Identifying Cervical Cancer Screening Challenges at a Tribal Health Center: A Qualitative Patient Perspective

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March 4, 2022

Abstract

BACKGROUND: Cervical cancer is preventable with well-studied screening interventions and an effective vaccine. For American Indian and/or Alaska Native (AI/AN) people, cervical cancer diagnosis carries a higher mortality rate than non-Hispanic Whites. The study site is currently establishing a cancer screening program, and 75% of their eligible patients are due or past due for screening. This study will identify current facilitators and challenges to cervical cancer screening from the perspective of the AI/AN user population.

METHODS: This is a qualitative study utilizing semi-structured interviews from individuals who are eligible for services at the Cowlitz Tribal Indian Health Clinic in Longview, Washington. Computer-assisted qualitative analysis software will assist thematic analysis by generating themes and subthemes.

RESULTS: Six emerging themes from the 13 participants include transportation, provider, patient access, cultural aspects to screening, knowledge as power, and finally, solutions.

CONCLUSIONS: Aligning with other studies, facilitators and challenges fall within the socioeconomic model rings, and screening services can be enhanced by multicomponent interventions when considering future needs, specifically patient empowerment with enhancing outreach, HCP-patient partnership, and utilization of patient navigator model.

Keywords: cervical cancer screening, American Indian/Alaska Native, tribal health center

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Introduction

Problem description

There has been a steady decline of cervical cancer in the United States since the 1970s, mostly due to the screening Papanicolaou test, also known as a pap smear (Buskwofie et al., 2020). Still, American Indian and/or Alaska Native (AI/AN) individuals have high rates of morbidity and mortality due to cervical cancer. The human papillomavirus (HPV) is the leading cause of cervical cancer. It has had an effective vaccine available since 2006, yet high-risk HPV causes invasive cervical cancer for AI/AN at a rate of 32.7% compared with 24.9% in non-Indigenous populations (Sethi et al., 2021).

In the Pacific Northwest, cervical cancer in AI/AN population increased by an annual average of 3.9% from 2007 to 2016 compared to the Non-Hispanic White population (Bruegl, 2020). As screening guidelines change in age range and frequency, of important note, is the significant two-fold disparity between AI/AN incidence and mortality of the ages of 50-65 compared to non-Hispanic Whites (Bruegl et al., 2020). This disparity is rooted in historical and current healthcare inequality, with the overburdened and underfunded Indian Health Service serving 2.2 million AI/AN and seated on public policy by colonial settlers with aims of assimilation and cultural annihilation (Dockery et al., 2018). An extensive body of research reveals that AI/AN are less likely to receive guideline-concordant care, experience discrimination, and experience social determinants of health.

Available Knowledge

Quantitative studies on AI/AN populations in the United States are limited, but early qualitative studies have explored cervical screening facilitators and barriers from a cultural lens (Strickland et al., 1990). Current studies examine First Nations people in Canada and other indigenous populations in New Zealand and Australia, highlighting the global impact of improving equitable access to the most vulnerable (Cerigo et al., 2011; Sethi et al., 2021; Wakewich et al., 2015). These findings intersect with AI/AN in the United States, with

substantial marginalized care, experiencing social determinants of health, and access barriers (Wakewich et al., 2015).

The American Cancer Society (ACS) recently revised cervical cancer screening guidelines to begin at age 25 with cytology every three years until 30, followed by cytology or primary HPV testing every three and five years respectively, until age 65 (2019). The proportion of AI/AN current on their screening was 54.8% vs. 69% of non-White Hispanic women (Bruegl et al., 2020). Electronic health record capabilities and provider knowledge may hinder documenting accurate pap history to meet the strict exit criteria (ACS, 2019). One quantitative study found that the age group of 50-65 had four times higher rates of high-risk HPV for AI/AN, compared to another study of various racial backgrounds (Lee et al., 2019). The rate of guideline-concordant screening has been decreasing in the United States, and not receiving recommendation from a healthcare provider was a commonly cited barrier; especially in those in the LGBTQ community (Suk et al., 2022).

