

## P-01 Privacy Policy in Respect of CHEO's Status as a Prescribed Person

Manual/Section: BORN Ontario Privacy and Security Policies and Procedures/Privacy Policies and Procedures

Policy No. P-01

Reviewed by/on: Privacy and Security Review Committee on April 11, 2011

<p><b>Purpose</b></p>	<p>To ensure that the Better Outcomes Registry &amp; Network, or BORN Ontario, has a privacy and security accountability framework to implement its status and overall responsibility as a prescribed person under the <i>Personal Health Information Protection Act, 2004</i>.</p>
<p><b>Policy</b></p>	<p><b>Status</b></p> <p>The Children's Hospital of Eastern Ontario (CHEO) is a prescribed person in respect of BORN Ontario as per section 13(1) of Ontario Regulation 329/04-General (Regulation), enacted under the <i>Personal Health Information Protection Act, 2004</i> for the purposes of facilitating or improving the provision of health care for mothers, infants and children.</p> <p>Section 13(2) of Ontario Regulation 329/04-General (Regulation), enacted under the <i>Personal Health Information Protection Act, 2004</i> requires BORN Ontario, as a prescribed registry:</p> <ul style="list-style-type: none"> <li>• To have in place practices and procedures to protect the privacy of individuals whose Personal Health Information BORN Ontario receives</li> <li>• To maintain the confidentiality of that information</li> <li>• These practices and procedures must be approved by the Information and Privacy Commissioner of Ontario every three years</li> </ul> <p>BORN Ontario is committed to complying with the provisions and regulations of the <i>Personal Health Information Protection Act, 2004</i> applicable to a person holding a registry, as well as any other applicable legislation.</p> <p><b>Privacy and Security Accountability Framework</b></p> <p>BORN Ontario has developed comprehensive privacy and security policies and procedures to ensure compliance with the <i>Personal Health Information Protection Act, 2004</i> and its regulation.</p> <p>The President and Chief Executive Officer of CHEO is ultimately accountable for ensuring compliance with the <i>Personal Health Information Protection Act, 2004</i> and its regulation and ensuring</p>

	<p>compliance with BORN’s privacy and security policies and procedures.</p> <p>The President and Chief Executive Officer of CHEO has delegated day-to-day responsibility for ensuring compliance with the <i>Personal Health Information Protection Act, 2004</i> and its regulation, and for ensuring compliance with BORN Ontario privacy and security policies and procedures to the BORN Ontario Leadership Team.</p> <p>The BORN Ontario Leadership Team has delegated the day-to-day management of the privacy and security program to the Privacy Officer who reports to the BORN Ontario Leadership Team on all related privacy and security matters.</p> <p>The duties and responsibilities of the Privacy Officer focus on developing and maintaining a strong culture of privacy at BORN Ontario and include:</p> <ul style="list-style-type: none"> <li>• Management of the privacy program and security program, including monitoring compliance, conducting regular audits and providing reports to senior management and recommendations for changes to policies or procedures</li> <li>• Execution of privacy training</li> <li>• Execution and oversight of privacy impact assessments</li> <li>• Responding to inquiries or complaints related to BORN Ontario privacy practices</li> <li>• Any and all related privacy and security oversight</li> </ul> <p>The Privacy Officer works in collaboration with the CHEO Chief Privacy Officer to ensure alignment between BORN Ontario privacy policies and any applicable CHEO privacy policies.</p> <p>The following committees and roles also form part of the privacy and security accountability framework.</p> <p>The Privacy and Security Review Committee has responsibility for:</p> <ul style="list-style-type: none"> <li>• Developing, reviewing and approving BORN Ontario policies and procedures</li> <li>• Overseeing implementation of the procedures</li> <li>• Conducting annual reviews of privacy and security policies and procedures (or more frequently as needed to ensure safeguards remain effective and to determine whether modifications are warranted)</li> <li>• Reviewing annually the collections, uses and disclosures of Personal Health Information to ensure adherence to the provisions and principles of the Personal Health Information Protection Act, 2004 and its regulation</li> </ul> <p>The Data Dictionary Review Committee has responsibility for conducting annual reviews of data holdings to ensure that the need for each data element has been identified and that BORN Ontario does not collect more Personal Health Information than is reasonably necessary to meet</p>
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	<p>its purposes.</p> <p>The Disclosure of Personal Health Information Review Committee also reviews all requests for use and disclosure of Personal Health Information for research purposes and for disclosure to a prescribed entity.</p> <p>The Scientific Manager has responsibility for reviewing all research requests to ensure that they comply with the requirements of the <i>Personal Health Information Protection Act, 2004</i> and its regulation.</p> <p>The Manager of Health Informatics has responsibility for the technology leveraged to collect and store the Personal Health Information used by BORN Ontario.</p> <p>See HR-08 and HR-09 Job Descriptions for Position(s) Delegated Day-to-Day Authority to Manage the Privacy and Security Programs.</p> <p><b>Collection of Personal Health Information</b></p> <p>BORN Ontario collects Personal Health Information to improve the quality of health care services provided to mothers, infants and children in Ontario.</p> <p>The types of Personal Health Information collected include demographic information (e.g. age, postal code) and clinical information about fetuses, newborn babies, children and their mothers (including pregnancy history, medical history and a summary of care provided during pregnancy, labour, birth and the newborn period).</p> <p>This information is collected from health information custodians involved in the care of both newborns and their mothers, in particular those providing pre- and post-natal care to pregnant woman across Ontario such as hospitals and patient practitioners like family physicians or midwives.</p> <p>BORN Ontario does not collect Personal Health Information if other information will serve the purpose and does not collect more Personal Health Information than is reasonably necessary to meet the purposes outlined above.</p> <p>BORN Ontario collects only those data elements that have been identified through the rigorous review process undertaken by the Data Dictionary Review Committee as per P-04 Collection of Personal Health Information and P-06 Statements of Purpose for Data Holdings Containing Personal Health Information. The Data Dictionary Review Committee process ensures that each identified collection is consistent with the Act and it's regulations.</p> <p>The Data Dictionary Review Committee has responsibility for determining:</p> <ul style="list-style-type: none"> <li>• The nature of the Personal Health Information required to enable BORN Ontario to fulfill its mandate</li> <li>• List of data elements to be collected, and any sub-elements, as applicable</li> </ul>
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- The health information custodians from whom the data elements will be collected
- The rationale or statement(s) of purpose for each data element in relation to the identified purpose of the Registry

