

# Feasibility of HPV self-sampling pathway in Kathmandu Valley, Nepal using a human-centred design approach

Swastika Shrestha,<sup>a</sup> Saki Thapa,<sup>b</sup> Paul Sims,<sup>c</sup> Andreea Ardelean,<sup>c</sup> Anamika Basu,<sup>d</sup> Maxine Caws,<sup>e</sup> Suman Chandra Gurung,<sup>f</sup> Gillian Holdsworth<sup>g</sup>

a Research Officer, Birat Nepal Medical Trust (BNMT), Kathmandu, Nepal. *Correspondence:* swastika@bnmt.org.np

b Advocacy Networking and Resource Mobilization Manager, Birat Nepal Medical Trust (BNMT), Kathmandu, Nepal

c Service Designer, Sexual Health 24 Hours (SH:24), London, UK

d Public Health Registrar, Sexual Health 24 Hours (SH:24), London, UK

e Senior Researcher, Birat Nepal Medical Trust (BNMT), Kathmandu, Nepal; Department of Clinical Sciences, Liverpool School of Tropical Medicine, Liverpool, UK

f Executive Director, Birat Nepal Medical Trust (BNMT), Kathmandu, Nepal; Department of Clinical Sciences, Liverpool School of Tropical Medicine, Liverpool, UK

g Director, Sexual Health 24 Hours (SH:24), London, UK

**Abstract:** *Cervical cancer is preventable and curable yet causes almost 2000 deaths in Nepali women each year. The present study aims to explore the feasibility and acceptability of a self-sampling-based approach for cervical cancer screening in urban and peri-urban Nepal and develop pathways for self-sampling using a co-design methodology. An iterative design approach was applied. Semi-structured in-depth interviews were conducted with 30 healthy women and four women who had had a prior cancer diagnosis on topics which included: sexual and reproductive health knowledge and human papillomavirus (HPV); use of the internet/social media platforms; their views regarding acceptability and usability of the self-sampling kit and the proposed user journey. Data collection was done between December 2020 and January 2021. Seven medical experts were also interviewed to explore the current service configuration for cervical cancer screening in Nepal. Knowledge regarding HPV and its association with cervical cancer was absent for the majority of participants. Although 70% (n = 21/30) had purchased items online previously, there was a general lack of trust in online shopping. Half of the women (n = 17/30; 56.7%) expressed a willingness to self-sample and provided recommendations to improve the clarity of the instructions. The proposed user journey was considered feasible in the urban area. There is a clear unmet need for information about HPV and alternative cervical screening options in Nepal. An online pathway for self-sampling service delivery to urban women is feasible but will need to be optimally designed to address barriers such as confidence in self-sampling and trust in online purchasing. DOI: 10.1080/26410397.2021.2005283*

**Keywords:** cervical cancer, cervical screening, sexual and reproductive health, digital health, online health service, HPV, human papillomavirus, HPV self-sampling, smartphone

## Introduction

Cervical cancer is one of the leading causes of cancer death in women, with more than 80% of the deaths due to cervical cancer occurring in low-to middle-income countries.<sup>1</sup> It was ranked as the fourth most common cause of cancer incidence and mortality in women worldwide in the year 2018.<sup>2</sup> Infection with the human papillomavirus (HPV) causes the majority of cases of cervical

cancer.<sup>3</sup> The World Health Organization (WHO) launched the Global Strategy to Accelerate the Elimination of Cervical Cancer in November 2020 following impressive evidence from early adopter countries that HPV vaccination can dramatically cut the prevalence of HPV infection and therefore incidence of cervical cancer.<sup>2,4-8</sup>

It is estimated that 2% of Nepalese women have cervical HPV infection with the major oncogenic

serotypes 16 or 18.<sup>9</sup> However, coverage rates for cervical cancer screening services are very low in Nepal. A national survey in 2019 showed that among the 30- to 49-year-old study participants, only 5.9% were tested for cervical cancer in the last five years.<sup>10</sup> As a consequence, the majority of cervical cancer patients in Nepal are diagnosed at an advanced stage which indicates a long duration between onset and diagnosis of disease.<sup>11</sup> Lack of privacy during screening, embarrassment among women, stigma and low priority given to women's health issues have been identified as factors contributing to the reluctance of women to access cervical cancer screening services in low-income countries.<sup>12</sup> A self-sampling pathway has the potential to overcome many of these barriers.

WHO has provided guidelines that recommend strategies for effective screening, diagnosis, treatment, and follow-up of cervical cancer.<sup>13</sup> Although the standard sequence of diagnosis of cervical intraepithelial neoplasia (CIN) is cytology, colposcopy, biopsy, and a histological confirmation, this is not feasible in many low-resource settings. Thus, an alternative method recommended by the WHO is to use a “screen-and-treat” approach which includes an HPV test, visual inspection with acetic acid (VIA), and Papanicolaou cytology test (Pap smear).<sup>13</sup> The National Guideline for Cervical Cancer Screening and Prevention in Nepal-2010 highlights the need for integration of cervical cancer screening programmes and prevention through national health policy and reproductive health programmes. The policy sets out a target to screen at least 50% of women aged 30–60 years every five years, with the aim of reducing mortality due to cervical cancer by 10%, but progress towards this target has been slow. VIA is the primary test offered for the standard cervical cancer screening to detect precancerous lesions. In the case of a positive VIA screen, women are referred for cryotherapy to cure the lesion.<sup>14</sup> The guidelines advocate for VIA as the primary screening method due to its cost effectiveness. Apart from VIA, Pap smear and HPV testing are only offered in a small number of centres in urban areas.<sup>15</sup> In recent years, highly sensitive self-sampling kits for HPV testing have been developed which have the great advantage of sample collection by the patient herself without requiring any trained personnel and infrastructure to perform pelvic examination.<sup>16</sup> Several studies in both high- and low-resource settings have shown that self-sampling is highly acceptable and its

acceptance can be further improved with proper communication of the process.<sup>6,17,18</sup> A recent meta-analysis<sup>5</sup> compared polymerase chain reaction (PCR) self-sampled HPV tests to clinician-sampled tests and found that sensitivity (96%) and specificity (79%) were comparable for detecting CIN grade 2 or above, regardless of sampling method. The meta-analysis also found that there was a moderate to excellent agreement between self-sampled and clinician-sampled tests ( $k = 0.46–0.88$ , Cobas 4800 HPV test (Roche Molecular Diagnostics) and the careHPV test kit (Qiagen) respectively) in randomised controlled trials and non-randomised studies. A clinician-sampled study showed that dry swabs could last up to a month in ambient uncontrolled temperatures without loss of sensitivity and specificity.<sup>19</sup>

