

## PRIVACY POLICY

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Category	Operational and Human Resource	Policy Owner	Privacy Officer
Policy No.	4.0	Review Frequency	Bi-Annual
Version No.	3.0	Status	Approved
Effective Date	May 29, 2020	Date Approved	May 29, 2020
Approver of Related Procedures	Privacy Officer	Approver(s)	Board of Directors

### 1.0 PURPOSE

1.1 This Policy establishes the guiding principles by which the Health Data Coalition (HDC) and its Personnel comply with their ethical, legal and contractual obligations for Privacy.

### 2.0 SCOPE

2.1 The Policy applies to HDC as an organization and to all Personnel, including contractors as applicable.

2.2 This Policy applies to all Personal Information in HDC's Custody and/or Control. This includes any information about an identifiable individual, regardless of format or how that information is stored or recorded

### 3.0 POLICY STATEMENT

3.1 Privacy is a guiding principle for the HDC and is built into HDC's services, infrastructure, policies and processes.

3.2 As a federally registered non-profit organization operating in British Columbia, HDC is subject to the *Personal Information and Protection of Privacy Act* (PIPA), which sets out the rules for how private sector organizations Collect, Use and Disclose and protect Personal Information.

- 3.3 In addition to complying with PIPA, HDC complies with the ten internationally recognized *Fair Information Principles*<sup>1</sup> outlined in this Policy, to ensure its privacy controls align with legal requirements and best practices across Canada.
- 3.4 HDC imbeds privacy into all aspects of its operations using the Privacy by Design Framework and is committed to maintaining the internationally recognized Privacy by Design Certification.

**4.0 EXCLUSIONS**

- 4.1 There are no exclusions to this policy.

**5.0 DEFINITIONS**

<b>Breach</b>	An action or activity that contravenes HDC policies or puts HDC in contravention of a law or legal agreement to which it is subject. A Breach may include an unauthorized Collection, access, Use, Disclosure, modification, or copying, disposal or destruction of Personal Information or confidential Information. It may include any unauthorized access to an HDC system or inability to account for any information in HDC’s Custody or Control.
<b>Collection</b>	To gather, obtain access to, acquire, receive or obtain Personal Information from any source by any means.
<b>Control</b>	An organization’s authority to manage a record or information throughout its life cycle, including restricting, regulating and administering its Use or Disclosure.  Organizations have Control of information they created, or that they collected directly from individuals with consent. Organizations may Control information that is not in their custody where they have contracted another organization to manage information or a service on their behalf.
<b>Custody</b>	Having possession of a record or information.  Organizations, such as HDC may have Custody of Personal Information without having any Control over that information

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<sup>1</sup> The Fair Information Principles make up of Schedule 1 of Canada’s private sector privacy legislation, the [Personal Information Protection and Electronic Documents Act](#) (PIPEDA).

	where they have records or data in their possession in order to provide a service on behalf of another organization or individual.
<b>Disclosure</b>	To transfer, share or make public Personal or confidential Information with individuals or organizations external to the HDC.
<b>Express Consent</b>	Situation where an individual has been presented with an option to agree or disagree to the Collection, Use, or Disclosure of Personal Information - and agrees with a clear indication of that agreement.
<b>HDC Client</b>	An individual, clinic or end-user who has entered into an agreement with the HDC to receive HDC's services.
<b>Implied Consent</b>	An assumption of permission to Collect and Use Personal Information as indicated by an individual's actions in the context of the situation.
<b>Personal Information</b>	As defined by PIPA, Personal Information means information about an identifiable individual. This definition includes employee information, but it does not include the information necessary to enable an individual to be contacted at their place of business (known as "business contact information"), or work product information.
<b>Personnel</b>	HDC employees, directors, officers, board members, volunteers and contractors, where applicable.
<b>Privacy</b>	The legal and ethical obligation of HDC and all its Personnel to protect the fundamental right of individuals to control information about themselves.
<b>Privacy Officer</b>	The delegated leader responsible for overseeing HDC's compliance with the PIPA and HDC's Privacy Policy.
<b>Use</b>	HDC's internal access and use of Personal Information to fulfill its purposes and objectives. Use includes access to Personal Information in HDC's Custody by authorized HDC Personnel.

