

## DATA ACCESS AND USE TERMS

### 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 from the COVID-19 Consent Registry (“Registry”) for the purposes of contacting patients who have recovered or are recovering for COVID-19.
- 1.2. The Registry is a program of the BC Centre for Disease Control (BCCDC), a department of the Provincial Health Services Authority (PHSA).
- 1.3 PHSA and the BCCDC are 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 will only be shared with the Recipient in compliance with FIPPA.
- 1.4. A Recipient who wishes to access and use Data agrees to be bound by and to comply with these Terms of Use, and must ensure that all members of the Project Team also 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 any access, use, disclosure, or loss or theft, of all or any portion of the Data not authorized by these Terms of Use or FIPPA;

“**Data**” means Personal Information about Affected Individuals maintained within the Registry.

“**data-linking**” has the meaning set out in FIPPA;

“**Data Request Form**” means the data request form for access to the Registry, a copy of which can be found at the following link: < >;

“**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 Office 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 BC Centre for Disease Control;

**“Project”** means the research or statistical analysis related to COVID-19 for which access to the Data has been granted to the Recipient;

**“Project Team”** means all other persons, in addition to the Recipient, who are authorized to work on the Project from time to time.

**“REB”** means a Research Ethics Board;

**“Recipient”** means a researcher or other party who has submitted a Data Access Request Form and been authorized by PHSA to access and use Data for the Project;

**“Registry”** means the COVID-19 Consent Registry;

**“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 who wish to access Registry Data must complete a Data Request Form and submit it to the PHSA. The Recipient represents that the details in the Data Request Form are complete and accurate, and the Data Request Form contains complete and accurate disclosure of the Recipient’s proposal for the recruitment of Affected Individuals to participate in the Project. 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 Registry is granted to 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 acknowledges and agrees that the Data may only be used for the purposes of contacting Affected Individuals to participate in the Project.

4.2 The Recipient further acknowledges and agrees that approval shall not be granted for the use of the Data for the Project unless PHSA is satisfied that the manner and processes for contacting Affected Individuals is privacy appropriate. PHSA reserves the right to withdraw approval for any Project and require that the Data be returned or destroyed by the Recipient if PHSA determines that the manner and methods for contacting Affected Individuals is disrespectful, invasive or intrusive. Contact by telephone or written communication (mail or email) will generally be considered acceptable.

4.3 If Affected Individuals agree to participate in the Project, the Recipient shall ensure that it obtains express written consent from the Affected Individuals and that it and the Project Team comply with the terms of such consents. Without limiting the foregoing, the Recipient must notify and obtain consent from Affected Individuals of any intended use of their Personal Information for data-linking.

4.3 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. 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 for no other use or purpose.
- 4.1.2. The Project Team may only access 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.
- 4.4 The Recipient represents that any use of the Data to perform data linking has been disclosed on the Data Access Request Form and agrees that such data-linking requires express written consent of both PHSA and of the Affected Individuals. The Recipient acknowledges that PHSA shall not approve such data-linking unless it is not harmful to Affected Individuals and the benefit to be derived from any Data linking is clearly in the public interest.
- 4.5. The Recipient shall only retain Direct Identifiers derived from the Data to the extent needed for the Project, and shall otherwise destroy them at the earliest possible time given the nature of the Project, unless the Affected Individuals have provided written consent that their information remain identifiable.
- 4.6 The Recipient shall promptly and securely destroy the Data of Affected Individuals who do not provide consent to participate in the Project, unless retaining such Data for longer is approved in writing by PHSA or consented to by the Affected Individual.
- 4.7. If the Recipient is based outside of Canada or the Data is stored or disclosed outside of Canada for the purposes of the Project, the details of such storage and disclosure must be set out in the Data Request Form and disclosed to Affected Individuals when they are first contacted to participate in the Project.
- 4.8. Reasonable confidentiality, privacy and security precautions must be put into place and maintained by the Project Team to protect against such risks as loss, theft, unauthorized access, modification, use, disclosure or disposal of the Data.
- 4.9. 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 Information Access Privacy for a response and will cooperate with PHSA in respect of any such request.
- 4.10. The Recipient shall ensure that the Data is securely destroyed when no longer needed or required to be maintained for the Project, subject to applicable data retention policies, laws, and or REB approval(s), and the Recipient will comply with all direction of PHSA concerning such destruction of the Data.
- 4.11. 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 containing and 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. PUBLICATIONS**

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

8.1.1 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;

8.1.2 Acknowledge the contribution by PHSA of the Data in such report, publication or presentation; and

8.1.3 if requested, provide the PHSA 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 Use 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.