Barriers to Accessing Cervical Cancer Screening

Voices from Women Survivors of Female Genital Mutilation (FGM)

August 2025

FORWARD

Contents

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Introduction

CERVICAL CANCER remains a major public health concern. Incidence and mortality rates are high globally, and they are high in marginalised and underserved communities. This form of cancer is highly treatable when it is detected early through screening services. However, in the UK, the NHS has raised concerns about the low uptake of screening services among women from Black and Minoritised communities. In addition, there are limited opportunities for hearing the voices of women in general, and vulnerable women in particular, to understand the disparities they face. The 2022 Women's Health Strategy for England, aims to change this over the next 10 years by "tackling taboos and stigmas [and] ensuring women are listened to by healthcare professionals" (Department of Health and Social Care, 2022). Two priority areas that the strategy aims to tackle – cancer and violence against women and girls – impact Black and Minoritised women differently from women of other ethnicities and backgrounds, including through harmful practices such as FGM.

Multiple barriers persist in access to cervical cancer screening for women, in particular for women from Black and Minoritised communities who are affected by female genital mutilation (FGM). On top of other barriers to accessing screening services, these women experience cultural barriers related to the widely used screening method for cervical cancer, commonly referred to as the Pap smear or the smear test. This test is a critical preventive measure, but women from African, Caribbean and Asian backgrounds face unique challenges in relation to it. These include cultural stigma and embarrassment; a lack of awareness; fear and anxiety around the test; the impacts of FGM; language barriers; and negative past experiences with healthcare services. These barriers contribute to lower screening rates and delayed treatment.

Understanding these barriers is crucial to developing effective strategies for promoting screening and reducing the burden of cervical cancer among these populations. Therefore, this report sets out to examine in greater depth some of the multifaceted barriers and fears that deter women from these backgrounds from participating in smear tests, focusing on the obstacles faced by survivors of FGM and sexual violence. By developing a deeper understanding of these challenges, we seek to propose targeted interventions that can improve the uptake and outcomes of screening programmes.

FORWARD is a pioneering organisation led by and for African women, with over 40 years' experience in working to end multiple forms of violence against women and girls (VAWG). As an organisation that addresses VAWG, we work with women who are not only from communities where cancer is an almost taboo subject, but who are also survivors of FGM or other forms of violence. Many of these women do not access cancer screening services, especially cervical smear tests, and this can impact their health. This study aims to explore this worrying pattern, identify the barriers that can prevent these women from accessing screening services, and find solutions that might help to reduce those barriers.

To this end, FORWARD has carried out this research to examine the experiences of women from Black and Minoritised communities living in the north-west London boroughs in relation to their use of local cancer services. The study combines the findings of a desk-based literature review with new data gathered through a survey and focus groups. The focus group format was chosen to enable these women to share their perspectives, experiences and suggested solutions in their own voices.

Objectives of this study

The five key aims of this research were to:

1. **Assess the participants' awareness and knowledge:** to evaluate levels of awareness and understanding around cervical cancer among women of Black and Minoritised backgrounds.

2. **Identify barriers to accessing cervical cancer screening:** to investigate the various cultural, socio-economic, and healthcare-related obstacles preventing these women from participating in screening programmes.

3. **Analyse participants' fears and anxieties:** to examine, in particular, the sources of fear experienced by the women around smear tests, and the impact on their access to related services.

4. **Develop interventions to increase uptake:** to design and propose culturally tailored educational and intervention programmes, which FORWARD and other actors could implement to increase screening uptake and early detection.

5. **Influence policy on cervical cancer prevention:** to provide evidence-based recommendations to policymakers regarding adaptations that could be made to the healthcare services around cervical cancer prevention and treatment, in order to better respond to the needs of women from diverse backgrounds.

What is FGM?

FGM refers to all procedures involving the partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons (World Health Organization, 2020). It is a deeply rooted cultural practice that is prevalent in parts of Africa, the Middle East and Asia, as well as in worldwide diaspora communities. FGM is often associated with cultural, religious and social factors within families and communities.

FGM is classified into four main types:

- **Type 1 (clitoridectomy): partial or total removal of the clitoris and/or the prepuce (clitoral hood).**
- **Type 2 (excision): partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora.**
- **Type 3 (infibulation): narrowing of the vaginal opening through the creation of a covering seal. The inner or outer labia are cut and repositioned, with or without removal of the clitoris.**
- **Type 4: all other harmful procedures to the female genitalia for non-medical purposes, such as pricking, piercing, incising, scraping and cauterising the genital area.**

A 2024 study by UNICEF, the United Nations Children's Fund, estimates that 230 million girls and women globally have survived FGM and live with its consequences (UNICEF, 2024, p. 1). The health impact includes short-term pain and severe bleeding, as well as long-term physical and psychological damage. Many girls and women affected by FGM also face complications in childbirth, including postpartum haemorrhage, stillbirth and infant mortality.

Prevalence and risk of FGM in the UK

There is a lack of reliable statistics on the prevalence of FGM in the UK, and estimates of the risk of FGM in the UK are outdated. In 2015, a study estimated that 137,000 women and girls living in England and Wales were born in countries where FGM was practised and in the UK, around 60,000 girls under the age of 15 years were estimated to be at risk of FGM (Macfarlane and Dorkenoo, 2015, pg. 6). This data does not reflect the full extent of the problem of FGM in the UK.

