

# Supporting Patient, Family, Public and Community Partner Engagement in COVID-19 Research in BC

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## Introduction

Involving patient and public voices in COVID-19 research ensures that our learnings about the pandemic are informed by, and in support of, the needs and priorities of British Columbians.

To support patient engagement in COVID-19 research, the BC SUPPORT Unit has provided additional funding and support to 8 research teams funded by the Michael Smith Foundation for Health Research (MSFHR) COVID-19 Rapid Response research award to ensure they can meaningfully engage with patient, family, public, or community partners in their research.

MSFHR developed the COVID-19 Research Response research award to support high-quality research to evaluate and inform BC's response to the COVID-19 pandemic. [Click here](#) to find out more about these projects and other research projects they have funded.

## **Risk and outcomes of COVID-19 patients exposed to immunosuppressive and immunomodulatory agents in British Columbia. A population-based study.**

### **Principle Investigator/ Institution**

Dr. Juan Avina-Zubieta, University of British Columbia

### **Description**

It is important to understand the risk factors for contracting COVID-19 and the outcomes of infection in vulnerable people, such as patients with auto-immune diseases, cancer or those with transplants who are being treated with immunosuppressive or immunomodulatory agents (IIA).

Patients using IIA for their care have raised fears about being at a greater risk of contracting COVID-19 as these medications lower the immune system. Also, they have uncertainties as IIA are being used to treat COVID-19.

This study is assessing:

- 1) The risk of COVID-19 infection among individuals who use IIA in BC,
- 2) The risk of serious outcomes among COVID-19 patient who use IIA compared to patients who do not use IIA.

### **Public / Patient Partner Engagement**

People living with auto-immune diseases, cancer or those with transplants who are being treated with immunosuppressive or immunomodulatory medication.

### **What are Public/Patient participants doing?**

- Co-/developing the survey (to ensure relevancy and comprehension).
- Augmenting dissemination through relevant networks for recruitment.
- Co-interpreting findings from the survey and helping with administrative analyses.
- Co-developing and disseminating key findings for the respective patient populations.

## Informing the COVID-19 Response for Vancouver's Urban Indigenous Population Using Community-driven Methods and Big Data Analytics

### Principle Investigator / Institution

Dr. Brittany Bingham, Vancouver Coastal Health

### Description

COVID-19 poses a significant threat to urban Indigenous populations. Vancouver Coastal Health Aboriginal Health is using a community-driven approach to examine patient data collected within Vancouver while seeking advice from urban Indigenous community organizations and stakeholders to identify gaps and improve the response.

The analyzed data is being used to develop an extensive data profile of Indigenous peoples who access care in the Vancouver region, including COVID-19 risk, comorbidities, and impacts to health service access.

This project aims to review the current urban Indigenous COVID-19 response in Vancouver with existing networks to develop recommendations by and for the Urban Indigenous community.

### Public / Patient Partner Engagement

Urban Indigenous peoples in the Vancouver community are providing a robust understanding of existing urban Indigenous COVID-19 response initiatives and identifying ways to support urban Indigenous communities.

### What are Public/Patient participants doing?

- Expanding community involvement in research decision-making and interpretation.
- Identifying urban Indigenous peoples' health care and research priorities during the COVID-19 pandemic.
- Supporting community stakeholders to host and disseminate research findings to urban Indigenous peoples in the Vancouver Community.

## Respiratory outcomes following COVID-19 infection in British Columbia: A prospective patient registry

### Principle Investigator / Institution

Dr. Christopher Carlsten, University of British Columbia

### Description

Thousands of people in BC will become infected with COVID-19. While most people thankfully recover, little is known about lingering problems experienced by survivors and what care they require.

This study aims to answer two key questions:

- What lung problems continue to challenge survivors of COVID-19?
- What tests are needed to meet the challenges to lung health and quality of life?

Because this is a new disease, it is crucial to develop a registry alongside a post-COVID clinic, to learn with and from patients. The registry is vital in identifying and addressing meaningful research questions that will help British Columbians get the care they need.

### Public / Patient Partner Engagement

People living with chronic lung conditions and people recovering from Covid-19

### What are Public/Patient Partners doing?

- Co-designing the registry and its operation.
- Assisting with patient recruitment.
- Co-developing and disseminating key messages from the findings.

## A Spatial Approach to Exploring Vulnerability in the Context of COVID-19 in British Columbia

### Principle Investigator / Institution

Valorie Crooks, Simon Fraser University

### Description

Maps are an excellent tool for communicating complex ideas. This project aims to develop maps that draw on population and location factors to show where British Columbians are vulnerable to:

- Developing COVID-19 infections, experiencing challenges to accessing ICU care for complex COVID-19 cases.
- Experiencing health-related secondary impacts of the pandemic.

The maps aim to inform decision-makers on where in BC they should focus COVID-19 mitigation efforts and other interventions.

The project team will work with officials to identify ways to improve the maps and integrate new evidence. They also plan to develop maps decision-makers request to support their planning.

The project team will work with officials to identify ways to improve the maps and integrate new evidence. They also plan to develop maps decision-makers request to support their planning.

### Public / Patient Partner Engagement

Members of the public with an interest in, and some experience with, map making.

