

## DATA ACCESS AND USE TERMS

### **1. DESCRIPTION**

- 1.1. These Terms of Use set out the responsibilities that apply to a Recipient who wishes to access and use Data for the purposes of conducting research or statistical activities, whether such activities are approved by a REB, or exempted from REB approval due to the activity being a Project.
- 1.2. As PHSA is subject to FIPPA, the law that governs the collection, use, disclosure and protection of Personal Information, in the custody or under the control of PHSA, Data may only be shared in compliance with FIPPA.
- 1.3. The Terms of Use apply to a Recipient in all circumstances whether or not an Affected Individual has consented to a Project and, with some exclusions, to Recipients who access and use De-identified Data in the custody or control of PHSA for a Project.
- 1.4. A Recipient who wishes to use Data or De-identified Data as outlined herein, agrees to be bound by and to comply with these Terms of Use.

### **2. DEFINITIONS**

- 2.1. In these Terms of Use, the defined terms have the meaning set out in this section:

**“Affected Individual”** means an individual to whom the Data relates;

**“Breach”** means unauthorized access, use, disclosure, or loss or theft, of all or any portion of the Data;

**“Data”** means Personal Information about patients, clients, employees of PHSA and other individuals where such Personal Information is in the custody of control of PHSA;

**“Data Request Form”** means either PHSA’s standard data request form, a copy of which can be found at the following link: [to be determined], or the specific data request form required by the relevant program/Data steward;

**“De-Identified Data”** is Data that has been stripped of Direct Identifiers and Indirect Identifiers;

**“Direct Identifiers”** means information that identifies an individual without additional Information. (Examples of direct identifiers

include an individual's name, personal contact information, personal health number or other unique identifier such as social insurance number or date of birth);

**"FIPPA"** means the *Freedom of Information and Protection of Privacy Act* (British Columbia);

**"Identifiable Data"** is Data containing Direct Identifiers or Indirect Identifiers;

**"Indirect Identifiers"** means information which may identify an individual when it is connected or combined with other available information. (An example of an indirect identifier is date of hospital admission or procedure);

**"IAP"** means the Information Access Privacy Office responsible for compliance with privacy at PHSA;

**"OIPC"** means the Officer of the Information Privacy Commissioner for British Columbia, who is the regulator of FIPPA;

**"Personal Information"** means personal information as defined in FIPPA;

**"PHSA"** means both Provincial Health Services Authority and British Columbia Emergency Health Services;

**"Project"** means a quality assurance, quality improvement, program evaluation, health care planning or public health initiative;

**"Project Team"** means all other persons, in addition to the Recipient, who is authorized to work on a Project from time to time.

**"REB"** means a Research Ethics Board;

**"Recipient"** means a researcher or other party who wishes to access and use Data or De-Identified Data to conduct research or other activity whether approved by a REB or exempted from approval by a REB due to the activity being a Project;

**"Research Privacy Director"** means the Director, Privacy and Access, Research and New Initiatives at PHSA, or in their absence, the Privacy Advisor, focused on research, in Information Access Privacy at PHSA;

**"Terms of Use"** means these Data Access and Use Terms.

**“Tri-Council Policy”** means the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

2.2 In these Terms of Use, a reference to the singular includes a reference to the plural and vice versa.

### **3. DATA REQUEST FORM AND PHSA APPROVAL**

3.1. Recipients wishing to access and use Data for a Project must complete a Data Request Form and submit it to the relevant program/Data steward for consideration. The Recipient represents that the details in the Data Request Form are complete and accurate. The relevant program/Data steward may request additional details from the Recipient before considering the Data Request Form. No access to Data will be permitted until the relevant program/Data steward has approved the Data Request Form, such approval to be granted in the sole discretion of the relevant program/Data steward, and may include such conditions that the relevant program/Data steward considers appropriate. If direct access to a system(s) is requested by the Recipient in order to obtain the Data, the Recipient must sign and comply with all applicable access agreements relating to such system(s).

### **4. DATA USE, PROTECTION, DISCLOSURE AND DESTRUCTION**

4.1. The Recipient accepts responsibility for the collection, use, disclosure, storage and protection of the Data by the Recipient, as well as by the Project Team the Recipient is working with. Specifically, the Recipient must ensure compliance with the following:

4.1.1. The Data is accessed, used and disclosed by the Project Team only for the purposes of the Project as set out in the Data Request Form and is expressly prohibited for any other purpose.

4.1.2. The Project Team only accesses the Data on a need-to-know basis in connection with the Project Team member’s particular role or function with respect to the Project, and access to Direct Identifiers and Indirect Identifiers will be limited to those members of the Project Team that necessarily require such access for the Project.

