OFFICE OF THE INFORMATION & PRIVACY COMMISSIONER FOR BRITISH COLUMBIA

Request to Disclose Personal Information for the Purpose of Contacting Individuals to Participate in Health Research

In accordance with the *Freedom of Information and Protection of Privacy Act* (FIPPA), public bodies may disclose personal information for a research purpose, including statistical information, if the conditions under FIPPA s. 33(3)(h) are met.

Cases involving disclosure of personal information from public bodies **for the purpose of contacting individuals to participate in research related to health issues** require prior approval from the Information and Privacy Commissioner for British Columbia under s. 33(3)(h)(ii)(B). Specifically, the Commissioner must approve the following factors:

(a) the research purpose;

(b) the use of the disclosed information for the purpose of contacting a person to participate in the research, and;

(c) the manner in which contact is to be made, including the information to be made available to the person contacted.

What is the purpose of this form?
This form must be completed and submitted to the Commissioner for review every time a public body is seeking the Commissioner's authorization under FIPPA s. 33(3)(h)(ii)(B) to disclose personal information for the purposes of contacting individuals to participate in research related to health issues.

Important notes:

* Please note that additional review and approval by the Data Stewardship Committee (DSC) is required for any data access requests involving the disclosure of data held in Health Information Banks, PharmaNet, or prescribed Ministry of Health databases for research purposes. In such cases, DSC approval is required **prior** to the Commissioner's review.

* You must complete all fields in this form, unless otherwise indicated.

* Please note areas where additional documentation is required. You will find a checklist of all required additional documentation at the end of this form. After submitting the form, the OIPC will send you a secure link with instructions on how to submit these documents.

* Delays in submitting requested documents/additional information could delay decisions.

General Project Information

1. Title of research project/program:

2. Public body requesting Commissioner's authorization to disclose personal information

Name of public body:

Name and title of public body employee making request:

Pronouns (optional):

Employee email address:

Employee phone number:

3. Researcher requesting to receive personal information from the public body

Name and title of Principal Investigator:

Pronouns (optional):

Affiliated institution:

Researcher email address:

Researcher phone number:

4. Person submitting this form

Is the person submitting the form the:

☐ same person identified in Question 2

☐ same person identified in Question 3

If the person submitting the form is not identified above, provide their information here:

Name:

Pronouns (optional):

Title:

Affiliated public body/institution:

Email address:

Phone number:

5. Is approval from the Data Stewardship Committee also required for data access?

☐ Yes
☐ No

If yes, have you received the approval certificate?

☐ Yes
☐ No

If yes, you will be asked to submit the approval notice after submitting this form.

If no, Data Stewardship Committee approval is required before the OIPC will review the application.

6. Does the researcher seeking the personal information from the public body have Research Ethics Board (REB) approval?

☐ Yes
☐ No
☐ Not applicable

If yes, please list the REB(s) and approval date(s):

Name of REB	Approval Date

If no or not applicable, please explain:

7. **Are there any REB submissions (e.g. amendments) currently pending approval?**

☐ Yes
☐ No
☐ Not applicable

If yes, please list the REB(s) and briefly describe what is pending approval:

Name of REB	Description

8. **Who is funding the research? Please list all public and private funding sources (including in-kind contributions). Include any information about who owns the research outputs:**

Name of funder	Type of contribution/funding

Please explain if any of the funders of the research will own the research outputs:

Details of Proposed Disclosure from Public Body

9. **How does the public body propose to identify potential research participants and source their contact information?**

   Please include details such as eligibility criteria and the names of the databases or source(s) from which the public body intends to select personal information to disclose to the researcher.

10. **Please list the precise data elements the public body proposes to disclose to the researcher, and the rationale for why each is required**:

    *For example, a **data element** may be "full name" and the **purpose/rationale** for its inclusion may be that it is "necessary for contacting potential participants."*

Data element	Purpose/rationale

11. How many individuals is the researcher requesting to receive the above information for? What is the researcher's anticipated response/uptake rate for study participation?

