

Data Sharing Agreement

This Data Sharing Agreement (DSA) takes effect when the last party signs this document.

BY AND BETWEEN:

Health Data Coalition (HDC)

- and -

("Clinical Data Contributor")

(Each of HDC and Clinical Data Contributor is a "Party" to this Agreement, and are collectively referred to as the "Parties").

- A. The Health Data Coalition (HDC) is a federal, not-for-profit organization, incorporated under the *Canada Corporations Act, Part II*, with a vision to provide trusted and meaningful access to health information that supports contributors and partners in the improvement and sustainability of health care;
- B. HDC's mission is to build and operate a physician-driven, distributed data network with the potential to achieve the following:
 - a. A set of tools for aggregating data from across different electronic medical record (EMR) systems
 - b. Provide data to drive and evaluate stakeholder initiatives and measure collective competence
 - c. Enable clinical quality improvement activities and continuing medical education (CME) reflective practice
 - d. Answer clinical and research questions of interest to frontline practicing primary care clinicians.
 - e. Answer population health questions to assist with health system management and improve patient care;
- C. To this end, HDC will develop, implement, and maintain a centrally hosted, web-based application to enable participating Clinical Data Contributors to collaborate and use aggregated Electronic Medical Record ("EMR") patient data (referred to as "HDC Data");

- D.** HDC will provide endpoint software and hardware to be used within physician offices or within HDC managed data centres, where a sub-set of EMR data (referred to as “Contributor Data”) will be stored and made available to the HDC central server for purposes of creating aggregate HDC data. This Contributor Data under the custody and stewardship of HDC and managed by the endpoint software will be hosted in a private and secure environment as outlined in this DSA and according to HDC’s Information Security Policy, HDC Data Access Policy and other security standards procedures.
- E.** The HDC application will be a single solution deployed in three phases, as follows:
- a. Phase 1: Approved Clinical Data Contributors (e.g. physicians, nurse practitioners or authorized clinic owners) who collect EMR data and provide HDC a sub-set of this EMR data to populate HDC’s clinic endpoints (“Contributor Data”) will have this data aggregated by HDC software, where it is securely transmitted to the HDC central server, located in Canada. The anonymized, aggregated data (“HDC Data”) can be viewed by other registered Users, given permissions have been granted for sharing by Clinical Data Contributors, via the application data sharing features;
 - b. Phase 2: Approved Support Staff Users (e.g. clinic managers, medical office assistants, coaches) will view HDC Data through the HDC application whereby Clinical Data Contributors can use features in the HDC application to provide explicit permission to share their own HDC Data for viewing within the HDC application for other HDC Users.
 - c. Phase 3: Approved HDC Partner Users will view a limited sub-set of HDC Data through the HDC application whereby Clinical Data Contributors using features in the HDC application can provide explicit permission to share their own HDC Data or their own clinic’s HDC Data, with these HDC Partner Users for viewing within the HDC application.
- F.** HDC’s application will facilitate HDC’s mission by allowing data sharing among Clinical Data Contributors, and other registered HDC Users through features that manage permissions for sharing between users, for viewing pre-defined reports, using custom report creation and features that allow for creating groups and viewing group HDC data for comparison purposes, and other features that support the Quality Improvement needs of HDC Users. HDC provides opportunities to participate in sponsored channels that provide a means for clinical data contributors to explicitly consent to share data for new approved purposes or uses.
- G.** The Parties acknowledge and agree that it is not the intention of either Party to share patient personal information or personal health information in identifying form via the HDC application, and HDC will use all reasonable efforts to ensure no such information is submitted to the HDC central server;
- H.** To clarify further, HDC’s application will not use or share any personal health information, and HDC will assess the impact of HDC’s national database operations on individual privacy if any research project or Quality Improvement project creates a risk of re-identification or involves the use of identifying personal health information to create linkages with other data sources or other data access requests for disclosure of record level patient data;

- I. Clinical Data Contributors agree to enter into this Data Sharing Agreement (“DSA”) as a condition of participation and use of the HDC application to further HDC’s mission. This DSA sets out the respective roles and responsibilities of each Clinical Data Contributor for the protection of HDC Data and to establish an accountability framework for data sharing between users and the HDC. This DSA is not intended to supersede or alter any existing legal obligations and/or accountabilities applicable at Clinician Data Contributors’ organizations.

