



Survey Consent: Personal Impacts of the COVID-19/Coronavirus Study

This consent form is for individuals over the age of 19 to complete. Individuals who are interested to participate but are under the age of 19 are asked to contact a parent/guardian to first complete this consent form, then followed by an assent form for youth under 19 years old.

Study Purpose:

The impacts of the coronavirus disease (COVID-19) pandemic may be widespread, extending beyond physical health aspects for youth, their parents and other adults. With an emphasis on the infection and mortality rates of COVID-19, its effects on individuals' thoughts, feelings and actions may be overlooked. Identifying the most effective resources and coping strategies is important for future individual and population-level interventions.

To better understand how the pandemic has impacted individuals, this survey aims to capture longitudinal person-centred outcomes with respect to feelings, thoughts and actions, in addition to learning resources and coping techniques over a one-year period.

This survey is not intended to replace a clinician's mental health assessment, that it cannot replace diagnosis by a professional, and that individual responses will not be reviewed by a clinician.

Inclusion and exclusion criteria

You are invited to participate if you are English-speaking, are a child/youth over 8 years old, or are the parent/guardian of a child/youth with a diagnosed mental illness or medical condition. You are also invited to participate if you have subscribed to *AnxietyCanada* MyAnxietyPlan anxiety management tool.

If you are not English-speaking or are a current or previous study participant, please do not complete the survey unless directed to.

Study Procedures:

You, and if applicable, the youth in your care, will be asked some questions about demography; awareness about COVID-19; restrictions due to COVID-19; general, social, and emotion impacts due to COVID-19; impacts on worries, actions, and daily activities due to COVID-19; and medical conditions. It will take approximately 20-30 minutes to complete the survey about yourself and (if applicable) another 15-20 minutes to complete an additional survey about each child you choose to report about. You will be asked questions about your child if you have a child 18 years old or younger. It will also take your child (if applicable) 20-30 minutes to complete the survey. The survey will be closed on December 31, 2021.

You will also be invited to participate in follow-up surveys. Should you be willing to participate, you will be asked to provide your e-mail address so we can contact you at a later time. You will be invited to participate once every month for a period of one year after completion of the initial survey. Missing a follow-up survey will not exclude you from participating in future follow-up surveys. If you want to stop participating in follow-up surveys after having provided your e-mail, you can do so by contacting the research staff listed below.

If the youth in your care is below the age of 8, they will not be asked to complete this survey. If the youth in your care is between the ages of 8 to 18, they will be asked to complete the child version of this survey. If the youth in your care is 19 years old or older, they will be invited to complete the adult survey separately. It is advised that there is sufficient privacy for respondents to answer questions on their own. However, should a youth need help, parents/guardians are encouraged to help them.

A separate assent or consent form is provided to the youth in your care, depending on their age. Assent forms are to be completed by the participating youth aged between 8 and 18 years after consent has been provided by their parent/guardian. By providing consent to participate in this study, you are consenting to your own participation as well as consenting to participation by the youth in your care. Should you decide for the youth in your care to not participate in this study, there is an option to express this decision under the Third-party Consent Statement below.

You can choose to participate on your behalf, even if the youth in your care choose not to or if you do not have children. If you and your child both participate, then you will be invited to complete a parental survey on behalf of your child, while your child would complete their own survey. If you participate but your child does not, then you will still be invited to complete a survey about yourself and your child, or children, if applicable.

Participation in this survey is entirely voluntary. You and, if applicable, the youth in your care can refuse to participate in this study. If you and/or the youth in your care decide to participate, you may still choose to withdraw from the study at any time without negative consequences to medical care, education, or other services to which you are entitled to or are presently receiving.

To compensate you for your time and effort, you and each participating family member will be entered into a draw to win one of ten \$50 gift cards announced each month. Each family member that participates will be regarded as a separate entry in the draw.

Potential Benefits:

There are no direct benefits to you nor the youth in your care by participating in this study. However, the results from this study can help better understand how an outbreak impacts people so better resources can be developed to help them cope. If you are interested in learning about the results of this study, group survey results will be available by emailing evelyn.stewart@ubc.ca after analyses are complete.

Potential Risks:

You and/or the youth in your care may find some questions in the survey distressing or upsetting, as certain questions ask about anxiety, stress, and coping actions. You and/or the youth in your care do not have to complete every question and are free to only answer questions that you and/or the youth in your care are comfortable with. Should you find it helpful, there are also community resources available at the end of this survey.

We expect that some children, youth and parents are struggling with mental illness at this time. If you are concerned about yourself or your child please contact your doctor or reach out to one of the many available community resources. These include [S.A.F.E.R](#), [Kelty Mental Health Resource Centre](#), [HeretoHelp](#), [CrisisCentreBC](#), and the suicide hotline (1-800-SUICIDE; 1-800-784-2433).

Confidentiality:

Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC Clinical Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law. The results of this survey will be de-identified/coded (any data that could be used to identify you will be stored *separately* from your responses and your name will be replaced with a study code). Once the survey is submitted, the respondent cannot review nor change their responses.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. You also have the legal right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information.

We do not intend to identify you. For open ended responses, please do not share information that might identify you or someone else. When survey results are reported, presented, or published we will not include any data that could identify you.

Only the study team and the technical support team at BC Children's Hospital Research Institute will access your information. The study team will run the survey and analyze the results. Survey data will be stored in PHSA's BC Children's Hospital Research Institute's Secured Network electronically for 5 years.

Contact for information about the study:

Questions about your information and this survey may be directed to Dr. Evelyn Stewart at 950 West 28th Avenue, Vancouver, BC, V5Z 4H4; (604) 875 2000, extension 4725; or evelyn.stewart@ubc.ca, or to Antony Au at (604) 875 2000, extension 3068, or antony.au@bcchr.ca. You may also contact the Principal Investigator if you wish to withdraw your consent.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598). Please reference the study number (H20-01043) when contacting the Complaint Line so the staff can better assist you.

Consent

I have read and understand this form. I voluntarily consent to PHSA collecting, using, and disclosing the information I provide as a survey participant. Your consent is implied when you complete this survey.

I consent (proceed to survey) <type full name> I do not consent (please exit from survey)

Month and year of birth

Last Name

First Name

Third-party Consent Statement

The study was also accurately explained to, and apparently understood by, the youth in my care. They were given an opportunity to ask questions, and all their questions have been answered.

I understand that by signing this form, I am giving permission for the youth in my care to be part of this study. I understand that the youth in my care will be given a similar form, where they can choose to assent to participate in the research. This means that even if I give consent, they are free to decline to participate.

- I consent for the youth in my care to be part of this study
- I do not consent for the youth in my care to be part of this study