

Exploring Somali American Women's Experiences and Perceptions of HPV Self-Sampling

Ayantu Tolessa

A thesis

submitted in partial fulfillment of the
requirements for the degree of

Master of Public Health

University of Washington

2025

Committee:

Paul Fishman

Rebekah Pratt

Megha Ramaswamy

Program Authorized to Offer Degree:

Health Systems and Population Health

©Copyright 2025

Ayantu Tolessa

University of Washington

Abstract

Exploring Somali American Women's Experiences and Perceptions of HPV Self-Sampling

Ayantou Tolessa

Chair of the Supervisory Committee:

Paul Fishman

Health Systems and Population Health

Background: Cervical cancer is preventable through regular screening, yet Somali American women face significant barriers that contribute to low screening rates and delayed diagnoses. These barriers include limited knowledge, stigma, language barriers, and cultural norms. Human Papillomavirus (HPV) self-sampling is an emerging alternative to in-clinic screening, offering privacy and convenience that may help overcome these challenges. This study explores Somali American's experiences with HPV self-sampling using the Socio-Ecological Model to identify factors at the individual, interpersonal, and community levels that influence screening participation. Findings aim to inform culturally relevant strategies to increase screening uptake and reduce health disparities. By understanding barriers and facilitators through the socio ecological lens, this research supports the development of more equitable cervical cancer prevention efforts.

Methods: We conducted a secondary analysis of qualitative data from the Isbaar Study, a 2022 NIH funded project led by the University of Minnesota. The study held 6 focus groups with 44 Somali American women aged 30-65 in Minnesota to explore knowledge, experiences, and decision making around HPV self-sampling. Discussions were audio recorded and transcribed. NVivo software was used to apply deductive coding guided by the Socio-Ecological Model across individual, interpersonal, and community levels. Thematic analysis identified key barriers and facilitators to screening. Additionally, the analysis guided the creation of personas and empathy mapping to capture recurring patterns in participants' experiences by organizing responses into five categories: says, thinks, does, and environment.

Results: Thematic analysis revealed four key themes shaping Somali Americans women's perspectives on cervical cancer screening and HPV self-sampling: 1) limited knowledge and varying attitudes toward screening, 2) preferences shaped by personal experiences with Pap smears and interest in self-sampling, 3) the influential role of healthcare providers and peer support, and 4) cultural and societal norms impacting screening behavior. To further capture participant experiences, six personas were developed using empathy mapping, capturing the behaviors and needs related to HPV self-sampling. These ranged from individuals unfamiliar of screening to proactive screeners and peer advocates to highlight the variation in screening decision making.

Conclusion: This study highlights the experiences and barriers Somali American women face regarding cervical cancer screening. Using the Socio-Ecological Model, personas, and empathy mapping, key factors influencing screening behavior were identified. Findings shown the importance of community informed strategies and expanding access to HPV self-sampling to reduce screening disparities.

Introduction

Regular screening is the most effective strategy for identifying and treating early-stage cervical cancer^[1], the primary cause of which is the Human Papillomavirus (HPV). National guidelines recommend screening for individuals with a cervix every three years beginning at age 21^[2].

Almost all (83%) of screening for cervical cancer is achieved through a Pap smear or cervical cytology done during a pelvic exam, during which a small sample of cervical cells is collected.

Women typically experience discomfort during the procedure, and although Pap smears can produce up to 20% false-negative results, regular screening has been shown to significantly reduce cervical cancer related mortality.

Disparities in Screening

Despite the safety and effectiveness of screening for cervical cancer, there are significant disparities among women of color and immigrant populations in the use of this preventive health service.^[3] White women have the highest rates of cervical cancer screening relative to women of color^[4] ^[5]. However, Hispanic and Black women tend to have higher rates of colposcopy, a procedure required after an abnormal Pap test result^[6]. Women of color are also more likely to be diagnosed at a later stage of cervical cancer, which may be due to the lack of guideline adherent screening intervals. Poorer outcomes regarding both screening and early detection of cervical cancer among immigrant women are likely due to additional social, cultural, and language barriers that impact access to and effective use of health and preventive services ^[7] ^[8].

Self-sampling for HPV testing has emerged as an alternative to traditional screening methods for all women but particularly for underserved and immigrant communities, for whom traditional

screening modalities have poor uptake.^[9] This method allows women to collect their own samples privately at home, which can help reduce discomfort, preserve modesty, and overcome clinic-related barriers.^{[10] [11]}

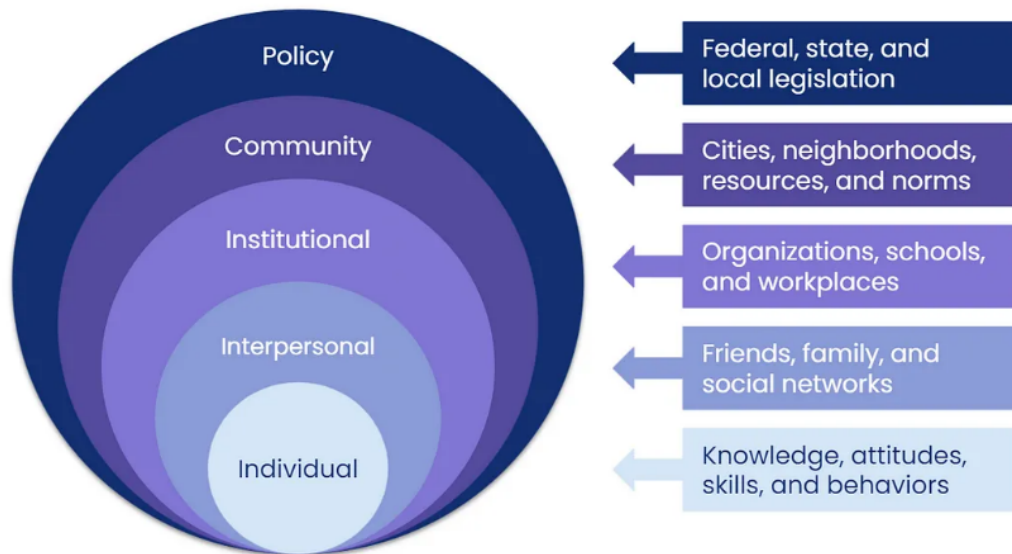
Although low rates of cervical cancer screening are found among people of color and immigrants to the United States, the lowest screening rates for any group of American women is among immigrants from Somalia.^{[12] [13]} Low screening rates have led to a disproportionate burden of cervical cancer, resulting in it being the second leading cause of death among Somali-American women between the ages of 15 and 44.

These disparities in screening rates and poor cervical cancer outcomes are the result of several factors included limited access to health care services, lack of familiarity with the healthcare system, negative past experiences with health care both in the United States and Somalia, patient-provider discordance and modesty norms given the Islamic faith to which may Somalian women adhere.^[5] For many Somali women, screening is not part of their routine care but is only considered during pregnancy or when symptoms arise.

Given the disparities in receipt of a critical health care service, we seek to better understand the barriers that women from Somalia experience, and by extension the broader experience of women facing similar disparities, in receiving recommended cervical cancer screening. By identifying these barriers we hope to provide input to developing interventions designed to address these barriers and ensure that all women have access to critical health care services.

Theoretical Foundation

Our research is guided by the Socio-Ecological Model (SEM) ^[14], represented in Figure 1, which provides a comprehensive framework for examining how health behaviors are simultaneously shaped by individual, interpersonal, and community factors. Applying the SEM provides the foundation for an exploration among the intersecting and overlapping influences, such as personal beliefs, provider relationships, cultural norms, and community dynamics that likely impact decision making around cervical cancer screening for Somali American women. The SEM model has been used in prior research to look at health disparities^[15], but it remains underutilized in studies focusing on immigrant populations and HPV self-sampling. By using this model to the qualitative data from Somali American women, our study can capture the complexity of lived experiences across the socioecological levels. This approach also helps differentiate the facilitators and barriers for each of the levels. Below, we identify the barriers that Somali American women face in receiving cervical cancer screening through the lens of the SEM.



