

Understanding the experiences of patients from the Penelakut Island First Nation receiving clinical pharmacy services

Project Acronym or Short Study Title: *U-PIPE: Understanding Penelakut Island Patient Experiences*

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and Co-Investigators**

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1. Protocol Synopsis

Pharmacists are often regarded as the most accessible health care practitioners making them well suited to service underserved populations (1). Penelakut Island is a rural and remote community part of the Gulf Islands which is home to the Penelakut First Nation. A pharmacist visits this island to provide care. The goal is to support community members and the health care team in improving health. To do this best, we hope to connect with community members by better understanding and learn from their experience with medication, what they perceive their needs to be, how they perceive our service, and how we can best engage with them to deliver it. This study is intended to improve our understanding of barriers to engagement and understanding, and to identify successful means of bridging these barriers.

2. Background & Rationale:

Clinical question: How do members of a remote and rural First Nations community experience care delivered by a clinical pharmacist, both in-person and via telehealth?

Generations of trauma and systemic oppression have led to a complex and problematic relationship between Indigenous people and the health care system. This has contributed to significantly poorer health outcomes for Indigenous people compared to non-Indigenous peoples (2,3). The factors contributing to the culturally inappropriate environment include a lack of trust and understanding between care providers and those they strive to serve and poor Indigenous literacy (4,5,6). For example, a common theme identified in the literature was the concept of “othering”, whereby health care practitioners cared for their Indigenous patients differently than their non-Indigenous counterparts (4,5). Goodman et. al. further demonstrated that the participants did not have their care needs addressed since their practitioners were more concerned with their illicit substance use (5).

In a study examining the interactions of Australian Aboriginal peoples and health care staff, Cass et. al demonstrated that there were serious miscommunications between practitioners and patients. Additionally, the participants reported that their cultural beliefs were not acknowledged

by their practitioners (4). Browne, et.al examined interactions between nurses and Canadian Indigenous women and mothers. Participants felt that they were dismissed by their nurses and physicians. Moreover, the participants reported negative stereotypes against Indigenous women. This was apparent when Indigenous mothers sought care for their ill children and were essentially accused of child neglect (4). However, Browne et. al. did identify some positive encounters. Most notably, the participants felt validated when they were actively involved in health care discussions. The women noted positive interactions with their care providers when the physicians and nurses affirmed their cultural beliefs and incorporated them into practice. Unfortunately, if an Indigenous woman had co-morbid substance use disorder, some were discriminated against and even had certain care measures denied to them (4). This was also observed by Goodman et. al (5). The variability in experiences among participants highlights the need to better understand patient's lived experiences within a health care setting centered on delivering care to Indigenous persons.

Pharmacists provide an important component of care shown to improve health outcomes among individuals with chronic medical conditions. Island Health Pharmacy recently implemented a pilot program providing clinical pharmacist care to the Indigenous community of Penelakut Island. Presently, this service is provided in collaboration with other visiting health care professionals once every two weeks. Patients can self-refer or be referred by the physician or nurse practitioner on the visiting team. As summarized above, we acknowledge that there can be strained relations between Indigenous peoples and non-Indigenous health care providers. We also recognize that there is some suggestion that improved cultural competency increases engagement, understanding and overall satisfaction (4,5,6,7). Increasing engagement, understanding and overall satisfaction is well-aligned with the patient-centered care mandates of both the BC Ministry of Health and Island Health (8,9). Since the Island Health Pharmacy Department's clinical pharmacy initiatives are new to Penelakut Island, it will be helpful to understand patients' experience with using these services. Understanding the lived experiences of patients will help pharmacists and other health care professionals deliver culturally competent care.

Most current research and reporting into the experiences of aboriginal people's health care experiences have been conducted in the context of the relationship between patients and a physician or nurse. Moreover, these studies were completed many years prior to the cultural safety movement meaning that their generalizability is eroding and that clinicians need more contemporary information to further evolve cultural competency when caring for Indigenous peoples. Pharmacy intervention in the First Nation setting has been studied on a clinical level but the data hasn't reported on the patient experience (10). To the best of our knowledge, no research has been published on the experiences of Canadian Indigenous peoples receiving care from a pharmacist. Hence, a clear gap exists in the literature on the understanding of Indigenous patient's experiences in the context of pharmacy care. Our study will address this gap and focus

on the patients lived experience rather than evaluating the efficacy of the intervention. The results of our study will help us understand their experiences and what quality care means to the patient.

