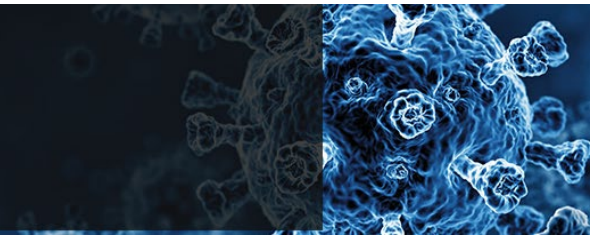


COVID-19 Clinical Research Coordination Initiative



How can researchers access contact information of potential study participants for COVID-19-related research?

This document provides guidance on how researchers can obtain contact information of patients or members of the public for purposes of recruitment to COVID-19-related research. *Please note that procedures may change over time, and if that occurs this document will be updated accordingly.*

This guidance augments, but does not supercede REB Guidance on initial contact and recruitment [Recruitment Guidance 5.4](#). It does not cover circumstances where the researcher or research team, already have access to the information and they can utilize processes outlined in their Institutional REB guidances, e.g. CREB Guidance Notes [General Guidance Notes 10 and 11](#).

It starts by identifying the various institutions and systems that have this information and provides a recommended path, given different interests and research scenarios.

Who is involved?

There are a number of institutions and organizations that have contact information of individuals who may wish to participate in either social-behavioural or clinical COVID-19 research. This guidance does not apply to the regular provision of clinical care (i.e. what follows is specifically about research), or to researchers who only require access to routinely-collected linked data (i.e. where there is no intent to contact people directly); those requests should go directly to Population Data BC.

The **BC Centre for Disease Control (BCCDC)** (which is part of PHSA) is responsible for retaining COVID-19 testing data, including both positive and negative results. The BCCDC also has responsibility for making an initial request for permission to contact COVID tested individuals for research, under authority of the public health emergency.(BC Public Health Act SBC 2008 C.28 s.54.1(k)

The BCCDC is creating a **BCCDC COVID-19 Consent to Contact Registry** that identifies all people tested for COVID-19 who have given consent to be contacted for research. The BCCDC Consent to Contact Registry is currently only receiving information about people who have tested positive and who have consented. This is because case loads make it infeasible to consent those who test negative. This information is collected in various ways across all of the Health Authorities and the process is evolving over time. BCCDC retains governance authority over the Consent to Contact Registry.

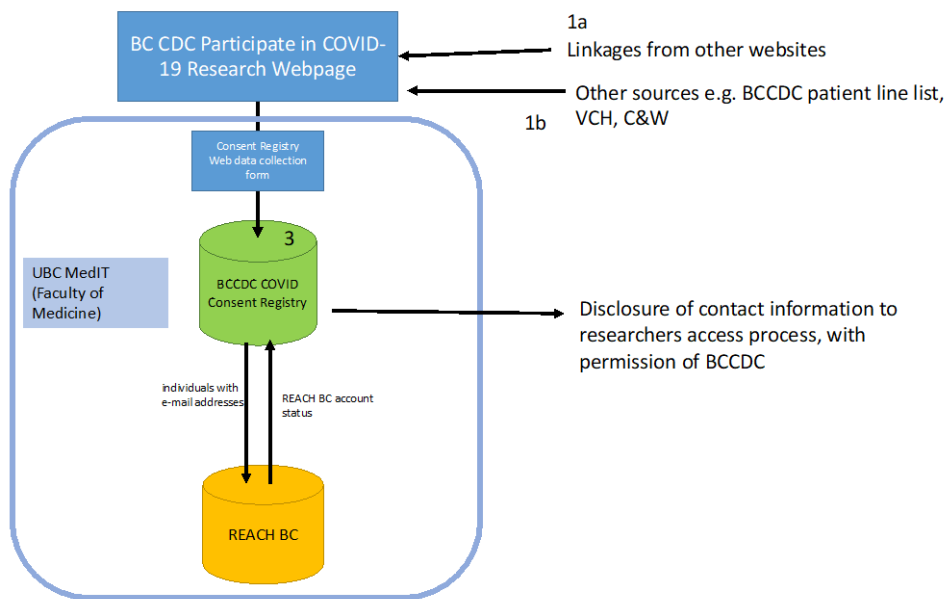
UBC (and specifically MedIT) is providing the technical infrastructure for the BCCDC Consent to Contact Registry, with the permission of the Provincial Health Officer. UBC has custodial responsibility but not governance authority for these data. UBC MedIT is developing a system in which secure and limited access to Consent to Contact Registry participant information will be available to approved researchers. The studies and the participants who are contacted, will be tracked by this system.

The **REACH BC** platform is also hosted by UBC MedIT. All people in the BCCDC Consent to Contact Registry are informed about REACH BC, but they may not have all signed up for the REACH BC platform.