Individual Level

At the individual level, Somali women may lack knowledge about HPV, cervical cancer, and the purpose of screening. Many may fear pain, discomfort, or potential diagnoses. ^[16]

Misunderstandings about what Pap smears involve, lack of awareness about the HPV cancer, and unfamiliarity with screening guidelines are all significant barriers. Research suggests that misunderstandings about reproductive health, uncertainty about the safety or accuracy of screening methods, and unfamiliarity with screening guidelines are all challenges within the immigrant community^{[17] [18]}.

Interpersonal Level

On the interpersonal level, communication between patients and providers plays a crucial role. [19]. Somali women have reported that providers often fail to explain that a Pap smear is being performed or do not offer sufficient information in a culturally or linguistically appropriate way^[11]. The lack of transparency can lead to confusion, mistrust, and discomfort.

In some cases, the absence of professional interpreters or family members present for translation limits effective communication, reduces privacy, and contributes to misunderstandings ^[20].

Women may not fully understand why screening is needed or what the results mean, which can deter them from participating in future screening. But on the other hand, when providers engage using trained and or visual aids, women feel more respected, empowered, and are more likely to engage in preventative care ^{[21] [22]}.

Community Level

Community norms, religious beliefs, and stigma also shape women's attitudes toward screening ^[23]. In Somali communities, conversations about reproductive health may be prohibited, and fear of judgment can discourage participation. The lack of visible community-based health education on cervical cancer leads to low awareness and screening hesitancy.

Recent studies have explored the cultural and social factors influencing HPV self-sampling among immigrants. For example, a qualitative study conducted semi-structured interviews with both Canadian and international cancer screening healthcare providers and policymakers to identify the facilitators and barriers to implementing HPV self-sampling in Canadian populations ^[24].

A scoping review was conducted to identify effective strategies for implementing self-sampling and engaging under screened populations. The study focused on Indigenous people, recent

immigrants, and individuals living in rural areas. It found that involving trusted community leaders was an effective strategy for successful recruitment and engagement across these diverse populations.^[24]

HPV Self-Sampling as an Emerging Solution

This study examined the use self-sampling to increase cervical cancer screening rates, while addressing the barriers that Somali immigrants experienced during clinical visits. Sewali et al.(2015) conducted a study between November 2013 and February 2014, involved Somali community health workers (CHWs) and recruited participants fluent in both Somali and English. The primary outcome was the successful completion of screening tests within three months of enrollment. The study found that the HPV self-sampling method was highly convenient for participants, who also expressed trust in the accuracy of the results. Somali community health workers introduced self-sampling to bilingual Somali women. Participants have found the method convenient and expressed trust in its accuracy.^[13]

Similarly, another study found that involving trusted community leaders and delivering education through familiar channels helped boost engagement in self-sampling programs among immigrants and rural communities.^[25] By incorporating self-sampling as a screening option will help reach individuals who usually delay or opt out of in clinic cervical cancer screening. Research has identified barriers and facilitators of self-sampling, including the convenience and time saving aspects of the method. ^[26] Participants appreciated being able to avoid long wait times at clinics, making the process more feasible within their routines.

Several other semi-structured interview studies in Canada have also highlighted significant gaps within the U.S. healthcare system regarding HPV self-sampling.^[7] The process for self-sampling for HPV provides where women would receive their tests through mail. Then after collecting the sample, they would then send the kits back to the lab for HPV testing. This method is very similar and modeled after the at home fecal occult blood test.

Indigenous, newcomers, and rural communities have been accepting self-sampling because it has helped reduce their experiences when accessing health services ^[25]. A user centered design approach prioritizes patients and ensures their needs are met ^[27]. Utilizing personas allows researchers to identify and categorize participants based on shared characteristics, while empathy maps provide deeper insights into their attitudes, behaviors, and experiences. For example, physician care personas have been used to better understand the characteristics, needs, and perspectives of primary care physicians^[28]. Using personas and empathy maps allows researchers to use a multi-level approach design to represent a range of experiences and knowledge levels.

Study Purpose

This study aims to explore how Somali American women experience cervical cancer screening and perceive HPV self-sampling, with the goal of identifying opportunities to improve cervical cancer screening rates. By using the Socio-Ecological model, this research seeks to better understand the barriers and facilitators of screening at the individual, interpersonal, and community level. The findings will help inform the development of personas and empathy maps, tools from user centered design to help target culturally tailored interventions and engagement

strategies to reduce screening disparities and ultimately improve health outcomes for Somali American women. The research aims are:

Aim 1: Using the socioecological model to conduct a thematic analysis of six focus groups with Somali American women exploring their views on cervical cancer screening and HPV self-sampling

Aim 2: Using a user centered design approach develop personas and empathy maps to inform the future development of a range of strategies and approaches to engaging Somali American patients in cervical cancer screening.

Methods

Study Design

This study used qualitative data from a prior project called the Isbaar Study. This study conducted focus groups with Somali women in 2022 as part of a study that assessed the effectiveness of the implementation of HPV self-sampling as a strategy to increase cervical cancer screening among Somali Americans. The Isbaar project was funded by the National Institute of Health. The project was led by the University of Washington and the University of Minnesota ^[29].

Data Collection

The Isbaar study conducted 6 focus groups with 44 Somali American women aged 30 to 65 residing in Minnesota, with each group consisting of 5 to 10 participants who were recruited

through flyers and by word of mouth^[30]. The discussions centered on the women's knowledge and experiences related to HPV self-sampling and in clinic cervical cancer screening, as well as the factors influencing their decision-making processes. Participants were also asked about potential impacts that might have shaped their experiences with HPV self-sampling. Facilitators guided the sessions and informed the participants of HPV self-sampling to explore participants' perspectives on cervical cancer screening and the various elements affecting their decisions. Participants were provided with details about the study and completed consent forms to be involved in the study. The discussions took place for an hour and were audio recorded.

Data Analysis

Focus group data was analyzed using two methods:

1. Thematic Analysis

NVivo software was used to deductively code the focus group transcripts following the completion of the IRB reliance process. Thematic analysis was conducted to identify key patterns and insights from the data. Codes was developed based on themes derived from the Socio-Ecological Model ^[14]. Once coding is complete, patterns and themes were identified across the transcripts to capture a comprehensive understanding of the barriers and facilitators influencing cervical cancer screening.

Using the socio-ecological model, we examined factors influencing HPV self-sampling at three levels: individual, interpersonal, and community. The individual level will focus on personal knowledge, perceptions, and attitudes toward cervical cancer screening, while the interpersonal

levels will explore the role of healthcare providers, family, and peer influences on screening decisions. The community level will examine cultural norms, stigma, and community driven promotion efforts.

By utilizing this framework, the analysis will provide a comprehensive understanding of the barriers and facilitators of HPV self-sampling among Somali American women. Identifying these factors will highlight opportunities for targeted interventions aimed to increasing screening participation and addressing challenges encountered.

2. Developing Personas/ Empathy Maps

As part of the qualitative analysis, we used a personas and empathy mapping approach^[31] to deepen our understanding of participants' experiences. This method involved organizing data into our four primary areas what participants *say, think, do, feel*. We adopted this approach to also add with an additional fifth category, *environment*, added to reflect the contextual influences shaping behavior. We developed personas on recurring patterns across the focus groups, aligning these insights with key themes that emerged during coding. This method helped illustrate diverse experiences and perspectives within the Somali American community and supported the interpretation of facilitators and barriers to HPV self-sampling.

