PHSA 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 which requires approval by an REB or statistical activities, which may be exempted from REB approval.
- **1.2.** As PHSA is subject to FIPPA, a 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 and other applicable laws.
- **1.3.** These Terms of Use apply to a Recipient in all circumstances whether or not an Affected Individual has consented to a Project and 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.
- 1.5. These Terms of Use may be supplemented by a formal information sharing agreement as required.

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 an electronic or paper form issued by PHSA for the purpose of requesting access, use, or disclosure of data in the custody or control of PHSA;

"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 identifier 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 when combined with other available information);

"IAP" means the Information Access Privacy Department at PHSA responsible for compliance with privacy at PHSA [privacy@phsa.ca];

"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 research, quality assurance, quality improvement, program evaluation, health care planning, performance measurement or public health initiative with or without a specific end date;

"Project Team" means all other persons, in addition to the Recipient, who are 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;

"Terms of Use" means these Data Access and Use Terms; and

"Tri-Council Policy" means the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and any amendments thereto.

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 PHSA for consideration and approval. The Recipient represents that the details in the Data Request Form are complete and accurate. PHSA may request additional details from the Recipient before considering the Data Request Form. No access to Data will be permitted until PHSA has approved the Data Request Form, such approval to be granted in the sole discretion of PHSA, and may include such conditions that PHSA 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.
- **4.1.4.** If Identifiable Data is requested for a Project:
 - 4.1.4.1. 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
 - **4.1.4.2.** 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.
- **4.1.5**. The Project Team will refrain from any attempt to re-identify an individual from De-Identified Data except as set out in the Data Request Form.
- 4.1.6. If the Data is disclosed outside of Canada, the details of such disclosure are set out in the Data Request Form.
- **4.1.7.** 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.
- **4.1.8.** 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 PHSA IAP for a response and will cooperate with PHSA in respect of any such request.
- 4.1.9. Any Data disclosed to the Recipient is securely destroyed when no longer needed or required to be maintained subject to applicable data retention policies, laws, and/or REB approval(s), confirmation of such data destruction will be sent to PHSA, and the Recipient will comply with all direction of PHSA concerning such destruction of the Data.
- **4.2.** The Recipient will ensure that the Project and their collection and use of the Data complies with all applicable laws.
- **4.3.** If the Project is one to which the <u>Tri-Council Policy</u> 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, misinterpretations or inability to use the Data.

6. BREACH

6.1. The Recipient must immediately notify IAP 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. <u>AUDIT</u>

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 cooperate and will ensure that the Project Team cooperates with PHSA (or any other representative appointed by PHSA) in relation to such audit. During an audit, the Recipient shall provide PHSA (or its appointed representative) with access to all relevant files, records, and documentation pertaining to the Data and the Project Team's activities. This access shall include, but is not limited to, documentation of Data use, security protocols, and any other records related to the Data.

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) (see http://www.phsa.ca/researcher/policies-forms).

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 PHSA with the findings to be published in such report, publication or presentation at least forty-five (45) calendar days prior to the intended reporting, publication or presentation to permit PHSA the opportunity to review and comment on the materials and to ensure that these Terms of Use have been complied with. Such provision or notification of future reports, publications or presentations will not be required unless there is a substantive change in those findings.
- **9.2.** PHSA may elect to waive this requirement set out in section 9.1 of these Terms of Use at their discretion. Such election must be made in writing.
- **9.3.** For greater clarity, the 45 calendar day review period applies to the intended date of publication. Initiation of the publication process, including but not limited to submitting a manuscript for review by an academic publication



outlet or an abstract to an academic conference, may occur prior to the 45 calendar day review period.

9.4. In all reports, publications, or presentations, a disclaimer must be included that all inferences, opinions, and conclusions drawn from reports, publications, and presentations are those of the author(s), and may not reflect the opinions or policies of the PHSA.

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 (see http://www.phsa.ca/researcher/policies-forms), as well as undertakings or other agreements governing access to the Data as provided by PHSA.

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.
- **11.2.** 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.
- **11.3.** These Terms of Use are governed by the laws of the Province of British Columbia and the laws of Canada, as applicable in British Columbia.
- **11.4.** 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.

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