

**Acceptance of human papillomavirus self-sampling in underserved and under-screened communities in Canada: a literature review**

Quinn Wonitowy, MPAS (Candidate), B.Sc.  
7808019  
wonitowq@myumanitoba.ca

Mentor: Lisa Moore, MPAS, CCPA, MFA  
Program Director: Rebecca Mueller, MPAS, CCPA, PA-C

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University of Manitoba  
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## **Abstract**

Cervical cancer is the fourth most common cancer among women. In Canada, the disease accounted for roughly 400 deaths from 1,550 diagnoses in 2017 alone. Nearly all cases of cervical cancer are due to persistent infection with human papillomavirus (HPV). Most cervical cancer cases can be prevented with screening, and those who develop cervical cancer tend to be classified as under-screened or never-screened. Often, these people belong to underserved groups such as immigrants, racialized individuals, and those living in rural communities. Traditional cervical cancer screening involves Pap (Papanicolaou) tests while self-sampling allows people with a cervix to collect their own sample, when and where they choose. This literature review examined Canadian studies exploring the acceptance of self-sampling amongst underserved populations. The findings of this review support the idea that most underserved and under-screened populations accept and support the idea of HPV self-sampling. Common reasons for acceptance of self-sampling included convenience, privacy, and timesaving. The most commonly reported concern was a lack of confidence in performing the test correctly. While the studies included in this review do not represent every underserved population in Canada, the results suggest that with proper education and support, HPV self-sampling could be a useful addition to cervical cancer screening in Canada.

## **Introduction**

Cervical cancer is the fourth most common cancer among women globally, disproportionately affecting younger women. (1) According to the World Health Organization, approximately 660,000 women were diagnosed with and 350,000 died from cervical cancer worldwide in 2022. In Canada, roughly 1,550 people were diagnosed with cervical cancer in 2017, with about 400 of those people dying from the disease. (2)

Nearly all cases of cervical cancer are due to persistent infection with human papillomavirus (HPV), a common sexually transmitted virus. (3) In fact, nearly all sexually active people will be infected with HPV at some point in their lives. (1) Generally, HPV infection can be cleared by the immune system, and people will be asymptomatic, but in cases of persistent infection by high-risk viral subtypes, — namely subtypes 16 and 18, which account for nearly all invasive cervical cancer cases (4) — abnormal cell growth and subsequent cancer can occur. (1)

Other risk factors for cancer development include immune compromise, the presence of other sexually transmitted infections, young age at first pregnancy, hormonal contraceptive use, and smoking. (1)

The majority of cervical cancer cases can be avoided with preventative steps, including screening. (3) Screening programs for cervical cancer can be effective since cervical cancer can often be treated successfully if detected early. (3) Treatments following a positive screening test can be simple and prevent the development of cervical cancer. (1)

Those who do develop cervical cancer tend to be classified as under-screened or never-screened, meaning they are either screened less often than is recommended or do not participate in

screening programs at all. (5) These commonly belong to underserved populations, including ethnic minority groups, people living in rural or remote areas, Indigenous communities, or those lacking access to a primary care provider. (6–9) In Canada and the United States, roughly two-thirds of invasive cervical cancers occur in people who are under-screened or never-screened. (10, 11)

However, cervical cancer incidence and mortality have decreased in Canada with the implementation of screening programs. (12) Between 2001 and 2010, cervical cancer mortality decreased by 2.3% per year, which is largely attributed to screening. (12)

Traditional cervical cancer screening involves Pap (Papanicolaou) tests, in which a healthcare practitioner performs a speculum exam to collect samples of cervical cells, which are then cytologically tested. Many countries, including Canada, have established effective screening programs based on the Pap test. (13) HPV testing is another method more recently adopted, wherein vaginal samples are tested for HPV DNA. This approach has been found to be just as effective as cytology-based methods and, in fact, outperforms Pap tests in the detection of high-grade cervical cancer in women over the age of 30. (2, 14)