Results

Thematic Analysis Findings

The analysis of the focus groups discussions revealed four main themes that shaped participants' perspectives on cervical cancer screening and HPV self-sampling: 1) knowledge, perceptions,

and attitudes toward screening; 2) preferences and experiences with different screening methods; 3) the influence of healthcare providers and interpersonal support; and 4) cultural and societal norms affecting screening decisions. These themes helped capture the complexity of decision making around cervical cancer screening among Somali American women.

Knowledge, Perceptions, and Attitudes Toward Screening

Many Somali immigrant women have limited awareness of HPV, cervical cancer, and the importance of regular screening, leading to misconceptions and doubts about both Pap smears and self-sampling. A lack of perceived personal risk for cervical cancer further discourages participation in screening and for some cervical cancer is only considered necessary during pregnancy care. One participant explained, “Yes, I took it after I had a baby, last year, when I was taking the check up after the baby. The doctor advised me to take it.” Fear and avoidance of screening are also common due to uncertainty about the procedure, concerns about pain, and general discomfort with the process. Another participant mentioned, “I have taken it. At my first pregnancy. It felt unbearable to me. I don’t know about other people, but it was unbearable to me, you know.” The fear of the screening process is also seen in the “Screening Hesitant” persona.

Many women felt uncomfortable or embarrassed discussing feminine health especially in mixed gender settings or in public. This discomfort makes it difficult for participants to seek screening. One participant mentioned, “Somali women were instilling doubt in me and asking me not to go; they said people are injected with diseases, you should be careful they might implant diseases in you, and because you are sick you can’t endure, don’t show your reproductive organ to doctors”.

These findings suggest that educational efforts must be using trusted messengers to help reduce fears towards screenings. By addressing the concerns, it can help improve Somali women's engagement in screening.

Preferences and Experiences with Screening Methods

Personal experience with Pap smears strongly influences women's attitudes toward screening, with some reporting positive interactions while others have had negative or uncomfortable experiences. A participant in the focus groups mentioned, "I wouldn't be comfortable doing this. First, my physician is a female and I would rather put up with her looking into my private parts than me inserting this stick." For women unfamiliar with Pap smears, uncertainty about the procedure can act as barrier to participation. Many express a preference for HPV self-sampling due to its convenience, privacy, and perceived ease of use, making it more acceptable alternative to clinic-based screening. One participant mentioned, "You may feel embarrassed, this will keep many things hidden and masked for us". Addressing screening related fears and hesitations is essential to increasing voluntary participation and ensuring that women feel comfortable and empowered in making screening decisions. Other participants in the focus groups mentioned past negative experiences where the process was either rushed or they were not given enough information. This tied with "Screening hesitant" persona where lack of information emerged as a concern.

These findings suggest that offering HPV self-sampling as a primary option through culturally appropriate message can increase the uptake among Somali women. Its critical to acknowledge

past negative experiences and present self-sampling as an alternative method to help address barriers.

Role of Healthcare Providers and Interpersonal Support

Healthcare providers play a critical role in influencing screening participation, but barriers such as language differences and limited patient provider communication can negatively impact trust and understanding. Effective use of interpreters and culturally competent communication can help bridge these gaps and improve women's confidence in the screening process. One participant mentioned, "I called an interpreter, and she told me you have to make an appointment right away. I went to the family doctor and told her 'This is what is happening.'" Additionally, peer support is a significant factor, as women are more likely to engage in screening when encouraged by trusted friends, family members, or community health workers. Peer-to-peer education and facilitator led discussions about self-sampling can further increase awareness and acceptance of this screening method.

Interpersonal relationships outside clinical settings influenced screening behaviors. One of the participants mentioned, "I will advise Somali women to do screening we have some shyness in us, but you are in new country, you are eating different food that you are not used to, you must screen yourself. Allah takes life. Health screening is an important thing." These findings suggest that interpersonal support like peer education are critical strategies to increase HPV self-sampling uptake among Somali American women.

Cultural and Social Influences on Screening Behaviors

Cultural and religious beliefs, including modesty practices, play a major role in shaping attitudes toward cervical cancer screening, with some women feeling uncomfortable with clinic-based exams. Stigma surrounding cervical cancer and screening procedures can also discourage participation, making community led education essential for changing perceptions. Fear and misconceptions about screening need to be addressed through culturally relevant and linguistically appropriate communication strategies. One of the participants suggested, “It will be great to have meetings like this one we have today, and to add TV programs, as well as raising awareness everywhere , especially it is widespread in our country, but in these advanced countries there are resources unless women choose not to do it.”. Increasing awareness through trusted community networks and health promotion efforts can help reduce anxiety and encourage greater engagement with self-sampling as a viable screening option.

Participants expressed that being examined by a male provider is unacceptable. One participant mentioned, “They feel shy and modesty, if the doctor is a man.” The importance of culturally sensitive care extends beyond clinical settings to the entire screening experience, from how information was delivered to how results were communicated.

Stigma surrounding cervical cancer was a significant barrier to screening uptake. Participants mentioned fear of being judged or misunderstood within their community if others knew they participated. One participant mentioned, “Somali women were instilling doubt in me and asking me to not go; they said people are injected with diseases, you should be careful they may implant disease in you, and because you are sick you can’t endure, don’t show your reproductive organ to doctors.” This aligns with the “Screening Hesitant and Screening Cautions” personas, whose

empathy maps reflected fear and uncertainty about screenings. Cultural and societal factors can create both barriers and opportunities for improving screening participation.