## 6.0 POLICY DESCRIPTION

6.1 HDC's Privacy Principles follow and comply with the 10 internationally recognized Fair Information Principles.

## **6.2 Accountability**

- 6.2.1 HDC is accountable for protecting Personal Information in its Custody and Control, regardless of format, including information that is managed, accessed or stored on HDC's behalf by contracted service providers.
- 6.2.2 HDC fosters a culture that respects Privacy. HDC's accountability for Privacy resides at the highest level of the organization with its Board of Directors, who have a fiduciary duty to ensure that HDC has sound privacy management practices.
- 6.2.3 HDC's Executive Director is charged by the HDC Board of Directors to deliver on HDC's overall strategy, including HDC's commitment to Privacy. The Executive Director is accountable for HDC's Privacy Policy and practices.
- 6.2.4 HDC's Privacy Officer is responsible for overseeing HDC's compliance with this policy, and:
  - a) Advocating for best practices related to Privacy throughout the organization;
  - b) Educating and ensuring all Personnel are informed of their Privacy responsibilities; and
  - c) Acting as the point of contact for internal and external questions about Privacy, including communications with the Office of the Information and Privacy Commissioner of British Columbia (OIPC).
- 6.2.5 All HDC Personnel are responsible for Privacy and complying with this policy.

## **6.3 Identifying Purposes**

- 6.3.1 HDC identifies its purposes for collecting Personal Information before or at the time of Collection.

## **6.4 Consent**

- 6.4.1 HDC respects the right of individuals to control information about themselves.
- 6.4.2 HDC relies on an individual's permission for all direct Collections, Uses and Disclosures of Personal Information in compliance with PIPA and best practices.
- 6.4.3 For Direct Collections of Personal Information, HDC ensures consent is meaningful and appropriate for the circumstances<sup>2</sup>. Implied Consent may be used only where

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<sup>2</sup> The Office of the Information Privacy Commissioner of British Columbia's guidelines on meaningful consent can be found at: <https://www.oipc.bc.ca/guidance-documents/2255>

both the purpose and scope of Personal Information Collected is obvious and reasonable given the circumstance. Other cases require Express Consent.

- 6.4.4 Where HDC collects Personal Information indirectly from another organization as part of a service offering provided by HDC (i.e. collection of patient information from HDC Clients), HDC relies on the Implied and Express Consent from the individual the information is about to the Organization that is Disclosing the information to HDC for the purposes that information was originally collected<sup>3</sup>.
- 6.4.5 Where HDC Collects Personal Information indirectly from another organization as outlined above, HDC adheres to PIPA. HDC's service offering, are and will be designed to directly support the Disclosing organization in fulfilling their purpose for Collecting that Personal Information.
- 6.4.6 HDC requests consent to use information in its Custody or Control for new purposes that were not previously identified or reasonably implied upon Collection. Exceptions exist only where the new purpose is both authorized and required by law.
- 6.4.7 HDC enables and supports individuals in withdrawing consent for the Use or Disclosure of Personal Information in HDC's Control without undue delay.

## **6.5 Limits to Collection**

- 6.5.1 HDC limits its Collection of Personal Information to only that which is reasonable and relevant for the purposes it has identified.

## **6.6 Limiting Use, Disclosure, Retention and Disposal**

- 6.6.1 HDC Uses Personal Information for the purposes that it identifies upon Collection, including those purposes that a reasonable person would consider appropriate in the circumstance.
- 6.6.2 HDC Personnel only access and Use Personal Information for legitimate purposes, on a need to know basis.
- 6.6.3 HDC only Discloses Personal Information for legitimate purposes, as authorized by law. These purposes include, but are not limited to:
  - a) Where an individual has provided consent for the information being Disclosed;

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<sup>3</sup> As per PIPA, section 18(2) and 18(3), Organizations such as Medical Clinics are authorized to share Personal Information about their clients (patients) with their service providers without explicit consent from those patients, providing, the services being offered enable the Medical Clinics to best provide their services.

