Data and Research Access Terms and Conditions

June 2023

These Terms and Conditions govern access by a principal investigator to data, patients/clients/residents/staff and/or facilities belonging to Northern Health Authority ("NH") the ("Health Organization"), for the purpose of conducting research as described in an approved Research Ethics Board application (the "Research Project").

Upon receiving approval by the Health Organization to conduct research, the principal investigator agrees to be bound by these Terms and Conditions and understands and agrees that these Terms and Conditions will apply to the principal investigator for each and every subsequent approved Research Project.

For clarity, the principal investigator will be referred to in these Terms and Conditions as "you" and "your" as the context requires.

1.0 DEFINITIONS

"**Authorized Person**" is a member of the principal investigator's research team who will be accessing Health Organization Data containing Personal Information, who has signed a Confidentiality Undertaking and is named in the approved Research Ethics Board application.

"**Confidentiality Undertaking**" means the "NH Confidentiality Undertaking for Research" (available online through the PHSA Learning Hub).

"**Data**" means Data in the custody and control of the Health Organization, which may include Personal Information.

"**De-identified Data**" means Data that has been modified so that the identity of the individual or group cannot be determined by a reasonably foreseeable method. De-identification methods include removing personal identifiers (e.g., names and personal health numbers); providing age groups instead of date of birth; and providing the fiscal period of admission instead of admission date. While the data may undergo de-identification methods, it may include preserving identifying information which could only be re-linked by a trusted party in certain situations.

"**FIPPA**" means the *Freedom of Information and Protection of Privacy Act* (British Columbia), and regulations thereto, as amended from time to time.

"**Personal Identifiers**" means any recorded information that could, either by itself or in combination with other information, be used to link or associate Personal Information to a particular individual (including but not limited to name, birth date, photograph, Personal Health Number (PHN), Medical Records Number (MRN), home address, postal code, personal telephone number, social insurance number (SIN), driver's license number, employee ID and other identity numbers).

"**Personal Information**" means any recorded information about an identifiable individual (including but not limited to name, PHN, MRN, age, race, home address, personal telephone number, employee ID and other identity numbers).

"**Research Ethics Board**" means a committee recognized by the Health Organization that is composed in accordance with the TCPS-2 and that is responsible for assuring the Research Project meets current ethical, regulatory, and scientific standards for the protection of human research participants.

"**TCPS-2**" means the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri- Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010.

"**Terms and Conditions**" means the requirements stated in this document and any additional requirements or terms and conditions included by reference.

2.0 CORE RESEARCH PRINCIPLES

2.1 You acknowledge that your primary responsibility as a principal investigator is to safeguard the rights and welfare of each research participant involved in the Research Project.

2.2 You recognize that research participants include, as applicable, persons directly involved in the Research Project such as a participant in a clinical trial, as well as persons whose data or human biological materials are used to conduct research.

2.3 You shall conduct the Research Project in accordance with the research principles set out in the TCPS-2 and comply with any other relevant federal or provincial laws or guidelines for the protection of human research participants.

3.0 ACCESS, USE, DISCLOSURE, RETENTION AND DESTRUCTION OF DATA

Health Organization Data is subject to FIPPA. You are responsible for complying with FIPPA by accessing, using, retaining, and destroying Data in accordance with the following terms:

3.1 You shall ensure that Data will only be used in connection with the Research Project as described in the approved Research Ethics Board application, and for no other purpose, unless as approved by the Health Organization.

3.2 You shall agree to take reasonable security precautions to protect any Data against unauthorized collection, access, use, disclosure, or disposal.

3.3 You are responsible for ensuring that every member of your research team completes a Confidentiality Undertaking and Privacy Training for NH Researchers (Learning Hub),

including new research team members not listed on the original Research Ethics Board application, and you shall inform the relevant research institutes and Research Ethics Boards about changes to your research team for the duration of the Research Project.

3.4 You shall ensure Data will only be disclosed as outlined in the approved Research Ethics Board application, except as otherwise authorized by law or as approved by the Health Organization.