Since 2015, the Department of Health and the NHS have introduced enhanced data on FGM from women to help build a national picture of the incidents of FGM in England. According to this data, since April 2015, 37,615 women and girls who had undergone FGM have been seen at NHS services in England, where FGM was relevant to their attendance. About 40% of women were between 18 and 29 years old at the time of their attendance in hospitals. A total of 6,775 were women with type-3 FGM, which involves the removal of both the inner and outer vaginal lips and stitching to form a seal. Women with type-3 FGM often face additional complications in health procedures, because the closure of the vagina affects the use of health equipment. Between April 2023 and March 2024, 104 NHS trusts and 56 GP practices submitted one or more FGM attendance records. However, since the collection of the enhanced data began in April 2015, Annual Report FGM attendance records have been submitted from a total of 150 NHS trusts and 282 GP practices (NHS England, 2024).

In relation to knowledge about FGM, the public survey conducted for the Department of Health in the development of the Women's Health Survey found that "only 9% of respondents said they had enough information about specialist services such as sexual assault referral centres and female genital mutilation (FGM) clinics" (Department of Health and Social Care, 2022).

FGM has been illegal in the UK since 1985, and the Female Genital Mutilation Act was amended in 2003. The Serious Crime Act 2015 then introduced several policy changes and further duties. Healthcare and regulated professionals now have a legal duty to report to the police all cases of under-18s who disclose that they have experienced FGM or have evidence of FGM. Additionally, health professionals are now required to submit patient data to the FGM enhanced dataset. However, data on the prevalence of FGM therefore remains challenging to obtain, and the data that does exist fails to capture the full nature of the problem and the impact on women and girls in the UK.

This study seeks to provide better insights to help educate healthcare providers, policy-makers and the general public about the specific barriers faced by FGM survivors to accessing cervical smear tests. In doing so, it aims to ensure that these women's unique needs can be better met, with cultural sensitivity and appropriate care.

Methodology

This study used mixed methods. These include a review of the existing literature, and gathering new data through a survey and a series of focus group sessions. Both methods were conducted by FORWARD.

The survey targeted women aged 21 years and above from Black and Minoritised backgrounds in the UK, with a special focus on survivors of FGM and sexual violence. The survey aimed to gather data on a range of issues related to cervical cancer, including:

- **levels of awareness;**
- **barriers to accessing screening services;**
- **the women's healthcare experiences; and**
- **their suggestions for improvements to screening services.**

The primary research questions for the study were as follows:

A. **What is the level of awareness and understanding of cervical cancer and its screening among women from Black and Minoritised backgrounds in London?**

B. **What cultural and healthcare-related barriers to access prevent these women from participating in cervical cancer screening programmes?**

C. **How do past traumas, FGM in particular, influence the experiences and attitudes of women regarding cervical cancer screening?**

D. **What interventions can be developed to increase the uptake of cervical cancer screening among these populations?**

E. **How can policy changes on cervical cancer prevention and treatment support improved healthcare services and patient support services for women from Black and Minoritised backgrounds?**

Participant recruitment

Recruitment was conducted through FORWARD's community outreach programmes and partnerships with community organisations. Information sessions were held in community centres, and at local events to explain the purpose of the study and invite participation. Recruitment flyers were distributed in areas with high concentrations of the target population, specifically targeting Black and Minoritised Women. While the majority of the participants were African women, a smaller number of participants were from other backgrounds, such as Middle Eastern communities.

Consent and ethics

Consent was obtained in line with ethical research standards to ensure that participants were fully aware of the study's purpose and procedures, as well as of their rights as participants. To this end, the participants were given information explaining the nature of the research, what their participation would involve, the possible risks and benefits, and the measures taken by FORWARD's research team to ensure confidentiality and data protection.

The participants were given opportunities to ask questions and discuss any concerns before giving their consent. For participants with limited literacy and those who spoke languages other than English, we provided multilingual staff members who were able to translate, to ensure that these participants fully understood the consent process.

Ethical considerations

Confidentiality: to protect the identities of the participants, all the data were anonymised, and a general analysis was then carried out.

Data security: the data was stored securely in protected files, which were accessible to the research team only.

Data-collection methods

Survey design

A questionnaire-based survey formed the primary method of data collection. The survey included a mixture of closed and open-ended questions, in order to gather both quantitative and qualitative data. Overall, 85 women were surveyed and 70 of them responded in full to the survey conducted.

The survey was designed to assess:

A. **awareness and knowledge of cervical cancer and its screening method;**

B. **barriers to accessing cervical cancer screening, including cultural, economic, and systemic factors;**

C. **participants' past experiences with healthcare services; and**

D. **participants' suggestions for making cervical cancer screening more accessible and acceptable.**

Focus group design

Eight focus groups were conducted with participants recruited in the manner explained above. The focus group sessions were conducted both online and in person, and a total of 387 women participated in the focus groups. These group discussions sought to gain valuable additional insights and information, as well as aiming to promote the participants' understanding of the topic and their proactive engagement in women's health in their communities.

To achieve this, the design of the focus groups fostered a supportive environment for open discussions about the participants' experiences and their perceptions of cervical screening. Notably, these sessions facilitated discussions around sensitive topics, such as FGM and past traumas, which might not otherwise have been fully captured through the survey format.

