



Early health. Lifelong health.
Début en santé. Longue vie en santé.

Privacy & Security at BORN Ontario

Responsibilities & Opportunities in our Framework

BORN Ontario
July 2011

Agenda

1. Personal Health Information – the Basics
2. BORN as a Prescribed Registry
3. Registry impact wrt Partners
 - Information providers
 - The public
 - Researchers
4. Privacy Operations at BORN
5. Skill-testing Questions

Privacy Landscape – PHIPA 2004

Health Information Custodian (HICs)	Share information with implied consent within the circle of care	<ul style="list-style-type: none"> •Physicians •Nurses •Allied health •Public Health Units
Other HICs	Require information for planning & facilitation but don't have direct patient access	<ul style="list-style-type: none"> •Public Health Units •MoHLTC •LHINs
Prescribed Entity	HICs are permitted to disclose PHI to an entity for the purpose of planning and management of the healthcare system	<ul style="list-style-type: none"> •CCO •CIHI •ICES •POGO
Prescribed Registry	HICs are permitted to disclose PHI to a registry for the purpose of improving the provision of healthcare	<ul style="list-style-type: none"> •Cardiac Care Network •Ontario Cancer Screening •BORN Ontario

Definitions

- **Personal Health Information (PHI)**
 - any identifying information* about an individual that relates to his or her physical or mental health, provision of health care, payment and eligibility for health care or health card number
- **Agent**
 - Every employee, contractor, student or volunteer with BORN with a signed confidentiality pledge which requires adherence to the BORN policies and procedures relating to privacy and security
 - Commits them to:
 - Only collecting, accessing, using, or disclosing confidential information for purposes required by the duties of the staff that are authorized by BORN
 - Protecting that information from unauthorized collection, access, use or disclosure. Also protect against unauthorized copying, modification or disposal
 - Alerting the Privacy Risk Manager of any unauthorized collection, access, use, or disclosure of confidential information

Definitions

- **Collect**
 - collect personal health information from a health information custodian
- **Use**
 - PHI collected only for the stated purpose(s) of the prescribed registry
 - secondarily, carry out research *without consent* of the individuals to whom information relates with research ethics board approval
- **Disclose**
 - as permitted or required by law
 - for purpose of facilitating or improving the provision of health care
 - to a researcher (with research ethics board approval and a signed agreement with the researcher)
- **Secondary Use**
 - Research ethics board approved research using BORN data
 - Individuals do not need to provide consent for this use of the data