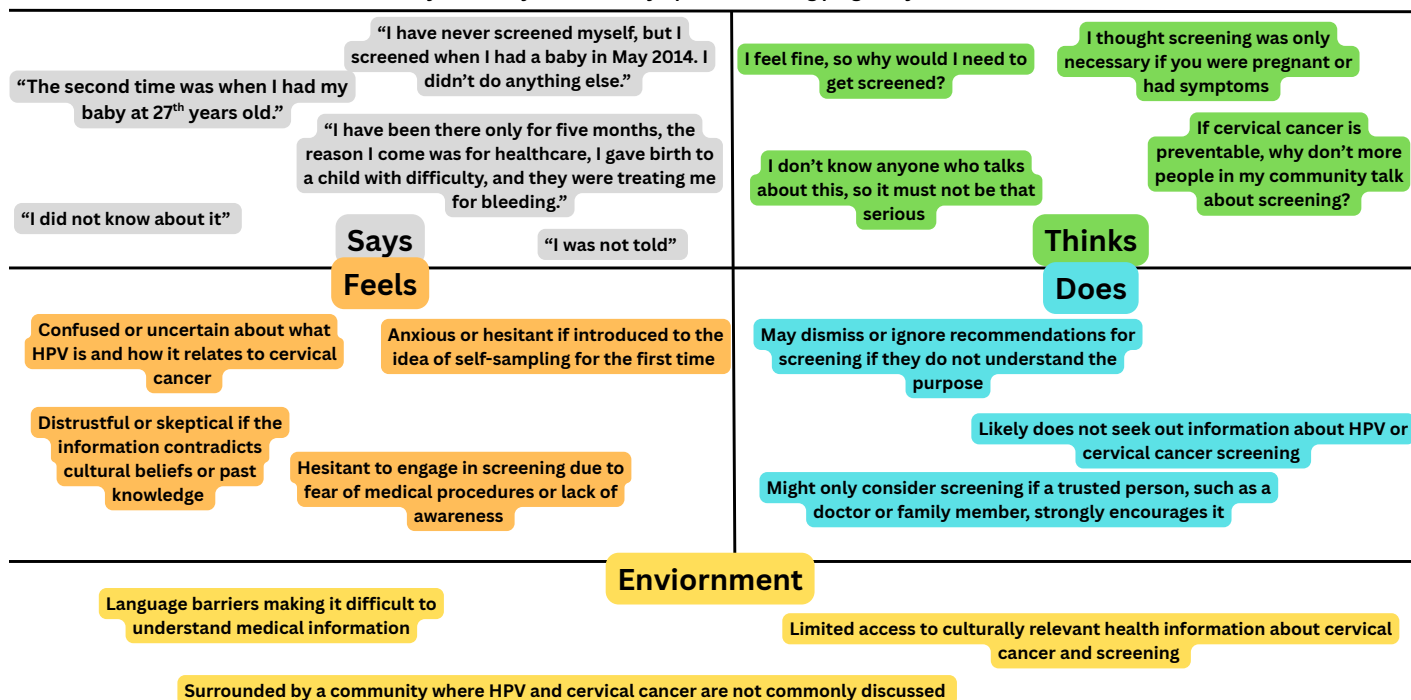
Personas and Empathy Maps

Six personas were developed following the thematic analysis of the focus groups. These personas were created to reflect the diverse experiences, attitudes, and behaviors of Somali women regarding cervical cancer screening and HPV self-sampling. Using an empathy map framework, each persona was examined through five ways: what the individual *says, thinks, feels, does*, and their *environment*. This approach helped bring to life the nuanced perspectives of participants and identify common barriers and facilitators to screening.

Unfamiliar Individual

This persona represented women who have never heard of HPV or self-sampling and had limited knowledge of cervical cancer. Their screening history was often tied to pregnancy, and they did not see routine screening as necessary unless they had symptoms. Their empathy map showed confusion, hesitation, and lack of access to culturally relevant health information that stemmed from language barriers and minimal community conversations on cervical cancer.

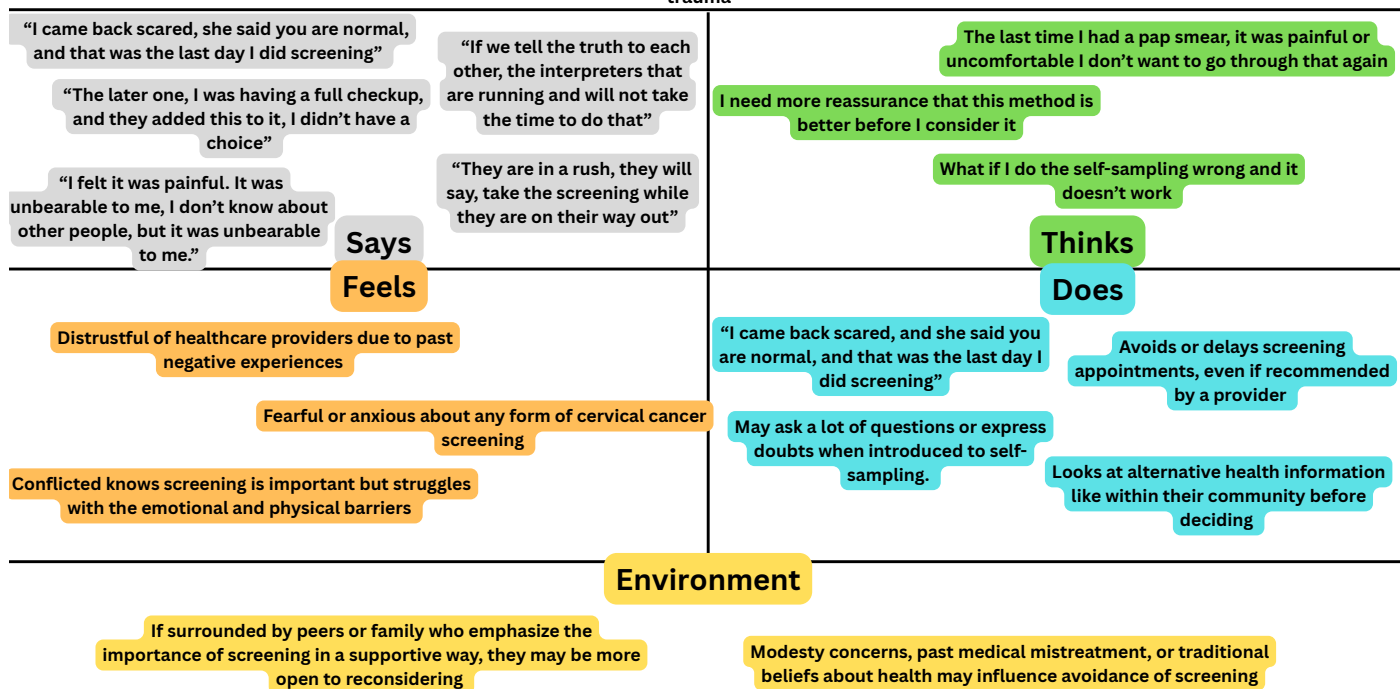
Unfamiliar individual: has never heard of HPV or self-sampling and has limited knowledge about cervical cancer, believing cervical cancer screening is only necessary if there are symptoms or during pregnancy care.



Screening Hesitant

These women had experienced discomfort or trauma during their previous experiences with Pap smears and were hesitant about all forms of screening. Their empathy maps reflected fear, distrust, and emotional discomfort tied to clinical screening procedures. Despite knowing screening is important, they expressed concerns about pain, lack of choice, and poor communication with providers.

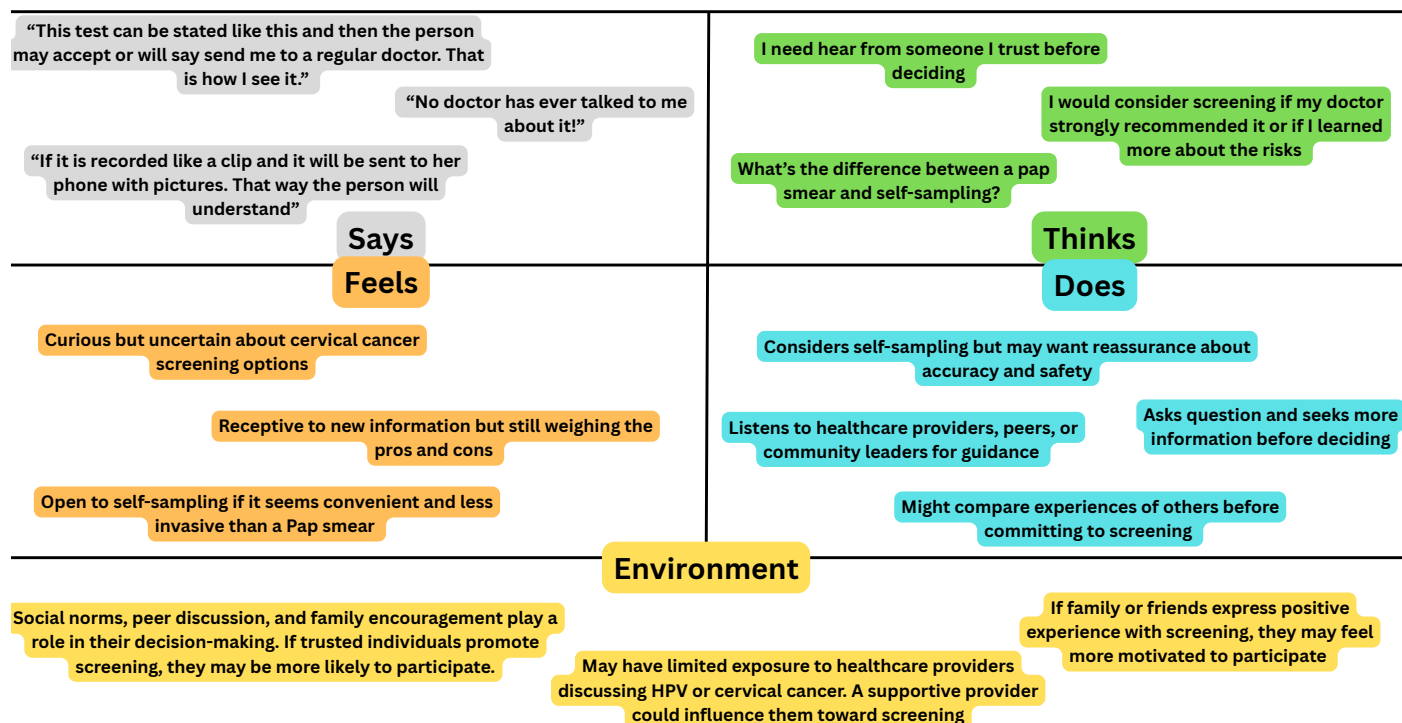
Screening Hesitant: has had a negative experience with Pap smear in the past and is hesitant about all screening options, has had experiences of pain or trauma



