

Guidance Document | Fraser Health

Informed Consent to Contact for Future Participation in Research for direct collection of contact information

Checklist

Submit your Informed Consent to Contact for Future Participation in Research template ([Appendix A](#)) to the Fraser Health Privacy office along with your Data Access Application and Agreement.

Mandatory Requirement
The Informed Consent to Contact for Future Participation in Research contains only the Fraser Health logo. No other logos should be added. Please only amend red sections in <i>italics</i>. Black font sections are mandatory and must be retained in the final template.
This form is intended to be used for contact information that was initially collected directly for research purposes (i.e. it was not originally collected for the purposes of providing care) If the research recruitment method includes using contact information that was received indirectly and collected for primary care purposes (i.e. from a private physician or a public body), consult the FH Initial Indirect Consent to Contact for Research Letter Guidance document.
Review the Phone Guide Script (Appendix B).

If you require further guidance or have questions on the privacy requirements of obtaining consent to contact for future participation in research, contact informationprivacy@fraserhealth.ca

For more information and resources on Fraser Health's informed consent requirements for research, visit [Fraser Health research guidance note](#).

Background

Informed consent is an on-going process that starts with the researcher's first contact with the individual and continues until the study is complete or the participant withdraws. Study participants must at all times be fully informed about how their personal information will be collected, used and/or linked, retained and destroyed during the research process.

For public bodies engaged in research activities, personal information is collected, used, and disclosed under the primary authority of the BC Freedom of Information and Protection of Privacy Act (“FIPPA”).

Direct Consent to Recruit for Study

Medical staff or clinical staff identify potential research participants within their patient population during routine interactions. They recruit or aid in direct recruitment for research during this practice. Patients may directly provide their contact information to a researcher or clinical staff for the purposes of research recruitment. Medical staff may approach patients in their care with information about a specific study that aligns with the patient’s medical history or condition.

Clinical staff or researchers may engage directly with patients in clinical settings to seek direct consent to enroll patients in active studies and/or will recruit patients who have provided contact information directly to clinical staff or research team for the purpose of research recruitment. This process prioritizes patient autonomy and decision-making regarding research participation and use of contact information. Patients may respond to the clinic, and/or healthcare provider to opt out of future research communications if they do not want to participate.

Patients can also be presented with research materials (i.e. brochures) to independently decide whether to reach out to designated research staff for further information. Refer to [Appendix B](#) for the verbal part of this process.

Direct Consent for Future Study

It is possible that a research team would like to contact participants for future research, in which the use of the participant’s personal information in other projects, including contact information for future participation in research, must be consented to. If future projects are anticipated, and a researcher wishes to use previously collected contact information from a different project to inform participants of future opportunities, it is necessary to seek the participants' specific consent for each new use or linkage of the participant’s personal information. If participants have not provided informed consent for these new uses or linkages—their personal information data cannot be used for any future projects.

Appendix A: Informed Consent to Contact for Future Participation in Research

Introduction And Purpose

At a high level, briefly state the general field of research in clear, layman's terms. The consent must invite, not ask, the participant to disclose their contact information for the purposes of being contacted to participate in future research. This consent form is not intended to spell out the specifics of a current or future research project. Instead, it is meant to seek consent from current research participants to collected, use, and disclose their contact information to inform them of future studies should they arise.

The Freedom of Information and Protection of Privacy Act (FIPPA) prohibits the use of contact information held in medical records to be used for the purposes of research recruitment. Moreover, researchers are obligated to obtain consent for use of personal information, such as contact information, that was previously collected for a different purpose (i.e. a previous research project). Thus, this limits the opportunity to share with you details about the projects that we are planning and that may be beneficial or of interest to you (e.g. treatment options otherwise not available in Canada, some assessments providing better understanding of your disease course, opportunities for physicians to provide educational reports to colleagues, etc)

We are interested in contacting participants for the purposes of sparking interest in participating in our future research or projects as they arise. We would like your permission for a member of our research staff to contact you at some future time.

The information you provide will be used exclusively to maintain contact with you for this reason and in the manner described below. Filling out this form is entirely voluntary.