BORN Vision

The best possible beginnings
for lifelong health



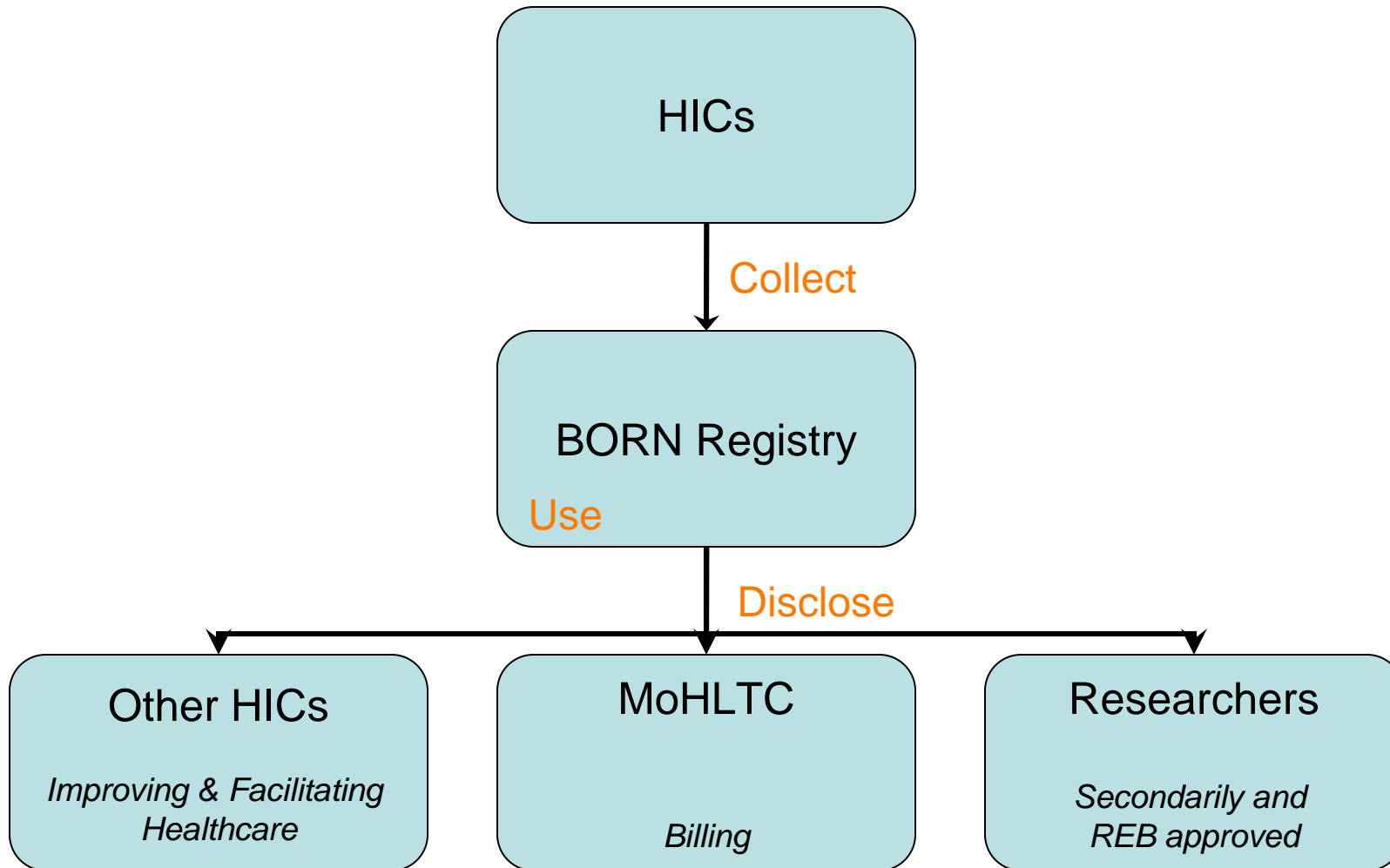
BORN is a PHIPA Registry

- BORN (as OPSS) was granted registry Status under the *Personal Health Information Privacy Act (PHIPA)* in Nov 2009
- Registry status affords BORN authority to collect, use and disclose personal health information **without consent** “for the purpose of “facilitating or improving the provision of health care” when it is impossible or impractical to obtain consent.