Scale-up of innovative and acceptable methods of screening could accelerate progress in ending unnecessary deaths of women due to cervical cancer in low-income countries like Nepal. This research intended to aid in the conceptualisation of human-centred design with an online model and care pathway for self-sampling HPV kits, applying a human-centred design approach. Human-centred design empowers an individual or team to design products, services, systems, and experiences that address the core needs of those who experience a problem.<sup>20</sup> This approach involves multiple consultations with prospective users during an iterative design process, to obtain feedback and refine the proposed product, service or solution to optimally meet user needs. The approach chosen supports the WHO self-care initiative<sup>21</sup> and explores innovative approaches to delivering medical care via online platforms in Nepal.

## Methods

In-depth interviews (IDIs) were conducted with three participant groups: 30 study participants with no experience of cervical cancer (hereafter termed “healthy women”); four women who had previously been diagnosed and treated with cervical cancer; and healthcare providers ( $n = 11$ ) including four female community health volunteers (FCHVs), two non-governmental organisation (NGO) stakeholders, three gynaecologists, an oncology nurse and a pathologist.

Healthy women were included in the study to evaluate their knowledge regarding sexual and reproductive health (SRH) and HPV; use of the

internet/social media platforms; their views regarding acceptability and usability of the self-sampling kit and the proposed user journey. Women with a history of cervical cancer were included to evaluate their understanding of the disease and the virus after experiencing a diagnosis and treatment. We also wanted to understand the limitations of the current SRH options available to women in urban Nepal from a user perspective, and whether they would have been willing to self-sample if the service had been available. This group was also included to understand the various treatment aspects related to cervical cancer in Nepal from a patient perspective. The health professionals, FCHVs and NGO stakeholders were included in the study to explore the current service configuration for cervical cancer screening in Nepal, to understand the technical aspects of the journey and to obtain their views regarding how feasible it would be to implement the proposed service configuration.

A semi-structured interview guide was used to conduct a 1–1.5 h interview with the participants, aiming to gain detailed information regarding their SRH and HPV knowledge, online access and use of social media platforms, their views regarding prototypes of the self-sampling kits and the proposed user journey. The research method applied a human-centred design approach which places the end-user needs at the centre of the process and utilises service design tools to create a viable, desirable and affordable customer journey. A multi-disciplinary team including designers and public health experts worked collaboratively, using an iterative “build, test, learn” approach that allowed for the proposed user pathway to be adjusted based on user feedback.

The IDIs were conducted in three stages, with interviews with a new group of 10 healthy women participants at each stage. The four women who had experienced cervical cancer were also interviewed during stage one to inform the design prototype (Figure 1).

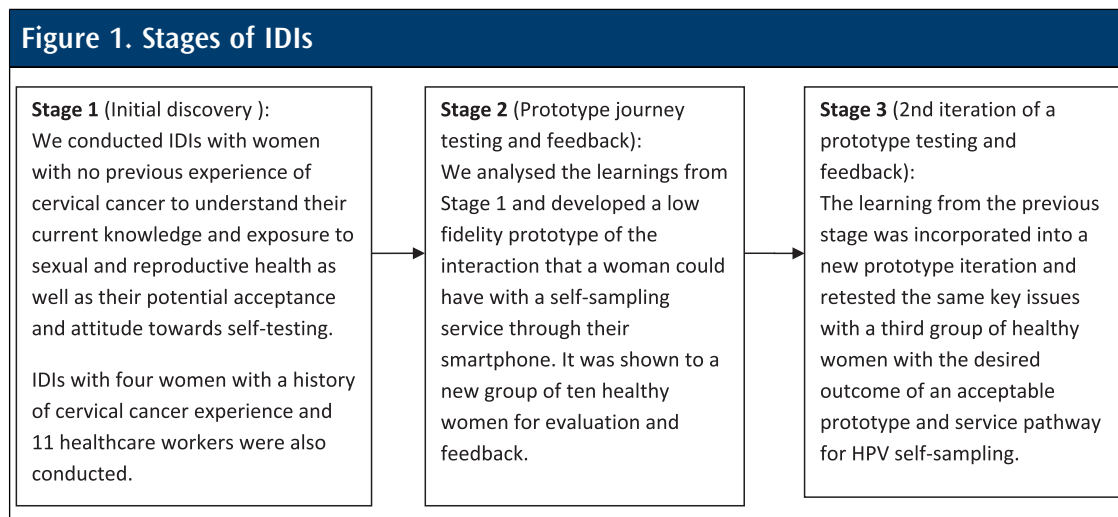
The Kathmandu valley was selected as the study setting to understand the feasibility and acceptability of a service providing a self-sampling kit requested by the user through an online interaction. Kathmandu has the highest level of internet access in Nepal. We selected Bhaktapur Cancer Hospital (BCH), a national tertiary referral cancer hospital, to recruit the women who had experience with cervical cancer. BCH is a 110-bed hospital that provides chemotherapy, radiotherapy,

surgery, brachytherapy services and palliative care services.