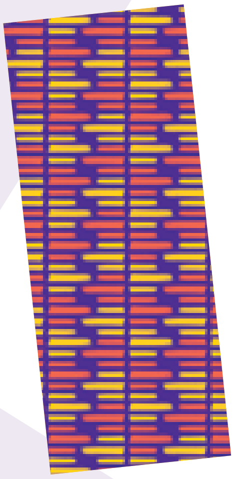
Qualitative and quantitative data analysis

The data gathered through the survey and the focus groups was processed and analysed as follows:

1. **The survey responses – which contained both quantitative and qualitative information – were initially coded and entered into a statistical software package (Qualtrics) for analysis.**

2. **The transcripts of the focus group discussions, meanwhile, were initially analysed using a thematic approach. This involved identifying themes and patterns through an iterative process of reading and re-reading the transcripts, coding topics and grouping these codes into broader themes.**

3. **Following these two initial steps, triangulation was used to validate the various findings and to ensure consistency and credibility, comparing the data from the survey and the data from the focus groups.**



Study findings and analysis

In this section, we present the key findings from our comprehensive research on the barriers faced by women from diverse backgrounds to accessing cervical smear tests, with a particular focus on survivors of FGM. We will explore the levels of awareness and understanding of cervical cancer among these women, as well as seeking to understand the barriers to accessing screening services, the psychological and physical challenges faced by FGM survivors, and participants' wider experiences of healthcare services.

The analysis will highlight the critical insights gathered from the survey responses and the focus group discussions, providing a nuanced understanding of these women's unique obstacles. To structure the discussion of the findings, we will separate out the key themes that surfaced recurrently in the research, such as low levels of awareness, or embarrassment and matters of modesty. Each of these common topics was assigned to a colour to aid the analysis.

By examining these findings, we aim to inform the development of targeted educational and healthcare interventions and policy developments, and ultimately to improve the uptake of cervical cancer screening and the healthcare experiences and outcomes among this underserved population group.

1.

Lack of awareness

Key finding

A significant number of the women surveyed indicated a lack of awareness about cervical cancer screening, its importance and its role in preventing cancer. Indeed, many participants reported that they had never even heard of cervical cancer screening (by any name) before taking part in this study. As a result, FORWARD's staff members and community workers collecting the data often needed to explain to participants what a smear test was, for example, or the purpose of screening services and their critical importance, before asking further questions.

Analysis and recommendations

In addition to the findings from the survey and focus groups, which highlighted significant gaps in awareness, these gaps were further substantiated by the FORWARD team's observations during the data collection. These findings were further informed and supported by the literature review, which provided additional context and insights. Consequently, the recommendations that follow are derived from both direct engagement with women and evidence from the literature.

Research has shown that patients' awareness of and knowledge around cervical cancer and its screening methods – are crucial determinants of screening uptake levels (Marteau, Dormandy, & Michie, 2011). In light of the concerns raised by the NHS about the low uptake of screening services among women from Black and Minoritised communities, the findings of our research and other studies therefore underscore the need for targeted and effective interventions.

Traditional healthcare education strategies may not reach these populations effectively due to cultural and linguistic differences. Mainstream public health campaigns often fail to address the specific contexts and needs of minority communities, and this can lead to significant educational gaps.

The solutions identified by the results of this study to overcome this barrier around low awareness on services include the following:

CULTURALLY ADAPTED EDUCATION INITIATIVES

Knowledge of cervical cancer screening can be improved by developing culturally tailored educational materials and translating them into multiple languages. Additionally, using community-based approaches to disseminate the information could increase its reach. This second method can have the added advantage of creating safe opportunities and spaces for the women in these communities to discuss topics like cancer, which are often taboo – especially when they relate in some way to sexuality or reproductive health.

COMMUNITY ENGAGEMENT

To further work around cultural taboos of this kind, trusted channels within the communities need to be supported to ensure that key information about the dangers of cervical cancer and the value of smear tests reaches all of those who may benefit. For example, collaborations with community-led organisations, community-based health or rights advocates, faith-based organisations, and local or social media channels that are run by and for members of the Somali community in the UK can enhance the reach and impact of educational initiatives. Collaborations of this kind could also substantially help to normalise screenings and reduce the stigma around them for community members.

Organisations such as FORWARD can play a vital role in the above by:

- **providing community health workers;**
- **coordinating initiatives around community education and women's health;**
- **advising healthcare bodies on the design of their information campaigns;**
- **providing professional training on the cultural sensitivities.**

2.

Barriers to access faced by survivors of FGM and sexual assault

Key findings

The FGM survivors and survivors of sexual violence who participated in the study described facing unique challenges when it came to cervical cancer screening. For many, the physical and psychological impact of their past experiences made the screening process especially difficult.

Of the FGM survivors in the study who had been for smear tests, many – and especially those living with type-3 FGM – described the screening procedure to be very painful and uncomfortable. Some women with type-3 FGM had found that healthcare professionals physically struggled to test them due to the FGM incision and the size of the speculum used in the test, observing that this method may simply not be feasible in their circumstances.

Many of the survivors of FGM and sexual assault reported finding the screening procedure highly triggering, in light of their past trauma and the invasive nature of the test. Before or during their smear test appointments, they had experienced high levels of anxiety and emotional distress, fearing re-traumatisation.

