

Participant Consent Form – Interview

Project Title: Understanding Yukoners Attitudes Towards Vaccines

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Partners:

Champagne and Aishihik First Nations

Daylu Dena Council

Liard First Nation

Selkirk First Nation

Purpose of the Research:

The Understanding Yukoners' Attitudes Towards Vaccines (ATV) Project is a collaborative project between the Council of Yukon First Nations, One Yukon Coalition, and Yukon University. The project aims to better understand how people make decisions about vaccines: who Yukoners trust, where they get their information, and why they choose to get vaccinated or not. The project will delve deeply into the attitudes and beliefs of Yukon First Nations round issues of communication, trust, history, and other factors that may influence the decisions people make around getting COVID-19 and flu vaccines.

Procedures:

You will participate in an interview to discuss how you make decisions about vaccinations and who you trust to communicate information about these vaccinations.

- The interview will be a guided conversation and will take approximately 45 minutes to 1 hour.
- The interviewer may be taking notes during the interview as well. These notes will be destroyed at the end of the study.
- With your consent, a representative from your community, working as a community researcher or research coordinator, may be present during your interview.
- With your consent, the interview will be audio recorded. At any time, if you wish to have the audio recording turned off, please inform the interviewer.
- You will receive a transcript of the recording approximately three weeks following the interview.

Please indicate below how you would like to receive the transcript:

- Email using a password protected link _____
- Mail _____
- In-person _____

You will have one month after receiving the transcript to review and make or request any changes to the transcription. If no revisions are received one month following your receipt of the transcription, the data will be accepted and included for analysis, and the audio-recording will be destroyed. Please indicate below if you would like a research team member to review the transcription with you, if you would like to review the transcription on your own, or if you would like to opt out of receiving the interview transcription.

- I would like a research team member to review the transcription with me.
- I would like to review the transcription on my own.
- I do not want to receive a copy of the transcription.

You will be given a copy of this signed document for your records.

Please feel free to ask any questions about the procedures and goals of the study and your role as a participant.

Funded by:

- Funded by the CIHR Innovation Grant. There are no conflicts associated with the funding.

Potential Risks:

- Participants will meet with the researcher in an identified location (chosen by the participant) to discuss personal decisions and decision-making around vaccinations. There is a minimal risk that the conversations could lead to some traumatic memories surfacing regarding vaccinations, health-care, or experiences during the COVID-19 pandemic.
- To minimize the risk of psychological or emotional discomfort, you can withdraw or stop the interview at any point. The interviews will be conducted at a pace suitable to you.

- We encourage you to seek mental health resources if any of the discussion triggers distress or trauma. We will provide you with a list of mental health resources that may be available to you.

Potential Benefits:

- You may directly benefit from reflecting on your decision-making processes, sources of trusted information, and history with vaccinations in that you may realize new information or new understanding of your experiences.
- Indirectly, the results of the research may benefit your community and the broader society. Yukon First Nation communities may benefit from new insights into the needs, priorities, and challenges their community perceives when it comes to making decisions about vaccinations. Community will be able to use the knowledge gained from participating in this project for potential future COVID-19 booster, flu, and other public vaccine campaigns.
- This project may also provide insight to support more effective, culturally sensitive communication in future health emergencies.

Compensation:

- Participants will receive a small gift as a token of appreciation for sharing their knowledge and time.

Privacy/Confidentiality/Anonymity:

- Every attempt will be made to support confidentiality. We will not use your name or any identifying information when data is shared. If used, direct quotations will be rephrased, stripped of identifiers, and returned to you to confirm that it does not include identifiable information.
- If you wish to attribute your name to information, this requires your consent and direction on how this will be done.
 - I wish to have my name publicly attributed to my data. I do not want my data to be confidential.
 - I acknowledge that, once results are published, information I have shared may be made public and, if so, will be directly connected to me.
- Participation is completely voluntary, and you may answer only those questions or provide feedback that you are comfortable with.
- You may withdraw your consent at any time during the process. If data has been included for analysis, it may be impossible to withdraw, however, you may withdraw consent from any future analysis.
- There will be no consequences if you choose to withdraw.

Storage of data:

- De-identified data collected during this process will be stored in a secure, encrypted online folder that can be accessed by all Research team members.
- De-identified data is data that has had all information that could connect you to your data, such as your name, address, role, etc., removed so that the information you have shared does not identify you as the person who has shared the information.

- After the study is complete, a list connecting you to your data, through a participant code, will be stored at the Council of Yukon First Nations for 5 years. This list will only be accessible to the CYFN Health Director. All de-identified data (copies of transcripts with identifying features removed, analysed data, etc.) will be stored at Yukon University, “in trust” for the respective First Nation government, for 5 years. This data will only be accessible to Research Team members and the First Nation government representative.
- After 5 years following the completion of the project, the First Nation community will decide if they would like the de-identified data destroyed, transferred, or repatriated.
- Identifying data will never be made public, nor shared with the First Nation community.