- b) Where HDC has an executed agreement with vetted service provider that has been contracted to work on HDC's behalf to support HDC's services;
- c) Where compelling circumstances exist that may affect the health or safety of an individual; or
- d) Where required by the terms of a court order, subpoena or warrant, or as otherwise authorized by law.

6.6.4 HDC will only retain Personal Information to fulfill the purpose for which it was Collected, or where required by law.

6.6.5 Where the reason for retaining Personal Information no longer applies, HDC securely disposes of the information in a timely manner, or as specified in any agreements that govern the management of the specified information.

## 6.7 Accuracy

6.7.1 HDC takes reasonable steps to ensure the accuracy and completeness of Personal Information in HDC's Control and supports individuals in correcting their information, as required by PIPA.

## 6.8 Safeguards for Personal Information

6.8.1 HDC proactively protects and secures Personal Information from collection to destruction, regardless of format, including that information that is managed, accessed and stored on HDC's behalf by its contracted service providers.

6.8.2 HDC's administrative, physical and technical security safeguards are appropriate for the sensitivity of the information.

## 6.9 Openness and Transparency

6.9.1 HDC ensures HDC Clients, stakeholders, Personnel and members of the public understand how the HDC Collects, Uses, Discloses, handles and safeguards Personal Information.

6.9.2 Where it is reasonable to believe that a Breach of a security safeguard involving Personal Information poses a real risk of significant harm to individuals<sup>4</sup>, HDC will report to the Office of the Information Privacy Commissioner (OIPC) and notify affected individuals.

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<sup>4</sup> HDC has adopted its principle to report breaches-based on Canada's federal law and international best practices. For guidance on assessing the "real risk of significant harm", see [https://www.priv.gc.ca/en/privacy-topics/business-privacy/safeguards-and-breaches/privacy-breaches/respond-to-a-privacy-breach-at-your-business/gd\\_pb\\_201810/#\\_Part\\_6](https://www.priv.gc.ca/en/privacy-topics/business-privacy/safeguards-and-breaches/privacy-breaches/respond-to-a-privacy-breach-at-your-business/gd_pb_201810/#_Part_6).

## **6.10 Access and Correction**

6.10.1 HDC respects an individuals' right to access and correct their Personal Information and supports individuals with this, as prescribed by PIPA, except where the law authorizes or requires otherwise.

6.10.2 In a situation where HDC must deny access to Personal Information, HDC will be transparent as to the reasons, as prescribed by PIPA.

## **6.11 Challenges to Compliance**

6.11.1 HDC ensures that individuals can challenge HDC's compliance with this policy. Individuals may write in confidence to [privacy@hdcbc.ca](mailto:privacy@hdcbc.ca) or HDC Privacy Officer, c/o the Health Data Coalition, suite 205-1009 Cook Street, Victoria, BC, V8V 3Z6.

6.11.2 HDC will direct any unresolved privacy concerns to the Office of the Information & Privacy Commissioner for BC, at PO Box 9038 Stn. Prov. Govt., Victoria B.C. V8W9A4

## **7.0 ASSOCIATED POLICIES AND PROCEDURES**

7.1 HDC Non-Disclosure and Confidentiality Agreement (Third parties)

7.2 HDC Privacy Notice

7.3 HDC Data Use and Disclosure Policy

7.4 HDC Information Security Policy

7.5 HDC Access Control Procedure

7.6 HDC Privacy Breach Management Procedure

7.7 HDC Destruction of Personal and Confidential Information Procedure

7.8 HDC Data Sharing Agreement

7.9 HDC Registration Agreement