Rationale

The Social Ecological Model (SEM) is a multi-level prevention model utilized in current research for screening modalities and consider both micro and macro level systems. SEM has five rings influencing a phenomenon, which include intrapersonal, interpersonal processes, institutional and organizational factors, community factors, and public policy (Nyambe et al., 2016). To help identify needs, facilitators and barriers can be considered in relation to each ring, such as the individual knowledge and social support to screening (intra/interpersonal) and current clinic practice (institutional).

Utilization of a qualitative participatory research (PR) design will help obtain valuable information to analyze with thematic analysis. Highlighted are four areas of relevance to qualitative participatory research within AI/AN communities: community engagement in research processes, community guidance and tribal regulation of research, cultural adaptation, and community research capacity (Woodbury et al., 2019).

Specific aims

Participatory research will examine facilitators and challenges to cervical cancer screening for future prevention efforts.

Methods

Context

The Cowlitz Tribe consists of the Upper Cowlitz (or Taidnapam) and the Lower Cowlitz (or Kwalhiokwa), which have a rich history of resiliency along the waterways in southwest Washington since time immemorial. The tribe prioritizes community, environment, culture, and language preservation while also being an economic leader (PAIHB, 2021). The Cowlitz Indian Tribal Health Clinic in Longview, WA, serves approximately 450 active patients, 33.5% of which are Cowlitz tribal members (PAIHB, 2021). Presently, two HCP's are available for cervical cancer screening. Electronic health record shows that 75% of eligible patients are overdue or behind for cervical cancer screening. Known barriers to these statistics include the lack of an EHR notification system and understaffing (R. Powell-Sexton, personal communication, June 23, 2021). The clinic serves Cowlitz Tribal members, members from other tribes, non-natives employed by the tribe, among other regulatory policies.

The Cowlitz Indian Tribal Health Clinic has recently partnered with the Native American Rehabilitation Association Breast and Cervical Cancer Screening and Early Detection Program to establish a cancer screening program, bringing resources and collaboration with a well-rooted AI/AN healthcare. Reminder letters have been mailed to those eligible and past due for cervical cancer screening and offer culturally appropriate gift incentives. This type of outreach is supported by the Community Preventative Service Task Force for evidence-based recommendations to improve cancer screenings; other supported interventions are those that increase community demand, community access, and provider delivery of screening (CPSTF, 2021).

Interventions

A semi-structured interview occurred with eligible individuals who responded to recruitment emails, clinic posters, and social media posts. Interview questions were formulated in collaboration with stakeholders and focused on overall health care experience, sharing the individual experience with cervical cancer screening (outreach, procedure, and results), and ideas to help improve screening rates. Participants were honored for their time with a $20 gift card and Pendleton® tote bag.

Study of the Intervention

This qualitative participant study will provide direct patient feedback for tribal health clinic providers and leadership (Tribal Health Board). Identifying current facilitators and challenges aims to help increase access to cervical cancer screening.

Measures

The process measures are the total number of participants and primary demographics (age, tribal affiliation, distance from the clinic, and location of last Pap).

Analysis

Data analysis began with interview recording after obtaining verbal consent. Researchers used Rev©, a human transcription service, and two reviewers to complete line-by-line coding analysis to reduce bias. Delve©, a computer-assisted qualitative analysis software (CAQA), helped generate codes and thematic analysis.

Ethical Considerations

It is important to note that, in addition to the historical trauma due to colonialism and genocide, more recent events (misusing blood specimens, religious items, and forced sterilization) have rightly so, created mistrust between AI/AN communities and research teams (Pacheco et al., 2013). Having this in mind, any study with tribal communities must respect history, place, culture, protocol, and tribal laws (NCAI, 2012). Cervical cancer screening is a sensitive topic, even more, when sharing personal experiences. Due to this, the verbal consent process is transparent that participants can stop the interview, may decline to answer any

questions, and access behavioral health resources. The study was submitted to the OHSU Investigational Review Board (Study #00023297) and was deemed not to be research involving human subjects and did not need further review.