Phenomenological analyses are a useful tool to understand the lived experiences of study participants. Phenomenological analyses use observational methods such as interview or focus group that encourage the participant to describe their own experiences with minimal interviewer input or interruption, thus decreasing interviewer bias and facilitating a rich narrative. The subsequent analytical methods will capture themes that describe the “essence” of the participant experience (11).

Source	Study Participants	Methods	Summary of Results
Beach <i>et al.</i> (7)	Various health professionals	Systematic Review of Health Care Provider Educational Interventions	<ul style="list-style-type: none"> • Cultural competence training improved health care provider knowledge, skills and attitudes • Cultural competence training improved patient satisfaction
Browne <i>et al.</i> (4)	Nurses and Aboriginal Women from a reserve community in a rural area	Two in-depth interviews were conducted with each participant. Data was validated using respondent validation.	<ul style="list-style-type: none"> • Invalidating encounters: <ul style="list-style-type: none"> ○ Participants felt dismissed by their health care providers ○ Negative stereotypes about First Nation women • Validating encounters: <ul style="list-style-type: none"> ○ Actively participating in health care discussions ○ Affirmation of personal and cultural identity
Cass <i>et al.</i> (6)	Physicians, nurses, health care staff and Aboriginal peoples in a renal dialysis unit in or near Darwin, Australia	5 videotaped clinical interactions between physician – patient, nurse – patient and an allied health professional – patient. Design was based on “grounded theory” and sampling was collected using maximum variation sampling. Data was validated using “respondent validation”	<ul style="list-style-type: none"> • Serious miscommunications emerged between patients and health care professionals <ul style="list-style-type: none"> ○ Included but not limited to different cultural approaches to discourse, staff dictated the setting and structure of the conversation and dominance of the biomedical model ○ The staff and patients had a lack of shared understanding
Goodman <i>et. al.</i> (5)	Aboriginal persons who use illicit drugs/alcohol in the Downtown Eastside of Vancouver, BC	Talking circle. Data was validated using “respondent validation”	<ul style="list-style-type: none"> • Common themes identified: <ul style="list-style-type: none"> ○ Participants reported being “treated differently” during their health care interactions ○ Participants felt that their health care providers were more concerned with their illicit drug use rather than their chief complaint and were subsequently denied analgesics

3. Study Objectives(s)/Purpose:

Primary objective: To understand community members’ lived experience when receiving care from a clinical pharmacist

4. Study Population

The study population includes community members on Penelakut Island who have received clinical pharmacy care from Island Health from April 2018 to present. Community members will be asked to participate in the study by clinic support staff during health clinic visits with the pharmacist. The clinic staff will refer all further recruitment conversations to designated community members and study investigators. Recruitment will include an explanation of the purpose, methods and time frame of the study and provide prospective participants with an information sheet about the study (Appendix B). The recruiter will also provide a detailed consent form to be read and signed prior to the initiation of the study.

Inclusion Criteria

- Individuals who are residents of Penelakut Island who receive care from an Island Health clinical pharmacist
- Individuals who identify as members of the Penelakut First Nation
- Must be able to communicate in English with the individual who is leading the talking circle and the unstructured interview

Exclusion Criteria

- Individuals who are not cognitively able to participate and who cannot provide consent for themselves

5. Study Design & Procedures

This study is a phenomenological analysis exploring the lived experience of clinical pharmacist care among Indigenous community members on Penelakut Island. Qualitative data will be collected through a focus group and unstructured interviews. All data collection, storage, analysis and disclosure will be done in accordance with the Royal Commission on Aboriginal Peoples' (1993) guidelines for ethical research with First Nations (12), the OCAP™ principles as outlined by the First Nations Information Governance Centre (13) and the Tri-Council Policy Statement 2 – Chapter 9, research involving the First Nations, Inuit and Métis Peoples of Canada (14). Local leadership and Elder input on all aspects of this proposal will be obtained prior to commencing the study, with resubmission to HREB if any substantive revisions are required to ensure that the investigation is culturally appropriate and for the benefit of the community. The Penelakut Band Council, led by Chief and Council, will review all materials prior to submission for publication. The Chief and Council have expressed their support and approval for this project (Appendix D).