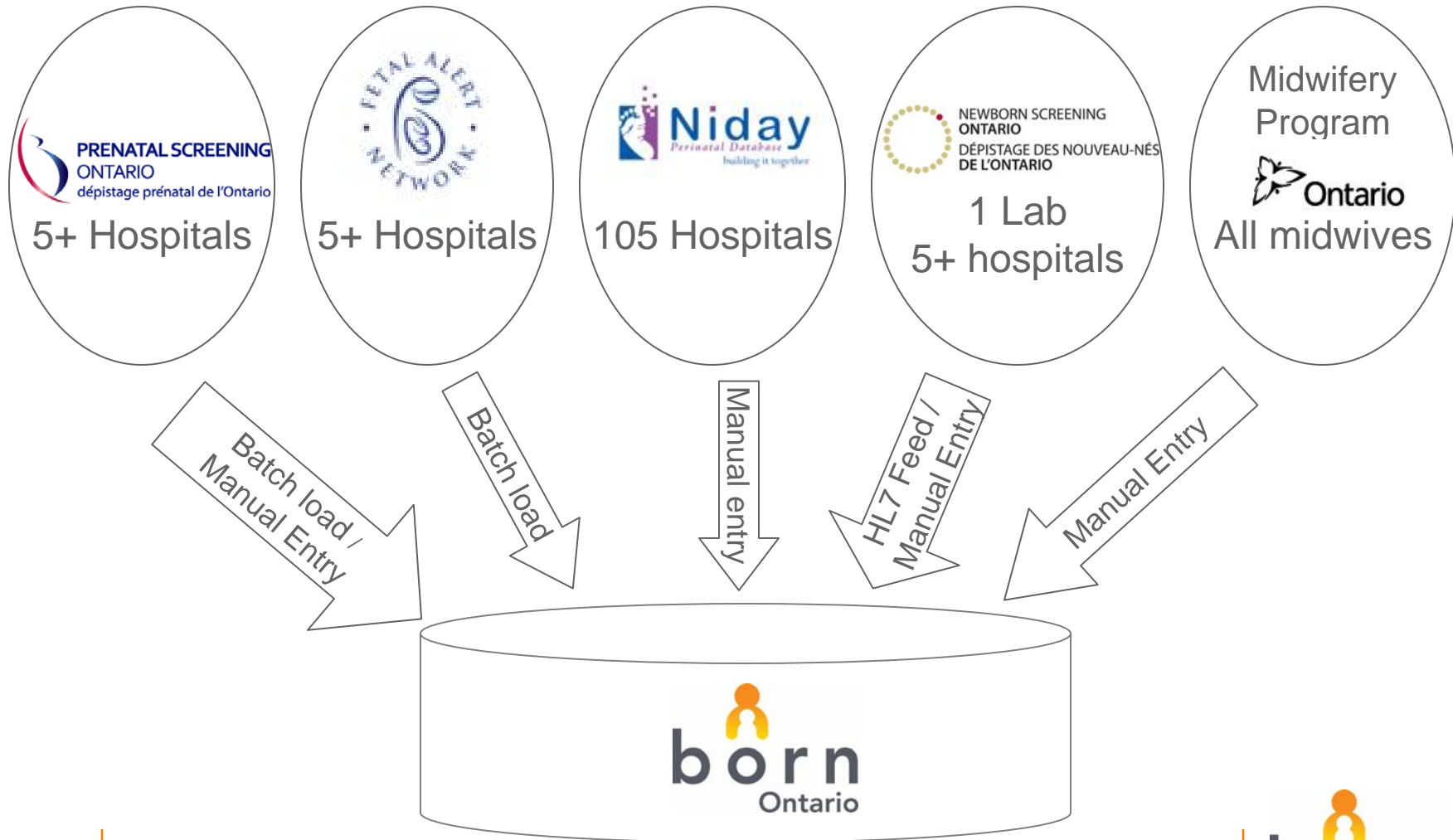


This special authority requires BORN to develop and adhere to rigorous privacy policies – and have them reviewed and approved by the Ontario Information and Privacy Commissioner

Privacy Role



Collect



Use & Disclose: BORN Purposes

- A. Identify individuals or settings where appropriate care has not been received and facilitate access to care and treatment for mothers, infants and children.
- B. Facilitate continuous improvement of healthcare delivery tools to minimize adverse outcomes.
- C. Determine where maternal and/or newborn outcomes are clinically or statistically discrepant with accepted norms and raise alerts where necessary.
- D. Enable health care providers to improve care by providing information & tools to compare their outcomes and performance with peers and/or benchmarks.
- E. Identify areas where best practice evidence needs implementation (knowledge translation strategies) to improve the quality and efficiency of care for mothers, infants and children.
- F. Create reports that can be used to provide the Ministry of Health and Long-Term Care, Local Health Integration Networks and Public Health Units with comprehensive and timely information for mothers, babies and children

BORN Data: Registry Relevance

Type	Data Element	Purpose (‘Use’ above)	Example
Identification	Mother	A	Quickly and correctly identify women
	Child	A	Quickly and correctly identify children
	Provider	A	Ability to contact provider quickly when required
Health Status	Antenatal Complications	A	Understand complications to understand requirements
	Maternal Health	A	Identify health issues requiring specific action – A& C. Combined with care received and outcomes to meet D & E
Health Risk Factors	Environmental	B	Identify risks requiring specific action to improve health outcomes – A & C. Understand impact of risks for B, D & E
Care Provided	Labour interventions	C	Combine with Health Status and Outcomes for C, D & E
	Healthcare Provider	C	Address inappropriate care directly with those providing it
Outcome	Newborn Screening result	A	Combined with follow-up information for B and E Timely reporting of result required for A and C
	Birth Outcome	B	As follow-up information for A, B, C, D & E, work cannot be done without clear understanding of risk to neonates

Responsibilities of the Registry

- Prescribed registries must put in place information practices and procedures to protect the privacy of personal health information
 - BORN Privacy & Security Manual
- Must make available to the public a plain-language written statement describing the function of the prescribed registry
 - www.BORNOntario.ca/privacy
- Must have a contact person to ensure compliance with PHIPA, respond to access requests, inquiries and complaints from the public
 - BORN Privacy Officer

BORN & Information providers

- You are the owner of your information
 - You will be provided full access to your information through the BORN system
 - Your organizations policies on privacy and confidentiality apply
- BORN will support you in protecting the information
 - Role-based accounts for all users in your organization
 - Strong password requirements
 - Access to information related to peers and others will adhere to re-identification risk guidelines