Many of these participants had also felt that the healthcare providers testing them lacked understanding and sensitivity regarding survivors of FGM or sexual violence, leading to feelings of mistrust and poor communication.

> **“When you have gone through FGM, [the smear test] is very painful and it takes me back to when I was going through the FGM.”**
>
> **(Participant 1)**

> **“The tool used is very big and hurts my private part; the nurse does not understand my scars even though she can see them.”**
>
> **(Participant 2)**
>
> **“I do not like going for my smear test although I know why I have to do it, because it reminds me of the time that I went through my FGM when I was a young child.”**
>
> **(Participant 3)**

Analysis and recommendations

In light of these findings, under current cervical screening methods and approaches, many survivors of FGM and sexual violence would seem to face major barriers to accessing positive health outcomes. The recommendations emerging from the study around this topic were numerous and varied. They include the following:

TAKE STEPS TO REDUCE PAIN AND DISCOMFORT

The physical discomfort associated with the speculum used in screening appears to be a major barrier to access for FGM survivors, especially those living with type-3 FGM. The current screening methods may therefore constitute a major obstacle to positive health outcomes for some FGM survivors. Smaller, more comfortable tools and gentle techniques should be considered to reduce discomfort.

SUPPORT RESEARCH INTO ALTERNATIVE SCREENING METHODS

Although the NHS provides human papillomavirus (HPV) self-sampling home kits in some areas, these are simply not always a satisfactory alternative to the cervical smear, because in many cultures it is deemed offensive and culturally inappropriate for women to touch their genitals. Therefore, it is imperative to support research into less invasive screening technologies, ideally ones that can detect cervical abnormalities without the need for a speculum. Advances such as liquid-based cytology, molecular testing methods and urine-based HPV testing could make cervical screening more comfortable and accessible for all patients, not just for survivors of FGM, and could encourage greater participation among underserved populations.

TRAUMA-INFORMED CARE DESIGN

To improve access to cervical cancer services for FGM survivors and those with a history of sexual abuse, our findings suggest that there is a need for more trauma-informed care approaches. These are approaches that recognise the impact of trauma on the individual and seek to create a safe and supportive environment (Behrendt & Moritz, 2005). In particular, healthcare staff performing the screening should be trained in trauma-informed care practices, as patients who are survivors of FGM or sexual abuse otherwise risk being re-traumatised when undergoing the smear test. This training should include understanding the physical and psychological impacts of abuse and FGM, and adapting the screening process to be as gentle and non-invasive as possible.

SPECIALISED FGM TRAINING FOR HEALTHCARE PROFESSIONALS

More investment is needed in training programmes that equip healthcare providers with the skills and knowledge to support FGM survivors effectively. Programmes of this kind can greatly improve survivors' experiences of care and the communication between them and their healthcare professionals. The training should provide an understanding of the cultural, physical and emotional impacts of FGM, and share practical information on how to address the specific needs of survivors. FORWARD can also take this finding on board by continuing to extend its FGM awareness training for healthcare professionals.

PSYCHOLOGICAL SUPPORT NETWORKS

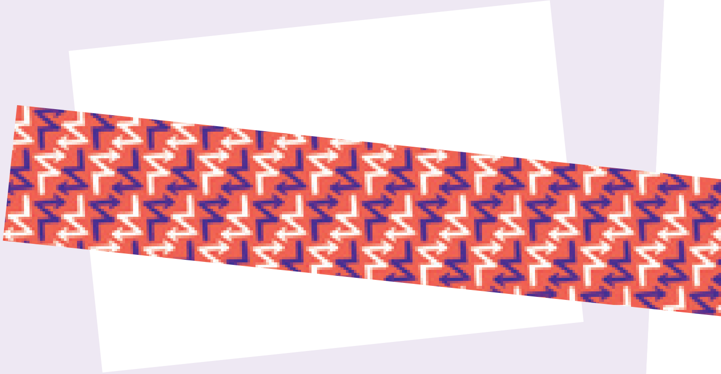
Establishing support networks for survivors of FGM, including counselling services and peer support groups, can provide survivors with emotional and psychological support around sensitive procedures like smear tests. These networks can also serve as a platform for sharing information and resources about cervical cancer screening. The availability of such psychological support systems is likely to improve uptake levels among traumatised women.

CULTURAL SENSITIVITY

Respect for cultural beliefs, values and practices during the provision of necessary medical care is essential for building trust and encouraging participation in screenings. Healthcare providers should be aware of the cultural significance of FGM in some communities; the topic should be approached with sensitivity and respect. Many women from practising communities believe that FGM is a religious requirement, although that is not the case. Therefore, cultural tact and a basic religious understanding among frontline staff can play a pivotal role in shaping attitudes towards cervical cancer screening among women from Black and Minoritised backgrounds.

FGM-RELATED ADVOCACY AND POLICY REFORM

Lastly, these findings suggest that ongoing advocacy is still critical for developing policies that better support the health and wellbeing of FGM survivors. In particular, FGM policy reform should ensure that funding is available for research into alternative cervical cancer screening methods and specialist services for women living with FGM, as well as for promoting a healthcare environment that is sensitive to the needs of all women.



3.