Results

A total of thirteen interviews were conducted via telephone between October-November 2021. All participants self-identified as female, and many of the participants were Cowlitz Tribal members (n=10), one was of another tribe (n=1), and two were non-native. The majority of the participants were over the age of 50 (n=10), and a total of five participants received cervical cancer screening at the clinic; the rest had a screening at outside clinics. Over half of the respondents (n=8) lived farther than 20 miles away from the clinic, and five lived within a 20-mile radius. After thematic analysis, six main themes emerged from the lived experience of the participants as follows.

Theme 1: Patient Access

This broad theme regards clinic hours, outreach, advertising, and other special topics (see Appendix A). Underlying this theme were interview questions about overall clinic experience, cervical screening outreach, and scheduling.

Facilitators. Instagram posts, flyers, and specialized outreach for cancer projects were received most if one lived >20 miles away. The front desk customer service and prompt scheduling received high remarks. Words such as compassionate, kind, positive, and caring were mentioned regarding the overall clinic experience. Receiving cultural-centered care was a key motivator for one patient stating, “It’s the one place I feel truly comfortable; it is in part of it being a tribal clinic.”

Challenges. Ten participants were concerned about not receiving clinic reminders or outreach. One participant of another tribe states, “so, they really haven’t reached out to me anymore,” after a few years of not seeking care. Most Tribal members (n=9) did not know what medical services were provided, such as current providers, services offered, and contact information. For example, one tribal member stated, “I honestly have no idea what providers, or

what they provide…It would be nice to know what services exactly are offered." Also mentioned are improving outreach to those without technology access and providing menopause support and education.

Theme 2: Location

Facilitators. An unexpected subtheme was the interest in medical services in DuPont, Washington. A Cowlitz Tribal member living >20 miles further explains, "I haven't quite heard that yet, but there is that capability, and DuPont's only about 20 minutes away from me." Notably, other tribal members sought care at the clinic, and Cowlitz Tribal members sought care at other Washington tribal clinics due to travel distance, highlighting the importance of tribal partnerships.

Challenges. Participants identified transportation issues, travel distance, gas cost, and childcare coverage as barriers when considering appointments for screening. As mentioned by one tribal member who lives >20 miles, "So it kind of limits me to be able to go to my own tribes' services because of transportation and limited driving." As previously highlighted, over half interviewed lived greater than 20 miles from the clinic. Two Cowlitz Tribal members (over age 50) voiced financial concerns when living greater than 20 miles from the clinic, "We're all paying out of pocket expense here in this area."

Theme 3: Healthcare provider

Systems that involve the HCP emerged here, including relationship/trust, pap procedure, relaying results, and turnover.

Facilitators. The HCP made the Pap experience positive with a clear explanation, having appropriate equipment and gowns for various body types. A participant explains how a provider utilized a patient-centered approach, "She explained what she was doing every step of the way." A notable finding is that all participants who had a positive pap experience completed these at the Cowlitz Indian Tribal Health Clinic.

Challenges. Over half of the participants mention the importance of empathy, having informed consent, and access to a female provider as ways to improve trust; a Cowlitz Tribal

member highlights, "Make it comfortable for them, let them know there is a female there that can do these [procedures].” The following quote depicts staff turnover: “The thing that bothers me is every time we get a really good practitioner, they quit.” Apprehension surrounding the procedure was also common, as depicted here, "I was just dreading it because they always…they just hurt.” Lastly, two participants were unaware if they were due for post-hysterectomy screening, which yields documentation of exit criteria from the HCP and patient education.

Theme 4: Cultural Aspects

On an intrapersonal level, concern for cancer was frequently mentioned (n=13) with a sense of worry by one participant; "But just that scare thinking I did have cancer was enough for me". A Cowlitz Tribal member emphasized the importance of culturally inclusive care both inside and outside of the clinic:

> I think as indigenous people, we really have a hard time being heard. It can take a lot for us to be able to articulate what's going on in a way that makes sense both to the person experiencing it and the person who's supposed to be providing help. And I think there's a disparity, whether it's communication or cultural relevance, definitely my experience as an Indigenous woman outside of a tribal clinic is really, really hit and miss.