This means that this platform includes a subset of those in the BCCDC Consent to Contact Registry (plus others who have heard about REACH BC through other means). The REACH BC platform thus includes information related to people who are interested in COVID-19 research but who may or may not have been diagnosed with COVID-19. PIs for research projects can post and share their projects on REACH BC by creating a Researcher account and submitting their studies. This is a way to attract attention and recruit participants. In this case, the study research ethics application must list REACH BC as a recruitment tool. Additional information on the submission process can be found on the [REACH BC website](#) under Researcher Resources (after you login). MedIT has custodial responsibility and REACH BC has governance authority for these data.

The main difference between the REACH BC platform and the BCCDC Consent to Contact Registry is that the REACH BC platform has information related to potential participants in any kind of research. Enrolment onto the platform is driven entirely by patients and other members of the public. The BCCDC Consent to Contact Registry is specific to COVID-19 positive patients and the public health emergency.

Figure 1: Relationships among the BCCDC Consent to Contact Registry, REACH BC and the UBC Faculty of Medicine.



British Columbia Health Authorities including Vancouver Coastal Health Authority, Providence Health Care and Provincial Health Services Authority each have processes in place to contact patients who have received health care services provided by that health authority to notify them about research opportunities. More information about these processes can be found by contacting relevant personnel at the applicable Health Authority (e.g., [Joleen Wright](#) at VCH, [Janet Scott](#) at PHC and [Holly Longstaff](#) at PHSA).

The **Office of the Information and Privacy Commissioner (OIPC)** has oversight over requests to access contact information, for example through data stored at the Ministry of Health or other public bodies. This applies in cases where that contact information is not available through other means, as provided in the REB guidance noted above.

The Ministry of Health's **Data Stewardship Committee** has oversight within the Ministry of Health for requests to access contact information of individuals whose data is held by the Ministry of Health. It is a liaison to the OIPC in circumstances where researchers need to contact individuals whose data they are requesting access to.

Population Data BC (PopData) is the “front door” for researcher requests for access to routinely-collected data that are linked across organizations or institutions. PopData assists researchers with requests to access contact information in context of a broader request for access to linked data.

I'm doing COVID-19-related research and need to contact people: What do I do?

In all cases, the usual expectations for approval for research apply, such as proof of scientific merit, REB approval (which includes information on recruitment processes), and appropriate engagement and approvals if you are conducting research that will involve Indigenous people or communities. The process you will follow as a researcher for contacting potential research participants then depends on the overall project scope and what types of people / patients you wish to contact.

The guidance below assumes that you are not able to recruit the potential participants directly through contacting them because they are patients in your clinic, through their family physicians etc. in accordance with current privacy and REB Guidelines. It is restricted to circumstances where you are seeking access to potential participant contact information from a public body such as the the Ministry of Health.

1. Who can help with my request?

The first thing you will want to determine is who can help you obtain access to potential participant's contact information for the purposes of your COVID-19-related research. This depends mainly on whether you need access to COVID-positive individuals, or others as well.

If you are planning to request routinely-collected data (e.g., hospitalizations, physicians visits) in addition to data you collect directly from people who are part of your research project, contact PopData BC for support. If your focus is on collecting data from research participants you recruited, you may need to follow more than one process, as outlined below.

2. What will be involved in making contact with potential research participants?

What is required depends on the type of people you intend to recruit to your COVID-19-related research project. For all of the options below, you can share your research study on the REACH BC directory to find participants who match your general eligibility criteria.

People who tested positive for COVID-19

This will require access to the BCCDC Consent to Contact Registry as that is the source for individuals who have given permission to be contacted for COVID research. These requests should go to the COVID-19 Clinical Research Coordination Initiative using their request form (<https://rc.med.ubc.ca/redcap/surveys/?s=WM7X3WHAAP>). Not all requests for access may be granted, as research projects will be prioritized. For more information about the review process, please see BCCDC Consent to Contact Registry - Information for Researchers.

People who tested negative for COVID-19

You will need to fill out an additional form for request to contact, which can be found [here \(form 5424\)](#). This form will be reviewed by OIPC, but coordination of that will be done on your behalf. Note that both the [MOH](#) and [PopData](#) provide guidance on consent forms, which are needed as part of this request. Once this has been approved, contact information for COVID negative study participants can be provided through BCCDC.

People from the general population, or who have specific health conditions other than COVID-19

There are different REB-sanctioned ways of recruiting research participants. The focus here is where you want to recruit based on particular demographics, health conditions, regions of residence etc.. In other words, this applies to cases where you need access to contact information to identify potential research participants.

If you are recruiting participants from a single Health Authority, you can go directly to that Health Authority.

Otherwise, as above, you will need to fill out an additional form for request to contact, which can be found [here](#). This form will be reviewed by OIPC, but coordination of that will be done on your behalf. Note that both the [MOH](#) and [PopData](#) provide guidance on consent forms, which are needed as part of this request.

I would like to contact people in some combination of the above scenarios (e.g., COVID-positive, COVID negative, and Health Authority patients with particular health conditions).

You will need to follow all processes that apply, as described above.