**SECTION 1
DEFINITIONS AND INTERPRETATION**

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| 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 contributing users include: physicians, nurse practitioners and other medically responsible providers 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. |
| Service Provider | Companies or individuals 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. |
| Partner | Partner organizations include, but are not limited to, General Practice Services Committee (GPSC), Practice Support Program (PSP), Shared Care |

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| | Committee or Divisions of Family Practice., organizations that support healthcare providers in quality improvement work. |
| 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. |
| HDC Data | Derived from Contributor Data, this fully aggregated and anonymized 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 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 | Refers to 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. |
| Clinical Data Stewardship Committee | An HDC board committee whose goal is ensuring a meaningful approach to measurement, assuring that the HDC system and the aggregate data collected and managed is being utilized in a manner consistent with the intended and communicated purpose. The Clinical Data Stewardship committee membership stipulates that a majority number must be physicians. |
| 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. A channel can be used as a mechanism to disclose HDC Data to approved HDC Partners who enter into data sharing agreements with HDC Users. |

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| HDC Base Channel | HDC Base is a channel containing all measures that have been approved 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 | Refer to 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. |
| Governing Law. | This Agreement, and the rights, obligations and relations of the Parties hereto, is governed by, and construed in accordance with, the laws of the Province of British Columbia and the federal laws applicable therein. The Parties irrevocably and unconditionally submit to the non-exclusive jurisdiction of the courts of the Province of British Columbia and all courts competent to hear appeals from them |

SECTION 2 TERM

- 2.1 This DSA takes effect from the date it is signed by the Clinical Data Contributor User, and remains in force until terminated in accordance with Section 6, referred to as the “Term.”
- 2.2 The Term of this DSA may be extended or reduced in writing through mutual agreement by the Parties to this DSA.

SECTION 3 RESPONSIBILITIES

The relationship between HDC and Clinical Data Contributors Users is based on mutually agreed upon responsibilities.

HDC agrees to:

- 3.1 Collect, store, monitor, and make available HDC Data in a timely and proficient manner, to support the sharing of data as part of its overall mandate.
- 3.2 Comply with applicable federal and provincial privacy legislation and corresponding regulations for the collection, use, disclosure, storage, transmission, disposal and destruction of HDC Data and Contributor Data.

- 3.3 Provide an effective privacy governance and committee structure for HDC to achieve its national mandate.
- 3.4 Grant approvals and delegate the appropriate permissions to applicable Clinical Data Contributors, other Users requesting access to HDC data through a manual authorization and authentication process, as described in the HDC Data Access Policy and Data Use and Disclosure Policies and other related procedures.
- 3.5 Provide support to the Clinical Data Contributors, and other Users accessing HDC Data, in the form of:
 - a) Contact information and liaison with key HDC staff, including a privacy contact person such as the HDC Privacy Officer;
 - b) Information for Clinical Data Contributors on proper procedures for adding and sharing data, to enable the proficient use of HDC application and to ensure data quality; and
 - c) Privacy documentation and information regarding the policies and procedures developed for HDC on the use, protection, retention, transmittal, disposal and destruction of hard copy or electronic data and the disciplinary consequences of not adhering to these requirements.

Clinical Data Contributors Users agree to:

- 3.6 Support the vision, mission, values and national mandate of HDC;
- 3.7 Use reasonable efforts to ensure that no personal information is included in data submitted to HDC, other than the User's own registration information and the personal health information contained in the Contributor Data which is encrypted and secured at the endpoint
- 3.8 Ensure that all Clinical Data Contributors and their personnel, treat confidential information, including Contributor Data and HDC Data, as secret and confidential, refrain from copying or disclosing it to any person without prior written consent of HDC, and maintain it in secure custody;
- 3.9 Identify and report all technical issues relating to HDC application software to HDC's technical support staff in a timely fashion to ensure coordinated efforts between appropriate technical experts and users as necessary to decide the most efficient and timely course of action to take;
- 3.10 Comply, and ensure that their personnel comply, with all applicable federal or provincial privacy legislation and corresponding regulations in addition to all applicable HDC policies, including the Privacy Policy, the Data Use and Disclosure Policy, the Privacy Breach Management Protocol, and section 4.3 of this DSA regarding the collection, use, protection, storage, transmission, retention, disposal, destruction, and privacy breach incident handling in respect of HDC Data and Contributor Data;
- 3.11 Ensure that all research projects using HDC Data have the appropriate REB approval, if necessary, in accordance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* prepared by the Canadian Institutes for Health Research; and
- 3.12 Support the HDC mandate by referencing HDC in publications where research uses HDC Data.