We are proposing that the focus group be conducted as a Talking Circle to encourage equanimity and a sense of closeness to the participant's culture. The Talking Circle will be led

by a local community leader who is fluent in the languages of all participants. The Talking Circle will begin as per local and cultural practices, which may include a cultural song or prayer. The community leader will then share an experience that they have had with their pharmacist to begin the discussion. This will lead in to a discussion amongst each of the participants. Responses will be recorded by 2 note takers in addition to voice recording. The note takers will take notes during the interviews and focus groups and will synthesize a verbatim transcript with the voice recording. At the close of the Talking Circle, the community leader will give an opportunity for anyone to share any final thoughts.

The investigators are proposing to conduct interviews in addition to the Talking Circles for several reasons. Firstly, interviews allow for a more personal interaction with each participant and are better designed than a focus group to build a meaningful rapport with the participant. Secondly, interviews are well suited to understand attitudes, values, beliefs and motives (15). Unstructured interviews allow for the participant's responses to guide the interview rather than a list of questions guiding their responses. Moreover, the participant has control over the pacing, detail, scope and emotional intensity of the interview (16). The interview may encourage some participants to share an answer that they may not have been comfortable sharing during the Talking Circle, thus allowing for better understanding of our study population (15). Finally, the interview may promote healing, empowerment and give a voice to those who may have been unheard (16).

The unstructured interviews will be conducted by one of the primary investigators. As outlined by the literature, the interview will have a guiding question which serves as an overarching theme of the discussion between interviewer and interviewee (16,17,18). The interview will take place in a confidential setting that is acceptable to the participant. The interview will be audio recorded to allow for the creation of a verbatim transcript which prevents meaning being lost from other methods of transcribing notes (15,16,17).

Each interview will begin with the investigator explaining the purpose of the interview in addition to reviewing the consent form. Participants will be reminded that they can withdraw from the interview at any time. Next, the interviewer will ask brief questions to help the participant get comfortable with the process and to start building rapport. This will be followed by a broad open-ended question intended to elicit the participant's experience when interacting with the clinical pharmacist.

The primary objective of the interviewer is to listen and record the responses of the interviewee (18). Should a response need to be clarified, the interviewer will interject without using a leading question. For example, if the interviewer wants to clarify a point about a recent experience that the interviewee had, the interviewer will respond by repeating a key word or phrase that the participant said in the form of a question, rather than providing a new question

(18). In doing so, we will reduce the likelihood of bias being introduced on the part of the interviewer or interviewee.

Our discussions may involve the participant sharing experiences which weren't favorable and may bring up unwanted trauma. We are not going to probe for any of these experiences, instead, we will listen to what they are willing to share. Ultimately, this study is being conducted with the betterment of patient relationships in mind. We have liaised with Kim Good, the Drug and Alcohol Counselor of the Penelakut Tribe. In addition to Ms. Good being present for the Talking Circle, she has arranged for two Cultural Support Workers (CSW) and one Resolution Health Support (RHSW) from the Tsowtunlelum Treatment Center to be present as well. The RHSW will be present to support anyone who may be triggered by the Talking Circle while the Cultural Support Worker will be present to ground study participants. The CSWs will also offer the participants an opportunity to be *brushed*. This is a cultural practice which helps participants to “brush off” negativity. Should the participants require further support, we can connect the participants to the KUU-US Crisis Service in addition to any social workers, counselors or other professionals who can be of assistance. Should we recognize that a participant is distressed during the interview or Talking Circle, the RHSW, CSWs and Kim Good will take the participant away from the Talking Circle and use their training and resources to support the participant.

