

DATA USE AND DISCLOSURE POLICY

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Approver of Related Procedures	Privacy Officer	Approver(s)	Board

1.0 PURPOSE

The purpose of this policy is to define principles, which will guide the use and disclosure of personal information, personal health information and aggregate health data in the custody and stewardship of the HDC.

2.0 SCOPE

The responsibilities described in this policy apply to all HDC personnel and HDC Users who have access to or handle data held by HDC. The policy applies to personal information, personal health information (Contributor Data) and aggregate health data (HDC Data) in the custody and stewardship of the HDC.

3.0 POLICY STATEMENT

The HDC will limit the collection, use and disclosure of its data holdings to only those purposes which support practice quality improvement by physicians and partners, ensuring compliance with legislative and ethical standards that align with best practices in privacy and security protection and health data management. HDC ensures personal or health information collected by HDC will only be collected, used, disclosed and/or retained in compliance with the *BC Personal Information Protection Act*.

4.0 EXCEPTIONS

Requests for exceptions to this policy must be submitted in writing to the HDC's Clinical Data Stewardship Committee (CDSC)¹. Exceptions shall be permitted only on receipt of written approval from the HDC's CDSC. The HDC Privacy Officer will retain documentation of any permitted exceptions.

¹ Terms of reference for this board committee are available describing the purpose and responsibilities of the HDC's Clinical Data Stewardship Committee.

5.0 DEFINITIONS

Privacy Officer	The designated HDC leader responsible for overseeing the HDC privacy policies and procedures.
HDC Personnel	HDC personnel includes board members, officers, employees and contractors of the HDC.
HDC Users	Approved and authenticated end-users of the HDC application, who have entered into a registration agreement that licenses them to use the HDC application software.
Clinical Data Contributor	Registered HDC Users who have executed a data sharing agreement to contribute and transfer a subset of their electronic medical record system (EMR) data to the custody and stewardship of the HDC, for purpose of practice quality improvement. Clinical Data Contributors include: physicians and nurse practitioners who are authorized to share patient data under their control.
HDC Partner Users	A registered user from an HDC approved stakeholder who may access data using the HDC application, but does not contribute any data.
Third Parties	External individuals or organizations who may have access to specified HDC data, outside of the HDC application, where approved by HDC. A third party is not an authorized user of the HDC application. For example, a patient advocacy group such as the Kidney Foundation may request an annual report from HDC on the prevalence of chronic kidney disease across the province.
Service Provider	Companies that perform services on HDC's behalf and for HDC's purposes and not their own. For example, service providers may be retained through a contractual agreement to assist HDC in a breach investigation.
HDC Partner	HDC Partner organizations include, but are not limited to, General Practice Services Committee (GPSC), Practice Support Program (PSP), Shared Care Committee or Divisions of Family Practice, the UBC Faculty of Medicine Continuing Professional Development, Northern Quality Improvement Collaborative, and other organizations that support healthcare providers in quality improvement.
Personal Information (PI)	Personal Information (PI) has the meaning given in the <i>Personal Information Protection Act</i> (BC). It means information about an identifiable individual, which includes employee personal information except for contact information or work product information.
Personal Health Information (PHI)	Personal Health Information (PHI) has the meaning given in the <i>E-Health Act</i> (BC). It means recorded information about an identifiable individual that is related to the individual's health or the provision of health services to the individual.