### What are Public/Patient participants doing?

- Assisting with interpreting the findings by reviewing mapping outputs
- Providing feedback for relevance and understanding

## Evaluation of rapid redesign and resource deployment in Long-Term Care during COVID-19

### Principle Investigator / Institution

Dr. Farinaz Havaei, University of British Columbia

### Description

Half of Canada's COVID-19 deaths are linked to long-term care (LTC) settings. In response to COVID-19, LTC settings have introduced rapid changes to resident care delivery.

This study tracks outcomes from these rapid changes, exploring how they have affected the quality and safety of care delivery and staff, residents, and their families.

Key stakeholders (leadership, staff, Family and Resident Councils) are represented on a steering committee, which will be involved in all research phases. This project aims to produce evidence-based LTC practices and policies for pandemic management as soon as possible.

### Public / Patient Partner Engagement

Residents and their families from the Louis Brier Long Term Care facility in Vancouver

### What are Public/Patient participants doing?

- Sitting on a steering committee.
- Participating in participant recruitment.
- Participating in interview guide development and survey design and validation.
- Reviewing and helping with the interpretation of the interview and survey findings.
- Actively participating in the dissemination of the research findings and co-creation of the knowledge dissemination tools.

## Preventing and mitigating the impacts of COVID-19 among im/migrants in British Columbia: Rapid mixed-methods data to inform policy and programmes.

### Principle Investigator / Institution

Dr Shira Goldenberg, Simon Fraser University

### Description

In BC, migrants make up over 25% of residents and are overrepresented in crucial roles as essential workers (eg, temporary foreign workers), yet may be disproportionately impacted by COVID-19 and face barriers to healthcare access.

Despite purported shifts to ‘universal’ coverage for COVID-related care, many im/migrants report severe ongoing inequities, including gaps in healthcare coverage, unsafe living/working conditions, and confusion about how changes are put in practice. Rapid adoption of virtual tools for service delivery may also compound inequities due to language or technology barriers.

This project is using health system data and interviews to understand migrants’ experiences with COVID-19 related care and health services coverage to ensure “no one is left behind” in the COVID-19 response and beyond.

### Public / Patient Partner Engagement

Precarious im/migrants who are disproportionately affected by COVID-19 and its associated public health measures.

### What are Public/Patient participants doing?

- data collection
- analysis
- knowledge translation (KT)

## Accelerating SARS-CoV-2 Seroprevalence Surveys through Dried Blood Spots (ASSESS-DBS)

### Principle Investigator / Institution

Muhammad Morshed, University of British Columbia

### Description

Phase 4 of BC's Restart Plan requires community immunity but seroprevalence studies – studies which use antibody testing to determine whether people have contracted COVID-19 – of people who are street entrenched, in prison, or live in remote or rural communities is challenging.

The most accurate serology (antibody) tests are lab-based Enzyme-Linked Immuno Assays (EIAs) that use blood drawn from veins, but with people who are not engaged into care, or who have collapsed veins due injection drug use or obesity, it's not a viable option. Point-of-care tests (PoCT) that use blood collected through finger prick (like a glucose test) seems to offer a solution but these tests lack specificity and therefore can't provide an accurate picture. We propose evaluating dried blood spot (DBS) which seems to offer the accuracy of EIAs and the ease of collection of a PoCT to determine BC seroprevalence.

### Public / Patient Partner Engagement

People with lived or living experience of incarceration in the BC correctional system, including Indigenous people and individuals with lived or living experience of substance use or mental health concerns.

### What are Public/Patient participants doing?

- Serving on the governance committee and overseeing all aspects of the study.
- Providing consultations to support recruitment.
- Addressing concerns about confidentiality and risk/benefits for participants and informing mitigation strategies for potential risks.
- Co-designing appropriate strategies for knowledge sharing of the findings back to the community.

## The Cedar Project: Preparing for culturally-safe, trauma informed COVID-19 response among urban Indigenous people who use drugs in BC

### Principle Investigator / Institution

Dr. Patritia Spittal, University of British Columbia

### Description

Indigenous people who use drugs in BC are facing two public health emergencies: COVID-19 and the ongoing overdose crisis. One likely creates additional risk for the other.

COVID-19 and its response may affect access to clean smoking/injection equipment, safe supply of illicit drugs, income, and health and social services. Pandemic fears and restrictions may also impact mental wellbeing. Additionally, substance use may increase COVID-19 risk through sharing smoking/injection equipment; barriers to physical distancing; and housing instability.

This study assesses impact of COVID-19 and the pandemic response, as well as its domino effects, among Indigenous people who use drugs. The study aims to inform a culturally-safe, trauma informed response for this population.

### Public / Patient Partner Engagement

Indigenous elder leaders are being engaged to support consultation with the young men and women in BC who use drugs, including partners from reserve and off-reserve communities in BC.

### What are Public/Patient participants doing?

- Discussing emerging pandemic issues and research priorities among young people.
- Identifying gaps in knowledge.
- Planning culturally-safe strategies that may reduce the impact of the dual pandemics of overdose and COVID-19.
- Fostering knowledge exchange regarding traditional methods of supporting young Indigenous people.
- Planning the development of culturally-safe and trauma-informed programming addressing the dual impacts of COVID-19 and the overdose pandemic.