Once all the responses from the interviews and Talking Circle have been recorded, the narrative will be categorized into common themes. A summary of the common themes shared with local leadership and the community leaders who led the Talking Circle. Next, the participants will be invited to attend a session where the results will be delivered to obtain oral validation.

Study Timeline

- June – September 2018: preliminary discussions with key stakeholders within Penelakut First Nation and the Penelakut Island Health Clinic
 - Jim Chisholm – Penelakut Island Band Manager
 - Nora Thomas – Health Director
 - Megan Henderson – Nurse
 - Normaline Charlie – Community wellness worker
 - Dr. Graham Blackburn – Health Clinic Physician
- September 2018:
 - Meeting with Penelakut First Nation Chief and council
- October – December 2018: Recruitment of participants
- January – February 2018: Conduct Interviews and Talking Circle
- March – June 2018: analysis and validation of data, synthesis of manuscript

How will the results be used?

Firstly, the results will be used to strengthen existing relationships between pharmacists and patients of the Penelakut Island health clinic. Moreover, the researchers will seek to understand the patient's sense of wellbeing over the course of this study. The results will also identify areas of improvement in our pharmacy service to the Island. The results may lead to future investigation of further pharmacy interventions on the Island, namely, the introduction of Telehealth pharmacy.

6. Statistical Considerations

The sample size of 6-10 participants per Focus Group is typical for phenomenological analyses. There are no planned statistical analyses aside from a summary of demographic variables. The narrative outputs of the Talking Circle and interviews will be reviewed and themed to capture the essence of the community members' experience of care.

7. Data Collection and Data Management

Data will be collected using a Talking Circle and interviews. The data will be recorded using a laptop computer/audio recording. Informed consent will be obtained from each participant using a standardized written consent form (Appendix A) prior to the commencement of the Talking Circle or interview. The document will outline the purpose and methods of the study, how confidentiality will be maintained, and contact information of the investigators. Participant confidentiality will be maintained by anonymizing participants using pre-assigned identification numbers. Data collected from each Talking Circle will be stored and processed on Island Health's encrypted computer servers with permission from the Penelakut First Nation. The primary investigators are the only individuals outside the community who have access to the data; any quotations that are published will be anonymized and have all identifiers removed. In accordance with OCAP™ principles, the data will be owned by and accessible to the Penelakut First Nation at all times. A data flow diagram has been attached in Appendix C.

8. Publication of Results

The manuscript will be written by Island Health investigators in collaboration with community members. The investigators will seek permission from the Penelakut First Nation to submit the manuscript for publication to an appropriate peer reviewed journal and share findings via presentations such as the BC Pharmacy Resident Research Night. Moreover, the research will be used to inform future research and program development, and will be presented at other knowledge translation activities such as local invited talks.

9. References

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10. Appendices

Appendix A – Informed Consent Form



Understanding the experiences of patients from the Penelakut Island First Nation receiving clinical pharmacy services

PARTICIPANT INFORMATION & CONSENT FORM

PRINCIPAL INVESTIGATOR AND STUDY TEAM:

Principal Investigator:

Sasha Maleki, BSc(Pharm), Pharmacy Resident

Address: Pharmacy Department, Royal Jubilee Hospital, 1952 Bay St, Victoria, BC V8R 1J8

Phone Number: 250-415-2028

Email: sasha.maleki@viha.ca

Co-Investigators:

Sean Spina, BSc(Pharm), ACPR, PharmD, FCSHP

George Nickoloff, BSc(Pharm)

David Forbes, BSc(Pharm), MPA, ACPR, BCPS, CTE

Background and Purpose of the Study

You are invited to participate in a research study. Your participation must be free and voluntary. You are free to withdraw at any time. The purpose of this study is to understand the experiences of Indigenous peoples who are receiving care from an Island Health pharmacist.

This project is important because it will allow Island Health to improve the services given to Indigenous people.

You are being asked to participate in this study because you are someone who identifies as a member of the Penelakut First Nation and is receiving care from an Island Health pharmacist

Location of Research

The research study will be conducted at the Penelakut Island Health Clinic and other locations within Penelakut Island.