A subcategory of this alternative method is HPV self-sampling, which allows people with a cervix to collect their own sample, when and where they choose. Samples are then tested in the same manner as those collected by a healthcare provider. (15) Studies have determined that HPV self-sampling is as reliable as healthcare provider-obtained sampling. (1)

Research has identified several advantages of HPV self-sampling over traditional Pap tests, including privacy, convenience, reduced embarrassment, cost-effectiveness, and increased

screening uptake. (16–18) HPV self-sampling is included in screening programs worldwide, including those in Australia, Finland, and the Netherlands. (19, 20) However, Canada’s screening programs are still largely based on cytology-based sampling (i.e., Pap tests). (15) Only recently, in 2024, has the province of British Columbia introduced self-sampling into its cervical cancer screening program. (21)

Individuals who are under-screened or never-screened for cervical cancer often belong to underserved groups such as immigrants, racialized individuals, and those living in rural communities. Barriers to care in these populations may include cultural factors, lack of access to a primary care practitioner, physical inaccessibility, and financial costs. (2)

HPV self-sampling can empower people with privacy, convenience, and comfort, and has the potential to make screening more accessible. However, few Canadian studies have examined the perspectives of those who could potentially benefit the most — those who are under-screened or who have never been screened for cervical cancer.

Research shows generally high acceptance and positive attitudes regarding HPV self-sampling. (2) Studies have been conducted on the reach of HPV self-sampling to communities in various Canadian provinces, including Newfoundland and Labrador (22), Ontario (9, 23, 24), Manitoba (25), and Saskatchewan (26). This literature review aims to investigate how HPV self-sampling has been accepted within underserved communities in Canada. The potential for self-sampling as a future option for cervical cancer screening depends upon community engagement and acceptance by patients.

## **Methods**

Searches were conducted in PubMed and Google Scholar in October 2024 to identify articles relevant to the research question. Key search terms used included combinations of (“HPV” or “cervical”), (“self-sampling”, “self sampling”, “self-sample”, “self sample”, “self-swabbing”, “self swabbing”, “self-swab” or “self swab”), (“Canada” or “Canadian”), and “acceptance”.

Articles were deemed relevant for this review if they met the inclusion criteria that included: publication in the English language between the years of 2000 to 2024; availability through free online access or through a University of Manitoba Libraries account; a focus on Canadian under-screened and underserved populations; and research investigating acceptance of HPV self-sampling.

The definition of an “underserved” population varied between studies, so the definition used by the authors of each article was adopted on a case-by-case basis. Seven articles met the criteria after initial screening and were included in this review. Two sets of two publications — Devotta et al. 1 and Devotta et al. 2 (9, 23); Lofters et al. and Vahabi and Lofters (27, 28) — are based on the same population and have been treated as companion studies for the purposes of this review.

## **Results and Discussion**

### *Demographics and Study Results*

A summary of the demographics and conclusions of each of the seven included publications can be seen in Table S1 (Supplementary Information).

Of the studies included in this review, two — Devotta et al. 1, Lofters et al. (9, 27) — gathered their findings via questionnaires, while the other five utilized focus groups: Devotta et al. 2,

Howard et al., Racey and Gesink, Vahabi and Lofters, Zehbe et al. (8, 23, 28-30). Sample sizes ranged from 25 to 108 participants, encompassing various age ranges, but with individuals aged 35 to 65 consistently included in focus groups.

Devotta et al.

Devotta et al. 1 and Devotta et al. 2 (9, 23) are two publications focusing on the same participant group. The first study gathered data through a questionnaire, while the second collected responses via focus groups. In both studies, the authors interacted with 108 people in Toronto, Ontario. Participants ranged in age from 30 to 69 and represented immigrant communities from West and South Asia, the Middle East, and North Africa.