We have adopted a constructivist worldview for this research, in which we based our interpretations on the views of the participants and the information they shared during the interviews we conducted with them. We employed an emergent design model, as our research is based on a human-centred design approach which involved adaptations to the prototypes as we moved forward, responding to the feedback of participants during each phase of the process.<sup>22</sup> In addition, we used phenomenological theory to explore the experiences of the participants relating to health-care-seeking behaviour for cervical cancer screening, their online service-seeking behaviours and their experiences of using social media and the internet. We used grounded theory to investigate the participants’ responses and reactions to the self-sampling kit and the proposed user pathway and to generate our interpretations of the acceptability of the proposed pathway to users in the urban Nepalese context.<sup>23</sup>

Almost half of the research team consisted of Nepali nationals who had lived experience of the Nepalese healthcare system and were also familiar with local platforms for online payments and local delivery options for online orders, social media usage patterns and preferences in Nepal – which were all components of the proposed pathway. This informed the formulation of context-specific and culturally sensitive questions in the urban Nepalese context. In contrast, the inclusion of foreign nationals from highly developed countries with advanced healthcare services, less restrictive societies and highly technologically literate populations incorporated external perspectives on the local context. Travel restrictions due to the global COVID pandemic resulted in changes to the implementation plan of the research project. The international team members were unable to join the Nepali researchers in the field, and discussions were conducted through online meetings which may have resulted in a less nuanced understanding of the Nepali context for the international members of the team.

The topic of the research is sensitive and therefore the researchers were careful to respect the preferences of participants for the location and timing of interviews. The two field researchers were local urban dwellers which we believe was important to obtain a sensitive, nuanced and rich interview, posing context-appropriate



questions and allowing participants to share information with someone who came from a setting similar to themselves. However, it may have been the case that local interviewers increased the social stigma and desirability bias surrounding sensitive topics of sexual health and activity, in comparison with an interviewer from an external international background. Following team discussion of the first round of feedback from potential users, the design team members in London devised the format of information provided in the prototypes. It is likely that the format of information provided subsequently then influenced the choices made by the participants regarding the medium through which they would prefer to receive information. The human-centric design approach is an iterative process, and further cycles of evaluation and adaptation may have refined the interpretation, but this was not possible within the current project due to the limited funding timeframe and the pandemic context during which the research was conducted. Future work will further explore the user experience with a larger group and refine the model during implementation.

#### Study participants and sampling process

Purposive and convenience sampling were applied to select IDI participants in the three groups. There were three categories of study participants: healthy women ( $n = 30$ ) (demographic characteristics are shown in Table 1), cervical cancer experienced women ( $n = 4$ ) and healthcare

providers ( $n = 11$ ). The 30 healthy women included participants aged 25–50 who did not have any experience of cervical cancer and with access to a smartphone, residing in Lalitpur, Kathmandu & Bhaktapur districts (the three urban areas of the Kathmandu valley). The four cervical cancer-experienced women were under treatment or follow up at Bhaktapur hospital. The healthcare providers included four female community health volunteers (FCHVs), two NGO stakeholders, three gynaecologists, an oncology nurse, and a pathologist. The researcher first set the interview date, time and place with the study participants via telephone, which was later followed by an in-person visit for an in-depth interview with the consenting study participants.

#### Data collection instruments and procedures

Data collection was conducted between December 2020 and January 2021 following the Nepal Health Research Council (NHRC) ethical approval. The questionnaire was developed by the research team to match the local context and to address specifically women's healthcare issues in Nepal. It was based on the methodology and approach laid out in the IDEO design toolkit<sup>24</sup> and has user experience (UX) embedded at the heart of the questionnaire and IDI process. Semi-structured interview guides were developed in English and Nepali. The Nepali version was used for obtaining information from the study participants. The IDI guide was pretested on five women and the interview guides were adjusted

**Table 1. Demographic and socio-economic characteristics of healthy women participants**

Categories	Healthy participants ( <i>n</i> = 30)	
	<i>n</i>	%
<b>Age group</b>		
25–30	9	30.0
31–35	9	30.0
36–40	3	10.0
41–45	8	26.6
46–50	1	3.4
<b>Total</b>	<b>30</b>	<b>100</b>
<b>Highest education level</b>		
No formal education	8	26.7
10th grade	4	13.3
12th grade	4	13.3
Graduate	9	30.0
Postgraduate	5	16.7
<b>Total</b>	<b>30</b>	<b>100</b>
<b>Socioeconomic status</b>		
Upper	6	20.0
Middle	17	56.6
Lower	7	23.4
<b>Total</b>	<b>30</b>	<b>100</b>

accordingly. The data from pretesting IDIs were not included in the final data analysis.

The IDIs were carried out by two female research officers (a public health master's graduate and a master's student). The interviews were digitally recorded, with consent. Additionally, field notes were taken to record the main themes of the discussion. The IDI interview sessions were held until no further new information was obtained, when the interviewer deemed that data saturation had been achieved. To assure internal validity, appropriate strategies, such as including multiple stakeholders as key informants, were included in the study method. Dependability of the research outcomes was ensured by meticulous documentation of the data along with triangulation during the coding and analysis phase amongst the researchers. Inter-researcher agreement was ensured through

inter-coder communications and discussion of any discrepancies arising.

#### Ethics statement

Ethical approval for the study was obtained from the NHRC [Ethical review board (ERB) Protocol Registration number: 786/2020 P] on 1st December 2020. Approval was also obtained from the Bhaktapur Cancer Hospital Institutional Review Board (IRB) [Approval number: 1452] on 18th November 2020 for the recruitment of women from the hospital who had experienced cervical cancer. Written informed consent was obtained from the recruited women prior to data collection by both explaining the information sheet verbally to the women and providing them with a participant information sheet. The women were assured of their right to terminate their participation at any time during the study. The participants were made aware that the IDIs would be recorded, and they were assured that the recordings would be used only for research purposes and that data and transcripts would be anonymised prior to analysis. Pictures were also taken with the explicit consent of the study participant to include in the report and research dissemination.

#### Safety and privacy consideration

Amidst the Covid19 pandemic, in order to prevent transmission of coronavirus disease (COVID 19) between participants and the research team, consultation meetings with experts were carried out via telephone and internet (emails, virtual calls), and in-person visits were carried out only when necessary. Interviews were taken in the study participants' homes or any other place identified and preferred by the women at their time of convenience. Appropriate safety measures were taken to minimise the risk of COVID 19 transmission to the study participants and researchers.