Screening Cautions

This persona included women who were open to screening but needed more information or reassurance before proceeding. They often expressed curiosity and willingness to participate if encouraged by a provider or trusted person. Their empathy map showed uncertainty and openness to alternative options like self-sampling, and the desire for accessible communication like visual aids.

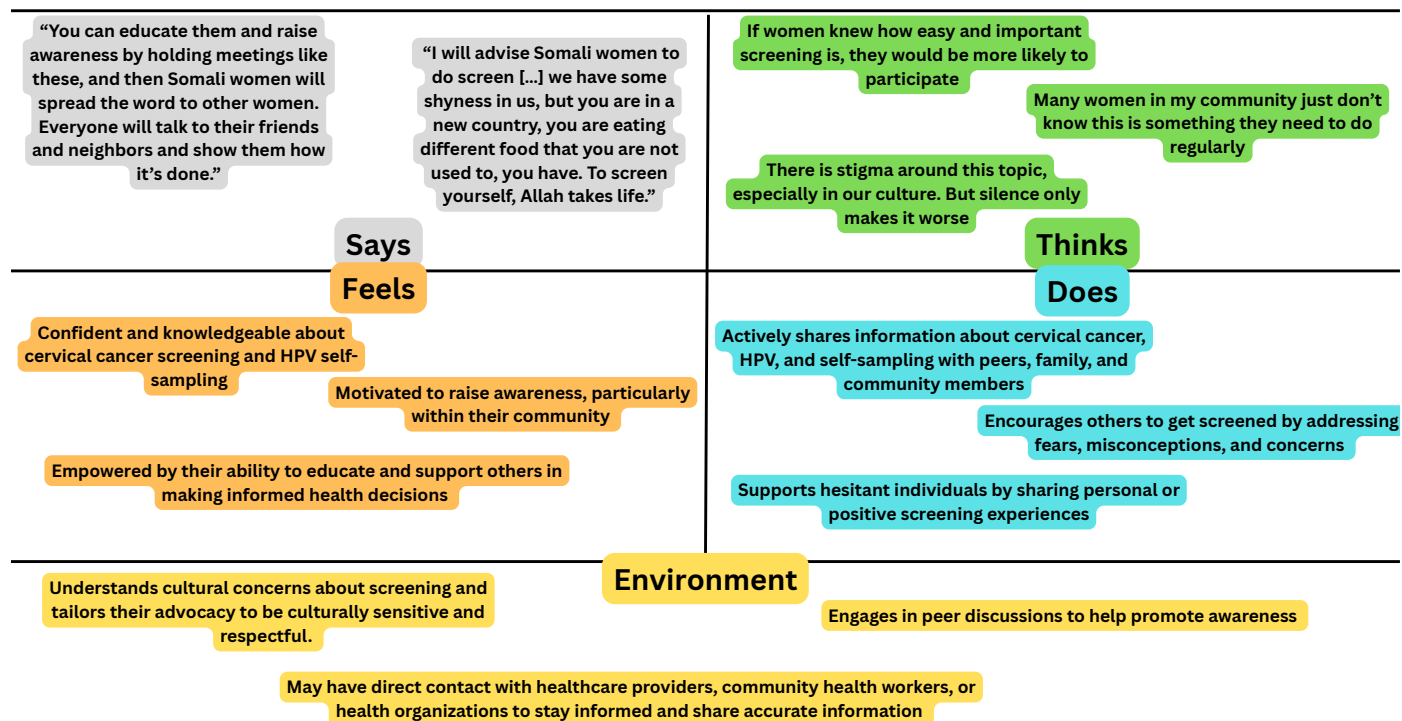
Screening Cautions: interested to learn more, would do screening if they had a reason to



Peer Advocate

This persona was well informed, these individuals actively encouraged screening within their communities. Their empathy maps highlighted empowerment, advocacy, and cultural awareness. They recognized the stigma around cervical cancer and worked to prevent misconceptions by educating peers through culturally sensitive conversations.

Peer Advocate: well informed about cervical cancer, understands the importance of screening, and educates peers on the importance of screening