Fear and anxiety

Key findings

Fear and anxiety about the screening process were prevalent among the women who responded to the survey. A number of different factors contributed to these feelings of fear.

The physical discomfort and pain associated with the speculum (the tool used in the screening appointments) was a significant concern. Women often described the tool as too large, and intimidating.

As mentioned above, heightened anxiety was reported by survivors of FGM and those with a history of sexual abuse; some feared re-traumatisation during the procedure. The fear of a positive cancer diagnosis itself was also mentioned by some study participants.

> **"The reason why I do not go and do smear tests, is because I get worried that they may say I have cancer. I would rather not know what is wrong with me."**
>
> **(Participant 4)**

In addition, fear of the unknown appeared to heighten these other sources of anxiety; many of the women were unaware of what exactly the screening process for cervical cancer entailed, or they had been unaware of this until their first test.

Analysis and recommendations

Emotional and psychological barriers are known to play a critical role in preventing women from undergoing cervical cancer screening (Marlow et al., 2017). Understanding the sources of these fears and anxieties is essential in order to develop interventions that can alleviate them.

The quotation from Participant 1 opposite, who is an FGM survivor, highlights the important role of healthcare providers in creating a supportive and compassionate environment for FGM survivors and women who have experienced other forms of violence who are undergoing cervical smear tests. As well as helping to reduce these women's physical and emotional discomfort, this can also empower them to take charge of their reproductive health with greater confidence and trust in the healthcare system.

In the same vein, several specific measures were identified by participants and the research team to reduce this barrier:

HOLISTIC HEALTHCARE DESIGN

Screening services should be designed and run by multidisciplinary teams that include gynaecologists and psychologists to address patients' comprehensive human needs, in particular their mental health and emotional wellbeing.

EDUCATIONAL INTERVENTIONS

By providing detailed explanations about the screening process, including what to expect during and after the test, educational information could help to alleviate patients' fear of the unknown. Educational campaigns can also help patients to overcome their fear of a cancer diagnosis by providing information about the benefits of early detection and the high treatability of cervical cancer when it is caught early. Visual aids and demonstrations should be provided, as they have been shown to be especially helpful to patients with limited literacy, who are neurodivergent, or who do not have access to materials in their native language.

PSYCHOLOGICAL SUPPORT SYSTEMS

Psychological support and counselling before, during and after the screening can help to mitigate patients' anxiety and fear, in particular for trauma survivors. Peer support groups can also provide valuable reassurance, as well as a platform for sharing experiences and coping strategies. Additionally, providing the option for women to bring a support person can be beneficial.

COMMUNITY ENGAGEMENT

As discussed in the section above on lack of awareness, cultural and linguistic differences can hamper the effectiveness of outreach and education programmes in reaching this target population. Therefore, engaging with the communities in question through tailored campaigns, and collaborating with community workers and community-level organisations such as FORWARD, can help NHS services to dispel the myths and fears surrounding cervical cancer screening.

Implementing these recommendations could help to develop an open environment in which women feel comfortable and relaxed enough to learn about cervical cancer and its dangers, and to take responsibility for their reproductive rights. There can be little doubt that the recommendations would lead to an increase in the rates of women who go through with the screening.

4.

Embarrassment and matters of modesty

Key findings

Embarrassment related to the intimate nature of the examination was listed as a common barrier to accessing cervical cancer screening among the women participating in this research. Also, cultural sensitivities, notably concerns around modesty and privacy, heightened these feelings of embarrassment, especially among women from conservative backgrounds.

Analysis and recommendations

Acute embarrassment around smear test screening was a common theme. For many women from these Black and Minoritised communities, the idea of exposing private and intimate areas of their bodies to healthcare professionals is deeply uncomfortable. The physical positioning required for the procedure was itself also mentioned repeatedly as a significant problem.

It is worth noting that other studies have already established this as an obstacle to cervical cancer screening, which is not unique to women from Black and Minoritised backgrounds. The physical exposure required for cervical cancer screening is a significant source of embarrassment for many women who have experienced sexual trauma (Cadman et al., 2012). Likewise, modesty-linked concerns – and the intimate nature of the examination – can contribute to feelings of vulnerability (Waller et al., 2009).

These feelings are often rooted in cultural beliefs and norms, some of which are gender-specific, around privacy and body exposure. Nevertheless, our findings suggest that these concerns may be a particularly strong hindrance for women from Black and Minoritised backgrounds.

Several measures were identified to help address this issue.

IMPROVED CULTURAL COMPETENCE

Providing the healthcare staff who carry out cervical cancer screening with cultural training would help them to understand and respect the modesty concerns of women from certain cultural backgrounds. This training should also suggest specific strategies for maintaining women's privacy and dignity during the examination.

GREATER PRIVACY AND COMFORT

Efforts to ensure greater privacy, and to help patients feel comfortable and relaxed during the procedure, can help to reduce embarrassment. These include providing female healthcare staff to carry out the test when possible, providing adequate draping during the examination, and giving patients opportunities to talk about their concerns and preferences before and after the test. Continuity of care (i.e., tests being performed by the same person each time) can also contribute to patients' feelings of trust and safety.