All participants who tried self-sampling and completed the follow-up questionnaire found the kit to be user-friendly. 93% found the instructions easy to follow, and 95% said they would use the self-sampling method again. Of the participants who had previously had a Pap test, 95% indicated a preference for self-sampling. Common reasons cited for wanting to try a self-sampling kit included ease of use, physical comfort, privacy, and convenience. (9, 23)

For study participants who opted not to try self-sampling kits, reasons in support of this decision included fear of screening, discomfort with self-sampling, and shyness around sexual health matters. One participant stated that she did not try the kit due to her husband's disapproval. Some people preferred to undergo screening in collaboration with a medical provider because of previous healthcare experiences or ongoing medical issues. Other participants did not see a necessity for screening, believing that screening was unnecessary or that their particular sexual history (e.g., only ever having one partner) negated their need to be screened. (9, 23). Some

respondents stated that the independence required to carry out self-sampling was a barrier to use, as they lacked confidence in their ability to use the kit correctly. (9, 23)

#### Howard et al.

Howard et al. (29) utilized focus groups with new immigrants and individuals of low socioeconomic status in Hamilton, Ontario. Their study included 77 participants, ages 35 to 65, who were married with children.

Focus group participants believed that self-sampling could be a suitable solution for individuals who lacked access to a physician or felt embarrassed about undergoing a Pap test. However, most of the participants in this study were not themselves interested in self-sampling. While these respondents were not personally open to self-sampling, they identified many advantages offered by the method, including privacy, convenience, and as an alternative for those who have had a previous negative experience with pelvic exams. Self-sampling was considered to be a suitable option for someone who did not have children (who were therefore presumed to have had fewer pelvic exams), whereas participants believed that physician-based screening was a clearly better choice for women who have given birth.

The primary concern raised regarding self-sampling was a lack of confidence in the method's accuracy. As previously discussed, HPV testing has been shown to be accurate (2, 14), underscoring the importance of public and patient education in the potential expansion of self-sampling to more communities across Canada. In contrast to the other studies reviewed, which found that people were generally agreeable to HPV self-sampling, Howard et al. (29)'s findings indicate considerable hesitation among study participants.

### Lofters et al. and Vahabi and Lofters

Lofters et al. and Vahabi and Lofters (27, 28) are companion studies addressing the same participant group, similar to the aforementioned publications by Devotta et al. (9, 23). Lofters et al. and Vahabi and Lofters (27, 28) focused on 30 Muslim immigrants in Toronto, Ontario, between the ages of 21 and 69. Lofters et al. (27) administered a questionnaire to participants while Vahabi and Lofters (28) conducted focus groups.

In the Lofters et al. survey (27), two-thirds of participants indicated a willingness to try self-sampling. While the proportion was not quantified by the authors, many participants in Vahabi and Lofters' focus groups (28) expressed similarly positive attitudes toward self-sampling. When asked to indicate their preferred screening method, self-sampling or sampling via a provider, just over half (56%) of participants indicated a preference for self-sampling.

Age was a factor in participants' attitudes toward self-sampling. Lofters et al. found that younger individuals (age range 21-39 years) were more open to the method, with 93% of younger women compared to only 44% of older women participants (age range 40-61 years) willing to use a self-sampling kit. Vahabi and Lofters observed a similar pattern in their focus groups. (27, 28)

Lofters et al. (27) also analyzed responses by ethnic background and found differences in attitudes toward self-sampling. Most women from Iran indicated willingness to try self-sampling (87%), compared to 47% of women from Pakistan and India. These findings suggest that cultural background may influence individual attitudes toward self-sampling.

Privacy and convenience were again cited as key benefits of self-sampling, particularly for those who are shy, modest, or busy. The ability to collect samples in a private manner was seen as an

advantage, particularly for Muslim participants. (28) The ability to carry out testing at home, and without the knowledge of family members, was an advantage identified during Vahabi and Lofters' focus groups, particularly for women who were sexually active but not married. (28) As premarital sexual activity is disapproved of in Muslim culture with potentially severe consequences, the privacy of self-sampling could provide an opportunity for unmarried but sexually active women to be screened without disclosing their sexual histories. (28)

Overall, participants viewed HPV self-sampling as easy, safe, time-saving, and convenient. Many participants also noted that self-sampling could have a secondary cost-saving benefit, eliminating the requirement to take time off work or pay for childcare to access traditional Pap testing. (27, 28) Although participants believed self-sampling to be easy, they emphasized the need for clear and user-friendly instructions to ensure the success of self-sampling screening.

