





CONSENT FORM

Study Title: Indigenous Peoples and Genomics: Starting a Conversation

Contacts:

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<p>Rochelle Lesueur, Co-Investigator 604-875-2968 rochelle.lesueur@cw.bc.ca Indigenous Health, BC Women's Hospital <i>Rochelle was born and raised in BC and is a descendant of Saskatchewan Cree ancestors and the Métis Nation.</i></p>	<p>Rachel Coe, Co-Investigator 604-875-2000 ext. 5622 rcoe@bcchr.ca Department of Medical Genetics, University of British Columbia <i>Rachel is of Swedish and British ancestry. She was born in Calgary, AB.</i></p>
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Why are we doing this study?

The “genome” is the name for all of our DNA, which guides the development and functioning of our bodies. A genomic sequencing test looks at all the DNA in detail, and for some medical conditions, this test is the best way to diagnose the condition.

To understand the test results correctly, doctors need to compare a patient’s results to a database of genomes from many other people with similar ancestry. Ancestry is like an extended family, and our genomes are most similar to people in that extended family.

Sometimes it is difficult for doctors to correctly read these tests for Indigenous patients. This is because the databases don’t have very many Indigenous genomes in them, so we can’t accurately compare the test results to these databases. This means that Indigenous Canadians do not receive the same quality of genomic healthcare as other Canadians.

This study will help to raise awareness of this issue. This study will also help us learn about some of the thoughts, opinions, values, and concerns that BC's Indigenous Peoples have about this issue. This is not a study about your personal genetics, your own family's genetics, or the genetics of your ancestors. It does not involve any medical care or treatment.

We are inviting you to take part in this study because you are an Indigenous person living in British Columbia. If you do not want to participate in the study, you do not have to.

What happens if you take part in the study?

First Sharing Circle

You will take part in a 2-hour sharing circle (focus group) that will discuss these issues. In this study, we will have sharing circles with 5 different groups of people, and each group will have 5-10 participants.

First, you will fill out a short questionnaire about yourself and your background, which helps us describe the study participants in general terms. The questions are all voluntary, so you don't have to answer any questions you aren't comfortable answering. Answering questions about ancestry is entirely voluntary. Then we will share a video that explains this issue in more detail. Next a facilitator (guide) will lead a conversation about your opinions, values, and concerns related to this issue. There will be a refreshment break part-way through the sharing circle. This sharing circle will be audio taped.

Afterwards, we will use the audio recording, without names or identifying comments, to look for themes, ideas, and opinions that represent what people said during the sharing circle. We will then draft a written report and a video about what we find. The video will use quotes from the sharing circles.

Follow-up Sharing Circle

Several months later, we will meet with the same sharing circle participants again for about 1 hour. We will share the drafts of the video and report and get your feedback and your interpretation. If the draft video uses a quote that you said, we will ask you to read over and sign a separate video consent form if you agree to have your quote used in the final video. (More details are in the "Confidentiality and Privacy" section below.) If you are not able to attend the follow-up sharing circle, we will send you a copy of the video, written report, and video consent form over email, so you can provide feedback. We will finalize the video and report based on your feedback.

Confidentiality and Privacy

We ask all participants to keep what is said during the sharing circles confidential, but we can't control what other participants do after it is over.

The sharing circles will be audio taped on a digital recorder, so we can look at what was said word for word. To protect your privacy, the transcript (word for word document) will use a pseudonym instead of your real name. We will keep all the data (consent forms, audio tapes, and transcripts) in locked filing cabinets and/or secure computer drives in a secure area at BC Children's & Women's Hospital.

We will make a video that uses quotes from the first sharing circle. During the follow-up sharing circle, we will show you a draft of the video, and you can decide if you want to have your quotes, voice, photo, and/or name included in the final video. If you want to include a quote in the video, but you want to stay anonymous, that is ok too. We can have an actor read the quote. After you have seen the draft video, we will give you a video consent form to read over and sign to record your choices about the final video. If you want, you can take the video consent form home and think about your decision before signing it.

It is possible that the draft video will be shown privately to the members of other sharing circles before you get to see the draft video. We will ask everyone at each sharing circle to keep the draft video private. The draft video will not use photos or names, but it will use voices. If you do not want to have your voice used in the draft video, please check this box:

- ☐ Please do **NOT** use my voice in the draft video.

The final video may be shared with the public and on the internet. After the final video is finished, we will destroy the original audio tapes from the sharing circles.

Study Results

We will share the video and final report from this study with you. You may also have any published academic journal articles about the study.

Potential Risks & Benefits

You do not give up any of your rights by agreeing to participate in this research. We do not believe there is anything in this study that could harm you or be bad for you. Some of the questions we ask, or answers other participants say, might upset you. An Elder will be present at the sharing circles to help with everyone's cultural safety, and you can let any of the study team know if you have any concerns.

There are no direct benefits to you from participating in this study. However, in the future, other Indigenous Peoples may benefit from what we learn in this study because doctors may be able to make more accurate diagnoses for Indigenous people if more Indigenous genomes are put in the databases.

Compensation

Participants will be offered an honorarium of \$40 for the first sharing circle and \$30 for the follow-up sharing circle.

Who can you contact if you have complaints or concerns about the study?

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 UBC Office of Research Ethics at 604-822-8598, or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

This research has been approved by the Langara Research Ethics Board, which is responsible for helping to ensure that the rights of research participants are respected. If you have any concerns about this research, you may contact John Russell, Chair Langara Research Ethics Board, at jrussell@langara.ca, 604-323-5453.

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Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your health care or relationship with anyone in the Department of Medical Genetics, the University of British Columbia, the Indigenous Health Program, or BC Children's and Women's Hospital. To pull out of the study, please contact a member of the study team on page 1 of this consent form.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Signature

Printed First & Last Name

Date

Your contact information:

Main phone: _____

Alternate phone: _____

Email: _____