- You do not need to complete this form if you do not wish to be contacted for participation in future research studies.
- If you indicate that you **do not** wish to be contacted, you may change your mind at any time by contacting the researcher at the email address or phone number provided below.
- If you **do agree** to be contacted, you may change your mind and withdrawal consent at any time without affecting any health care support or treatment you receive from Fraser Health.
- You have a right to access, correct, or amend the personal information you share.
- This information will be stored in a secure, password-protected, and encrypted Fraser Health approved device or cloud services in appropriate locations.
- All information you provide will be kept confidential and will not be used for any other purpose than to contact you to inform you about upcoming research that you might be interested in participating in.

- If you do agree to be contacted for future participation in research, you will be invited to engage in a separate consent process where all details of the specific research or project will be shared with you. Agreeing to be contacted to learn about future research **does not** mean you are required to participate in the research or program presented to you.

Do you wish to be contacted?

☐ YES
☐ NO

If you have selected “YES”, please indicate how you would like to be contacted by checking the boxes below.

Do you wish to be contacted by phone? ☐ Yes ☐ No
If yes, your phone number is: _____

Is it okay to leave a message? ☐ Yes ☐ No

Do you wish to be contacted by regular mail? ☐ Yes ☐ No
If yes, your mailing address is: _____

Do you wish to be contacted by email? ☐ Yes ☐ No
If yes, your email address is: _____

By signing below, I confirm that I am 19 years of age or older and that I have read and understand this consent-to-contact form. I also understand that I can refuse to be contacted by research staff of Fraser Health at any time and that this will not affect the health care I receive in any way.

I hereby give consent to *[enter researcher name or clinic]* to contact me for the purposes indicated above:

SIGNATURES

_____ Participant signature	_____ Printed name of participant	_____ Date
_____ Signature of person administering consent	_____ Printed name/title of person administering consent	_____ Date

If you have any questions or concerns regarding this form, please contact *[researcher name, phone number and/or email address]*.

FORMAT GUIDELINES FOR CONSENT FORMS

Consent forms should be written at a Grade 7 level of understanding.

- 1) Type size – no smaller than the type on this page (12 point)
- 2) Use headings, small paragraphs and spaces between the paragraphs
- 3) *Use simple lay language – explain medical terms and jargon.*
- 4) Write out all acronyms the first time they appear in the consent form.
- 5) Number the pages in the following manner: “1 of 3”, “2 of 3”, “3 of 3” etc.
- 6) Include a footer ON EACH PAGE with the version date and/or version number
- 7) The consent form submitted for review should be in its final form (as it will be seen by the participant), including letterhead.
- 8) Spelling and grammar must be corrected before it is submitted for review.
- 9) Use second person pronouns for the participant information part of the consent form (you/your). Use first person pronoun (“I”) for only the final “consent statement” portion of the form.
- 10) Use “participant” throughout the consent form rather than ‘patient’ or ‘subject’.
- 11) Include the [Fraser Health logo](#) at the top of the first page.

Please consult the REB [guidance on consent process](#) and use as appropriate.

Appendix B: Verbal Script Sample

Hello, is this (patients name)?

*My name is (insert first and last name). I am working with Fraser Health on [research project name] and I am connecting to follow up to see if you would be interested in sharing information regarding this research study you may be interested in.
Is this a good time to talk?*

[Explain study]

Are you interested in learning more about this study? Do you have any further questions that I could answer at this time?

Participant says yes to learning more or participating

[Share more information and answer questions]

Please share your contact information in which you would like to be contacted by the research team.

If you change your mind or have any questions about this study, please do not hesitate to contact me. Again, my name is (insert name), the study is _____. My phone number is _____.

Thank you for your time.

Note: Client's response must be documented. Best practice is to document by signature on a consent to be contacted form.

Participant says no to participate

If you change your mind or have any questions about this study, please do not hesitate to contact me. Again, my name is (insert name). My phone number is (provide phone number).

Thank you for your time.

Participant relays that they do not wish to be contacted to participate in anything or seems upset by the contact

If the participant does not wish to be contacted again in the future for any purpose or if the participant seems upset by the contact, participant may be directed to contact the Fraser Health Privacy Office to discuss their concerns. You may also ask the participant if they would like the Fraser Health Privacy Office to contact them about their concern.

Please alert the Fraser Health Privacy Office of these scenarios and ensure all details are documented including reference to initial signed consent form to contact the participant.