BORN Information & the Public

- When an individual makes a request for access to his/her personal information, BORN will inform them:
 - Whether or not BORN has the personal information
 - The source of the information
- BORN will direct the individual to the health information custodian who was the source of the information
- Requests for correction must come from the originating health information custodian

BORN Information & Researchers

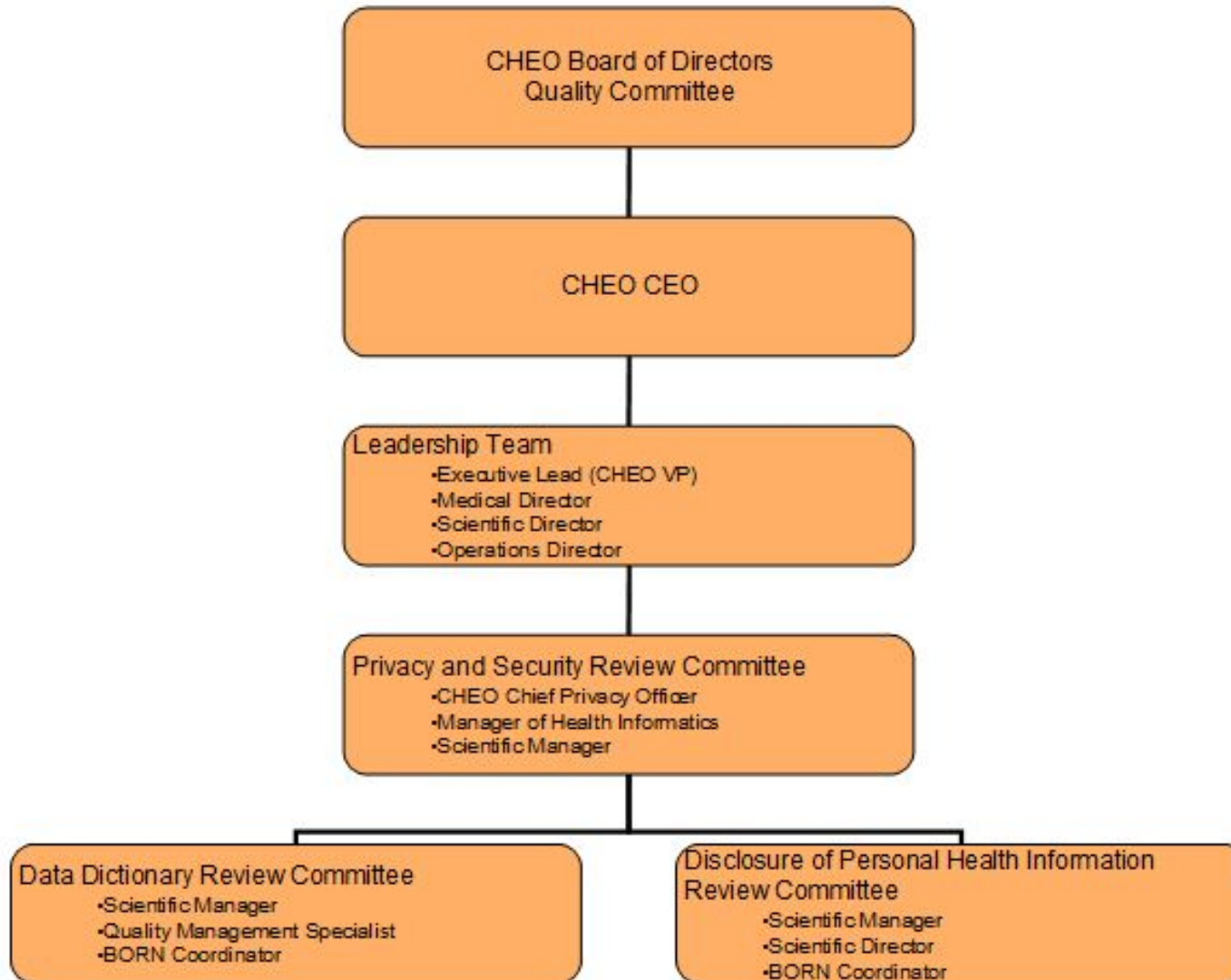
BORN data can be used *secondarily* for research