Theme 5: Knowledge as Power

All participants were aware of the importance of cervical cancer screening and sought to ameliorate barriers by noting the importance of early cancer detection, the value of talking circles to share and collaborate solutions, and the importance of generational knowledge. Comments include: “I love that you want to hear from people because I support data-driven decision making, especially when you’re capturing the voice of the people that you’re serving,” and another advocating for improving screening for everyone, “But I do think an overall women’s health and having information being provided to other women within the tribe, I think there are many others that don’t really get the appropriate care they need.”

Theme 6: Solutions from Participants

Comments on ideas to reduce barriers include community outreach (n=8), integrated services (n=6), providing naturopathic services (n=5), increasing technology services such as MyChart and telehealth (n=4), and utilizing mobile services (n=1).

Discussion

Themes found in this study align with cultural, geographical, socio-economical, and policy barriers found in AI/AN cancer screening literature. Emerging facilitators in the first two SEM rings (intrapersonal/interpersonal) include cervical cancer screening knowledge and cultural access barriers and prioritizing screening access to eligible AI/AN individuals. Challenges arising in these individual rings include transportation issues (>20 miles), financial costs (>50 years), the concern of cancer, painful procedures, and unawareness of medical services. With the high interest in offering medical services at the Dupont site, mobile or specialty clinics could alleviate this transportation burden, significantly impacting screening rates (Burhansstipanov et al., 2017). Other individual and interpersonal level outreach can involve patient navigators to help remove barriers (CDC, 2013).

The organizational ring revealed both facilitators and challenges that impact screening. Evident by using a patient-centered approach at the clinic, all Pap procedures performed at the Cowlitz Indian Tribal Health Clinic were positive experiences. The clinic currently provides trauma-informed care to staff, which further supports this facilitator. There was an emphasis on the challenges of HCP turnover and preference for a female provider. Interaction with staff and scheduling had high remarks, yet the sense of outreach for screening was reported as a challenge and a solution. With the clinic already utilizing evidence-based interventions with birthday reminder cards, including an updated provider list and medical services could both acknowledge current services and providers available. The CPSTF model encourages a multicomponent intervention that can expand to HCP incentives, enhancing transportation, group education, and using alternative screening hours/sites, to name a few (see Appendix B).

The fourth circle of the SEM highlights the awareness of cervical cancer screening at a community level. Participants voiced the importance of cervical cancer screening and mentioned how others might not have this knowledge and lack access to available screening. A community-level intervention that aligns with participant solutions of integrating health services and transportation is a mobile health service and educational advertising campaigns on radio and Instagram platforms. The last ring examines state, local and tribal policies to promote cervical cancer screening, which did not reverberate in this study. Still, other Indigenous studies have found an underlying trauma in forced governmental policy on AI/AN communities in this final SEM ring (Sethi et al., 2021). Yet, grassroots activism across Indian Country has led to national and state task forces for Missing and Murdered Indigenous Women and People creating new avenues for tribes to restore the safety of AI/AN women and girls (Washington State Office of Attorney General, 2021).

Limitations

Using a qualitative study approach has limitations, such as human reviewers and limited validation of inter-rater reliability due to study timeline. With a small sample size, the results cannot be assumed to represent the Cowlitz Tribe accurately and are not generalizable to other tribes or populations. Using convenience sampling also limits recruiting those who have access to social media, a cell phone or landline, and the clinic waiting area. Not including the HCP perspective due to turnover and low-staffing set limitations to investigating specific clinic processes and procedural concerns. Future research to evaluate the in-clinic process and recruiting unique populations in which the Cowlitz Indian Tribal Health Clinic serves can help future policies and initiatives for cervical cancer screening efforts.

Conclusion

Findings from this study can serve as a sounding board for clinic and Tribal leaders to help align public health frameworks with future screening interventions. Prioritizing community-identified solutions within Indigenous health studies has been shown to have greater resonance for future policies (Sethi et al., 2021). The Cowlitz Indian Tribal Health Clinic

has a resilient community willing to work together to achieve the best health for current and future generations to come.

