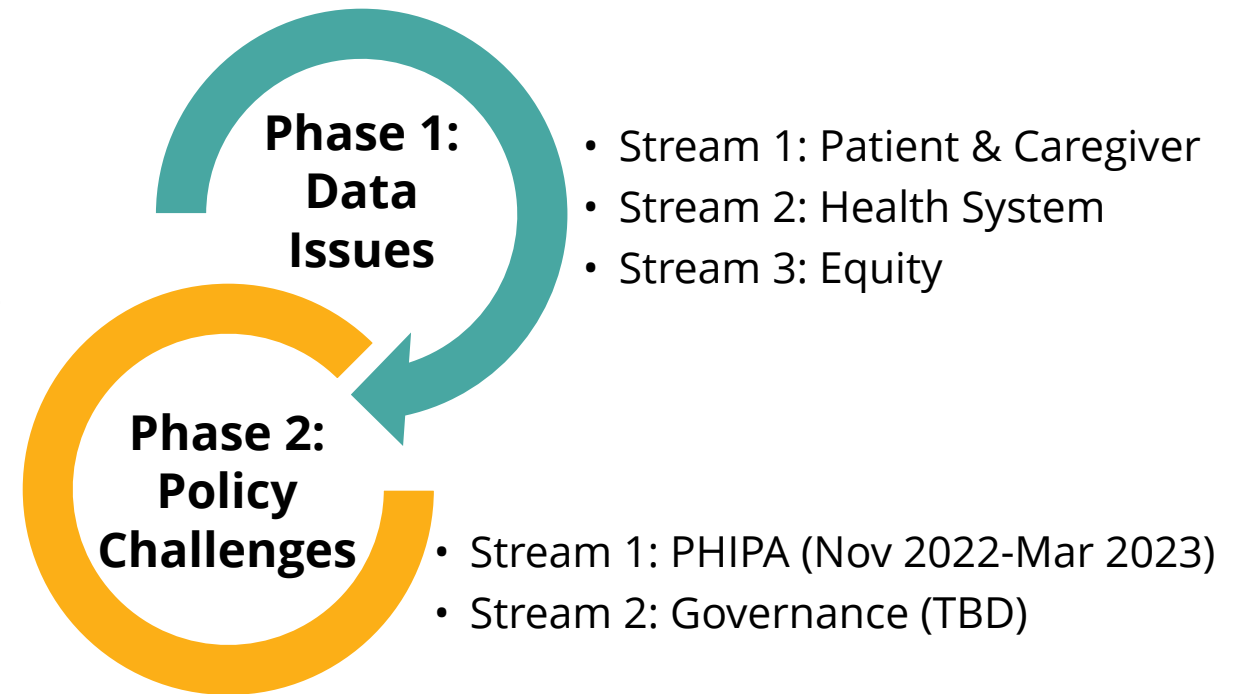


Phase 1 of Dialogue on Data painted a vivid picture of how health is impacted when patients, providers, health system analysts, and policymakers don't have access to high quality, integrated, accessible, standardized health data.

# Dialogue on Data Phase 2 will identify and investigate policy challenges

- Phase 2 of Dialogue on Data will seek to identify the actual and perceived policy barriers and solutions concerning health data in Ontario, including those in legislation, regulation, and other policy instruments.
- Stream 1 of these consultations, starting in November 2022, will focus on health data policy challenges specifically concerning the *Personal Health Information Protection Act (PHIPA)*.**
- Later streams will focus on understanding other perceived policy barriers, such as challenges with governance.

## *Dialogue on Data Consultations*





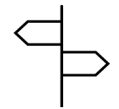
# In the past we've heard that many perceive PHIPA to be a barrier and administratively burdensome

## Perceived barriers to 'collect data once, use multiple times':



- Each data user must collect data themselves each time they need it, resulting in inefficiencies, including duplicate and overlapping data flows in the health care system, complicating the governance of health data.

## Perceived to contribute to a culture of risk avoidance among HICs to share data for permitted purposes:



- Custodians shoulder the primary burden of compliance, but they may experience difficulties complying with the legislation due to a lack of support or capacity.
- Permissive language leads to varying implementation, also leading some custodians to interpret the legislation conservatively so as to protect against legal risk.
- A frustrating reliance on data sharing agreements (DSAs), which can take months or even years to negotiate, have become one of the primary instruments used to hold data sharing custodians to account, used even by the MOH to clarify roles and responsibilities.

## Perceived to be inadequate to the task of regulating an increasingly digital and data-rich system:



- Created in 2004, when most records were paper-based, PHIPA has been continuously updated, but it has never undergone substantial overhaul to respond to changes in Ontario's health system.

**Do any of these issues speak to your experience with PHIPA?**

**Tell us what you think**

# Consultation Topics

The Ministry of Health needs your input to ensure future PHIPA modernization responds to your needs and addresses any pain points.