If this information varies for different cohorts of participants (e.g. controls and cases), please use separate rows for each group.

Cohort type	Number of persons researcher proposes to contact	Anticipated response rate

12. If the Commissioner authorizes this disclosure, will the head of the public body approve and impose the following conditions on the researcher before disclosing the personal information, as per FIPPA s. 33(3)(h)(iv)?

(A) security and confidentiality of the personal information

☐ Yes
☐ No

(B) the removal or destruction of individual identifiers at the earliest reasonable time

☐ Yes
☐ No

(C) the prohibition of subsequent use or disclosure of the information in individually identifiable form without the express authorization of the public body.

☐ Yes
☐ No

If no selected for any of these conditions, please explain:

13. If the Commissioner authorizes this disclosure, will the public body that discloses the personal information require the researcher to sign an agreement to comply with the conditions set by the public body, FIPPA, and the public body's policies and procedures relating to the confidentiality of personal information, as per FIPPA s. 33(3)(h)(v)?

- ☐ Yes
- ☐ No

If no, please explain:

Overview of Research Project

14. Please describe the purpose of the research project and how it relates to a health issue:

15. Please provide a detailed summary of the proposed research, including key objectives/research questions, brief rationale, overview of methodology, and intended research outputs/impacts:

16. How many participants are needed to conduct the research? (i.e. what is the target sample size for participation, in order to achieve statistically valid results?)

If this information varies for different cohorts of participants (e.g. controls and cases), please use separate rows for each group.

Cohort type	Targeted number of participants

Use of the Requested Information to Contact Individuals

17. Explain why participant recruitment cannot be accomplished without obtaining the requested information from the public body:

18. Have alternative methods of participant recruitment been attempted for this study?

☐ Yes
☐ No

If yes, please describe what other recruitment methods have previously been tried, and the outcomes:

If no, please explain why other recruitment methods have not been tried:

19. Please list all parties who will have access to the requested data elements at any point in the research process:

Job title/institution	Rationale

20. Does the researcher intend to link the requested personal information with other data elements already in their possession, in order to identify potential research participants to contact?

☐ Yes
☐ No

If yes, please list these additional data elements and explain the rationale:

Data element	Purpose/rationale

21. Does the researcher intend to link the requested personal information with other data sets at any point in time?[1]

☐ Yes
☐ No

If yes, please describe the data-linking:

[1] Under Schedule 1 of FIPPA (Definitions), "data-linking" means "the linking, temporarily or permanently, of 2 or more data sets using one or more common keys"; and "data set" means "an aggregation of information that contains personal information".

22. Describe the proposed approach for contacting potential study participants, including contact methods (phone, mail, e-mail, etc.), what information will be provided to individuals, and who will initiate contact:

Note: After submitting this form, you will be asked to submit the information that will be made available to contacted individuals, such as the telephone script and/or template letter/email that the researcher proposes to use to contact individuals to participate in the research.

<u>Obtaining Consent</u>:

23. Describe the methodology for consenting individuals into the research study:

Note: After submitting this form, you will be asked to submit copies of study consent and assent forms.

Please add any additional comments you feel are important for this assessment:

Document checklist

When you submit this form, the OIPC will email you to request the following documents where applicable. Please prepare these in advance of the request:

- ☐ **Data Stewardship Committee approval**
- ☐ **Planned communication (such as telephone script and/or template letter/email) that the researcher and their staff will propose to use to contact individuals to participate in the research**
- ☐ **Study consent and assent forms**
- ☐ **Any other information (e.g. recruitment materials) that will be made available to individuals contacted to participate in the research.**

Note: The OIPC may request additional information and documentation beyond what is listed here depending on the specifics of the research.

Submit completed form to info@oipc.bc.ca with the subject heading "OIPC health research request." The OIPC will send you a confirmation email containing a link to upload the additional required documents.

END