Appropriate engagement with Indigenous communities on the analysis of the Community STI Testing Survey data

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On our learning journey

This report documents an issue related to Indigenous engagement in a past survey we did, and our reflections on the issue. We are committed to applying the lessons learned to our research going forward. As part of our ongoing learning journey to appropriate Indigenous community engagement, our team is also holding bi-weekly Truth and Reconciliation discussion sessions that offer a space to learn and act together. Topics discussed include learning about ethical practices for Indigenous research, the Indigenous peoples we would like to engage with and approaches to building relationships. In addition, our team is fortunate to have the opportunity to be working with Elder Doris Fox, from the xʷməθkʷəy̓əm (Musqueam) Indian Band. Her teaching always reminds us to centre our work on the people we serve, and to focus on relationships as the foundation of our work. In the end of the document, we have summarized the actions recommended to us by Indigenous leaders at a meeting on March 11, 2024 and our next steps.

What is the issue?

In the summer of 2022, our team did a survey about testing for sexually transmitted infections (STI) in five communities across British Columbia (BC) where GetCheckedOnline, BC's digital STI testing service, is located. At the time we did not intend to analyze data specifically for

Indigenous people and did not engage with Indigenous organizations prior to or during the survey.

In the year following recruitment, two issues came up for our team related to engaging Indigenous communities in analysis of the survey findings:

- As part of analyses using the entire sample we found potentially important findings for Indigenous people (e.g., that Indigenous people were more likely to be aware of GetCheckedOnline, but not more likely to use the service)
- We realized that a large number of Indigenous people participated. Of the 1658 total survey participants, 209 (13%) self-identified as Indigenous. Our team discussed this with Chee Mamuk, BCCDC's all-Indigenous health and wellness team. We learnt that data about Indigenous experiences with STI testing is rare, and that this information can help with service planning for Indigenous populations in BC.

We did not have a process set up prior to the survey for engaging with Indigenous communities about interpretation of study findings, and did not know the best way to do this for a survey that spanned multiple communities. We also went ahead with a secondary analysis of the data for the 209 Indigenous participants with the Chee Mamuk team, before realizing that we had not considered our ethical obligations to the Nations on whose territories the survey took place (and pausing further use of this data with Chee Mamuk’s agreement). In discussing these issues with Dr. Daniele Behn-Smith, Deputy Provincial Health Officer, Indigenous Health, she suggested that we start by doing a critical reflection of the survey to see where we may have mis-stepped in the planning process, and where we could do better as a research team for similar studies in the future.

About the Community STI Testing Survey

Our research team conducted the Community STI Testing Survey in Summer 2022. We had two objectives for this survey:

- Our main objective was related to GetCheckedOnline. We wanted to know how many people know about and use GetCheckedOnline in communities where it's available, and why people use or don’t use GetCheckedOnline for STI testing.
- Our second objective was to describe region and community-specific outcomes of interest related to GetCheckedOnline as well as STI testing generally and sexual health care.

The survey took place in 5 cities across BC: Victoria/Langford, Maple Ridge, Kamloops, Nelson, and Kimberley (including Cranbrook). These are communities where GetCheckedOnline is available outside of Vancouver. The survey was open to people who lived in BC, were 16 years of older, and had at least one sex partner in the past year. The survey was designed in consultation with our team's Community Advisory Group, which included 6-8 members across BC, with experience relevant to STI testing and barriers to testing and included one Indigenous person. Our team does not have relationships with Indigenous communities in or near the geographic areas of the survey.

The survey recruited participants in-person and online. We set up survey tables at several venues such as community organizations, farmer's markets, Pride parades, music festivals, and so on where people were asked to complete a paper survey. These venues likely reached local community members as well as people from surrounding areas (e.g., people coming from up-Island to attend Victoria pride). Recruitment to an online survey was done through community-specific social media and networks (e.g., community organizations were asked to distribute the survey link by email or on social media). Participants could enter to receive one of five $100 gift cards upon completion of the survey.