#### Data analysis

The qualitative data from the recordings of the IDIs were first transcribed and translated into English. The transcribed document was read and re-read to evaluate patterns within the content (words or phrases) and the frequency in which it occurs in the transcript. The verbatim quotes from the participants were shortened, condensed, and coded. Coding was based on the related words or phrases mentioned by the interviewees or in the documents. The codes were given names, and codes that covered the same meaning were



merged into a specific subcategory. The final stage of the analysis was carried out by all the researchers together wherein the subcategories were discussed until agreement was reached on the development of themes. Six major themes were identified: SRH knowledge, healthcare accessing behaviour, online access, online purchasing habits, reaction to the proposed journey and recommendations to the proposed journey. These results were analysed using the Miro.com software package, which is used extensively by human-centred design experts to graphically illustrate the most prevalent and important themes that arise out of the analysis.

### Results

A broad spectrum of women were interviewed in terms of age, socioeconomic status, residence, digital literacy and education level. There was an almost equal representation of women from each district in the valley with 10 (33.4%), 9 (30.0%) and 11 (36.6%) participants from Kathmandu, Lalitpur and Bhaktapur respectively.

There was an overall lack of SRH knowledge amongst both the healthy women and women who had experienced cervical cancer. Women often referred to “uterus problems” as an umbrella term for anything related to SRH issues. All the healthy participants ( $n = 30/30$ ; 100%) had heard of human immunodeficiency virus (HIV), but only half the participants ( $n = 15/30$ ; 50.0%) had heard of syphilis and a few other sexually transmitted infections (STIs). Only five (16.6%) participants had heard of HPV and only 6.5% ( $n = 2/30$ ) knew of the connection between HPV and cervical cancer. Women usually reported obtaining SRH knowledge from informal sources such as church, school, radio and movies. The cervical cancer-experienced women ( $n = 4/4$ ; 100%) were also unaware that cervical cancer was caused by a virus or that it was sexually transmitted. A woman interviewed mentioned that she thought the cause of her cervical cancer could be the adulterated food that was available in the market, that was full of pesticides.

Only a third of the healthy participants ( $n = 11/30$ ; 36.6%) had heard of cervical cancer, however, 36.6% ( $n = 4/11$ ) of them were unaware of the difference between cancer of the uterus and cervical cancer. A third of the participants ( $n = 10/30$ ; 33.3%) mentioned that they were aware of a regular screening Pap smear that was suggested

by their doctors to check for any abnormalities in the uterus, but did not know that it was for cervical cancer screening. Women who knew of the Pap smear mentioned that they had the test done at one- or two-yearly intervals previously but the pandemic had prevented doctor’s visits for routine testing in the last year. When informed about HPV and the self-sampling kit, 56.7% ( $n = 17/30$ ) of the participants expressed confidence they would be able to self-sample at home, especially after reading the instructions. They said they felt empowered and appreciated the privacy of conducting the self-sampling in their own home, in their own time. However, 43.3% ( $n = 13/30$ ) of the participants were not confident to self-sample and expressed a preference for visiting a hospital, or having an FCHV or a friend to help them collect the sample. Their principal concerns raised were hurting themselves ( $n = 6/13$ ; 46.2%) or not performing the test correctly ( $n = 5/13$ ; 38.4%) or both ( $n = 2/13$ ; 15.4%).

All the participants ( $n = 30/30$ ; 100%) reported not visiting a doctor unless they had a health problem. Regular screening and health check-ups were not perceived as necessary, many citing the out-of-pocket costs entailed in visiting doctors, which they preferred to use for household necessities. Regarding the self-sampling kit, the women were willing to accept the self-sampling kit if it was available at a cost that was not too expensive. However, the range of cost perceived as reasonable for the kit ranged from 100 Nepali Rupees (NRs) to 10,000 NRs depending upon the socioeconomic status and also the familiarity of the women with laboratory service costs. It was found that 40.0% ( $n = 12/30$ ) of the participants were only willing to pay 500 NRs (\$US 4.3) or less, 26.6% ( $n = 8/30$ ) were willing to pay up to 1000 NRs (\$US 8.6), 20% ( $n = 6/30$ ) were willing to pay up to 2000 NRs (\$US 17.2) while two ( $n = 2/30$ ; 6.7%) were willing to pay up to 10,000 NRs (\$US 86.4) while the remaining 6.7% ( $n = 2/30$ ) were unable to state a value (exchange rates fixed by Nepal Rastra Bank).<sup>25</sup> Regarding the usage of menstrual hygiene products, only nine of the 30 participants (30.0%) were aware of menstrual cups and tampons and only 13.3% ( $n = 4/30$ ) of the participants had ever used one. Three quarters ( $n = 3/4$ ; 75%) who had tried using menstrual cups mentioned that they were not comfortable using it. The remaining participants used pads or cloths during their menstruation.

When the women were shown the proposed journey (Figure 2) with verbal explanation for the service delivery of the HPV self-sampling kit, more than half of the women ( $n = 17/30$ ; 56.7%) said they would prefer to buy the self-sampling kit from a shop, such as a pharmacy, or collect it from local government offices or clinics. A fifth ( $n = 6/30$ ; 20.0%) preferred to order it online, as proposed in the journey, not only for the convenience of not having to take the time to collect it, but also for privacy reasons. The remaining seven (23.3%) participants mentioned that they may be willing to obtain the kit online only after having enough information and experience with it by first purchasing from a shop. The proposed journey also included returning the collected sample through a delivery person to the lab for the analysis. 56.7% ( $n = 17/30$ ) of the participants expressed a preference for returning the sample themselves to a designated centre or the laboratory itself because returning a product purchased online was perceived as a “hassle”. However, the remaining 43.3% ( $n = 13/30$ ) of the participants considered a collection service for the sample acceptable.