COMMUNITY DIALOGUES

Many participants felt that open dialogues within communities about cervical cancer screening could help to normalise the procedure and thus reduce feelings of embarrassment, as well as modesty concerns. These dialogues should be facilitated by trusted community members who are able to address the cultural and religious concerns. The participants thought that these conversations would be most effective if they were repeated at regular intervals – for example, at regular coffee mornings or through local talks given by nurses or healthcare professionals.

COLLABORATION WITH RELIGIOUS LEADERS

To promote the importance of cervical cancer screening, cooperating with religious leaders and faith-based organisations can be an effective strategy. These individuals often play influential roles in these communities. FORWARD's teams have often observed that their endorsement of or opposition to health practices can strongly sway attitudes and behaviours in the wider community. Educating these leaders about the health benefits and necessity of smear tests can therefore lead to faster community-wide acceptance and support. Moreover, some religious leaders have a healthcare background; it can be worthwhile to enlist these individuals first, to help educate others.

5.

Negative past experiences

Key findings

Some of those study participants who had attended cervical cancer screening appointments in the past had had a range of negative experiences, which had discouraged them from attending further screenings. These negative experiences varied among the participants.

Of particular concern, as mentioned previously, some women with a history of sexual abuse or trauma from FGM described finding the smear test procedure to be triggering and distressing. In addition, a worryingly high number of the women surveyed who had been to screening appointments described feeling confused, fearful and unsupported because the healthcare professionals conducting their smear tests had not communicated sufficiently about the procedure, its importance and what to expect.

Some of the women reported experiencing discomfort or physical irritation (such as spots) following their cervical screening test, which had contributed to their negative perceptions of the procedure. Additionally, some participants who had attended multiple tests felt that their experience had been made more stressful because they had been seen by different healthcare workers for each screening, leading to a lack of continuity. Having to repeatedly explain their personal histories and concerns had led to feelings of frustration, discomfort and shame or had resulted in a perception of being unsupported, undermining their trust and engagement in the screening process. In this regard, it is important to note that for cultural reasons related to modesty, many participants were uncomfortable about multiple different healthcare professionals seeing their private areas and emphasised a preference for consistency in care.

Time pressure was another negative experience. Some of the women in the survey stated that they had felt rushed during the whole testing process. A few had even been pressured into taking the test when attending unrelated appointments with their GP, giving them no time to prepare mentally or emotionally.

> **“When I last went for my smear test which I was told to do it there and then. The lady who did my test was very rude and I did not like her tone.”**
>
> **(Participant 5)**

Analysis and recommendations

Negative past experiences during cervical screening emerged from the research as a significant barrier to future participation, especially for women with a history of sexual abuse or trauma, including survivors of FGM. Many participants with such histories described the smear test procedure as triggering and distressing, underscoring the critical need for trauma-informed care.

For several participants, their past experiences had eroded their confidence in the healthcare system overall and alienated them from screening services. Patients who feel that their concerns could not be adequately addressed during previous appointments, including due to time pressure at their healthcare provider, may be less inclined to return. This is of course especially true for patients with trauma; negative experiences are likely to lead to heightened anxiety and a reluctance to undergo future screenings.

Addressing some of the causes of these negative experiences and creating more supportive and inclusive environments for cervical screening could therefore significantly increase uptake rates, especially among women from ‘Black and Minoritised backgrounds.

Several suggestions came out of the research in this regard:

TRAUMA-INFORMED CARE

It is important to ensure that women with histories of trauma or FGM are treated with sensitivity and understanding, as discussed previously. This includes providing dedicated support staff to assist women who may find the screening procedure distressing.

TRAINING IN CULTURAL SENSITIVITY

As discussed elsewhere in this report, this is essential to address concerns related to modesty and privacy. Moreover, women from Black and Minoritised backgrounds should be given the option to request female healthcare professionals whenever possible.

ADDRESSING PAIN AND DISCOMFORT

Measures to reduce the physical discomfort experienced by some patients should be further explored, especially for FGM survivors. This includes the development of smaller or more comfortable tools. In addition, healthcare providers should discuss the possibility of discomfort and the potential post-procedure effects with patients in advance, and offer them strategies for managing any discomfort.

PATIENT-CENTRED COMMUNICATION

Clear and empathetic communication is another critical factor in improving patients' experiences. Healthcare professionals should explain the procedure, its significance, and what to expect at every stage, including the possible post-procedure effects. Time should also be allowed to address any concerns a patient has and to offer advice for managing any discomfort resulting from the test. Culturally sensitive educational materials can further reinforce these efforts and enhance patients' understanding.

Research indicates that effective communication is central to improving patient adherence to treatment plans and ensuring patient satisfaction (Kwame and Petrucka, 2021, p. 2). Furthermore, practitioners must take into consideration the impact of health messaging as women who are 'less acculturated to the West' may not engage as well as intended due to language barriers, therefore providing clear explanations and additional support so full comprehension is received is critical (Scientific Advisory Groups for Emergencies, 2020, pg.5).

APPOINTMENT TIMES

Adequate time should be allocated for appointments to avoid rushing and to provide comprehensive care. Women from Black and Minoritised backgrounds should not be pressured into undergoing screening during unrelated appointments but instead invited to attend dedicated screening sessions. Flexible appointment scheduling should also be implemented to accommodate women's diverse responsibilities, and mobile clinics or community-based programmes should be deployed to enhance accessibility and reduce logistical barriers to access.

