



Privacy Statement

The electronic Child Health Network (eCHN) was established in 1997¹ and is operated as a not-for-profit, government funded organization, dedicated to using modern technology to promote the sharing of paediatric health care data, information and knowledge among health care providers for the purpose of medical care.² It is designed to provide the communications infrastructure to support children's health services in Ontario.

The Ontario Provincial Privacy Legislation - Personal Health Information Protection Act, 2004 (PHIPA) establishes rules concerning the collection, use and disclosure of Personal Health Information (PHI) by Health Information Custodians (HIC) and other persons.

Under PHIPA, eCHN is defined as both an "agent" of the Health Information Custodian and a "Health Information Network Provider".

"agent", in relation to a health information custodian, means a person that, with the authorization of the custodian, acts for or on behalf of the custodian in respect of personal health information for the purposes of the custodian, and not the agent's own purposes, whether or not the agent has the authority to bind the custodian, whether or not the agent is employed by the custodian and whether or not the agent is being remunerated;

"health information network provider" or "provider" means a person who provides services to two or more health information custodians where the services are provided primarily to custodians to enable the custodians to use electronic means to disclose personal health information to one another, whether or not the person is an agent of any of the custodians.

¹ eCHN was established in 1997 it went Live in 1999.

² Access to information contained in eCHN Data Repositories may not be used for research purposes.



For a list of the Health Information Custodians (HIC) that share or access Personal Health Information with eCHN, <http://www.echn.ca/memberorgs.html>



eCHN complies with the provincial privacy legislation. Our privacy policy is based on The Ten Principles of the CSA Model Code for the Protection of Personal Information and the provincial Personal Health Information Protection Act, 2004 (PHIPA):

1. Accountability for Personal Health Information (PHI)
2. Identifying the Purposes of Personal Health Information (PHI)
3. Consent for the Collection, Use and Disclosure of Personal Health Information (PHI)
4. Limiting the Collection of Personal Health Information (PHI)
5. Limiting the Use, Disclosure and Retention of Personal Health Information (PHI)
6. Accuracy of Personal Health Information (PHI)
7. Safeguards for Personal Health Information (PHI)
8. Openness about the Management of Personal Health Information (PHI)
9. Individual Access and Amendment of Personal Health Information (PHI)
10. Challenging compliance

1. Accountability for Personal Health Information (PHI)

eCHN is responsible for all Personal Health Information (PHI) persisted in its data repositories. Accountability for eCHN's compliance with the Personal Health Information Protection Act 2004 (PHIPA) rests with eCHN's Chief Executive Officer. As the Chief Executive Officer is accountable for eCHN's compliance to PHIPA, this role has decision-making authority regarding the interpretation and application of the associated privacy principles and policies in place at eCHN.

eCHN's Privacy Officer is responsible for providing leadership on privacy matters throughout the organization.

eCHN enters into an agreement with each Health Information Custodian (HIC) concerning the services provided to the Custodian. This agreement includes a privacy addendum and its mutual agreement is a pre-requisite to eCHN membership.

Note: eCHN membership, prior to Personal Health Information Protection Act, 2004 (PHIPA), has been reviewed and all member sites have been asked to sign a Privacy Addendum to the existing Memorandum of Understanding.

2. Identifying Purposes of Personal Health Information (PHI)

Identifying the purposes for which eCHN receives Personal Health Information (PHI) allows eCHN to both determine the information it needs to fulfill these purposes as well as confirm that the information received, is received under the approved conditions.



eCHN does not directly collect PHI from the patient but rather accepts an electronic copy of the PHI record from the Health Information Custodian (HIC). At all times, the HIC remains in possession of the original PHI record; eCHN retains a copy of the PHI record, which it keeps in the eCHN data repositories.

Before any PHI is shared with eCHN, the HIC and eCHN document the purpose for which data is held by eCHN. The purpose for data holding identifies those purposes for which PHI is collected, used, disclosed and retained.

The purpose of data holding is for direct clinical services by authorized individuals within the patient's circle of care.

The PHI accessible via eCHN Portal is not available to any government or insurance organization and is not used for research purposes or health care management³.

Note:

The eCHN Portal Application "POGO Shuttle Sheets" is a disparate application specific to individual (Health Care Providers) who work under the supervision of POGO. It is not accessible by any other eCHN Portal Users. In 2004, POGO was designated as a 45 entity under the Personal Health Information Protection Act (PHIPA, 2004).

As approved by POGO privacy office, the CRA's will continue to have access to the POGO Shuttle Sheet Content of the eCHN Portal at the tertiary centres. It is acknowledged that the CRA's will subsequently only disclose the clinical information to the clinical study groups affiliated with the POGO centres (hospitals). The POGO Privacy Office understands and agrees that the CRA access shall be restricted to the POGO Shuttle Sheet Application only.