- Registry must receive from researcher:
 - an application in writing
 - a written research plan
 - a copy of approval by a Research Ethics Board
- Registry must have a written agreement with the researcher requiring compliance with any restrictions or conditions imposed by the Prescribed Registry
- In addition to the requirements in PHIPA, BORN has policies and procedures governing disclosures to researchers

Privacy Operations at BORN

- Governance
- Roles & Responsibilities
- Privacy & Security Management Plan

Governance & Oversight

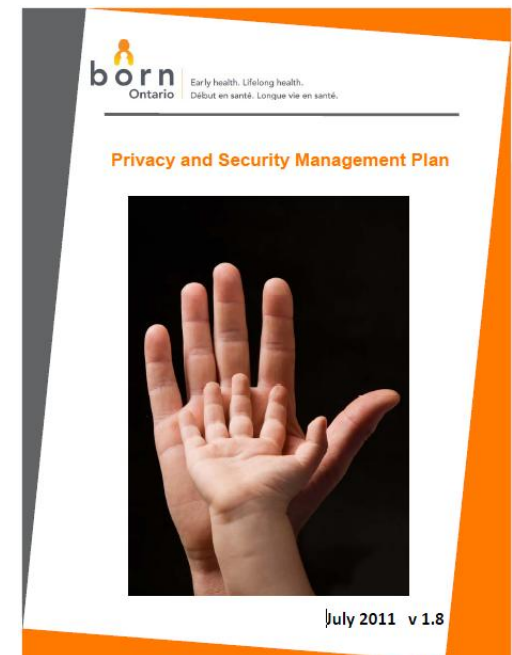


Roles & Responsibilities

- CHEO CEO
 - Michel Bilodeau
- CHEO Chief Privacy Officer
 - Tyson Roffey
- BORN Privacy Officer
 - Pranesh Chakraborty (Acting)
- Privacy Administrator
 - Joan Mongeon
- Acting Director
 - Mari Teitelbaum
- Scientific Manager
 - Ann Sprague

Policies & Procedures

- The BORN Privacy & Security Management Plan (P&SMP) outlines BORN's mechanisms for protecting PHI
 - 17 Privacy policies & procedures
 - 15 Security policies & procedures
 - 8 Organizational policies & procedures
 - 15 Logs
- Being approved by Information Privacy Commissioner/Ontario



P&SMP: Agent Access & Use to Data

- Access to PHI by BORN Agents is based on the “need to know” principle, embodied in role-based access.
 - Agents use the minimum amount of identifiable information reasonably necessary for carrying out their day-to-day responsibilities
- Agents will apply for PHI access
 - Purpose of access
 - Data required
 - Duration of access
 - Type of access
- Access will need to be renewed annually

P&SMP: Disclosures (NOT for Research)

- PHIPA allows for disclosure of PHI for a number of reasons
 - Section 49(1)(a) – improve and facilitate care
 - Missed Screen
 - Gestational diabetes follow-up
 - Section 45
 - Data sharing with prescribed entity
 - ICES
- Approval process followed prior to disclosure

P&SMP: Breach

- A privacy breach or potential breach occurs when personal health information is collected, retained, used or disclosed in ways that are not in accordance with the provisions of the *Personal Health Information Protection Act*.
- It is important to respond *immediately* when faced with a breach or potential breach. The following steps should be carried out simultaneously or in quick succession.
 - Step 1:* On discovering a breach or potential breach, immediately notify the Privacy Officer
 - Step 2:* Act quickly to limit the breach or potential breach
 - Step 3:* Work with the Privacy Officer through evaluation and communication
- Individuals found to be responsible for the breach may be terminated as per terms of the BORN Confidentiality Agreement

P&SMP: Audit

- Privacy Officer has an annual audit plan which includes
 - Assess organizational compliance with privacy policies and procedures
 - Assess compliance of Agents permitted to access and use Personal Health Information
 - Assess compliance of Researchers with research agreement requirements
- Anyone with access to the BORN database, or researchers with BORN datasets, can be audited at any time

P&SMP: Quarterly & Annual Report

1. Governance Structure
2. Training & Awareness
 - Training
 - Website
 - Public engagement
3. Audits & Compliance
 - Audits
 - PIAs
4. Incident Management
 - Breaches
 - Complaints
 - Inquiries
5. Status of Recommendations

Skill Testing Questions

- Use the 'Chat' window on the Webinar to answer the question.
- The first correct answer will win a prize
- 3 questions

Questions?



- Info@BORNOntario.ca
- privacy@BORNOntario.ca
- mteitelbaum@BORNOntario.ca