Project Funding

This project is being funded by the Island Health Authority Pharmacy Practice Residency Program

What is Required if I Participate?

If you agree to participate, you will be asked to participate in a focus group which will be ran as a Talking Circle. You will be asked to attend an interview where the interviewer ask you to share your experiences with the care that you have received from the Island Health Pharmacist at the Health Clinic. This will give you the opportunity to share experiences that you may not have wanted to share during the Talking Circle.

What are the Possible Inconveniences of Participating?

- You will be required to participate in an interview with one of the researchers that will be 30-60 minutes
- You will be required to participate in a focus group that will run for approximately 60 minutes on a separate day than your interview
- You will be required to return for a brief session which we will present our findings and you and your peers will validate or reject them

Will there be someone to support me in case of emotional distress?

Yes. Kim Good, Drug & Alcohol Counselor for the Penelakut Tribe will be present, as will two Cultural Support Workers (CSW) and one Resolution Health Support (RHSW) from the Tsowtunlelum Treatment Center. They will be present during the Talking Circle and will be readily available during the interview. The CSWs will conduct brushing ceremonies for those who wish to participate.

What are the Possible Benefits of Participating?

The experiences that you share will help the Island Health Pharmacy department reflect and implement new strategies to better serve the Penelakut First Nation and other Indigenous peoples.

Do I Have to Take Part?

You are free to accept or decline participation.

Will I be Paid for Taking Part?

You will not be provided with any payments or coverage of costs for participating in this study.

How will my Personal Information will be used?

- Upon study enrollment, your contact information will be collected and will only be seen by the researchers. No other Island Health employees or any other individuals will have access to this data.
- Your data will be blinded. You will not be identified by name in any reports of the completed study.
- Results from the study will be shared with the Penelakut First Nation Chief and Council as well as the Band Manager for approval.
- Collection and storage of data will follow the Ownership, control, access and possession (OCAP™) principles as outlined by the First Nations Information Governance Centre
- Data will be collected in a private setting and will not be viewed by anyone other than study investigators. You will not be identified by name in any of the reports of the completed study. This data cannot be used for any future purpose without the consent of the Penelakut First Nation Chief and Council.
- Your consent for us to collect your information for the purpose of this research project will expire when you complete the study.

Future Use of Data

Research data from this study will be retained for a total of five years. As per OCAP™ principles, the data is owned by the Penelakut First Nation.

Disposal of Data

Your information from this study will be disposed of in the following manner:

Data Source	How Destroyed	When Destroyed
Recordings and transcriptions of interviews and Talking Circle	Permanently erased from the Island Health's database by Island Health's IT department	These will be retained for five years after study completion. This is the length of time recommended by the Research Ethics Board.

Sharing of Study Results

The study results will be presented in the form of a research poster and short discussion at the British Columbia Pharmacy Residency Research Event in Vancouver in May of 2019, with potential for future journal publication. The study results may also be presented at related conferences. A summary of the study results will be provided to you upon request

Who Should I Contact if I Need More Information or Help?

Sasha Maleki is the principal investigator and will serve as the primary contact for research participants. He can be reached by phone or email at:

- Phone: 250-415-2028
- Email: sasha.maleki@viha.ca

For questions or concerns about your rights as a research participant, please contact the Island Health Research Ethics Office in Victoria at (250) 370-8620 or email: researchethics@viha.ca.

CONSENT

Your signature below indicates that:

- 1. All sections of this Consent form have been explained to your satisfaction
- 2. You understand the requirements, risks, potential and responsibilities of participating in the research project, and;
- 3. You understand how your information will be accessed, collected and used.
- 4. All of your questions have been fully answered by the researchers.

Name of Participant
(print)

Signature

Date

Name of Person Administering
Informed Consent

Signature

Date

Role of Person Administering
Informed Consent

A copy of this consent form will be given to you, and a copy will be kept by the researcher.