Funding

Gift incentives were provided by the NARA Breast and Cervical Cancer Screening and Early Detection program. The author paid for Rev© and Delve© services independently.

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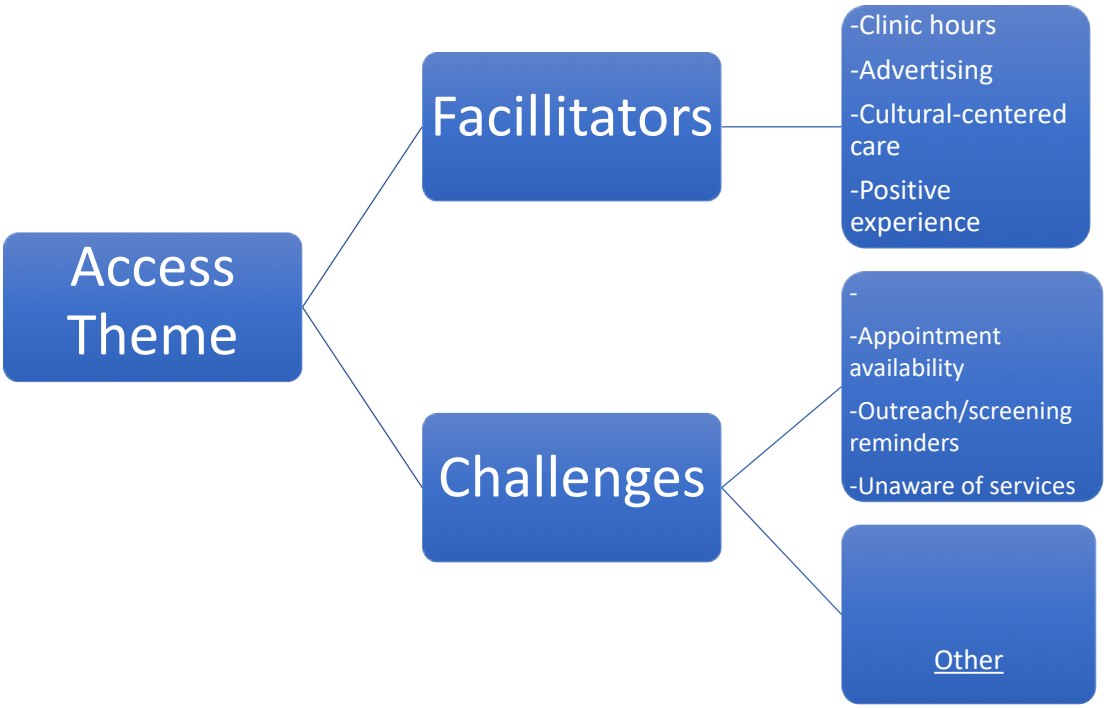
Appendix A

Access Theme and Subthemes



Appendix B

CPSTF Evidence-based Multicomponent Interventions

Cancer Screening Interventions by Strategy

Increase Community Demand	Increase Community Access	Increase Provider Delivery
○ Group Education ○ One-on-one Education ○ Client Reminders ○ Client Incentives ○ Mass Media ○ Small Media	○ Interventions to Reduce Client Out-of-Pocket Costs ○ Interventions to Reduce Structural Barriers • Reducing Administrative Barriers • Providing Appointment Scheduling Assistance • Using Alternative Screening Sites • Using Alternative Screening Hours • Providing Transportation • Providing Translation • Providing Child Care	○ Provider Reminders ○ Provider Incentives ○ Provider Assessment and Feedback

Appendix C

Project Timeline

	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec-Mar
Finalize project design and approach (703A)	X							
Complete IRB determination or approval (703A)		X						
Study site visit		X						
Meeting's w/ clinic & NARA Finalize interview questions/ computer & recording software training			X	X	X			
Begin interviews						X	X	
Thematic analysis								X
Write sections 13-17 of final paper (703B)								X
Prepare for project dissemination (703B)								X