The survey was anonymous and no unique identifying information was collected. The survey consisted of five parts:

1) Awareness, use, benefits and drawbacks of GetCheckedOnline
2) Experiences with STI testing, including how often people test, where people test, and barriers they face accessing testing
3) Sexual health, including where usually go for health care, any history of STI and number of partners
4) Sociodemographic factors including substance use
5) Using the Internet, and skills in using health information found online

Demographics questions included one asking whether participants self-identified as "Indigenous (First Nations, Métis, or Inuit)" as has been our team's practice to date. The data does not allow us to distinguish between the three Indigenous populations. We asked for the first three digits of participants' postal code, but did not ask what community they lived in. We are unable to identify which Indigenous participants are members of local First Nations or Metis communities (see Table for details).

A one-page summary describing the overall findings from this survey can be found on our team's research website (link).

Acknowledging the colonial harms of research on Indigenous people in BC

Colonial research has harmed generations of Indigenous peoples in BC and Canada. Much of the research conducted does not benefit Indigenous people who participate, nor reflect the priorities of Indigenous communities. In many cases, research was conducted unethically: informed consent was not obtained, and individuals were knowingly put at serious risks that the research involved. One notorious study was the nutrition experiments conducted at six residential schools, including the Port Alberni School in Port Alberni, BC, from 1948 to 1952. Children involved in the experiments were not informed. Malnourished children were denied adequate nutrition, and the experiments continued even as children died.

Colonial research has focused on deficits (e.g., how Indigenous peoples compare poorly to non-Indigenous peoples). Interpretation of research findings usually excludes Indigenous peoples, with presentation of findings often highlighting negative findings related to Indigenous communities without acknowledging the context of historical trauma. For example, numerous studies on health issues such as alcohol consumption in Indigenous communities have focused on individual behaviours without acknowledging the social challenges resulting from colonialism.

Data and biospecimens collected from Indigenous peoples are commonly possessed by non-Indigenous researchers. Data and biospecimens have also been used, accessed, and distributed inappropriately. A study conducted in the mid-1980s collected blood samples from Nuu-Chah-Nulth people of Vancouver Island to study genetic causes of rheumatoid arthritis. However, the Nuu-Chah-Nulth tribe later found out their blood samples had been used for other research without their knowledge and permission. While the researchers profited from these samples, the community saw no benefits returned.

The issues related to colonial harms of research on Indigenous people are extensive, and many are still harming communities today in BC and Canada.

Our process:

1. Review of the planning process and protocol

We started by reviewing the planning process and protocol and the decisions made regarding Indigenous people. Mark Gilbert is the Principal Investigator for the study and responsible for these decisions, which were made either by himself or in consultation with other study Investigators and our research team. We identified the following key decisions relevant to our reflection:

- GetCheckedOnline is also available in Duncan, where we knew the setting up of service was initially done by the Island Health Authority in partnership with the Cowichan Tribes who are one of the local treatment sites. In recognition of this involvement, we decided not to include Duncan as a survey site. Instead, we set aside funding to support a research project with the Cowichan Tribes that would not be tied to the survey. We spoke with their Research Advisory Council which eventually led to conversations with Health Centre staff who, in discussing our work, prioritized self-collection kits for STBBI testing, not GetCheckedOnline. This is a separate stream of work being led by BCCDC program leads and is not a research project at this time.
- We worked with the Regional Health Authority partners involved with GetCheckedOnline in each community to identify region and community-specific outcomes of interest (Objective 2).
- While we weren't intending to conduct any analyses specific to Indigenous populations, we did recognize that the sample would include Indigenous people and that there may be findings relevant to Indigenous people in analyses including race/ethnicity data. However, we thought this could be addressed after the survey by engagement with Indigenous stakeholders if this scenario occurred, which was based on the experience of how this has been handled by other researchers.
- Our approach was to over-sample populations that faced testing barriers in each community which we identified in consultation with regional Health Authority partners (which included Indigenous people in each community).
- We developed our detailed protocol and training materials for survey staff in the two months leading up to the survey. As we were developing detailed procedures for recruitment, we realized as we had not engaged with local First Nations and did not have an established process for engaging with Indigenous leaders about the survey, that our study was not structured in a way that meets ethical standards for recruiting Indigenous participants including data ownership. We decided to handle this by proceeding with the survey but not approaching local First Nations or Indigenous organizations, or groups or

events, in each community for participation. The relevant section of our training manual is included in Appendix B).