³ eCHN does not use or disclose Personal Health Information for purposes other than providing healthcare, except as required by law.



3. Consent for the Collection, Use and Disclosure of Personal Health Information (PHI)

eCHN acknowledges the principle that “the knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate”⁴. eCHN consults with Health Information Custodians (HIC) about the implementation of this consent principle. As the Health Information Custodian is the owner of the information, it is the ultimate responsibility of the HIC to determine the preferred consent method (express or implied).

An individual or their authorized representative may withdraw consent at any time, subject to contractual restrictions and reasonable notice. The individual or their authorized representative must attend the Health Information Custodian(s) that retains the original record. *eCHN will not directly process withdrawal of Consent by individual and will refer the individual back to the Health Information Custodian that retains the original record.*

Withdrawal of consent is not centralized at eCHN but rather each individual HIC. Correspondingly, the individual can request that eCHN will provide a list of Health Information Custodians that have shared information with eCHN.

Reference – SEPF - 820 eCHN PHI Inquiry Form.

eCHN will permanently retain an audit log of all changes in consent notification request. Correspondingly, as indicated in the Protection of Information (Privacy) Addendum, all changes in consent status will be processed via the Consent Management Application of the eCHN Portal.

eCHN recommends that the Health Information Custodian (HIC) discuss/inform the individual of the implications of consent withdrawal.

eCHN will process a consent withdrawal request by permanently blocking existing PHI in the eCHN data repositories.

⁴ From: Model Code for the Protection of Personal Information, CSA 1996



4. Limiting Collection of Personal Health Information (PHI)

eCHN will limit the collection of Personal Health Information (PHI) to that which is necessary for the purposes identified in the eCHN/Member Site *Memorandum of Understanding* and *Addendum to the Memorandum of Understanding*. It is the discretion of the HIC to determine what PHI is shared with eCHN.

5. Limiting Use, Disclosure and Retention of Personal Health Information (PHI)

eCHN does not use or disclose Personal Health Information for purposes other than providing healthcare, except as required by law.

eCHN will not disclose any Personal Health Information to which it has access in the course of providing the services for the Health Information Custodians (HIC).

eCHN may provide access to Personal Health Information contained in the eCHN data repositories only when:

- Access to PHI is granted to the Healthcare Information Custodian (HIC) that originally provided the Personal Health Information (PHI) to eCHN.
- Access to PHI is granted to authorized and authenticated eCHN Portal Users.

All access to PHI contained in the eCHN Portal data repositories is logged and the audit file containing such accesses is retained permanently. eCHN recommends to the Healthcare Information Custodian (HIC) that their authorized and authenticated users access to eCHN Portal be audited in accordance to their internal policy standards governing use. eCHN has provided an on-line Audit Reporter Application to facilitate this task.

Exception: eCHN will comply with legal court order. Such requests must be supported by appropriate documentation and require direct approval by the Privacy Office and eCHN CEO.

Personal Health Information is retained only as long as necessary for the fulfillment of those purposes.



6. Accuracy of Personal Health Information (PHI)

The Personal Health Information data shared by the Health Information Custodians (HIC) with eCHN and displayed on eCHN WebChart may not be a complete health record. Information from Health Information Custodians (HIC) and individuals not contributing to eCHN will not appear as a part of WebChart.

It is up to the discretion of the Health Information Custodians (HIC) whether the entire patient record is shared with eCHN. The HIC makes this decision during the eCHN Member Site Integration.

It is eCHN's responsibility to ensure that the agreed data elements that form the PHI record from the HIC are profiled to correct electronic health record. eCHN does not correct/change or modify the Personal Health Information record held at the HIC. Any queries regarding accuracy of the PHI held in the eCHN data repositories are the direct responsibility of the HIC.

Accordingly, the individual can request that eCHN will provide a list of Health Information Custodians that have shared information with eCHN.

Reference – SEPF - 820 eCHN PHI Inquiry Form.

eCHN updates Personal Health Information as it is received from Health Information Custodians (HIC).

eCHN uses quality assurance processes, data analysis tools and data coding standards to facilitate the collection and use of quality Personal Health Information. Health Information Custodians (HIC) are responsible for ensuring the Personal Health Information they provide to eCHN is accurate, complete and up-to-date for the purpose specified.

During data normalization to industry standards⁵ (if applicable), the HIC is responsible to confirming the normalized data. The normalized data remains under the ownership of the original contributing HIC. In any event, the original data remains available on the application.