Appendix D

IRB Approval Letter

IRB MEMO

Research Integrity Office
3181 SW Sam Jackson Park Road - L106RI
Portland, OR 97239-3098
(503)494-7887 irb@ohsu.edu

NOT HUMAN RESEARCH

August 19, 2021

Dear Investigator:

On 8/18/2021, the IRB reviewed the following submission:

Title of Study:	Identifying Cervical Cancer Screening Challenges at a Tribal Health Center: A Qualitative Patient Perspective
Investigator:	Jonathan Soffer
IRB ID:	STUDY00023297
Funding:	None

The IRB determined that the proposed activity is not research involving human subjects. IRB review and approval is not required.

Certain changes to the research plan may affect this determination. Contact the IRB Office if your project changes and you have questions regarding the need for IRB oversight.

If this project involves the collection, use, or disclosure of Protected Health Information (PHI), you must comply with all applicable requirements under HIPAA. See the HIPAA and Research website and the Information Privacy and Security website for more information.

Sincerely,

The OHSU IRB Office

Appendix E

Site Letter of Support

Letter of Support from Clinical Agency

Date: 3/21/2022

Dear Annette Sampson ,

This letter confirms that I, *Stephanie Moyers*, allow *Annette Sampson* (OHSU Doctor of Nursing Practice Student) access to complete his/her DNP Final Project at our clinical site. The project will take place from approximately July 2021to *June 2022*.

This letter summarizes the core elements of the project proposal, already reviewed by the DNP Project Preceptor and clinical liaison (if applicable):

- **Project Site(s)**: *Cowlitz Indian Tribal Health Clinic, 1044 11th Ave, Longview, WA 98632*
- **Project Plan: Use the following guidance to describe your project in a brief paragraph.**
  - Identified Clinical Problem: : Cervical cancer is preventable with well-studied screening interventions and effective vaccination. For American Indian and/or Alaska Native (AI/AN) people, cervical cancer diagnosis carries a higher mortality rate than non-Hispanic Whites
  - Rationale: *The Cowlitz Indian Tribal Clinic is utilizing evidence-based improvement tools, and this project hopes to utilize a patient perspective to help guide future efforts by identifying current facilitators and challenges in relation to the prevention framework of the social-ecological model.*
  - Specific Aims: *Identify current facilitators and challenges to cervical cancer screening.*
  - Methods/Interventions/Measures: *Process measures are the total number of participants and primary demographic collection (age, tribal affiliation, distance from clinic and location of last pap smear).*
  - Data Management: *Convenience sampling and de-identification will be done by the researcher. Qualitative analysis with recording and use of computer-assisted qualitative analysis software will help generate codes and thematic analysis.*
  - Site(s) Support: *Posting recruitment flyer on social media and advertising in clinic. Space is provided at the clinic for those requesting in-person interviews.*
  - Other: *Presentation of results to the Cowlitz Indian Tribal Clinic staff, and the Cowlitz Indian Tribal Council.*

During the project implementation and evaluation, *Annette Sampson* will provide regular updates and communicate any necessary changes to the DNP Project Preceptor.