SECTION 4 CONFIDENTIALITY AND PRIVACY

- 4.1 **Acknowledgements:** The Parties to this DSA acknowledge that they are subject to applicable privacy laws and associated regulations when dealing with Contributor Data and HDC Data in connection with HDC. Each Party will at all times comply strictly with this DSA in such a manner that its acts or omissions do not result in any Party to this DSA being in violation of the applicable privacy laws and regulations, in addition to the general privacy requirements set forth in section 4.3 below.
- 4.2 **Privacy Contact Person:** HDC will identify the privacy contact person responsible for managing the relationship and interaction between HDC and each Clinical Data Contributor User, such as the HDC Privacy Officer.
- 4.3 **General Privacy Requirements:** HDC will take reasonable steps to protect HDC Data, Contributor Data and confidential registration data submitted to it against loss, theft, and unauthorized access, use, disclosure, copying, modification, disposal or destruction in accordance with applicable federal or provincial privacy laws and regulations. HDC will also follow HDC policies and procedures related to how HDC will retain, protect, transmit, store, dispose, destroy and handle privacy breaches involving HDC Data and Contributor Data. HDC, Clinical Data Contributors Users will act in accordance with the Privacy Policy, Data Use and Disclosure Policy, and Privacy Breach Management Protocol with respect to HDC Data and Contributor Data.
- 4.4 **Use and Disclosure of HDC Data:** HDC, and registered Users, will use HDC Data solely for their respective permitted purposes under the Data Use and Disclosure Policy, and will not disclose HDC Data to any affiliated or unaffiliated third party without the approval of HDC, except as required by law.
- 4.5 **Access Control:** HDC will implement and monitor access and authentication, as indicated in the Access Control Policy.
- 4.6 **Confidentiality:** HDC, Clinical Data Contributor Users will treat as secret and confidential, and maintain secure custody of, all confidential information disclosed to it, including HDC Data, Contributor Data and confidential registration data.
- 4.7 **Safeguards:** HDC will implement adequate and current physical, administrative and technical safeguards for the protection of HDC Data, as more particularly described in HDC policies. This includes, but is not limited to, strong authentication and access controls such as encryption, firewalls, passwords, and restricted access protocols.
- 4.8 **Inquiries and Complaints:** Clinical Data Contributor Users will promptly report in writing to and cooperate with HDC if there is any inquiry, complaint or investigation with respect to HDC Data and including, without limitation, by a patient or clinical provider whose information may form part of HDC Data.

- 4.9 **Privacy Breach Notification Requirement:** All Parties must comply with the HDC Privacy Breach Management Policy and procedures and cooperate with the HDC Privacy Officer in the event of a possible or actual breach. Clinical Data Contributor Users must immediately notify HDC in writing in the event that HDC Data is lost, stolen, accessed, used, disclosed, copied, modified or disposed of by unauthorized persons or in an unauthorized manner or both. Each Party to this DSA agrees to work in consultation with one another and in liaison with its respective Privacy Contact Person to remedy the breach and in accordance with the Privacy Breach Management Policy established for HDC. The relevant privacy legislation should be consulted for any mandatory breach notification requirements to affected individuals and/or the Privacy Commissioner of British Columbia.

SECTION 5 PUBLICATIONS

- 5.1 **Publications:** Unless directed otherwise, HDC must be acknowledged in any publication or presentation using HDC data, and the following disclaimer must appear on any materials developed for public distribution with data used under this DSA: "The views expressed herein do not necessarily represent the views of HDC."

SECTION 6 TERMINATION

- 6.1 HDC and each Party to this DSA may terminate participation in this DSA by providing written notice to one another causing such termination sixty (60) days thereafter. Where either Party breaches a material provision of this DSA and such breach cannot be remedied, either party may terminate this DSA immediately by notice in writing.
- 6.2 Upon the termination of this DSA, HDC will cease the ongoing collection of data covered by this DSA. In the event that this DSA is terminated by a Clinical Data Contributor, Contributor Data will no longer be collected from the terminating Clinical Data Contributor User.
- 6.3 Any rights and causes of action arising out of the act(s) or omission(s) occurring prior to the date of completion or termination of this DSA will survive any termination.
- 6.4 Where HDC is required by law to destroy HDC Data, it will do so in a secure manner to the point that it cannot be reconstructed and keep a record of the individual whose information was destroyed, if applicable, including the time period, method of destruction and the person responsible for supervising the destruction. HDC will provide written confirmation of same upon request of the Clinical Data Contributor that supplied data to HDC.

SECTION 7 AMENDMENT

- 7.1 This DSA can be amended in writing subject to the approval of HDC and the Parties therein. Amendments are only valid if signed by or on behalf of each Party to this DSA.

SECTION 8 NOTICES

- 8.1 A notice, request, demand or communication under or in connection with this DSA must be in writing and must be delivered in person during normal business hours on a business day and left with the addressee or other responsible employee at the relevant address or sent by fax or other means of recorded electronic communication as follows:

To HDC:

HDC Privacy Officer
c/o 204-1009 Cook Street
Victoria, BC
V8V 3Z6

To the Parties:

Party Contact Information added here

SECTION 9 GENERAL PROVISIONS

- 9.1 This DSA constitute the entire data sharing agreement and all prior oral and/or written understandings by and between the Parties will be deemed to have been superseded by this DSA.
- 9.2 The Parties agree to use reasonable efforts to resolve among themselves any dispute arising out of this DSA. No Party hereby waives its/his/her legal rights.
- 9.3 No other right, license, patent or otherwise is granted to any Party hereto to use either the User's personal data or HDC Data or Contributor Data for any use or purpose other than as expressly provided therein.
- 9.4 HDC and its respective employees or agents will not be deemed to be acting as agent for or on behalf of any Party to this DSA. No Party to this DSA and its respective employees or agents will be deemed to be acting as agent for or on behalf of HDC.
- 9.5 Any new Party wishing to participate in HDC and gain access to HDC Data or Contributor Data through the HDC application or via other means must enter into this DSA, or alternatively, a substantially similar agreement to this DSA.