Research Ethics Board (REB)	An REB “Is a multi-disciplinary and independent local board established within a particular institution that is responsible for reviewing the ethical standards of research projects within their institutions that involves human subjects.... This board is mandated to approve, reject, propose modifications to, or terminate any proposed or ongoing research involving human subjects that is conducted within, or by members of, the institution, using the considerations set forth in the TCPS as the minimum standard. (Tri-Council Policy Statement”. (TCPS2, Chapter 6; http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter6-chapitre6/)
Consent	The concept of consent is related to the right to privacy. Privacy is respected if an individual has an opportunity to exercise control over personal information by consenting to, or withholding consent for, the collection, use and/or disclosure of information. ²
Confidentiality	The ethical duty of confidentiality refers to the obligation of an individual or organization to safeguard entrusted information. The ethical duty of confidentiality includes obligations to protect information from unauthorized access, use, disclosure, modification, loss or theft.
Secondary Use	The use of personal information or HDC Data for purposes secondary to those for which the information was originally collected.
HDC Data	Derived from Contributor Data, this aggregated health data is sent to the HDC central server and is available for viewing through the HDC application by authorized HDC Users.
Contributor Data	Identified patient level data that HDC is authorized to transfer from contributing users’ EMR systems. Contributor Data is stored in an encrypted state in the universal schema of the HDC endpoint located within the practice or at an HDC managed data centre.
HDC Partner Agreement	Is an agreement between HDC and an HDC Partner that binds the Partner to a set of terms and conditions for their use of HDC Data within the HDC application software.
HDC Measure	A measure that is generated by an HDC Clinical Data Stewardship Committee approved clinical query. HDC measures are used to generate aggregate data (HDC Data) that is viewed in the HDC application software.
HDC Channel	An HDC Channel is a feature in the HDC application software that allows for groups of measures to be subscribed to under a single data sharing agreement by end users. Users control and maintain their subscriptions to channels.
HDC Base Channel	HDC Base is a channel containing all measures that have been approved

² http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf (page 58, Chapter 5 – Privacy and Confidentiality)

by the Clinical Data Stewardship Committee. All registered data contributor users are automatically subscribed to the HDC Base Channel upon execution of registration and data sharing agreements with HDC.

System Groups

The segmentation of HDC Data based on geographic areas such as Province, Health Authority, Health Service Delivery Area (HSDA), Local Health Area (LHA) System groups are used as sources of comparative data by users in the system. Data contributing users are automatically added to system groups based on the Division of Family Practice they self-select when they complete their HDC registration. As a security control, some user types are limited to viewing only select system groups.

6.0 POLICY DESCRIPTION

HDC only uses patient health information (Contributor Data) that is shared by healthcare providers with HDC for the purposes identified in the data sharing agreement, to create aggregate HDC Data, which is anonymized for patient identities. This HDC Data is used and disclosed through the HDC web application. Contributor data is never shared or disclosed without HDC gaining additional consent from healthcare providers.

This policy describes mechanisms that control and limit the collection, use and disclosure of Contributor Data and HDC Data by the HDC.

6.1 Purposes for Use and Disclosure of HDC Data

6.1.1 HDC Data is intended to be used to support a culture of continuous learning in primary care using a data driven, quality improvement approach, in order to:

- a) Facilitate better patient health outcomes;
- b) Improve the effectiveness of health service delivery;
- c) Identify areas where cost efficiencies can be achieved,
- d) Support population health analysis at a community, regional and provincial level; and
- e) Support ethics-approved clinical research projects.

6.1.2 HDC's provision of data is to support:

- a) Professionalism and confidentiality for healthcare providers and their patients, who are contributing data;
- b) Use of data for purposes that are clinically relevant and meaningful; and
- c) Informed quality improvement at an individual, clinic, group and system level.

6.1.3 Explicit consent from clinical data contributors is required for any new use that is not included in the list above in section 6.1.1. Depending on the nature of the requested use, additional provider and/or patient consent may also be required.

6.2 Use of HDC Data for Quality Improvement

HDC intent is that the use of HDC Data for quality improvement is aligned with guidelines for the use of health data from the Doctors of BC.³

6.2.1 For clarity:

- a) HDC uses patient data for the purpose of creating aggregate health information (HDC Data) which are data derived from approved queries against each provider's patient data.
- b) This aggregate data does not reveal patient identity and controls are in place within our application to limit access to data where a denominator is less than 5 as well as in selection of measures where there is a re-identification risk due to rare conditions or sparse populations.
- c) HDC facilitates sharing views of this aggregate data with approved HDC Users via the HDC web application.
- d) Different types of users see different levels of aggregate data as documented in HDC's access control procedures.
- e) Data contributors control who sees aggregate data related to their own practice and clinic leads or clinic admins (delegated by clinic lead) control who sees aggregate data for the clinic.
- f) Viewing of system group aggregate data is dependent on the type of measure – system groups for population measures are viewable by all HDC Users, while more sensitive measures have additional controls that require permission from HDC for viewing by HDC Partner Users.