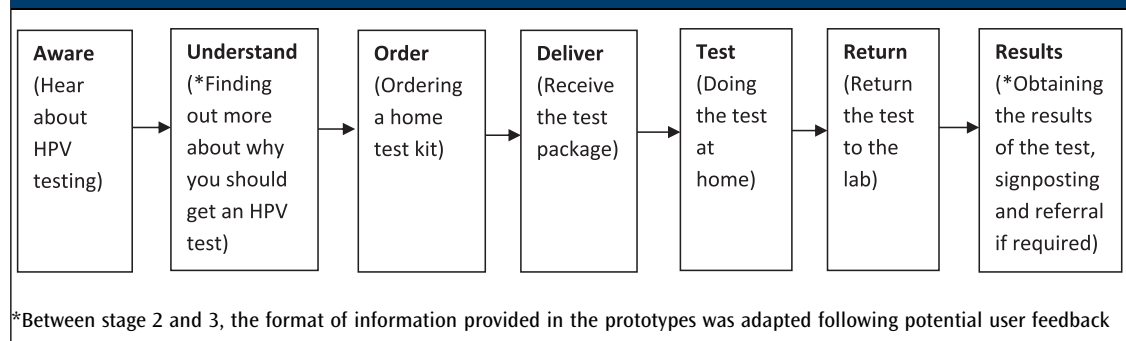
When asked about the ways in which the women would like to receive the test results, 46.7% ( $n = 14/30$ ) of the participants preferred to receive the results via Facebook Messenger or via SMS (short message service), with an option to call a health professional if the test result was positive. There was positive feedback on the option of receiving a document with the test results which service users could download. Forty per cent ( $n = 12/30$ ; 40.0%) of the participants expressed a preference for receiving the results by telephone so they could ask questions

about the interpretation of the results and clarify any necessary subsequent actions. Illiterate women ( $n = 8/30$ ; 26.6%) preferred this due to their literacy concerns. Only 13.3% ( $n = 4/30$ ) of the participants expressed a preference for receiving results by email. The advantage of this method perceived by the women was an ability to receive detailed information which could be printed for later reference.

With regards to online purchasing and transactional habits, 70.0% ( $n = 21/30$ ) of the participants described having a previous experience of purchasing items online. A fifth of those respondents who had previously purchased online ( $n = 5/21$ ; 23.8%), described reliance on their husbands or children to purchase items online for various reasons, such as inadequate digital literacy and lack of confidence while ordering online. Only 23.3% ( $n = 7/30$ ) of the participants reported experience of online monetary transactions. The nine women aged 25–30 years (30% of participants) were more open towards ordering things online and experimenting with online purchasing as they were more familiar with the technology and financially independent. This group also mentioned that the online availability of the kit could provide them with privacy and lack of judgement as 88.8% ( $n = 8/9$ ) of them were unmarried. Women who belonged to the lower socioeconomic group ( $n = 7/30$ ; 23.3%) refrained from online purchasing because of a lack of trust in the online market and a fear of poor value resulting in wasted money if the product delivered was not consistent with the expectation.

The pictorial instructions evaluated were perceived as useful but insufficient for all women to

**Figure 2. Proposed user journey presented to the participants in stage 2 and 3\***



feel confident self-sampling. Sixty per cent ( $n = 12/20$ ) of the participants in stages 2 and 3 of the research indicated they would prefer to watch a video for clarity in performing the test and to reduce concerns about inflicting harm on themselves during sampling. Participants also stated that it would be important for the instructions to be in both Nepali and English. The women ( $n = 14/30$ ; 46.6%) also indicated that since the idea of returning a product, in this case a sample, is novel, it would be useful to have a drop-off centre, which could be a local pharmacy, hospital or a laboratory, where women could take the sample. A participant mentioned that if the self-sampling kit was available in a cheaper price range, women could also gift it to other women in their lives so that they too could self-sample and be tested. The findings on the proposed user journey from the healthy women participant feedback are shown in [Table 2](#). Illustrative quotations from the interviews with healthy women participants are shown in [Table 3](#).

### Expert opinions

Many of the experts expressed that it will be important to educate the women about HPV and that its presence does not necessarily mean the diagnosis of cervical cancer. With regards to the self-sampling kit, they mentioned that it may be useful to introduce the HPV self-sampling kit without mentioning STIs, smoking or sexual activity because of the stigma associated with these words. The experts also shared their view that an ideal service needed to have screening and a referral pathway stressing that the outcome of an intervention in the form of self-sampling should be measured by the number of treatments and not just by the number of screenings.

An NGO stakeholder mentioned that women tended to value paid medical services more than they valued free services. It was also mentioned that although the FCHVs are invaluable in rural settings, that is not the case in urban areas. This was also noted by the FCHVs themselves, who mentioned that “well off” and educated people in the community often chose to ignore them during their regular community visits. They mentioned that women in urban settings usually obtained information regarding SRH issues from their doctors or online. It was suggested that online platforms could be a better route for spreading information about the self-sampling method amongst urban women, as gynaecologists

may have a conflict of interest since their income is through consultations and referring to a self-sampling service may not be in their financial interest.

### Discussion

This study was able to draw some important conclusions to inform the design of an acceptable, feasible and culturally sensitive HPV self-sampling service initiated via an online pathway in urban Nepal. The service user feedback highlighted the potential to overcome some of the existing barriers to HPV screening in Nepal, including knowledge, access, and stigma. Participant feedback also provided important information regarding the design and overall implementation approach for such a testing service.

One of the major challenges unveiled was that urban Nepali women had very limited knowledge regarding cervical cancer and there was no understanding of the connection between HPV and cervical cancer. Limited knowledge about cervical cancer and HPV has also been reported in other settings.<sup>7,26,27</sup> Women were unaware of the difference between cervical cancer and cancer of the uterus. This could be because of the terminology used in Nepali for cervical cancer, termed “cancer of the mouth of the uterus”, which lacks clarity in distinguishing it from “cancer of the uterus”. Understanding of HPV as a causative agent is essential for women to be willing to undergo screening tests. Thus, there is a clear and urgent need to raise awareness. All of the participating women were familiar with at least one form of social media platform (primarily Facebook) with varying levels of engagement, suggesting awareness could be raised using social media platforms. Audio visual media such as videos would be ideal to enable women with low or no literacy also to access clear information in this way.