4.1.3. The Project Team does not use the Data for the purposes of contacting individuals to participate in research except as authorized by PHSA, or where the

Affected Individual has provided prior written consent.

iv. If Identifiable Data is requested for a Project:

- 4.1.3.1. The Recipient represents that: (A) the Project cannot reasonably be accomplished unless such Identifiable Data is used or the Project has been approved by the OIPC pursuant to FIPPA; (B) any Data linking is not harmful to the Affected Individuals; and (C) the benefit to be derived from any Data linking is clearly in the public interest; and
  - 4.1.3.2. All Direct Identifiers and Indirect Identifiers are removed from the Data at the earliest possible time given the nature of the Project, unless the Affected Individuals have provided written consent that their information remains identifiable.
  - 4.1.4. The Project Team refrain from any attempt to re-identify an individual from De-Identified Data except as set out in the Data Request Form.
  - 4.1.5. If the Data is disclosed outside of Canada, the details of such disclosure are set out in the Data Request Form.
  - 4.1.6. Reasonable confidentiality, privacy and security precautions are taken by the Project Team in respect of the Data to protect against such risks as loss, theft, unauthorized access, modification, use, disclosure or disposal.
  - 4.1.7. If any information access request for the disclosure of Data is received from a third party, the Recipient will refer the party making the request to IAP for a response and will cooperate with PHSA in respect of any such request.
  - 4.1.8. The Data is securely destroyed when no longer needed or required to be maintained subject to applicable data retention policies, laws, and or REB approval(s), and the Recipient will comply with all direction of the relevant program/Data steward concerning such destruction of the Data.
- 4.2. If the Project is one to which the [Tri-Council Policy](#) applies, the Recipient will ensure that the use of the Data complies with the requirements of the Tri-Council Policy and all other conditions imposed by the applicable REB.

## **5. NO WARRANTIES OR LIABILITY**

5.1. The Data is provided on an “as is” and “as available” basis and PHSA makes no warranties or representations relating to the accuracy, completeness, reliability or fitness for use of the Data. PHSA assumes no liability for any loss or damage arising out of the use, misuse or inability to use the Data.

## **6. BREACH**

6.1. The Recipient must immediately notify Information Access Privacy of any breach of these Terms of Use or any Breach. The Recipient must provide a written report detailing the nature of the Breach and any remedial action taken. If requested, the Recipient will provide its full cooperation to PHSA in responding to the Breach or recovering the Data. In the event of a Breach, and in addition to any other remedies available at law, PHSA reserves the right to suspend the provision of further Data to the Recipient or to require the immediate return or destruction of any Data previously provided to the Recipient. The Recipient will promptly comply with any such request.

## **7. AUDIT**

7.1. PHSA may conduct an audit to ensure the Recipient and the Project Team is in compliance with these Terms of Use. The Recipient will ensure that the Project Team cooperates with PHSA (or any other representative appointed by PHSA) in relation to such audit.

## **8. PROPERTY IN AND CONTROL OF DATA**

8.1. The Recipient acknowledges that it will not own any intellectual property in the Data and the Data will remain, at all times, within the control of PHSA. Any intellectual property developed by the Recipient and/or the Project Team as a result of the Project will be governed by applicable PHSA intellectual property and research policy(ies).

## **9. PUBLICATIONS**

9.1. If the Recipient intends to report, publish or present on the findings of the Project, the Recipient must:

9.1.1 ensure that it uses only De-Identified Data for the purposes of such report, publication or presentation, unless all Affected Individuals have provided written consent to the disclosure or publication of their Identifiable Data;

9.1.2 acknowledge the contribution by PHSA of the Data in such report, publication or presentation; and

9.1.3 provide the relevant program/Data steward with advance copies of such report, publication or presentation at least forty-five (45) calendar days prior to the intended reporting, publication or presentation to permit the relevant program/Data steward the opportunity to review and comment on the materials and to ensure that these Terms of Use have been complied with.

## **10. COMPLIANCE**

10.1 Compliance with these Terms of Use is a condition of the Recipient's access to Data. Failure to comply with these Terms of Use may lead to immediate termination to access or possession of Data in addition to legal action by PHSA.

10.2 When accessing Data, the Recipient agrees to comply with all PHSA policies, undertakings or other agreements governing access to the Data.

## **11. GENERAL**

11.1. These Terms of Use will survive the completion or termination of the Project, and will continue in full force and effect until all Data has been securely destroyed by the Recipient. No partnership, joint venture or agency is created by these Terms of Use between PHSA and the Recipient, or PHSA and any member of the Project Team. These Terms of User are governed by the laws of the Province of British Columbia and the laws of Canada, as applicable in British Columbia. Any dispute arising under or in connection with these Terms of Use will be subject to the exclusive jurisdiction of the Courts of British Columbia, Canada.