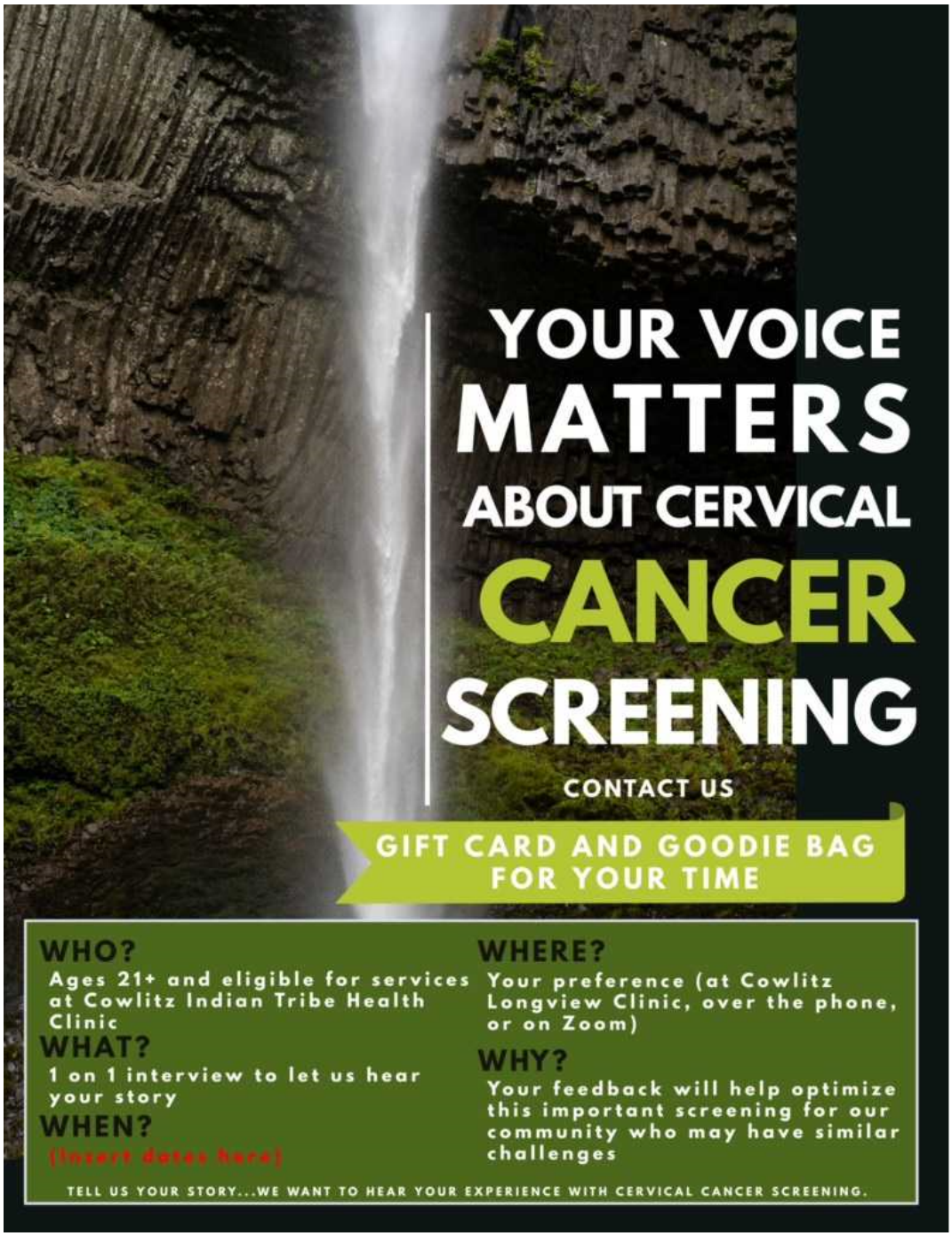
Our organization looks forward to working with this student to complete their DNP project. If we have any concerns related to this project, we will contact *Annette Sampson* and *Jonathon Soffer* (student's DNP Project Chairperson).

Regards,

Stephanie Moyers	Medical Clinic Manager
DNP Project Preceptor	Job Title
S.Moyers	6/22/2021
Signature	Date Signed

Appendix F

Recruitment Poster



Appendix G

Recruitment Poster

YOUR VOICE MATTERS

ABOUT CERVICAL CANCER SCREENING

Tell your story...We want to hear your experience with cervical cancer screening.

Who?

- Ages 21+ and eligible for services at Cowlitz Indian Tribe Health Clinic

What?

- 1 on 1 interview to let us hear your story

When

- (insert dates here)

Where

- Your preference (at Cowlitz Longview Clinic, over the phone, or on Zoom

Why

- Your feedback will help optimize this important screening for our community who may have similar challenges

Contact Us

Gift card and goodie bag for your time!