Healthcare seeking patterns among the women did not include screening tests, and low priority was given to preventive medicine. Women mentioned that they did not visit a doctor unless they had health problems, while acknowledging that regular check-ups could in fact aid in earlier diagnosis of diseases. Although basic health care has been identified as a fundamental right by the Government of Nepal, high quality health care is often only accessible to those who can afford it.<sup>28</sup> Healthcare costs are covered by out-of-pocket expenditure which is often catastrophic



**Table 2. Findings on the proposed user journey as per the healthy participants' feedback**

Stage in proposed user journey	Key findings identified during in-depth interviews
Hear/ know about HPV testing online	<ul style="list-style-type: none"> <li>– All literate participants engaged with concept</li> <li>– Limited literacy participants had passive interaction with social media content</li> <li>– Participants with limited literacy would be able to engage in the concept if it had more audio visual component</li> </ul>
Finding out more about importance if an HPV test via chat /video	<ul style="list-style-type: none"> <li>– All participants were familiar with some form of social media with varying degrees of engagements</li> <li>– All interviewees were familiar with Facebook Messenger (FBM)</li> <li>– Many factors influenced the choice to engage in a chat with a healthcare provider:               <ul style="list-style-type: none"> <li>○ if symptoms were present</li> <li>○ if the chat was free of cost</li> <li>○ if they stumbled into the information when they were not engaged in work</li> </ul> </li> </ul>
Ordering an HPV test online	<ul style="list-style-type: none"> <li>– There was an overall low experience &amp; trust in online purchasing</li> <li>– Varied perception of cost from 100 to 10,000 NRs</li> <li>– Only 7 of the 30 participants (23.3%) had used digital payment methods</li> </ul>
Receive the test package via a delivery person	<ul style="list-style-type: none"> <li>– Online parcel delivery was possible to local landmarks as well as home address</li> <li>– There was a general preference to buy from a pharmacy</li> <li>– There were some concerns about the identity of driver and privacy</li> </ul>
Self-sampling	<ul style="list-style-type: none"> <li>– Mixed response to self-sampling. (56.7% (<math>n = 17/30</math>) of interviewees willing to self sample and 43.3% (<math>n = 13/30</math>) said they were hesitant and would like some professional aid to do the self-sampling.)</li> <li>– There were some concerns of breaking the swab or doing the process incorrectly (and getting a false negative result)</li> <li>– Although useful, the imaged based instructions were not easy to understand at times, perhaps because of the language barrier</li> <li>– Women suggested that a video-based instruction would be useful to both raise awareness and understand the instructions</li> </ul>
Returning the sample to the lab	<ul style="list-style-type: none"> <li>– Low confidence in having the sample collected by a pick up person</li> <li>– There were some trust issues in the driver returning the sample safely</li> <li>– There was a positive feedback on dropping the sample at a suitable location e.g. clinic, hospital</li> </ul>
Obtaining results of the test + signposting and referral	<ul style="list-style-type: none"> <li>– There was mixed response to receiving results via chat channel</li> <li>– There were concerns over privacy, literacy and understanding the results</li> <li>– Participants who preferred getting message wanted it in a downloadable format to use the results with their doctors</li> </ul>

for families,<sup>29</sup> leading many people to wait until health becomes a pressing issue before they choose an intervention. Although some of the women were aware of regular screening services, such as the Pap smear, they lacked information regarding the purpose of this test. This could be partially a result of the overburdened healthcare system where the human resource for health density is 7 per 10,000 population,<sup>30</sup> resulting in

limited interaction time between patients and doctors. Doctors, therefore, lack time to explain the procedure and its purpose in detail. Self-sampling is a new concept in the context of Nepal, so that many of the participants seemed to be unfamiliar with the concept and were hesitant to self-sample. Promotion and the opportunity to self-sample under the guidance of a healthcare provider at first use may facilitate

<b>Table 3. Quotes from the healthy participants</b>
<b>On SRH issues:</b>
<p><i>“I think many Nepali people are negligent about their SRH. For instance, people don’t even change their undergarments every day, people don’t follow proper hygiene habits after using public toilets, and people don’t pay attention to what chemicals they are using near their private parts, or to wash them.”</i></p> <p><i>“I don’t think I am well informed regarding the SRH. When I was growing up, sex was always a taboo subject, nobody would talk about it freely. I never put forward any questions regarding it and nobody in the family came forward to educate me about it . . . . Till now I am not really open about talking about the SRH issues with anyone, it’s via movies that I know a little and there is the internet which provides a bulk of the information.”</i></p>
<b>On STIs and cervical cancer:</b>
<p><i>“I thought cancer of the uterus and cancer of the mouth of the uterus were the same.”</i></p> <p><i>“I have heard of cervical cancer in the news sometimes but I don’t know anything in detail of the tests that can be done.”</i></p> <p><i>“I think I would not be too uncomfortable [to discuss about STIs] because I have a kid, and I think women with children or who are married will have less hesitation to talk about it than women who are unmarried. Unmarried women may have problems talking about it for the fear of what people would say about how she got this disease even before getting married.”</i></p>
<b>On use of internet &amp; apps:</b>
<p><i>“I don’t know how to put up posts, so I just look at what others put up as posts. I know how to like and share the posts, that is all. Mostly I pay attention to the photos and videos put up there, but I am limited to the post that comes in my feed. I don’t know how to navigate the app properly.”</i></p> <p><i>“I use the internet only when I have the time. But having said that I do use the internet to play music in the background when I am working. But I use Facebook to see what others have posted, if someone has posted some health related information, I do read them if I have the time.”</i></p>
<b>On online purchasing and transactions:</b>
<p><i>“I do tend to do online shopping quite a bit. I used to engage in it before as well, but obviously, now it’s become more frequent in many people’s lives due to COVID. From small groceries to other non-essentials, I get them from ‘Daraz’ [online shopping store]”</i></p> <p><i>“I think online shopping is for people who are very busy and don’t have time to go in person to buy things. But since we are free at home, I think it’s better that we go out and get things ourselves. Also because we are housewives, it’s important that we try and use the money earned by our husbands in the best possible economic way by searching for places where things can be bought in the cheapest price.”</i></p>
<b>Reaction to the kit:</b>
<p><i>“I would use it [the swab in the kit], put it back in the packet and the box. And because of the medical literacy that we have all built because of COVID, everybody sort of knows that this is like a swab instrument. It’s not alien medical equipment to us anymore.”</i></p> <p><i>“I would not want to do it on my own because I would worry whether I did the test correctly or not, and how painful the insertion might be. I would worry if the cervical brush might break inside and get stuck there, what would I do in such a situation? Owing to all these fears, I would want to go to the doctor themselves”</i></p> <p><i>“I think a video would help. By video I mean animation. If all the steps written here are shown there in an animated version, perhaps it can be more informative. Here just the pictures are shown, I don’t know in which position I am supposed to be when I insert this, a video could make it clearer.”</i></p>
<b>On online availability/ delivery of the kit:</b>
<p><i>“I think online [availability of the kit] would be better. Even if you put the kit in pharmacies, even to this day, women get embarrassed in buying birth control pills and other contraceptives from the pharmacies. So I think online is best.”</i></p> <p><i>“I think pharmacies can be a better alternative for our context. That can make it more accessible for many people”</i></p> <p><i>“Yes, I think so too [buying it online] because many times women may be busy with their chores and may not get the time to go out to buy things”</i></p>