CONTINUITY OF CARE

Consistent care is paramount. Ideally, women should be seen by the same healthcare professional for each appointment to build trust and minimise discomfort and anxiety. Where this is not feasible, a robust handover system should be implemented to ensure that healthcare providers are fully informed about patients' histories and concerns.

Requiring women to repeatedly explain their personal history and concerns can lead to frustration, a sense of being unsupported, and heightened feelings of shame and discomfort during intimate examinations. This is particularly significant for women with complex medical histories, cultural sensitivities or experiences of trauma. For women affected by FGM, particularly Type 3 FGM, they require much more specialised medical care and attention.

PATIENT FEEDBACK

To promote continuous improvement, anonymous feedback mechanisms should be introduced to capture patients' experiences and identify recurring issues. This could help to avoid the repetition of certain, usually isolated, negative perceptions and experiences, while also improving patients' trust in healthcare processes by making them feel that their concerns are heard and valued.

6.

Practical challenges in accessing healthcare services

Key findings

Many of the women surveyed suggested that English was not their first language and that the resulting difficulties, both in navigating the healthcare system generally and in understanding what the screening process would entail, had hindered their interest in having further smear tests.

> **"English is not my first language and so it is difficult to understand why I need to do this."**
>
> **(Participant 6)**

Some participants had struggled to find time in their busy schedules for screening appointments, alongside their professional and private-life commitments, due to the complexity of finding a suitable appointment.

Analysis and recommendations

It became clear during the research that certain other logistical challenges had created further barriers to the participants' ability to access cervical cancer screening services.

On the basis of the research findings and the wider experience of FORWARD's teams, we can offer the following recommendations:

LANGUAGE SERVICES

Language barriers can be a significant obstacle to accessing healthcare services; this is equally true for cervical cancer screening. Providing comprehensive language support services, such as interpreters and translated written materials, is crucial for improving access and understanding. Healthcare facilities should have policies in place to ensure that language services are readily available.

APPOINTMENT FLEXIBILITY

Offering flexible appointment times and reducing waiting times can help to accommodate women with busy schedules or childcare responsibilities. For instance, if appointments are scheduled too far in advance, women may find it difficult to confirm their availability, as future work or childcare commitments are often uncertain until closer to the date. Mobile clinics and community-based screening programmes can also improve accessibility.

ONLINE APPOINTMENT SYSTEMS

Offering online appointment booking systems can streamline the booking process and provide convenience for patients who have difficulty scheduling appointments around their work or family commitments. Online systems can also offer privacy by reducing the need for phone conversations on reproductive health topics, which can be uncomfortable or even culturally frowned upon for some women from Black and Minoritised communities.

7.

Barriers around virginity

Key findings

Study participants who were virgins shared specific fears and anxieties about the smear test procedure. These included physical discomfort, sensory sensitivities and the fear that if they underwent smear-testing, they could lose their virginity.

> **“The tool used is very large and very uncomfortable, and also there is the concern that it will take away my virginity.”**
>
> **(Participant 7)**

The cultural emphasis on virginity in some communities in particular is an obstacle to some women accessing cervical screening. A gynaecological examination can be seen as compromising a young woman’s virginity or purity. Moreover, because virginity is often linked to family honour, this belief or fear is frequently reinforced by older family members and by the young women’s mothers, who may discourage or outright forbid their daughters from participating in screening programmes.

Analysis and recommendations

These findings suggest that a current lack of tailored information and support for this demographic – and their families – may constitute a significant barrier to their access to testing services. Addressing the unique needs of virgins from Black and Minoritised communities requires targeted approaches that consider their specific concerns and requirements.

The following recommendations emerged from the research:

TAILORED INFORMATION

Providing virgins with targeted information would help to address their fears, especially for those who have never undergone any gynaecological examinations before. The information should include a reassurance of virginity, along with detailed explanations of the procedure and advice on pain management.

INCREASED AWARENESS AMONG HEALTHCARE PROVIDERS

Another helpful measure would be to ensure that healthcare providers recognise the emotional and psychological concerns that women from diverse backgrounds may have, especially if they are young and have limited experience of healthcare. They should allow ample time for questions and to address all concerns thoroughly, and staff should communicate with empathy and sensitivity before proceeding with the examination.

DEVELOP ALTERNATIVE TESTING METHODS

As with other concerns discussed in the previous sections, adapting testing methods, such as the use of a smaller speculum, could also help to alleviate these women’s fears around virginity.

Conclusion and recommendations

This research study confirms that women from Black and Minoritised backgrounds, in particular survivors of FGM and sexual violence, face significant and multifaceted barriers to accessing cervical cancer screening. These obstacles include not only the physical pain and psychological trauma associated with previous abuse, but also low awareness of cervical cancer, fears around the procedure, embarrassment and matters of modesty, negative past experiences with healthcare, language difficulties and logistical challenges, and concerns about virginity.

These barriers, left unaddressed, contribute to lower screening uptake, delayed diagnosis and preventable deaths. However, they are neither inevitable nor insurmountable. Targeted, culturally sensitive interventions that are rooted in trust, respect and accessibility can help to transform outcomes for the majority of women. By integrating trauma-informed approaches, improving communication, and tailoring services to the lived realities of these communities, the healthcare system can significantly reduce disparities in cervical cancer incidence and mortality.