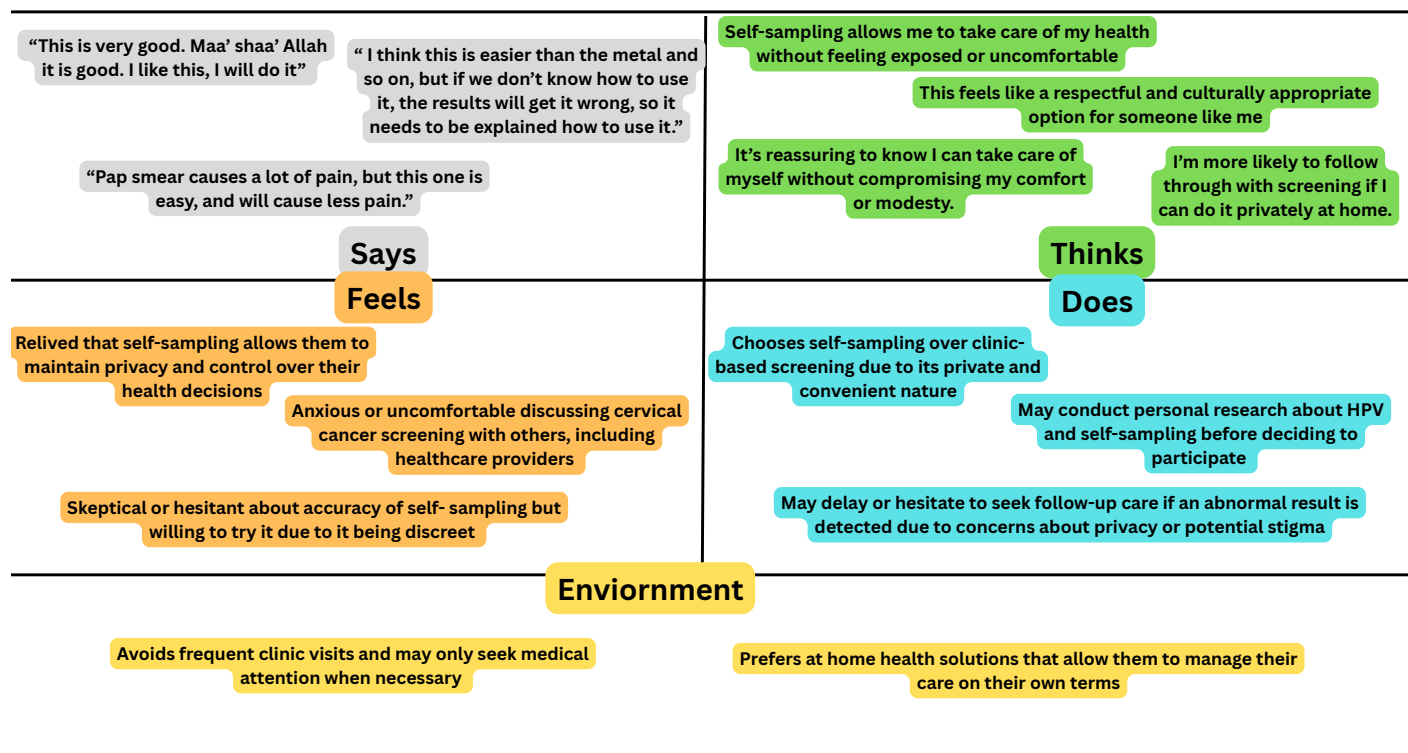


Discreet Participant

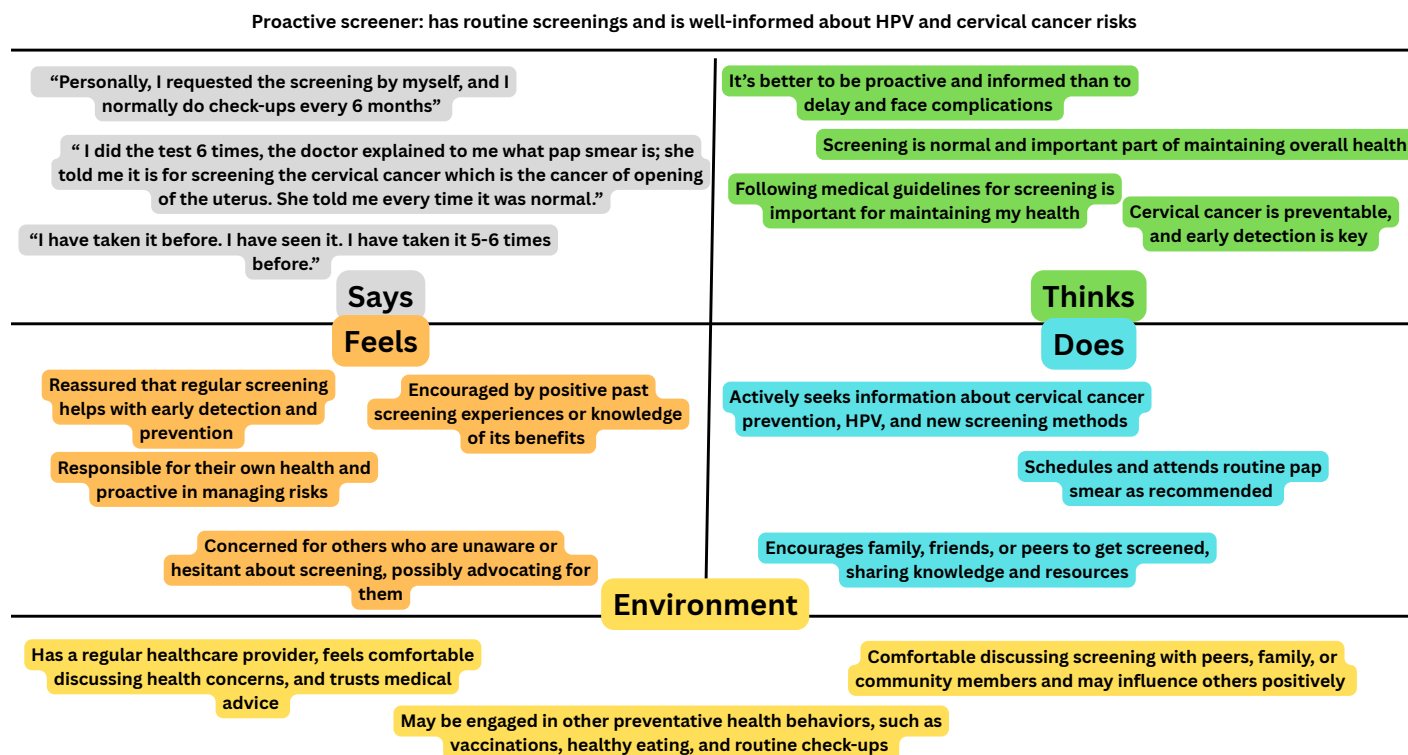
This group preferred self-sampling because it allowed them to maintain privacy, comfort, and modesty. Their empathy maps showed a strong desire to control their own health decisions.

While they appreciated the less invasive nature of self-sampling, they sought for clear instructions and assurance. Their health choices were influenced from modesty, privacy, and fear of stigma.

Discreet Participant: prefers self-sampling because it offers privacy

Proactive Screener

These women had consistent engagement with preventative healthcare and were well informed about HPV and cervical cancer risk. Their empathy maps showed confidence and trust in medical systems. They often encouraged others to screen and reported positive past experiences. This persona was a good example of how access and knowledge can support one's choice to be screened.



Discussion

The study addressed the research question of how Somali American women’s experiences with HPV self-sampling viewed through the lens of the Socio-Ecological Model influence their participation in cervical cancer screening programs. We learned that knowledge and comfort with the healthcare system strongly influenced screening behavior. Women who were more informed and engaged with health services were more likely to get screened. Most of the participants expressed a preference for HPV self-sampling over traditional Pap smears. This preference was rooted in the privacy that self-sampling provides, allowing women to perform the test in the comfort of their own space.

Our findings align with existing literature that mentions cultural, interpersonal, and systematic barriers to cervical cancer screening among immigrant women. Previous studies confirm that modesty, fear, and limited provider communication are recurring barriers. [13] [25] However, this study adds a new perspective by applying the Socio-Ecological Model to organize and contextualize these barriers across individual, interpersonal, community levels.

Incorporating personas and empathy maps offered us to look at a different lens for interpreting focus group data. These tools allowed us to distinguish patterns among participants, revealing what women say, do, think, and feel. By doing empathy maps helped highlight experiences across different levels of trust in the healthcare system, knowledge about HPV, and preferences for screening.

Given the response to HPV self-sampling, next steps should include expanding access to this method across more regions in the U.S., especially in communities with large Somali or other underserved immigrant populations. Public health efforts should work to integrate community health workers and trusted cultural leaders to deliver education and distribute self-sampling kits. Policies should work to support multilingual, culturally appropriate materials and outreach strategies that respect modesty.

Limitations

The study was conducted exclusively in Minnesota and included only Somali American women living in that region, which may limit the generalizability and the findings to other geographic settings or Somali communities elsewhere. Additionally, the study focused on women aged 30 to

65, although cervical cancer screening is recommended to begin as early as 21. Including younger adults' participation may have provided a broader perspective, especially since many younger Somali American women have grown up in the U.S. and may have different experiences, levels of awareness, or attitudes toward cervical cancer screening.

Conclusions

This study highlights the diverse experiences, beliefs, and barriers that Somali American face regarding cervical cancer screening and HPV self-sampling. By using a thematic analysis with the Socio-Ecological Model, incorporating personas, and empathy mapping, we were able to identify key factors at the individual, interpersonal, and community levels that shape screening behaviors. The findings emphasize the importance of community informed strategies to promote HPV self-sampling as an alternative to clinic-based screening. By expanding access to self-sampling and tailoring outreach to meet the needs of different community can help reduce disparities in cervical cancer prevention.