**On sending the sample:**

*"I am concerned about sending the sample. I am concerned what if the delivery person doesn't take the sample with the level of care that the sample needs to be transported with? What if someone actually has some sort of infection and if the delivery person does not take proper care during the transport, what if the infection [infectious organisms] increases in the kit? So the report may show increased infection in comparison to what one actually may have."*

*"In case the lab is far away, I would probably use the delivery personnel provided by the lab or organization. For eg: after I do the self sample, if I have the option of dropping it off at my local pharmacy or nearby hospital, I can do it myself. But if I would need to travel to a hospital to a distance like that of Bir Hospital, then I might feel lethargic and just not do the test itself."*

**On obtaining the results:**

*"They could call. If they sent messages, since I can't read that well, it would be difficult for me."*

*"Email because it is instantly accessible. I don't have to go collect results, so it's practical. Another key factor is that it's accessible, but at the same time, unlike the SMS service [mobile messaging service], it doesn't randomly pop up on your phone, when you're hanging out with friends or family."*

*"But if the result is positive then I should get the opportunity to meet Dr. Rina Kumari, and consult with her. If the test is negative, messaging like this is fine."*

*"If the result is told to the women via phone, one only gets to hear it, one will not be able to see the report. So I prefer to get the result via email so that I could print it and show that to the doctor next time I visit the doctor."*

uptake of a self-sampling service. Video-based instructions on self-sampling were also requested in preference to pictures, to enable women to feel confident that they are taking the sample correctly and safely. Studies have shown that video-based instructions are often impactful for patient comprehension regarding the instructions provided.<sup>31,32</sup> Video-based instructions on self-sampling can not only aid in better comprehension but also raise awareness regarding HPV, cervical cancer and the self-sampling kit and pathway. Development and testing of video instructions should be carried out during the next pathway iteration to ensure clarity of instructions and confidence for the users. Another contributing factor to hesitancy in self-sampling may be the fact that experience using tampons or menstrual cups was very limited amongst the women. Women's prior experience with tampons reduces the novelty of inserting a swab to self-sample and reduces the concern of hurting themselves or taking the sample incorrectly. Women with limited experience of tampons are able to perform the test safely unsupervised,<sup>33</sup> but confidence will be essential to ensure widespread adoption of the method. Based on the potential users' feedback, video-based instructions alongside the already available written instructions complemented with a support back-up by a health professional online would facilitate uptake.

Concerning the proposed journey, it was clear that it would be essential to provide multiple options to the user for provision of information, including email, text, online chat and voice call service. This would allow users to choose the option they are most comfortable with, improving acceptability and broadening access to include women with low literacy or online confidence. Encryption, confidentiality and privacy would need to be ensured for the sharing of results, so although several women expressed a preference for receiving results via social media or online chat, this would probably not be feasible because of security issues. Since many women had previously purchased online and had items delivered, receiving the kit via this mechanism was acceptable. However, since returning a package is not a common practice, many perceived it to be inconvenient, describing it as a "hassle". Adapting the proposed journey by including alternate pathways of returning the sample, for example by using a drop-off centre or making provision for self-delivery to the laboratory, may be necessary. As for providing the test results, potential users expressed different concerns over privacy, literacy and understanding of the results, thus it may be necessary to provide secure options to users during the sample submission process regarding how they would prefer to receive the results.

The study also highlighted a lack of consumer trust in the online marketplace in Nepal. This

could present a barrier to the successful uptake of the proposed online journey, particularly among women in lower socioeconomic groups who had more cautious attitudes towards online purchase due to perceived financial risks. Consideration should be given to options such as introducing the kits via shop-based purchase initially to familiarise target users with the product. Once women are aware of the HPV self-sampling kit via the conventional purchasing route, confidence will increase in an online purchasing pathway. The willingness of pharmacists to provide this service will depend upon the compensation model and the financial benefit to them of doing so. It may also be useful to distribute free samples initially to reach women in the lower socioeconomic strata for them to self-sample using the kit and feel confident in both the product quality and its application. Women often reported relying on word of mouth for recommendations for visiting healthcare services or purchasing items online, so building trust among the users will be crucial for women to be willing to recommend it to others. It will also be necessary for the results to be acceptable to women's healthcare providers so that they do not need to retest, which incurs an additional cost for the women testing positive. The current model of cervical screening requires the patient to visit the health facility where the sampling is conducted by a health professional. The self-sampling pathway would provide an alternative, convenient user-centric service which would reduce existing barriers to access including time limitations, stigma around being tested for a sexually transmitted infection (HPV); and reluctance to undergo intimate medical examination due to cultural traditions. Thus, online platforms may be effective platforms to raise awareness about HPV, cervical cancer and screening methods. Clear uptake of self-sampling via the proposed journey would depend on trust and word of mouth. It will therefore be essential to ensure that implementation of such a service is fully optimised to the local cultural and economic context through rigorous piloting and iterative design cycles. Offering users a choice of methods for both return of the samples and receipt of information would appear to be important for increased accessibility of the service.