2. Review of our ethical requirements

As a group, we next reviewed the requirements of the Tri-Council Policy Statement 2 (TCPS-2, 2022) Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada. As our survey was funded by the Canadian Institutes for Health Research, we are required to meet these requirements. We reviewed each article in Chapter 9, discussed how this guided research with Indigenous people, and analyzed how this related to the Community STI survey. We present here some of our reflections.

In our review of this chapter, we identified one article that we had not met in our work on this survey, which was to seek ethical approval prior to conducting secondary analyses of Indigenous participants within a larger research dataset (as we had conducted this analysis and shared with the Chee Mamuk team). As our study was not based on First Nations, Metis, or Inuit lands (defined as including Indian reserves, Métis settlements, and lands governed under a self-government agreement or an Inuit or First Nations Land Claim Agreement), and did not recruit only Indigenous people, we met all other ethical requirements as outlined in Chapter 9 of the TCPS-2. When we contacted the UBC Research Ethics Board about obtaining ethics approval for secondary data analysis and describing the study, we were informed that a community engagement plan would not be needed as part of the ethics application.

Our team’s reflection:

Overall, we decided that the TCPS-2 policy statement sets the minimal ethical requirements for our team. As a research team, we are focused on equity in relation to digital and sexual health services, for Indigenous people and other groups facing barriers accessing these services and are committed to the principles of Truth and Reconciliation. There is more that we can and should do to ensure our research is respectful, just, and beneficial. We recognize that trusting and reciprocal relationships are the premise of research involving Indigenous peoples. Building relationships takes time, but only through this we will be able to ensure research conducted is meaningful and appropriate. While we are doing our best to follow the right process and building relationships with the Cowichan Tribes as a known partner involved with GetCheckedOnline, we did not sufficiently consider our ethical obligations to local First Nations and Indigenous people in the Community STI Testing Survey.

First, while our survey did not focus on Indigenous peoples, we knew they would take part in our sample. We also knew Indigenous people were a group facing more barriers to STI testing. Thus, we could have expected a larger number of Indigenous participants due to our sampling strategy. We understand now that this reinforced colonized practices. On one side, we acted as if Indigenous people were "non-existent." On the other side, we assumed the process of collecting and analyzing data did not need their input. We should have recognized this earlier when designing the study and not late in the planning process and should have determined and established an appropriate community engagement strategy from the outset of this study.

Second, our main partners for this survey were regional Health Authority leads involved in implementing GetCheckedOnline. We worked with them on identifying community and regional outcomes of interest, and used a community engagement approach where contact with Indigenous organizations would only occur through trusted relationships of the regional Health Authority (described in our procedure manual; Appendix B). This reflected our team's overall research approach of working closely with health authority partners involved in GetCheckedOnline. It was also influenced by the experience of BCCDC staff on our team that contact with local organizations may be more appropriate through regional health authorities than directly from us as members of a provincial organization. While we are a research team embedded at BCCDC, we realize that as researchers we need to consider our ethical responsibilities to Indigenous people and take appropriate actions which may involve us building relationships directly with regional Indigenous partners. In such circumstances, it may be sufficient to discuss the engagement with, but not require the approval of, regional Health Authorities.

Third, we have started analyses of this survey's data focused on equity without an Indigenous community engagement plan. Some of these analyses have included comparisons between groups, including Indigenous people. Now, we find ourselves with results that we are not able to appropriately interpret. Before proceeding with new analyses, we need to determine and establish the appropriate Indigenous community engagement model for secondary analyses of this data. We also need to consider data sovereignty and how this applies for multi-community or provincial research data on Indigenous people which are not distinctions-based.

Fourth, our recruitment strategy resulted in a large sample of Indigenous participants. In discussion with the Chee Mamuk team, we realized how little published information there is for Indigenous people related to STI testing. We understand how valuable this is for Indigenous organizations and researchers. Thus, we have the responsibility to enable partnerships to access and use this data.