6.2.2 The viewing of HDC Data, aggregate health data, within the HDC application to support quality improvement is considered "secondary use" of personal health data. HDC uses personal health information for a new purpose other than that for which was it was originally collected. HDC takes active steps and implements safeguards to comply with secondary use of personal health information for research and statistical purposes under BC's privacy legislation.⁴

6.2.3 Guidance from the College of Physicians and Surgeons of BC suggest that health services planning, maintenance or improvement are valid uses of EMR data by a physician.⁵ In this context, healthcare providers can disclose their patient's personal health information without consent to the HDC for purposes as described above in section 6.1. HDC uses a patient's personal health information only to create HDC Data for viewing within the HDC Application.

6.2.4 HDC provides notification to clinics about its use of personal health information from their patients and provides an option for Clinical Data Contributors to allow individuals to opt-out of the collection of data by HDC.⁶

6.3 Use of HDC Data for Research

6.3.1 The process for granting access to HDC Data for research will follow applicable legislation and professional guidelines.

³ <https://www.doctorsofbc.ca/resource-centre/physicians/managing-practice/privacy-toolkit>

⁴ From BC PIPA [http://www.bclaws.ca/Recon/document/ID/freeside/00_03063_01#section18] and Section 22 Disclosure for Research or Statistical purposes

⁵ CPSBC Appendix B Frequently Asked Questions. PSG-Data Stewardship FAQ Appendix B.pdf

⁶ http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_03063_01#section8 Section 8 (Implied Consent) AND http://www.bclaws.ca/civix/document/id/complete/statreg/96165_03 Section 33.1 (s), 34, 35.

6.3.2 Researchers requesting access to HDC Data must show documented Research Ethics Board (REB) approval. Depending on the context and objectives of the research project, individual patient consent may be required from patients participating in the research study.

6.3.3 At this time, HDC limits requests for use of HDC Data for the purposes as outlined above. HDC will begin to invite requests from researchers once statistically significant amounts of data are flowing and organizational capacity permits.

6.4 Disclosure of Personal Information (provider or other stakeholder)

6.4.1 HDC will not disclose patient personal information. The only time HDC will disclose provider or other stakeholder's personal information to other organizations is:

- a) When third party organizations work jointly on initiatives that require certain pieces of information to be shared to fulfill the third party organization's function such as the distribution of newsletters or other HDC communications; or
- b) If a service provider is contracted to perform services on our behalf such as notification to an EMR vendor that execution of clinic registration and data sharing agreements has been completed and data transfers to HDC can proceed; or
- c) As is required by law.

6.4.2 In the instance where a third-party organization does require a disclosure of clinician personal information, they will sign a confidentiality agreement that legally obligates them to strictly adhere to HDC privacy policies and procedures regarding personal information.

6.4.3 The HDC will conduct periodic reviews on HDC's personal information holdings to ensure that they are only being used and disclosed in accordance with the purpose under which they were collected and to ensure that they are destroyed in accordance with HDC retention schedules.

6.5 HDC Users

HDC Users are approved and authenticated end-users of the HDC application, who have entered into a registration agreement that licenses them to use this software, to gain access to view HDC Data.