#### **Strengths and limitation of the study**

The concept of medical self-sampling is novel in the Nepali healthcare market. This exploratory

study was performed in a small population of prospective users in an urban setting, where such a service is most feasible. The results of the study cannot be generalised nationally, due to the lower rates of literacy, smartphone access and digital literacy among the rural population outside Kathmandu valley. However, the findings are likely to apply in other major urban centres such as Bharatpur and Biratnagar.

Capacity of the health system to appropriately manage and treat any increase in cervical cancer patients was not explored in this study, which focused on the user perspective of screening pathways, but is an important aspect for consideration before implementation of any diagnostic service. A successful long term screening programme would result in resource reallocation from cancer treatment (due to a decrease in cases) to appropriate management of positive screening cases.

Due to the sensitive nature of the topic and a conservative traditional society, participants' social desirability bias may have influenced the results. However, the findings demonstrate that there is an appetite for and willingness to experiment with novel medical testing pathways, particularly among younger women in Nepal. Early adopters are likely to raise awareness and trust in such a system, and concurrent awareness campaigns to raise knowledge of the need for testing would also fuel uptake.

#### **Conclusion**

There is a clearly demonstrated urgent and unmet need for increased awareness of HPV screening and access to alternative testing pathways among Nepali women. An online self-sampling pathway has potential to address this need and to remove some of the current barriers to testing, such as stigma. Women in urban areas have online access and there is growing acceptance of online shopping and delivery services in the country; however, there is a tendency to seek health care only when symptoms are present. Widespread uptake of self-sampling via the proposed journey would depend on trust, word of mouth and increased awareness of HPV infection as a cause of cervical cancer. Important issues to consider in the design of such a service in Nepal are the need for video-based instructions, multiple options for returning the sample and for receiving the test results and mechanisms or consumer building confidence to self-sample. Such a service

has high potential to transform access to screening for HPV and other STIs in urban Nepal.

#### Disclosure statement

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## Résumé

Le cancer du col de l'utérus peut être évité et soigné. Pourtant, il provoque la mort de près de 2000 Népalaises chaque année. La présente étude souhaitait explorer la faisabilité et l'acceptabilité d'une approche fondée sur un autotest pour le dépistage du cancer du col de l'utérus au Népal urbain et périurbain et elle a mis au point des modalités pour l'autotest à l'aide d'une méthodologie de conception conjointe. Une approche de conception itérative a été appliquée. Trente femmes en bonne santé et quatre femmes qui avaient eu un diagnostic préalable de cancer ont participé à des entretiens approfondis semi-structurés sur des thèmes comme les connaissances de santé sexuelle et reproductive et le virus du papillome humain (VPH); l'utilisation des plateformes internet/des réseaux sociaux; leurs avis concernant l'acceptabilité et la facilité d'utilisation de la trousse d'autotest et le parcours utilisatrice proposé. Les données ont été recueillies entre décembre 2020 et janvier 2021. Sept experts médicaux ont aussi été interrogés pour étudier la configuration actuelle des services de dépistage du cancer du col de l'utérus au Népal. Les connaissances concernant le VPH et son association avec le cancer du col de l'utérus étaient absentes chez la majorité des participantes. Même si 70% ( $n = 21/30$ ) d'entre elles avaient déjà acheté des biens en ligne, on a observé un manque de confiance général dans ce mode d'achat. La moitié des

## Resumen

El cáncer cervical es evitable y curable; sin embargo, cada año causa casi 2000 muertes de mujeres nepalesas. El presente estudio tiene como objetivo explorar la viabilidad y aceptabilidad de un enfoque basado en la autotoma vaginal para detección de cáncer cervical en zonas urbanas y periurbanas de Nepal y crear vías para la autotoma utilizando la metodología de codiseño. Se aplicó un enfoque de diseño iterativo. Se realizaron entrevistas a profundidad semi-estructuradas con 30 mujeres saludables, así como con cuatro mujeres que habían sido diagnosticadas anteriormente con cáncer, acerca de los siguientes temas: conocimiento de la salud sexual y reproductiva y del virus del papiloma humano (VPH), uso de internet o plataformas de las redes sociales, sus puntos de vista sobre la aceptabilidad y usabilidad del kit de autotoma y el itinerario de usuaria propuesto. Se realizó la recolección de datos entre diciembre de 2020 y enero de 2021. Además, siete expertos médicos fueron entrevistados para explorar la configuración actual de los servicios de detección de cáncer cervical en Nepal. La mayoría de las personas participantes carecían de conocimientos sobre el VPH y su asociación con el cáncer cervical. Aunque el 70% ( $n = 21/30$ ) había comprado ítems en línea anteriormente, en general carecían de confianza en realizar compras en línea. La mitad de las mujeres ( $n = 17/30$ ; 56.7%) expresaron estar

femmes ( $n = 17/30$ ; 56,7%) se sont déclarées prêtes à s'autotester et ont fait des recommandations pour améliorer la clarté des instructions. Le parcours utilisatrice proposé était considéré comme réalisable en zone urbaine. Il existe clairement un besoin insatisfait d'information sur le VPH et les autres options de dépistage du cancer du col de l'utérus au Népal. Des modalités en ligne sont possibles pour la délivrance du service d'autotest aux femmes urbaines, mais devront être conçues de manière optimale pour lever les obstacles tels que le manque de confiance dans l'autotest et la méfiance à l'égard des achats en ligne.

dispuestas a realizar la autotoma y proporcionaron recomendaciones para mejorar la claridad de las instrucciones. El itinerario de usuaria propuesto fue considerado factible en las zonas urbanas. No cabe duda de que en Nepal existe una necesidad insatisfecha de recibir información sobre el VPH y otras opciones de detección de cáncer cervical. La vía de entrega en línea para la autotoma es factible, pero debe diseñarse de manera óptima para abordar barreras tales como la falta de confianza en la autotoma y en realizar compras en línea.