⁵ LOINC: Logical Observation Identifiers Names and Codes v2.19



7. Safeguards for Personal Health Information (PHI)

eCHN implements generally accepted industry standards and practices in order to safeguard the sensitivity of the personal health information. These standards and practises are implemented to protect personal health information against theft or loss, as well as unauthorized access, disclosure, copying, use, or modification.

The nature of the safeguards will depend on the sensitivity of the information that has been collected, the amount, distribution, and format of the information, and the method of storage. A higher level of protection safeguards more sensitive information. eCHN's Security Policy is based on ISO27002 2005.

Careful consideration is given in the disposal or destruction of Personal Health Information to prevent unauthorized parties from gaining access to the information. Destruction of Data by third parties is conducted under contractual agreement.

eCHN Personnel are made aware of the importance of maintaining the confidentiality of Personal Health Information through a privacy and security training program.

eCHN Personnel will be made aware of the importance of maintaining the confidentiality of Personal Health Information. As a condition of employment, all eCHN Personnel must sign an eCHN Confidentiality Agreement.

eCHN will perform, and provide to the Health Information Custodian (HIC) a written summary of the results of, an assessment of the services provided to the Health Information Custodian (HIC) with respect to:

- threats, vulnerabilities and risks to the security and integrity of the Personal Health Information (Threat Risk Assessment or TRA); and
- how the Services may affect the privacy of the individuals who are the subjects of the Personal Health Information (Privacy Impact Assessment or PIA)

Note: eCHN considers the TRA and PIA to be controlled documents and correspondingly are only electronically accessible under Non-Disclosure Agreements.



8. Openness about the Management of Personal Health Information (PHI)

eCHN will make information about its policies and practices with respect to the management of Personal Health Information readily available to individuals. This information can be accessed via eCHN's web site, eCHN's brochures and posters. eCHN's brochures and posters are available through the Health Information Custodian.

The information made available includes:

- The name or title, and address of the person who is accountable for eCHN privacy policies and practices and to whom inquiries or complaints may be forwarded;
- The means to request a list of Health Information Custodians that have shared information with eCHN and what records were shared.
- The means to request a list of authorized eCHN Portal Users that have accessed their Personal Health Information.
- A copy of any brochures or other information that explains eCHN's mandate, activities, policies, standards, or codes.

9. Individual Access and Amendment of Personal Health Information (PHI)

On request, eCHN informs an individual of the existence, use and disclosure of his or her Personal Health Information provided by the Health Information Custodian (HIC). eCHN indicates the source of this information and refers the individual to the Health Information Custodians (HIC) concerned. In addition, eCHN provides an account of the use that has been made, or is being made of the individuals' Personal Health Information and its use.

An individual is required to provide sufficient information to permit eCHN to provide an account of the existence, use and disclosure of Personal Health Information. The information provided is only used for this purpose. eCHN responds to an individual's request as soon as possible but no later than 30 days after receiving the request.

When an individual challenges the accuracy and completeness of the Personal Health Information and requests to have it amended as appropriate, eCHN refers the individual to the Health Information Custodians (HIC) to make amendments. Only the HIC has the authority to make amendments to Personal Health Information.

When a Health Information Custodian notifies eCHN that the individual has successfully demonstrated the inaccuracy or incompleteness of Personal Health



Information, the Health Information Custodian (HIC) amends the Personal Health Information as required and this update is communicated to eCHN.

10. Challenging Compliance

eCHN is committed to protecting the privacy of personal information under the custody or control of eCHN as required by law and in accordance with Ontario's *Personal Health Information Protection Act, 2004*.

Any individual concerned with the privacy practices of eCHN has the right to make an inquiry and/or complaint to the Chief Executive Officer of eCHN and/or to the Privacy Officer. Any such inquiry must be put in writing and be directed to eCHN's CEO.

electronic Child Health Network
180 Dundas St. W. Suite 2405
Toronto, Ontario - M5G 1Z8
Attention: eCHN CEO

Telephone: 416 813 8807
Toll Free: 1 877 252 9900
FAX: +1 416 813 8294
e-mail: echnmail@echn.ca
e-mail: privacy@echn.ca

Reference:
SEPF - 820 eCHN PHI Inquiry Form
SEPF-822 eCHN Privacy Complaint Form

All complaints and inquiries are responded to promptly and in accordance to eCHN's compliant procedures. Follow-up actions will be taken and policies and procedures revised, when appropriate, in response to privacy breaches.

In addition, an individual has the right to complain to the Information and Privacy Commissioner/Ontario pertaining to eCHN's compliance to with the principles set out in this policy.

The Commissioner can be reached:
Information and Privacy Commissioner of Ontario
2 Bloor Street East, Suite 1400
Toronto, ON - M4W 1A8
www.ipc.on.ca