Appendix B – Study Information Handout:



We are proposing a project to help the people of Penelakut Island to improve their health through the best possible use of medications. This project will involve having an Island Health clinical pharmacist see patients at the local clinic, working alongside Valerie Jefferd and Dr. Graham Blackburn.

Clinical pharmacists specialize in helping people to understand the medications that they may need, and to be confident that

- their medication will provide optimal benefit,
- their medication is consistent with their care goals
- any risk of harm is known and, where possible, minimized

While most clinical pharmacists work in hospitals, the best time to solve medication problems may be before these problems make people unwell. Clinical pharmacists can connect with people in their home community, listen and understand their health problem(s), help establish realistic medication treatment goals, identify and resolve drug therapy problems, and support people in making informed treatment decisions. This work will be designed and performed in respectful collaboration with existing caregivers, community members and leaders.

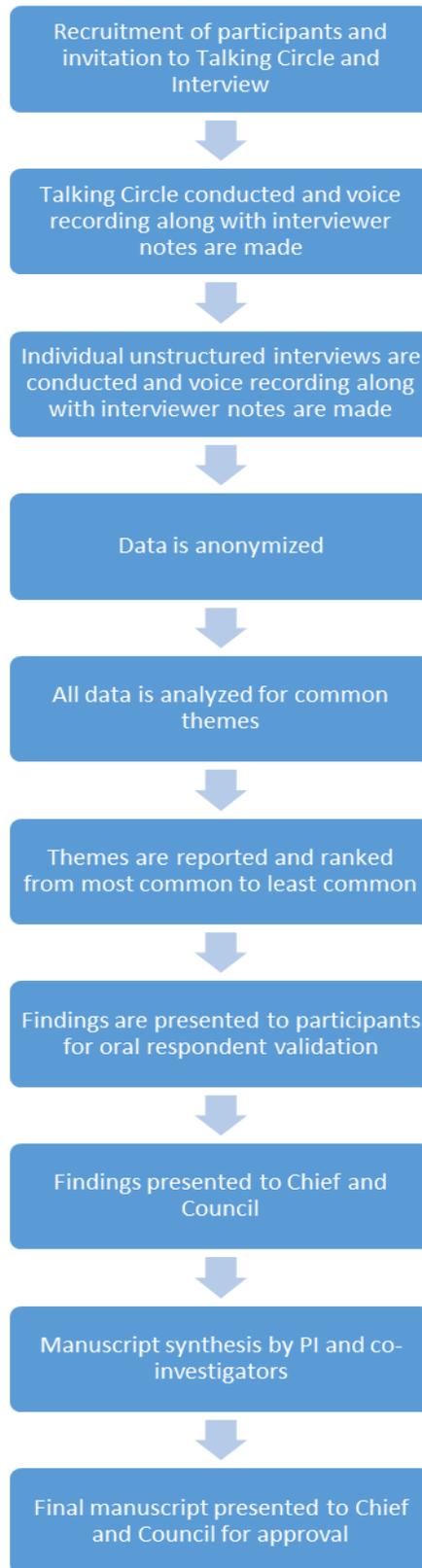
Please contact the primary investigator, Sasha Maleki, for any further questions!

We look forward to speaking with you.

Sincerely,

Sasha Maleki, Pharmacy Resident
Island Health Pharmacy Department
Phone: 250-415-2028
E-mail: sasha.maleki@viha.ca

Appendix C – Data flow diagram:



Appendix D – Summary of meetings with Penelakut Island First Nation Leadership

The following is a summary of George Nickoloff's meetings with Penelakut First Nation membership:

Having confirmed support for our project with Penelakut Health Director, Nora Thomas, and Band Manager Jim Chisholm in meetings on July 24th, I was invited to attend the Chief and Council Meeting on September 4th. I presented a Power Point presentation outlining the ideas behind the project, its goals and unique focus on community member engagement and co-leadership, and briefly explained the residency project component. From the start of the presentation, I emphasized that the ideas and feedback from the group would be highly valued. Response from councillors was positive, with some helpful input toward possible success factors. Chief Brown specifically indicated that the project would be beneficial for the community members, and has her support, as did the other members of the council. A more formal research agreement will be presented when available.