References

1. OKUNADE, K. S. (2020). Human Papillomavirus and Cervical Cancer. *Journal of Obstetrics and Gynaecology : The Journal of the Institute of Obstetrics and Gynaecology*, 40(5), 602–608. <https://doi.org/10.1080/01443615.2019.1634030>
2. Cervical Cancer Screening—NCI (nciglobal,ncicenterprise). (2022, October 13). [pdqCancerInfoSummary]. <https://www.cancer.gov/types/cervical/screening>
3. Spencer, J. C., Kim, J. J., Tiro, J. A., Feldman, S. J., Kobrin, S. C., Skinner, C. S., Wang, L., McCarthy, A. M., Atlas, S. J., Pruitt, S. L., Silver, M. I., & Haas, J. S. (2023). Racial and Ethnic Disparities in Cervical Cancer Screening From Three U.S. Healthcare Settings. *American Journal of Preventive Medicine*, 65(4), 667–677. <https://doi.org/10.1016/j.amepre.2023.04.016>
4. Malone, C., Barnabas, R. V., Buist, D. S. M., Tiro, J. A., & Winer, R. L. (2020). Cost-effectiveness studies of HPV self-sampling: A systematic review. *Preventive medicine*, 132, 105953. <https://doi-org.offcampus.lib.washington.edu/10.1016/j.ypmed.2019.105953>
5. Rosowicz, A., & Hewitt, D. B. (2025). Disparities in Cancer Screening Among the Foreign-Born Population in the United States: A Narrative Review. *Cancers*, 17(4), 576. <https://doi.org/10.3390/cancers17040576>
6. CDC. (2024, May 7). *Cervical Cancer Screening Among Medicare Beneficiaries*. *Cancer*. <https://www.cdc.gov/cancer/research/cervical-cancer-screening-among-medicare-beneficiaries.html>
7. Zeno, E. E., Brewer, N. T., Spees, L. P., Des Marais, A. C., Sanusi, B. O., Hudgens, M. G., Jackson, S., Barclay, L., Wheeler, S. B., & Smith, J. S. (2022). Racial and ethnic differences in cervical cancer screening barriers and intentions: The My Body My Test-3

- HPV self-collection trial among under-screened, low-income women. *PLoS ONE*, 17(10), e0274974. <https://doi.org/10.1371/journal.pone.0274974>
8. Ferdous, M., Lee, S., Goopy, S., Yang, H., Rumana, N., Abedin, T., & Turin, T. C. (2018). Barriers to cervical cancer screening faced by immigrant women in Canada: A systematic scoping review. *BMC Women's Health*, 18(1), 165. <https://doi.org/10.1186/s12905-018-0654-5>
 9. Elmore, C. E., Laughon, K., & Mitchell, E. M. (2020). Self-collection of samples for HPV testing to increase participation in cervical cancer screening by immigrant women: An integrative review. *Public Health Nursing*, 37(5), 677–695. <https://doi.org/10.1111/phn.12782>
 10. Tsegaye, A. T., Winer, R. L., Cole, A., Szpiro, A. A., Walson, J., & Rao, D. W. (2025). Modeling HPV Self-Sampling Impact on Cervical Cancer in East African Immigrants. *American Journal of Preventive Medicine*, 68(3), 508–517. <https://doi.org/10.1016/j.amepre.2024.11.012>
 11. Pratt, R., Szpiro, A., Fordyce, K., Lin, J., Weiner, B., Ghebre, R., Ramer, T. J., Bliss Barsness, C., Winer, R., Desai, J., Yohe, S., Ibrahim, A., & Winer, R. (2024). Somali American Perspectives on Human Papillomavirus (HPV) Self-Sampling to address Cervical Cancer Screening Disparities. *Annals of Family Medicine*, 22(Suppl 1), 6340. <https://doi.org/10.1370/afm.22.s1.6340>
 12. Ghebre, R. G., Sewali, B., Osman, S., Adawe, A., Nguyen, H. T., Okuyemi, K. S., & Joseph, A. (2015). Cervical Cancer: Barriers to Screening in the Somali Community in

Minnesota. *Journal of Immigrant and Minority Health*, 17(3), 722–728.

<https://doi.org/10.1007/s10903-014-0080-1>

13. Sewali, B., Okuyemi, K. S., Askhir, A., Belinson, J., Vogel, R. I., Joseph, A., & Ghebre, R. G. (2015). Cervical cancer screening with clinic-based Pap test versus home HPV test among Somali immigrant women in Minnesota: a pilot randomized controlled trial. *Cancer medicine*, 4(4), 620–631. <https://doi.org/10.1002/cam4.429>
14. Ewald, D. R., Orsini, M. M., & Strack, R. W. (2023). The path to good health: Shifting the dialogue and promoting social ecological thinking. *SSM - Population Health*, 22, 101378. <https://doi.org/10.1016/j.ssmph.2023.101378>
15. Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.). (2008). *Health behavior and health education: Theory, research, and practice, 4th ed* (pp. xxxiii, 552). Jossey-Bass/Wiley.
16. Afsah, Y. R., & Kaneko, N. (2023). Barriers to cervical cancer screening faced by immigrant Muslim women: A systematic scoping review. *BMC Public Health*, 23(1), 2375.
17. Luque, J. S., Mason, M., Reyes-Garcia, C., Hinojosa, A., & Meade, C. D. (2011). Salud es Vida: Development of a Cervical Cancer Education Curriculum for Promotora Outreach With Latina Farmworkers in Rural Southern Georgia. *American Journal of Public Health*, 101(12), 2233–2235. <https://doi.org/10.2105/AJPH.2011.300324>
18. Gele, A. A., Qureshi, S. A., Kour, P., Kumar, B., & Diaz, E. (2017). Barriers and facilitators to cervical cancer screening among Pakistani and Somali immigrant women in Oslo: A qualitative study. *International Journal of Women's Health*, Volume 9, 487–496. <https://doi.org/10.2147/IJWH.S139160>
19. Chorley, A. J., Marlow, L. A. V., Forster, A. S., Haddrell, J. B., & Waller, J. (2017). Experiences of cervical screening and barriers to participation in the context of an

- organised programme: A systematic review and thematic synthesis. *Psycho-Oncology*, 26(2), 161–172. <https://doi.org/10.1002/pon.4126>
20. Morrison, T. B., Wieland, M. L., Cha, S. S., Rahman, A. S., & Chaudhry, R. (2012). Disparities in preventive health services among Somali immigrants and refugees. *Journal of Immigrant and Minority Health*, 14(6), 968–974. <https://doi.org/10.1007/s10903-012-9632-4>
21. Fernández, M. E., Gonzales, A., Tortolero-Luna, G., Partida, S., & Bartholomew, L. K. (2005). Using intervention mapping to develop a breast and cervical cancer screening program for Hispanic farmworkers: Cultivando La Salud. *Health Promotion Practice*, 6(4), 394–404. <https://doi.org/10.1177/1524839905278810>
22. Hoyo, C., Yarnall, K. S. H., Skinner, C. S., Moorman, P. G., Sellers, D., & Reid, L. (2005). Pain predicts non-adherence to pap smear screening among middle-aged African American women. *Preventive Medicine*, 41(2), 439–445. <https://doi.org/10.1016/j.ypmed.2004.11.021>
23. Gele, A. A., Qureshi, S. A., Kour, P., Kumar, B., & Diaz, E. (2017). Barriers and facilitators to cervical cancer screening among Pakistani and Somali immigrant women in Oslo: A qualitative study. *International Journal of Women's Health*, Volume 9, 487–496. <https://doi.org/10.2147/IJWH.S139160>
24. Wood, B., Lofters, A., & Vahabi, M. (2018). Strategies to reach marginalized women for cervical cancer screening: A qualitative study of stakeholder perspectives. *Current oncology (Toronto, Ont.)*, 25(1), e8–e16. <https://doi.org/10.3747/co.25.3851>
25. Fullerton, M. M., Ford, C., D'Silva, C., Chiang, B., Onobrakpor, S. I., Dievert, H., Yang, H., Cabaj, J., Ivers, N., Davidson, S., & Hu, J. (2024). HPV self-sampling implementation strategies to engage under screened communities in cervical cancer screening: a scoping