Respondents who were not willing to participate in self-sampling identified a lack of knowledge about the method and limited confidence in their own abilities to perform the test as barriers, and felt they would have more trust in their providers to do so properly and be accurate. (27, 28) The potential financial costs of self-sampling were also a concern, as this method is not currently funded within most provincial cervical cancer screening programs. (27, 28)

### Racey and Gesink

This study (29) used focus groups to gauge the attitudes of 25 rural Ontario residents aged 18 to 70 toward HPV self-sampling.

Study participants had a positive response to self-sampling, citing convenience and ability to overcome logistical barriers like lack of time and difficulty accessing appointments. Participants

also felt that self-sampling could help overcome the physical and emotional discomfort associated with pelvic exams.

While participants in this study were generally supportive of self-sampling, they identified a lack of confidence in collecting samples and uncertainty about the reliability of the test.

#### Zehbe et al.

Zehbe et al. (30) conducted focus groups with 69 participants, aged 18 to 70, from a First Nations community near Thunder Bay, Ontario. The authors also conducted focus groups with healthcare providers working in this community, however, only the patient group will be discussed in this review.

Participants in this study viewed HPV self-sampling as both less invasive and less painful than a Pap test. Respondents were more comfortable with the idea of self-swabbing than undergoing a pelvic exam with a healthcare provider. Self-sampling was seen as a way to address the discomfort sometimes associated with male healthcare providers and was viewed as a more comfortable and less embarrassing option.

One individual commented that she felt women would feel less nervous about performing self-sampling versus traditional screening. Self-sampling was viewed as a means of alleviating the fear or shyness some patients experience with healthcare providers in general, and with male, locum, and non-Indigenous clinicians in particular. These clinical scenarios were seen as potential barriers to care that self-sampling could help to mitigate.

Some participants felt that the availability of self-sampling kits at home may encourage some people to undergo screening, even if they were initially hesitant. One participant said she might

be likely to just “eventually...try it” (30 p. 6) if a kit were available for home use. Participants also viewed self-sampling as easy, comfortable, and more convenient than traditional screening, which requires scheduled appointments and travel to access a clinician. One participant specified time-saving and cost efficiencies of self-sampling (not requiring time off work), similar to the findings reported by Lofters et al. and Vahabi and Lofters (27, 28). Like Lofters et al. and Vahabi and Lofters (27, 28), this study determined that self-sampling kits were particularly of interest to younger individuals compared to older women.

Participants expressed apprehensions about the stigma associated with sexually transmitted infections (STIs), and the risk of social consequences if others learned they had tested positive through self-sampling. Respondents were also concerned about the potential impact of publishing on-reserve HPV prevalence rates, which some feared could reinforce harmful stereotypes, such as the perception that “all native people have HPV.” (30 p. 7)

### *Notable Themes*

#### Positive Acceptance

Across the studies reviewed, attitudes toward HPV self-sampling were largely positive. This sampling method was positively regarded by individuals from a range of backgrounds and communities. Commonly cited benefits of self-sampling include convenience, privacy, and time-saving. Every study identified the importance of convenience and privacy factors to participants (8, 9, 23, 27-30), while all but Devotta et al. (9, 23) specified that timesaving was also an advantage of self-sampling (8, 27-30). These findings align with broader research on self-sampling, reinforcing the potential for this method to improve care in under-screened communities.