The list of data holdings is reviewed annually by the Data Dictionary Review Committee as per P-04 Collection of Personal Health Information and P-06 Statements of Purpose for Data Holdings Containing Personal Health Information and is posted on the BORN Ontario website (<http://www.bornontario.ca/privacy/statement-of-information-practices>) along with the name, address and phone number of the Privacy Officer from whom further information may be obtained in relation to the purposes, data elements and data sources for each data holding of Personal Health Information.

### **Use of Personal Health Information**

BORN Ontario uses the Personal Health Information that it collects to:

- Identify where appropriate care has not been received and facilitate access to care and treatment for mothers, infants and children (e.g. identifying false negative screens and informing the relevant health care provider in order to enable them to offer parents appropriate care for their baby)
- Facilitate continuous improvement of screening thresholds to minimize missed cases
- Raise alerts where maternal and/or newborn outcomes are clinically or statistically discrepant with accepted norms
- Identify strategies to improve the quality and efficiency of care for mothers, infants and children
- Create reports that can be used to provide the Ministry of Health and Long-Term Care, Local Health Integration Networks (LHIN) and Public Health Units with comprehensive and timely information to support effective planning and management of health care delivery for mothers, babies and children in the province

Information provided in reports to the Ministry, Local Health Information Networks and Public Health does not contain Personal Health Information or identify individuals; they only present an overview of aggregated health care data. The reports are carefully reviewed to ensure there is no risk of re-identification through small cell counts or other forms of possible residual disclosure *as per* P-24: De-Identification and Aggregation. The reports are made available through the BORN Ontario website at [www.BORNOntario.ca](http://www.BORNOntario.ca).

BORN Ontario ensures that each identified use of personal health information is consistent with the uses of personal health information permitted by the Act and its regulations. BORN Ontario does not use Personal Health Information if other information will serve the purpose and does not use more Personal Health Information than is reasonably

	<p>necessary to meet the purpose, using de-identified or aggregate information wherever possible.</p> <p>BORN may use Personal Health Information to conduct research only when the strict requirements of the <i>Personal Health Information Protection Act, 2004</i> are adhered to, including review by a Research Ethics Board as per P-10: User of Personal Health Information for Research.</p> <p>BORN Ontario remains responsible for Personal Health Information used by its Agents. Access and use by BORN Agents is strictly controlled. Agents are trained on their privacy obligations and sign a Confidentiality Agreement acknowledging the requirements to use only the information necessary for their work, to keep Personal Health Information secure at all times, and to notify BORN Ontario of any discovered or suspected breach as per:</p> <ul style="list-style-type: none"><li>• P-08: Limiting Agent Access to and Use of Personal Health Information</li><li>• P-29: Privacy Breach Management</li><li>• HR-01 and HR-03: Privacy and Security Training and Awareness</li><li>• HR-05: Execution of Confidentiality Agreements by Agents</li></ul> <p><b>Disclosure of Personal Health Information</b></p> <p>BORN Ontario does not disclose Personal Health Information if other information serves the purpose and does not disclose more Personal Health Information than is reasonably necessary to meet the purpose.</p> <p>Personal Health Information is disclosed to the following groups and for the following purposes, in accordance with the disclosures of Personal Health Information permitted by the <i>Personal Health Information Protection Act, 2004</i> and its regulation:</p> <ul style="list-style-type: none"><li>• To health care providers, when facilitating access for mothers, babies and children for care and treatment; for example, to ensure appropriate screening is offered in a meaningful timeframe</li><li>• To a prescribed entity for the management, evaluation, monitoring or planning for the health system</li><li>• To researchers for research purposes as defined in the <i>Personal Health Information Protection Act, 2004</i>. Personal Health Information is provided to researchers only if de-identified information is not sufficient to conduct the research. The research plan must be approved by a Research Ethics Board, meet the requirements set out in the Personal Health Information Protection Act, 2004, and be approved by the Scientific Manager who ensures that the minimum amount of Personal Health Information and the least identifiable information is disclosed. The Scientific Manager is assisted by assessments conducted by the Electronic Health Information Laboratory</li></ul> <p>More information on the disclosure of Personal Health Information is</p>
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provided in:

- P-12: Disclosure of Personal Health Information for Purposes Other Than Research
- P-13: Disclosure of Personal Health Information for Research Purposes and the Execution of Research Agreements
- P-24: De-Identification and Aggregation

### **Disclosure of De-identified and/or Aggregate Personal Health Information**

The BORN Ontario Scientific Manager has responsibility for reviewing all de-identified and/or aggregate information prior to its disclosure in order to ensure that it is not reasonably foreseeable in the circumstances that the information could be used, either alone or with other information, to identify an individual. The BORN Ontario Scientific Manager is assisted by assessments conducted by the Electronic Health Information Laboratory that determine the risk of re-identification.

De-identified and aggregated Personal Health Information may be disclosed to the following groups and for the following purposes including:

- To Public Health Units to facilitate the appropriate planning, monitoring and provision of health care.
- To Researchers for research purposes
- To the Ministry of Health to inform policy and planning

More information on the disclosure of Personal Health Information is provided in:

- P-12: Disclosure of Personal Health Information for Purposes Other Than Research
- P-13: Disclosure of Personal Health Information for Research Purposes and the Execution of Research Agreements
- P-24: De-Identification and Aggregation

### **Secure Retention, Transfer and Disposal of Records containing Personal Health Information**

BORN Ontario ensures that both **paper** and **electronic** records are kept safe and secure as follows:

- **Where Paper** records exist, they are to be considered transitory; they will be converted to electronic records at the earliest opportunity and destroyed as per S-08 Secure Disposal of Records of Personal Health Information
- **Electronic** records will be maintained in identifiable form within the transactional database for 28 years and then converted to a de-identified format as per S-05 Secure Retention of Records of Personal Health Information and S-06 Secure Retention of Records of Personal Health Information on Mobile Devices. The

reporting database will only include de-identified information to protect Personal Health Information from the broader BORN Ontario report user community

- Records of Personal Health Information in both paper and electronic format will be securely transferred and disposed of as per S-07 Secure Transfer of Records of Personal Health Information and S-08 Secure Disposal of Personal Health Information.

### **Implementation of Administrative, Technical and Physical Safeguards**

BORN Ontario has in place administrative, technical and physical safeguards to protect the privacy of individuals whose Personal Health Information is received and to maintain the confidentiality of that information. BORN takes steps to protect Personal Health Information against theft, loss and unauthorized use or disclosure and to protect records of Personal Health Information against unauthorized copying, modification or disposal. These safeguards are set out in:

- S-01: Information Security Policy
- S-09: Passwords
- S-13: Back-up and Recovery of Records of Personal Health Information
- S-14: Acceptable Use of Technology
- HR-05: Execution of Confidentiality Agreements by Agents

Privacy and security policies and procedures are reviewed annually, at a minimum, by the Privacy and Security Review Committee as per S-02: Ongoing Review of Security Policies and Procedures.

### **Inquiries, Concerns or Complaints Related to Information Practices**

All inquiries, concerns or complaints related to the privacy policies and procedures of BORN Ontario and BORN Ontario's compliance with the *Personal Health Information Protection Act, 2004* and its regulation must be directed to:

BORN Ontario Privacy Officer  
Suite 106-1785 Alta Vista Drive  
Ottawa ON K1G 3Y6  
E-mail: [privacy@BORNOntario.ca](mailto:privacy@BORNOntario.ca)  
Phone: 613-523-3781  
Fax: 613-523-9057

See the BORN Ontario website at [www.BORNOntario.ca](http://www.BORNOntario.ca)

Individuals may also direct complaints regarding the compliance of BORN Ontario to the Information and Privacy Commissioner of Ontario :

Information and Privacy Commissioner of Ontario  
2 Bloor Street East

Suite 1400  
Toronto, Ontario  
M4W 1A8

Telephone:

Toronto Area: 416-326-3333

Toll Free (within Ontario): 1-800-387-0073

TDD/TTY: 416-325-7539

Fax: 416-325-9195

**Transparency of Practices in Respect of Personal Health Information**

BORN Ontario makes available on the BORN website at [www.BORNOntario.ca/Privacy](http://www.BORNOntario.ca/Privacy) the P01- Privacy Policy in Respect of CHEO's Status as a Prescribed Person and the Statement of Information Practices.

The privacy policies can also be obtained by contacting the Privacy Officer as per above.