Recommendations

Many of the solutions already exist and are known – notably the community-led, culturally adapted initiatives pioneered by FORWARD and similar "by and for" organisations. What is needed now is sustained investment, stronger policy support, and a commitment to embedding these approaches into mainstream healthcare practice. The recommendations are highlighted below.

1

Enhanced training for healthcare providers

- **Deliver comprehensive training on cultural competence and trauma-informed care for all staff involved in cervical screening, with dedicated modules on the needs of FGM survivors, sexual violence survivors, women for whom virginity has high cultural importance, and neurodivergent patients.**
- **Equip providers with skills to adapt screening techniques, offer alternative methods and communicate with sensitivity.**
- **Ensure providers are equipped with the necessary tools and knowledge in order to provide longer appointments for patients with trauma histories or complex concerns, and ensure opportunities for clear explanations and reassurances before any procedure.**
- **Extend proven training programmes, such as those run by FORWARD, to embed best practice at scale.**

2

Community-based educational interventions

Develop and implement community health education programmes in collaboration with local organisations. The educational programmes provided by FORWARD are a good example. Conceived specifically for women from Black and Minoritised backgrounds, such programmes can play a significant role in raising awareness about cervical cancer, its prevention, and the importance of undergoing regular screenings, and could alleviate patients' fears and anxieties.

- **Partner with trusted community-led organisations to deliver health education in multiple languages, tailored to cultural contexts.**
- **Address key concerns – trauma adaptations, modesty, virginity and physical discomfort – using clear, accessible explanations and visual aids.**
- **Use trusted messengers, including community leaders, faith leaders and diaspora media, to normalise conversations about cervical health.**
- **Facilitate regular community dialogues (e.g., coffee mornings, talks with healthcare professionals) to provide safe spaces for discussion and myth-busting.**

3

Research into alternative screening methods

Explore alternative screening methods and other ways to reduce pain and discomfort. This is vital to overcoming the barriers faced by women from Black and Minoritised backgrounds to accessing cervical screening services. Conventional approaches, such as using a speculum for smear tests, can be uncomfortable and distressing for some women, especially survivors of FGM and sexual violence.

- **Invest in and pilot technologies that are less invasive – such as urine-based HPV testing, molecular diagnostics, or improved cytology methods – to reduce pain and distress.**
- **Collaborate with community organisations to design and test these methods in culturally sensitive ways.**
- **Train healthcare staff on communicating and implementing these alternatives to encourage uptake.**

4

Language and accessibility support

Many of the women surveyed highlighted that language barriers had significantly hindered their understanding of the importance of cervical screening and made navigating the healthcare system challenging. Comprehensive language support services, including trained female interpreters and translated written materials, are essential to ensure that these women fully understand the screening process and can take a more active role in their healthcare journey.

- **Provide trained female interpreters, translated materials, and culturally adapted educational resources.**
- **Offer dedicated, pre-booked screening appointments rather than opportunistic testing during unrelated visits.**
- **Allow sufficient time for explanations and questions, and offer flexible scheduling to accommodate patients' varied work and caregiving commitments.**
- **Ask patients if they would like to bring a trusted support person with them and encourage them to do so.**

5

Psychological support and continuity of care

Screening services should be designed and delivered by multidisciplinary teams, including psychologists who can cater to patients' mental health and emotional wellbeing. There is a particular need for more trauma-informed care approaches, which recognise the impact of trauma on patients and seek to create safe, supportive environments. But psychological support should not be limited to patients with trauma, as many other women experience feelings of anxiety and vulnerability around cervical cancer screening. A holistic approach to care delivery could improve many patients' experiences and would probably lead to increased uptake of screening services, especially among women in Black and Minoritised communities.

- **Integrate trauma-informed, culturally sensitive care into screening services, with the option to request female providers.**
- **Offer counselling and peer support before, during and after appointments.**
- **Where possible, ensure continuity of care with the same member of staff; otherwise, implement robust handover protocols to avoid women having to repeatedly disclosure sensitive histories.**
- **Foster patient-centred communication that explains the procedures, anticipated sensations, and after-effects clearly and with empathy.**

6

Policy advocacy

Advocate for policies that allocate funding to culturally sensitive healthcare initiatives, including services that better support the health and wellbeing of FGM survivors and survivors of other forms of abuse. Policy reform should notably ensure that funding is available for research into alternative cervical cancer screening methods and specialist services for women living with FGM.

- **Advocate for policy reforms and sustained funding for culturally tailored healthcare initiatives and specialist services for FGM survivors.**
- **Prioritise investment in innovative screening methods and the scaling-up of proven community-based programmes.**

7

Research and feedback processes

- **Establish continuous feedback systems to capture patient experiences, address emerging barriers to access, and improve services in real time.**
- **Support ongoing research into alternative screening methods and their effectiveness for underserved groups.**

In summary, implementing these recommendations would not only improve cervical screening uptake among Black and Minoritised women but also advance health equity and protect lives. This requires a shared commitment from policy-makers, healthcare providers, and community leaders to deliver care that is safe, respectful and informed by the communities it serves.

FORWARD's leadership in community-driven, culturally competent interventions demonstrates that change is both possible and effective. With sustained investment and systemic adoption, these approaches can close the screening gap, reduce preventable mortality and uphold the reproductive rights of all women.

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