## Concerns

While views about HPV self-sampling were generally favourable, participants did express some concerns about the method. The most commonly reported concern was a lack of confidence by participants in their own ability to properly perform the sampling. This apprehension was noted by Devotta et al. (9), and Lofters et al. and Vahabi and Lofters (27, 28), where some respondents preferred provider-based care to ensure sampling accuracy. Concerns about competency in self-sampling can be addressed through education, clear instructions, or in conjunction with healthcare providers. However, the latter approach may compromise convenience and patients' sense of autonomy, which are often viewed as important advantages of self-sampling.

It is notable that while six of the seven publications reviewed found openness to self-sampling, Howard et al. (29) reported significant hesitation amongst participants. This contrast highlights the importance of cultural and societal influences on perceptions toward sexual health, particularly when designing and implementing screening programs. Without thought out approaches to screening, uptake may be hindered. Howard et al. (29)'s study is the oldest publication included in this review, and was conducted more than a decade ago. Perhaps the hesitancy expressed by participants in this older study can be attributed to the differing social context in which it was conducted. It is possible that views on sexual health have evolved in recent years and have impacted the attitudes of individuals toward topics like cervical cancer screening and HPV self-sampling.

### Age

In the publications that analyzed responses by age (Lofters et al., Vahabi and Lofters, Zehbe et al.) (27, 28, 30), younger individuals were more likely to be accepting of self-sampling than older participants. The reasons for this difference are not directly explored. It may reflect the willingness of younger people to engage with novel health technologies or a greater social openness around sexual health matters amongst young people.

### Low Socioeconomic Status

The study conducted by Howard et al. (29) was the only publication that specifically examined the views of people from lower socioeconomic backgrounds. Participants considered self-sampling to be a positive option in theory, but were hesitant to try self-sampling for themselves. Participants from a low socioeconomic background were included as a distinct cohort within the study's 11 ethnolinguistic groups and were found to hold opinions on self-sampling that were consistent with the other populations studied.

### Rural

Racey and Gesink (8) examined the attitudes and opinions of rural individuals. These participants believed that HPV self-sampling would be convenient and perceived additional advantages in the method, including time savings and reduced travel requirements. This finding may be particularly relevant for individuals in rural communities who may be required to leave their home community in order to attend traditional screening appointments.

### First Nations

Another underserved population discussed was First Nations communities, as studied by Zehbe et al. (30). These participants expressed unique concerns about traditional screening methods, including discomfort with healthcare providers, particularly those from outside of their community, and the need to travel to seek screening services. Another key concern was the stigma associated with STIs, including HPV, and the potential for tests to reinforce harmful views about people in Indigenous communities. These concerns reflect broader societal issues of stigma and stereotyping that extend beyond HPV and demonstrate the importance of education and activism.

### Immigrants

Several of the studies reviewed here (Devotta et al. 1, Devotta et al. 2, Howard et al., Lofters et al., Vahabi and Lofters) (9, 23, 27-29) focused on immigrant populations. A common concern amongst these participants was their lack of confidence in their own abilities to carry out self-sampling or the accuracy of the eventual test results. These findings again highlight the importance of culturally appropriate education and easy-to-understand instructional materials.

Most of these participants agreed that self-sampling is easy, convenient, and improves privacy and modesty. This study also indicates that cultural background can affect attitudes toward self-sampling. For example, modesty and privacy were important to Muslim participants, and the Iranian group in Lofters et al.'s and Vahabi and Lofters' studies (27, 28) was more willing to try self-sampling than those from Pakistan or India. These results showcase the diversity that exists within Canada and underscore the need for culturally specific approaches to successfully implement HPV self-screening programs throughout the country.

## Definitions

One challenge encountered during this review was the lack of agreement amongst the studies included as to what constitutes an “underserved” population. Every author applied unique criteria, even when studying similar groups (i.e., people from immigrant communities). This raises questions such as: When is an individual no longer considered a “new immigrant”? What classifies a location as “rural”?