Finally, we recognized that we need to apply the lessons learned from this experience and think about processes for Indigenous community engagement that we need to develop for our team prior to conducting similar research studies in the future. We need to start building relationships with Indigenous partners involved in GetCheckedOnline, and more actively engaging and collaborating with Indigenous partners on research design, implementation and knowledge translation. We also need to develop procedures around use and access of data collected for research following the OCAP® principles. We also need to build the relationships with Indigenous rightsholders in order for our team to better support Indigenous-led research that addresses community priorities.

What we heard

We recognize there are steps we need to take now and in the future to meet our ethical commitments to Indigenous people as part of our research. A priority will be to start building relationships with Indigenous communities involved in GetCheckedOnline, where we are mindful that engagement may look different for each community. We are committed to shifting our research from deficit-based to asset-based (e.g., focusing more on the strengths Indigenous communities have), and managing data from Indigenous participants following the OCAP® principles. We recognize that as a research team led by settlers, we are influenced by the colonial systems affecting our life experiences and ways of working, and that taking these next steps may be difficult for us.

Before deciding on our next steps, we approached Indigenous leaders with whom we had relationships related to research, STBBI and public health to ask their guidance. We were fortunate to be able to host a discussion on March 11, 2024 with these leaders, and we are grateful for the guidance they provided. Specifically we would like to thank for their time and wisdom:

- Elder Doris Fox, xʷməθkʷəy̓əm (Musqueam) Nation
- Dr. Daniele Behn-Smith, Office of the Provincial Health Officer
- Jennifer Cochrane, First Nations Health Authority
- Jessica Chenery, Chee Mamuk
- Judy Sturm, Chee Mamuk
- Amanda Porter, Chee Mamuk
- Naomi Dove, Chee Mamuk

After presenting the results of our team's reflection, we asked four questions of the group. What we heard is captured below, organized by these questions.

1. **Are there other aspects to our ethical reflection that we overlooked and/or need to do more work on?**
   - We need to recognize the urgency and importance of moving forward with the analysis of data on Indigenous survey participants. This information is important for Indigenous communities to have and there have been missed opportunities to use

the data to advocate for Indigenous people. Not utilizing this data would reinforce inequity.

2. **Should we engage with the First Nations on whose territories the survey took place, and Metis communities? (and if so, what is the recommended approach)?**
    - It is important to return the findings to Indigenous people including the First Nations and Metis communities from the lands on which the survey took place as well as provincial organizations representing Indigenous people.
    - Given that it is not possible to identify survey participants who are members of specific First Nations or Metis communities, the engagement and findings shared would be about Indigenous participants as a group.
    - We need to recognize that this will be time consuming and a lot of work.
    - We should be fully transparent and respectful about what data we have and what we are doing and intend to do with the data.
    - We need to respect the workload/burden of engagement on these communities and minimize the burden involved (and recognize that First Nations and Métis communities are dealing with many priorities and this may not be important to them).

3. **How should principles of data sovereignty apply to the survey if our data is not distinctions-based (ownership, control, access and possession)?**
    - We can assume that Indigenous people who consented to participate in the survey are doing so because they want their information used, and it is important to respect this in our path forward.
    - It is important to think about the nature of the findings that would be shared and their relative risk (for example, findings related to access to GetCheckedOnline and other health services are low risk compared to more sensitive information such as history of STI)
    - It is important moving forward to do this work in a 'good way' which is not necessarily the 'right way' as we did not follow Indigenous data governance from the outset of the study

4. **Who should be involved in developing Indigenous community engagement plans for analysis of the Indigenous participants in the survey data?**

- This was not a major focus of the discussion.
- One suggestion was to consider engaging with FNHA Knowledge Translation Exchange and FNHA Primary Care.

5. **Other points from our discussion**
   - It is likely that other researchers have had similar mis-steps but have not been transparent about it.
   - It is important to share this reflection and our process with the public health research community (e.g., Grand Rounds)
   - It would be helpful to find out more about the review process of the institutional REB (e.g., whether and how many Indigenous reviewers are on the board).
   - Cultural humility is saying "I messed up, what can I do to start making it better, and I see you, I hear you, and I believe you."