6.5.1 Clinic Data and Clinical Data Contributors

- a) HDC enters into data sharing agreements with the Most Responsible Provider (MRP)⁷ designated for a clinic practice and subsequently with individual healthcare providers working within the clinic practice. The former data sharing agreement provides HDC with Contributor Data for all patients rostered with the clinic. The latter agreement provides HDC with patient data for only an individual health provider where they have been identified as the MRP. The purpose of collecting the clinic level Contributor data is to ensure HDC can provide population-level data that includes patients who may not have a direct and continuous relationship with a single individual health provider.
- b) An approved HDC Clinical Data Contributor (MRP for the clinic or designate) may authorize a clinic staff person, such as a medical office assistant (MOA) or a Clinic Manager working on behalf of an approved MRP for the clinic, to act in a clinical administrative role. The clinic administrator may then act on behalf of the MRP for the clinic and authorize the registration of additional clinical data contributors or clinical support staff members within the clinic.

⁷ <https://www.cpsbc.ca/files/pdf/PSG-Data-Stewardship-Framework-v2-4.pdf> Page 21 Data Stewardship Policies & Guidelines

- c) Once registration is verified, the clinician data contributor is auto-subscribed to the HDC Base channel, entering into a data sharing agreement with the HDC. The terms and conditions of registration and data sharing are defined in the respective agreements presented to the user during the registration process.
- d) Data contributed is automatically included in the creation of system groups that are high level groups of aggregate data. These system groups are largely geographical and provide a source of data that HDC Users can use to compare to their own individual and clinic aggregate data. All HDC Users have access to view system level HDC Data for measures in a particular channel.
- e) An HDC approved clinician who contributes data collected during their work to HDC, controls the access to their HDC Data and may share views of their HDC data with other users using features built into the HDC application. An individual Clinical Data Contributor must explicitly share a view of their own individual or clinic's data with another Clinical Data Contributor to access HDC data at the individual or clinic level. This invitation to share, once accepted, can be declined at any time by either Clinical Data Contributor or their delegated clinic administrator. Control of access to clinic or individual data resides with the Clinical Data Contributor.

6.5.2 Clinical Support Staff Users

- a) A Clinical Support Staff User is an HDC approved user who may view HDC data using the HDC application, but does not contribute any data.
- b) An approved clinical support staff user will gain access to HDC Data by means of a registration process such as that described above for a clinical data contributor but will not enter into a data sharing agreement with HDC. Instead of a data sharing agreement, clinic support staff users will undertake privacy awareness training and must acknowledge a standard code of conduct as part of the registration process.
- c) Once registered to use the HDC application, clinical support staff can request viewing permissions from clinical data contributors through the sharing process within the HDC application.

6.5.3 HDC Partner Users

- a) HDC supports quality improvement in primary care for groups and communities working at system-level quality improvement and aligned to the purposes described in 6.1.1. Access to HDC Data through the HDC application will be available for approved HDC Partners.
- b) An approved HDC Partner will enter into a Partner Agreement that defines the terms and conditions of use of the HDC application for prospective HDC Partner Users. Access to HDC Data for HDC Partner Users is limited to views of system groups for measures that are deemed to be appropriate to share broadly by the HDC Clinical Data Stewardship committee.
- c) As part of the Registration process, each HDC User will be presented with privacy awareness training and must acknowledge a standard code of conduct. This training outlines the privacy and security obligations that are required for use of the HDC application, ensuring the importance of the HDC's trusted relationship with Clinician Data Contributors is understood and accepted.
- d) Individual clinical data contributors can arrange to share views of their data explicitly with HDC Partner Users through the sharing process within the HDC application. HDC Partner Users can request permission for viewing system level aggregate data for the more sensitive types of measures as determined by the Clinical Data Stewardship Committee.

6.5 Principles Guiding the HDC Response to Requests for Use and Disclosure of HDC Data

This section applies to requests, made by a registered HDC User, HDC Personal, HDC Partner or third-party individual or organization, to use HDC for permitted purposes as previously described. HDC

expressly forbids the use of HDC Data for anything other than permitted purposes as described in section 6.1.

6.5.1 Healthcare providers act as guardians of a body of specialized evidence-based knowledge and act in the best interests of patients and society. In return, they are granted a special role, autonomy and the right to self-regulation.⁸ HDC works with participating health providers to protect provider and patient privacy, and help to preserve professional autonomy and independence in the work we do.