Data Use:

- Data collected from this study will be collated and analyzed. Analysis will be done both manually and using software to develop themes and subthemes.
- Analyzed data will be provided to project partners, shared at a community event, and may be published. Individual data and/or information will not be shared.
- You may request a copy of study publications.
- Wherever deemed necessary, and with explicit consent of participants, direct quotations will be used, but will not be attributed to an individual unless explicitly requested, in writing.

Future use of data:

- Your First Nation community may choose to hold data for longer than 5 years.
- Your First Nation community may choose to use data for future research purposes outside of those outlined in this project.
- If you agree to share your data for future research purposes, it is expected that researchers will analyze this data for purposes that benefit your community; however, it is impossible to predict all ways this data could be analyzed in the future.
- Your identifiable information will not be shared with anyone outside of the present study team. Your identifiable data will not be shared with your First Nation government.
- Please indicate your consent to be contacted about this possible future use of data, below:

I consent to be contacted about the use of my data for future research purposes, other than those outlined herein.

I do not consent to be contacted about the use of my data for future research purposes, other than those outlined herein.

Right to withdraw:

- Your participation is voluntary. Answer only those questions that you are comfortable with.
- You have the right and may request that the audio recording device be turned off at any time.
- You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.

- Should you wish to withdraw, you can inform the researcher or any team member that you wish for your information to be deleted. All data connected to your will be deleted, except data already integrated into analyses, for which it may be impossible to disaggregate and re-identify.

Removal of data from the project

- This project aims to uphold the principles of OCAP, outlined in Appendix 1.
- In upholding the principles of OCAP, each First Nation the owns and controls data from their community.
- Each First Nation has signed a community partnership agreement to engage in this project.
- As part of this agreement, each First Nation has the ability to withdraw from participating in this project.
- If your First Nation community chooses to withdraw from this project, do you consent to having your data withdrawn from the project also.
- Withdrawing data from this project means that the information you shared in an interview or focus group will not be included for analysis in the project.

I consent to having my data withdrawn in the event my First Nation chooses to withdraw from the project.

I do not consent to having my data withdrawn in the event my First Nation chooses to withdraw from the project.

Follow up:

- Results of this study will be shared with participating communities through a community event.
- If you would like to be notified of publications resulting from this study, you may contact the researcher.

Questions or Concerns:

- If you have any questions or concerns, please contact the researcher(s) using the information at the top of page 1.

Questions or Concerns about Ethical Conduct:

- This project has been reviewed on ethical grounds by the Yukon University Research Ethics Board. Any questions regarding your rights or ethical concerns you may have as a participant may be addressed to the REB Co-Chairs by emailing ethics@yukonu.ca.

Demographic data

I am a citizen of _____ First Nation / Council.

I am living with a citizen of _____ First Nation / Council.

I am 19 years of age or older _____.

I am 18-25, 26-40, 41-60, 61+ years of age.

I am Man / Woman / non-binary / prefer to identify another way _____ / prefer not to say.

Option 1 - Signed Consent

My signature below indicates that:

- I have read and understand the description provided.
- I have had an opportunity to ask questions and my questions have been answered.
- I consent to participate in the research project.
- I am not waiving any of my legal rights by signing this form.
- I am free to withdraw from participating in the research project and this will not affect me now, or in the future.

	Yes	No
I agree to be audio-recorded	<input type="checkbox"/>	<input type="checkbox"/>
I agree to the use of direct quotations	<input type="checkbox"/>	<input type="checkbox"/>
I am willing to be contacted following the interview to verify that my comments are accurately reflected in the transcript	<input type="checkbox"/>	<input type="checkbox"/>

<i>Name of Participant</i>	
<i>Participant Signature</i>	
<i>Date</i>	
<i>Researcher's Signature</i>	
<i>Date</i>	

Option 2 – Oral Consent

I read and explained this Consent Form to the participant before receiving the participant’s consent, and the participant had knowledge of its contents and appeared to understand it.

<i>Name of Participant</i>	
<i>Researcher’s Signature</i>	
<i>Date</i>	

A copy of this consent will be left with you, and a copy will be taken by the researcher

Appendix 1: Principles of OCAP

OCAP (Ownership, Control, Access, and Possession) is a set of principles developed by the First Nations Information Governance Centre (FNIGC), that asserts that First Nations ought to have control over data collection, use, and storage, as part of First Nations sovereignty.

O	Ownership - A community or group owns information collectively in the same way that an individual owns his or her personal information.
C	Control - First Nations and their communities may control all aspects of research and information management processes that impact them, including the control of resources and review processes, the planning process, management of the information and so on.
A	Access - First Nations must have access to information and data about themselves and their communities regardless of where it is held.
P	Possession - While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.