Taking action – our next steps

Following our reflection and taking action on the guidance from Indigenous leaders our team will undertake the following actions:

- As a first step, we will submit an application to the UBC ethics board for the secondary analysis of Indigenous participants in the survey, describing our community engagement plan (below).
- We will contact the First Nations and Métis communities for the cities where recruitment took place, (Table 1) to let them know we are planning an analysis of Indigenous participants in the survey (explaining that we are not able to identify specific members of their community). We will be transparent about the decisions we have made and the data that we have, and will provide several options for participation if they are interested in doing so:
  - As a member of the Steering Committee we will establish for this project
  - To receive draft copies of any reports from this project and have an opportunity to provide feedback.
  - To receive final copies of the reports from this project.
- Once established, we will follow the guidance of the Steering Committee for how the analysis should be conducted and findings shared.
- We will share our experience with the BCCDC Research Community through a presentation and sharing copies of the report, as well as apply to bring this forward

to the Fall 2025 Research Week. We will also contact the BCCDC Grand Rounds committee about presenting at the 2024/25 grand rounds.

- We will post a copy of this report to our research team website.
- For our team's future research, we will consider the most appropriate forms of Indigenous engagement at the initial stages of the project (starting with grant application)

Table: First Nations, Métis communities and Aboriginal Friendship Centres for the cities where survey recruitment took place

Community Surveyed	Local First Nations	Métis Charter Communities[1]	Aboriginal Friendship Centres
Victoria / Langford	Lkwungen People - Songhees and Esquimalt First Nations communities	The Métis Nation of Greater Victoria Association	Victoria Native Friendship Centre
Maple Ridge	Katzie and,wantlen First Nations		
Kimberley	Ktunaxa Nation	Rocky Mountain Métis Association	
Kamloops	Tk'emlúps te Secwépemc territory, Kamloops Indian Band	Two Rivers Metis Society	Kamloops Aboriginal Friendship Society
Nelson	Sinixt, the Syilx, and the Ktunaxa peoples / Ktunaxa, Nisga'a Nation	West Kootenay Metis Society	

Note: With the way our survey was designed, we cannot identify Indigenous participants that are members of these local First Nation or Metis communities. Our classification of participants to these communities is based on the following criteria:

- Having a Forward Sortation Address (FSA) that were decided on discussion with Health Authorities to reflect the catchment area for GetCheckedOnline, **or**

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[1] Based on communities identified on the Métis Nation chartered communities map of BC.

- Indicated that they lived, worked or visited that community only

Appendix: Section of the survey manual of procedures related to recruitment of Indigenous participants

How should we approach organizations or partners that represent Indigenous groups in the community?

One of the many negative impacts of colonization on Indigenous people in Canada is a profound distrust of research, as there is a long history of research being done by non-Indigenous researchers on or about Indigenous people without their consent or control over the research process. Many Indigenous communities have participated in research without any control over the research questions, how the data is collected, or how the findings are used, interpreted or shared. These are unethical practices, and research involving Indigenous peoples now requires decision-making authority in research studies by Indigenous leaders. For example, Indigenous communities should hold full authority over how research data is collected, stored, analyzed and shared.

The Community STI survey is focused on the geographic communities where GCO is available. Like many studies that are based on a geographic area, our survey does not have a specific focus on research involving Indigenous people. However, Indigenous people are a group that face barriers to testing within these communities who may benefit from GCO, and as part of the community Indigenous people will be recruited to participate in the survey through a number of venues.

Our team will not be conducting any analyses of the survey data that specifically analyzes data in detail on Indigenous people as a subset of survey participants or in comparison to non-Indigenous people, as we have not structured our study in a way that meets ethical standards for doing so. If there arises a need to look at this Indigenous-specific data at a community level or overall in the future, this will only be done if the appropriate relationships with Indigenous leaders are in place to ethically allow us to do so.

For these reasons, as a general rule survey staff will not independently contact Indigenous organizations, networks, contacts, venues or events about the survey. Any contact which occurs within a community will only be with the approval of or facilitated by the Health Authority leads based on their existing relationships and considering their key role in sharing survey findings back to any Indigenous partners involved in the survey.