6.5.2 HDC recognizes the responsibility of healthcare providers to support the planning, management and quality improvement inherent in the health system in which they practice.⁹ HDC will provide clear, appropriate and controlled access to HDC partners and third-party stakeholders for data shared with HDC by data contributing users for use in quality improvement at the group and system levels.

6.5.3 HDC limits creation of HDC Data and access to HDC Data in the following areas:

- a) An approval process for adding new data elements to the universal schema to ensure that data collected from providers remains relevant to the intended purpose;
- b) An approval process for the creation of new HDC Data (via queries against the endpoints); and
- c) Controls present in the application that limit the views of HDC Data for different types of measures and for different types of users; this allows data contributing users to have granular and explicit control of who views HDC Data derived from their own patient panels or from those of their clinic as a whole, from within the HDC application.

6.5.4 Precedence will be given to data requests from our HDC members and registered HDC users and to those requests that seek to provide value to patients, the broader primary care community and the health system that supports both.

6.5.5 In responding to request for access to HDC Data, HDC will apply the following requirements.

- a) HDC's goal is to make available accurate data within its control in a timely manner to parties throughout the health sector for legitimate quality improvement purposes.
- b) Cost recovery for the expense of preparing and delivering access to HDC Data will be passed on to the data requestor, with the estimated fee provided in writing, in advance of providing access.
- c) HDC will not provide aggregate (clinic-level or levels above) data where the number of responses falls below 5 ($n < 5$) where there is a reasonable risk of identifying an individual and will review other aggregate data requests for any privacy risk to the providers on a project by project basis.
- d) HDC constrains denominators for clinical measures to levels that make it difficult or virtually impossible to reverse engineer patient identity through cell size controls, access and display controls and selection of measures where rare conditions in sparsely populated areas may create small denominators.
- e) The HDC Partner or third-party requestor may be required to provide assurance that best practices in privacy and security are applied to the management of personal health information (PHI) and may be required to enter into legally binding agreements to ensure this.
- f) Requests for access to HDC Data will be adjudicated through a data stewardship process approved by the HDC Board.

⁸ BCMA Policy Paper on Exploration of Physician Professionalism September 2013.

⁹ From College of Physicians and Surgeons of BC (<https://www.cpsbc.ca/files/pdf/PSG-Data-Stewardship-Framework-v2-4.pdf>)

6.6 Guidelines for Requesting Access to the HDC Data

This section applies to any individual or entity requesting access to HDC Data outside of the HDC application.

6.6.1 This section also applies to HDC Clinical Data Contributors requesting access to HDC Data collected from other HDC Data Contributors as well as other HDC Partners' or Third Party sponsored quality improvement or research projects for access to aggregate HDC Data.

6.6.2 HDC reserves the right to conduct evaluations of requests in such circumstances as it considers necessary. Review of data requests will consider:

- a) Whether the proposed project will duplicate other projects in progress using HDC Data;
- b) If the request is consistent with the HDC mandate and business objectives;
- c) If the project or research study, where applicable, has been peer reviewed or otherwise demonstrates reasonable scientific merit and the HDC has the capacity to support research applications;
- d) If it is feasible for HDC to provide the data requested under current operating conditions; and
- e) The quality of data available and/or the amount of additional data required to complete the request, the congruence of the proposed data elements as compared the HDC Contributor Data available.

7.0 BREACH OF THIS POLICY

Violations of this policy may result in the loss of data access privileges.

HDC Clinical Data Contributors, clinic support staff and other users, HDC Partners and third parties approved for access or disclosure to HDC Data are responsible for ensuring that their employees, consultants and contractors employed within their sites are familiar with and adhere to this policy.

8.0 APPEALS PROCESS

In cases where requests for access or disclosure of HDC Data are denied, or restrictions are placed on the data elements requested, HDC will explain the rationale and provide a means for appealing a decision.

9.0 AWARENESS

HDC will provide guidelines and training for employees, consultants, contractors and members of the organization and other HDC Staff as appropriate to ensure compliance with this policy.