3.5 You shall ensure that no Data containing Personal Information is accessed from or stored outside of Canada, except as authorized by FIPPA and the Health Organization.

3.6 You shall remove all Personal Identifiers within the Data at the earliest possible time unless the individual the information is about has provided written consent to remain identifiable.

3.7 You shall limit access to Personal Identifiers to only those of the Authorized Persons whose role in the Research Project requires access to those Personal Identifiers.

3.8 Where De-identified Data has been provided to you, you shall not use the Data to re-identify any patients/clients/residents/staff, except as approved by the Health Organization.

3.9 You shall not use the Data to contact the individuals to whom the Data is about in order to participate in any research, including research related to the Research Project, unless the individuals have provided consent, or the Health Organization has provided approval.

3.10 You agree to destroy the Data as specified in the approved Research Ethics Board application, subject to any applicable data retention policies or laws or written approval from the Health Organization to do otherwise. If requested by the Health Organization, you shall provide a written statement, in a form satisfactory to the Health Organization, which confirms the details of the destruction or return of the Data.

3.11 You acknowledge that as between the Health Organization and you, the Data remains at all times the property of and within the control of that Health Organization, unless that Health Organization agrees otherwise under a separate contract or agreement.

3.12 If a request is made to you for access to Data, for example by law enforcement, court order or subpoena, you shall not respond to the request. You shall immediately advise the Health Organization Information Privacy Office of the request and you will collaborate and assist the Information Privacy Office in responding to the request.

3.13 You shall ensure that Data is utilized, transferred, or stored in accordance with the approved Research Ethics Board application and any other terms imposed by the Health Organization.

4.0 DATA SECURITY AND PROTECTION OF PRIVACY

4.1 You shall be responsible for the confidentiality and security of the Data while it is in your or your research team's custody, and you will use reasonable measures to maintain the confidentiality and security of the Data against such risks as unauthorized collection, access, use, modification of use, disclosure, or disposal.

4.2 Where the research activity will be conducted on Health Organization premises or using Health Organization information technology or systems, you shall comply with these Terms and Conditions, the Confidentiality Undertaking, applicable systems terms of use, and any Health Organization policies.

4.3 You are required to immediately notify the Health Organization Information Privacy Office, as outlined in Section 7 of this agreement, and provide a detailed written report of the circumstances of any unauthorized collection, access, use, disclosure or modification of the Data, or breach of confidentiality or security breach of a computer or network (the "Breach") and any remedial actions taken.

4.4 In the case of a Breach, as defined above, if the Health Organization considers the remedial actions taken by you are not sufficient, the Health Organization may suspend the provision of Data to you or require the return or destruction of the relevant Data provided to you, in addition to other measures.

5.0 ACCURACY AND USE OF INFORMATION

5.1 The Data is provided on an "as is" and "as available" basis and the Health Organization makes no warranties or representations regarding the accuracy, completeness, reliability, or fitness for use of the Data.

5.2 The Health Organization assumes no liability for any losses or damages arising out of your use, misuse, or inability to use the Data.

6.0 PUBLICATIONS

6.1 If you intend to publish findings or reports based on research conducted using Data, you agree to only use De-identified Data in a publication, unless the individual the information is about has provided written consent.

6.2 You agree to acknowledge the contribution of the Health Organization in all reports or publications resulting from your use of the Data and, where required, to provide to the Health Organization a copy of such reports or publications.

7.0 GENERAL

7.1 You agree to explain the requirements described herein to all members of your research team.

7.2 You acknowledge and agree that your obligation to maintain the privacy, security and confidentiality of the Data provided to you will survive these Terms and Conditions.

7.3 You acknowledge and understand that you are responsible for your conduct and that of your research team while performing research using Data or at a Health Organization facility, and that you may be legally liable for harms or expenses caused by you or your research team's negligence, omissions, or failure to comply with these Terms and Conditions.

7.4 You will immediately notify the Health Organization Information Privacy Office, as identified in Section 8, of any non-compliance with these Terms and Conditions.

8.0 HEALTH ORGANIZATION CONTACT INFORMATION

Northern Health Information Privacy Office

Email: privacy@northernhealth.ca