These inconsistencies limit the direct comparability of the findings but also reflect the diversity of communities across Canada. There is no one definition of “underserved” in the literature, and its interpretation may vary based on cultural and geographical factors. For example, given the population density within Manitoba, and the disproportionately high rates of incidence and mortality from cervical cancer, with a risk of diagnosis 2 to 20 times the risk of the general population (30, 31), Indigenous people would be an important and relevant underserved population to consider in this province.

Care should be taken to differentiate between “underserved” and “under-screened” populations. While these definitions often overlap, these words are not synonymous. The publications included in this review focused on communities that were both underserved *and* under-screened, specifically.

## *Limitations and Future Directions*

While the efficacy and practical advantages of HPV self-sampling are well-documented, little information is available on community-specific concerns that may be addressed by this screening method. These community perspectives are crucial to the implementation of HPV self-sampling into broader cervical cancer screening programs.

This review was also limited by the subjective and inconsistent definitions of “underserved” communities, which reduced the comparability and generalizability of the findings. However, the common themes expressed amongst the studies – the convenience, comfort, and general acceptability of HPV self-sampling may be relevant to a range of underserved populations in Canada.

The studies included in this review included small sample sizes and focused on the subjective opinions of individuals. While these opinions are valuable, particularly through a patient-centred care lens, further research is needed on self-sampling as a viable cervical cancer screening methodology. Future research should include larger-scale studies, clinical pilot projects, and collecting quantitative data from specific underserved communities. Increased research in this area will support the eventual implementation of HPV self-sampling in Canada and within existing provincial frameworks.

### *Conclusion*

This review indicates general acceptance of HPV self-sampling amongst many underserved and under-screened populations in Canada. While the studies included in this review do not represent every underserved population in the country, the results suggest that self-sampling could be a useful addition to existing cervical cancer screening programs. With adequate public education and culturally appropriate supports, self-sampling has the potential to empower individuals, expand access to HPV screening in Canada, and ultimately reduce the burden of cervical cancer in Canada.

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## Supplemental Information

Table S1. Summary of the seven reviewed articles

| Study                          | Location    | Population Group                              | Age Range | Sample Size | Design        | Conclusions   |
|--------------------------------|-------------|---|-----------|-------------|---------------|---|
| Devotta et al (2023) (9)       | Toronto     | Immigrants                                    | 30-69yr   | n=108       | Questionnaire | Some but not all UNS women viewed HPV self-sampling as an acceptable alternative to a Pap test for cervical screening.  |
| Devotta et al (2023) (23)      | Toronto     | Immigrants                                    | 30-69yr   | n=108       | Focus groups  | Some but not all UNS women in Ontario viewed HPV self-sampling is an acceptable alternative to a Pap test.  |
| Howard et al (2009) (29)       | Hamilton    | New immigrants/low SES; married with children | 35-65yr   | n=77        | Focus groups  | Perceptions of self-sampling for HPV were similar across cultures. Concerns pertained to confidence in self-sampling.   |
| Lofters et al (2017) (27)      | Toronto     | Muslim immigrants                             | 21-69yr   | n=30        | Questionnaire | HPV self-sampling may provide a favorable alternative model of care to the traditional provider-administered Pap testing.   |
| Racey and Gesink (2016) (8)    | Ontario     | Rural   | 18-70yr   | n=25        | Focus groups  | HPV self-collected testing was perceived as a facilitator for screening, and it was well accepted in this rural community.  |
| Vahabi and Lofters (2016) (28) | Toronto     | Muslim immigrants                             | 21-69yr   | n=30        | Focus groups  | Muslim immigrant women screening uptake could be encouraged with efforts to increase their knowledge of the Canadian healthcare system and alternative modes of screening like HPV self-sampling. |
| Zehbe et al (2017) (30)        | Thunder Bay | First Nation                                  | 18-70yr   | n=69        | Focus groups  | Self-sampling in conjunction with community engagement and culturally sensitive education and could be a viable option for under-screened Canadian First Nations women.                           |

UNS = under- or never-screened; Pap = Papanicolaou; SES = socioeconomic status; HPV = human papillomavirus