- review to inform screening programs. *Frontiers in public health*, 12, 1430968.
<https://doi.org/10.3389/fpubh.2024.1430968>
26. Vega-Crespo, B., Neira, V. A., Maldonado - Rengel, R., López, D., Delgado-López, D., Guerra Astudillo, G., & Verhoeven, V. (2024). “Barriers and Advantages of Self-Sampling Tests, for HPV Diagnosis: A Qualitative Field Experience Before Implementation in a Rural Community in Ecuador.” *International Journal of Women’s Health*, 16, 947–960.
<https://doi.org/10.2147/IJWH.S455118>
27. De Vito Dabbs, A., Myers, B. A., Mc Curry, K. R., Dunbar-Jacob, J., Hawkins, R. P., Begey, A., & Dew, M. A. (2009). User-Centered Design and Interactive Health Technologies for Patients. *Computers, Informatics, Nursing : CIN*, 27(3), 175.
<https://doi.org/10.1097/NCN.0b013e31819f7c7c>
28. Personas: Primary care physicians. (n.d.). https://www.mcmasterforum.org/docs/default-source/rise-docs/partner-resources/hcsl_primarycarephysicianpersonastool.pdf?sfvrsn=aef557d5_3
29. Lin, J., Winer, R. L., Barsness, C. B., Desai, J., Fordyce, K., Ghebre, R., Ibrahim, A. M., Mohamed, S., Ramer, T., Szpiro, A. A., Weiner, B. J., Yohe, S., & Pratt, R. (2025). Design of a pragmatic trial integrating human papillomavirus (HPV) self-sampling into primary care to reduce cervical cancer screening disparities in Somali American individuals: The Isbaar project. *Contemporary Clinical Trials*, 148, 107754.
<https://doi.org/10.1016/j.cct.2024.107754>
30. Pratt, R., Barsness, C. B., Lin, J., Desai, J., Fordyce, K., Ghebre, R., Hassan, F., Ibrahim, A., Ramer, T., Szpiro, A., Weiner, B. J., Xiong, S., Yohe, S., & Winer, R. L. (2024). Integrating HPV self-collect into primary care to address cervical cancer screening

disparities. *Preventive Medicine Reports*, 38, 102599.

<https://doi.org/10.1016/j.pmedr.2024.102599>

31. Roybal, K. (2024, December 9). *Leveraging research-informed empathy maps and personas to inform the equitable implementation of multi-cancer early detection tests*. 17th Annual Conference on the Science of Dissemination and Implementation.

<https://academyhealth.confex.com/academyhealth/2024di/meetingapp.cgi/Paper/69134>

Appendix

Code	Code Definition	Notes
Individual Level		
Addressing screening phobia	Identifying strategies and approaches mentioned by participants to reduce fear, anxiety, or emotional discomfort related to screening	Patients expressed fears of pain, embarrassment, or potential negative results associated with screening
Avoidance of cervical cancer screening	Expressions of fear, discomfort, uncertainty, or lack of knowledge that contribute to avoiding or delaying screening	Participants shared emotional and cognitive barriers such as fear of pain, or not knowing what screening entails
Comfort with privacy screening	Positive attitudes or expressions of comfort related to completing self-sampling privately	
Concerns/doubts about self-sampling	Expressions of uncertainty, skepticism, or hesitation about the effectiveness, safety, or ability to correctly perform self-sampling	
Educating women about HPV self-sampling	Providing participants with clear information about the purpose, process, and benefits of HPV self-sampling to increase understanding and promote informed decision making regarding cervical cancer screening	
Limited understanding of pap smear	Participant shows minimal or incorrect knowledge about what a Pap smear is, its purpose, or how it's performed	
Negative experience with pap smear	Participant reports a past Pap smear experience that was physically or emotionally uncomfortable, painful, or traumatic	This experience can lead to long lasting fear, mistrust, or avoidance of future cervical cancer screening
No experience with pap smear	Participant reports never having had a Pap smear and/ or is unfamiliar with what the procedure involves	This may stem from limited healthcare engagement, or absence of communication from providers

Painless screening experience	Participant describes undergoing cervical cancer screening, without experiencing physical pain	These experiences may increase comfort and willingness to return to future screening
Positive experience with pap smear	Participant describes a Pap smear screening experience that was comfortable, reassuring, and contributing to a sense of trust in the process	
Prefer pap smear instead of self-sampling	Participant expresses a preference for clinic-based Pap smear screening over HPV self-sampling due to perceived accuracy, professional oversight, and comfort with clinic setting	Stem from trust in healthcare providers, reflect concerns about doing the test incorrectly or doubts about the effectiveness of self-sampling
Prefer self-sampling instead of pap smear	Participant expresses a preference for self-sampling over clinic-based Pap-smear screening due to greater privacy and convenience	Arise from past negative experiences with Pap smears and culture religious values related to modesty
Screening linked to pregnancy care	Participants reports having undergone cervical cancer only as part of prenatal or obstetric (OB) care, not as a routine or preventative health measure.	Some women may associate Pap smears solely with pregnancy related visits and may not seek screening outside of these contexts
Interpersonal Level		
Cultural norms	Beliefs and expectations within the Somali community that influence behavior, attitudes, and decision-making regarding health and cervical cancer screening	Participants might refer to be what is “shameful,” “private,” or “not talked about” in the community.
Facilitator guided self-sampling education	Instances where the facilitator provided explanations or demonstrations on how HPV self-sampling is done, including step by step instructions, clarifications of misconceptions, or answering participants’ questions	
Improving patient provider communication	Discussions or suggestions focused on enhancing the quality, clarity, or effectiveness of communication between	

	healthcare providers and patients	
Interpreter facilitated communication	Use of interpreter to support communication between healthcare providers and patients who do not share the same language	
Peer support	Encouragement, education, or influence from peers to engage in cervical cancer screening	
Peer to peer health promotion of self-sampling	Instances where participants encourage or educate one another about the importance of HPV self-sampling by emphasizing the benefits of proactive health behaviors	May include direct conversations, support, or advice given by one participant to another during focus groups
Role of provider	Participants' reflections on their interactions with healthcare providers, particularly regarding the communication and information shared about cervical cancer screening.	
Community and Organizational		
Community-led health promotion	Health education and awareness efforts led by trusted community members or organizations to promote cervical cancer screening among Somali women.	Participants emphasized the importance of receiving health information from familiar, culturally aware community figures
Culturally relevant communication methods	Participants suggest or describe communication strategies that are tailored to Somali cultural norms, values, and language to effectively promote cervical cancer screening.	Reflects the importance of culturally appropriate messaging to build trust and understanding
Increase awareness/education about self-sampling	Strategies or suggestions to improve understanding and knowledge of HPV self-	

	sampling among Somali women	
Reducing fears about screening	Identifying approaches or interventions to address and alleviate fear, anxiety, or discomfort related to cervical cancer screening.	
Religious or cultural modesty	Beliefs and practices rooted in religious or cultural values that emphasize modesty, regarding the female body, which may influence women's comfort with cervical cancer screening or discussion about reproductive health	
Social media as a health education tool	Using social media tools commonly used by Somali community to communicate the importance of screening	Ex: Facebook, radio stations, etc.
Stigma	Negative perceptions, shame, or judgement associated with cervical cancer screening, that may discourage individuals from participating in screening	May stem from cultural religious, or community norms that associate cervical cancer