For the following topics and questions, please reflect on your organization's experience working with PHIPA.

1. The Role of HICs
2. Data Sharing Agreements
3. PHIPA's Administrative Burden
4. Implementing consent
5. Using PHI for beneficial purposes

**Please feel free to describe use cases that your organization has struggled with.**

# The Role of HICs

- Health information custodians (HICs) are responsible for ensuring the confidentiality and security of personal health information (PHI), and that it is shared and used only for appropriate purposes and with appropriate authorities under the law.
- Sometimes it can be challenging to determine who the responsible HIC is, and HICs may not always be fully aware of their obligations and permissions under the law.
- In complex or unconventional organizations, the responsible HIC may not be the one responding to privacy breaches or maintaining the EMR.
- These disconnects can create confusion between providers, who are anxious to use and disclose information only in appropriate, privacy-protective ways.

## Questions:

- Have you experienced situations where it wasn't clear who the responsible HIC is? Can you describe your experiences?
- Have you experienced any situations where the administrative burden of maintaining records or EMRs doesn't fall on the responsible HIC? Can you describe your experiences?



# Data Sharing Agreements

- Custodians bear the primary burden of protecting, sharing, and using their patients' personal health information.
- Some of PHIPA's provisions are *permissive*, meaning that custodians may share or use information in certain ways, but they are not *obliged* to do so. This may create differing interpretations of the legislation.
- As a result, some stakeholders have described data sharing agreements (DSAs) as necessary to clarify roles and responsibilities when sharing information.

## Questions:

- When do you use data sharing agreements, and why do you use them?
- What do you tend to include in data sharing agreements?

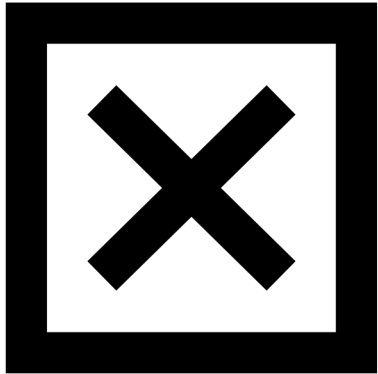
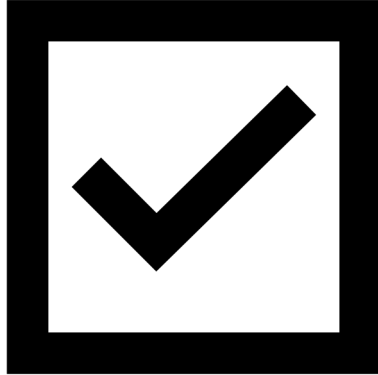


# Administrative burden of PHIPA

- Some stakeholders have expressed that PHIPA places a large administrative burden on custodians.
- Many have described problems with the custodianship model, including confusion and uncertainty over what HICs can and cannot do according to the legislation.
- Others have mentioned difficulties training privacy officers, including ensuring that consistent training is provided to these professionals.

## Questions:

- Can you describe your organization's experiences training individuals to understand and implement PHIPA?
- Can you describe the administrative burden on your organization that PHIPA requires?



# Consent

- PHIPA protects patient privacy in part by requiring that patients consent to the collection of their PHI, though this consent may be “implied” or “assumed implied” rather than “express”.
- PHIPA also protects patients’ privacy rights by allowing patients to place *consent directives* on their PHI.
- PHIPA does not require a minimum age for consent, but instead only requires that an individual who gives consent must be *capable*.
  - for individuals under the age of 16, parents or guardians may also consent on their behalf.

## Questions:

- Are PHIPA’s consent rules easy to understand and implement?
- Have you experienced any difficulties implementing consent directives from patients?
- Have you experienced difficulty with consent and minors?

# Enabling the use of PHI for beneficial purposes

- As Ontario's health system becomes more data-rich and digitally integrated, new ways to use health data are arising.
- Custodians must be supported to use and disclose health data for the benefit of all Ontarians, while fulfilling their obligations to protect the privacy and security of personal health information.
- In response to new technologies and changes in care delivery, PHIPA must be continuously updated.

## Questions:

- What new technologies, systems, or procedures for health data has your organization started using or hopes to use? In your opinion, does PHIPA enable these uses of health data?
- Are there uses of PHI that you'd like to enable that PHIPA doesn't permit?



# Thank you!

Thank you for your participation in this consultation. We will follow up with a survey to collect further thoughts that you might like to contribute.

For questions about Dialogue on Data, please contact:

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The Ontario Health Data Council recently published their report on challenges that Ontario's health data ecosystem faces. Please find it here: [Ontario Health Data Council Report: A Vision for Ontario's Health Data Ecosystem | ontario.ca](#)