IT'S A SMEAR CAMPAIGN!

Breaking barriers, building trust: towards trauma-informed and culturally sensitive cervical screening.



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Trigger warning: Report contains details which may be distressing.

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IT'S A SMEAR CAMPAIGN

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About Nottingham Women's Centre

Nottingham Women's Centre is a women's community space dedicated to helping women overcome barriers, have their voices heard, and seek solutions that create a better future for themselves. As a hub for women's services in the city, we work holistically and in partnership to ensure support is accessible and joined up. For over 50 years, we've provided support, opportunities and advocacy, amplifying women's voices and driving greater equality.

Nottingham Women's Centre (NWC) provides a vital bridge between women's lived experiences, frontline services and policymaking. Engaging with more than 17,000 women each year, NWC has a unique reach into Nottingham's diverse communities and a strong track record of translating women's experiences into evidence, practical policy recommendations and service improvements. Its evidence on women's reproductive health in Nottingham was cited multiple times by the UK Parliament's Women and Equalities Committee in its 2024 report on medical misogyny, demonstrating how locally generated evidence can inform national debate and scrutiny. NWC has also contributed to work associated with the Ockenden Maternity Review, helping to ensure that women's voices inform efforts to improve the safety, quality and responsiveness of women's healthcare. This combination of trusted community relationships, substantial reach, and policy expertise places NWC in a strong position to identify where services are not working for women and, importantly, to help shape practical solutions that can be delivered locally and inform wider policy.

About this report

This report presents findings from Nottingham Women's Centre's '*It's a Smear Campaign!*'. It forms part of our broader Women's Health Matters campaigning strand, in partnership with Nottinghamshire Sexual Violence Support Services (NottsSVSS) and funded by the Rosa UK Voices from the Frontline fund. The campaign aims to bridge the gap between how healthcare professionals deliver cervical screening and the real needs and access barriers women experience. Research indicates that certain groups of women – such as those at younger or older ages, LGBTQIA+ individuals, people living in deprived areas, those with disabilities, from minoritised ethnic groups, with severe mental illness, or whose first language is not English – are less likely to attend routine cervical cancer screenings.[1]

For survivors of sexual abuse, cervical screening can feel especially distressing and triggering due to the invasive nature of the procedure. There are some examples of positive, supportive care during cervical screening, but this isn’t experienced consistently.

The overarching goal is to ensure that everyone with a cervix can access consistent, culturally sensitive, and trauma-informed cervical screening and gynaecological care. Central to this ambition is fostering a shared understanding of women's experiences, ensuring these are recognised and respected, and encouraging healthcare professionals to reflect on and improve how care is delivered. The underlying principle is that when care is consistently accessible and responsive to women's needs, they are more likely to feel informed, confident, and supported in making decisions about their health. By improving experiences of care and addressing barriers, these changes will, in turn, contribute to increased cervical screening uptake.

The campaign was led by a steering group of seven women, including healthcare professionals, to deliver two key priorities:

- To work with Nottingham City Primary Care Networks (PCNs) to respond to and act on insights gathered through community listening sessions to improve the delivery of culturally sensitive, trauma-informed cervical screening.

- To develop a practical resource to empower women: Informed by lived experiences, a pilot version of the Cervical Screening Checklist has been developed and is included in this report as Appendix A. The checklist aims to strengthen women’s knowledge, confidence, and ability to navigate cervical screening by providing clear, accessible information on the support available before, during, and after appointments. The checklist will undergo a structured process of piloting, evaluation, and refinement. This will involve gathering feedback from women, community groups, and relevant healthcare stakeholders to assess its clarity, accessibility, cultural appropriateness, and practical relevance. Findings from this evaluation will inform revisions to the resource and ensure the final version is both fit for purpose and responsive to the needs of the women it is intended to support.

About the campaign steering group

The campaign adopted a participatory approach and was intentionally designed to bring together women from a range of communities, including health professionals, within the steering group. This created a valuable combination of lived experience, community insight and professional expertise. The group's diversity created a shared space where women could exchange knowledge, learn from one another, identify common concerns, and contribute different perspectives to shape the campaign's development and direction.

Campaign partner: Nottinghamshire Sexual Violence Support Services (Notts SVSS)

As part of '*It's a Smear Campaign!*', Nottingham Women's Centre worked in partnership with Nottinghamshire Sexual Violence Support Services (Notts SVSS), an organisation commissioned to provide specialist support to survivors of sexual violence aged 18 and over living in Nottingham and Nottinghamshire. Notts SVSS played a key role in the campaign, co-facilitating listening sessions as a specialist representative, co-authoring this report.

This partnership was particularly important in recognising and addressing the barriers that survivors of sexual violence and trauma may face when accessing cervical screening. Working collaboratively with a specialist sexual violence support service enabled the campaign to embed trauma-informed principles throughout its research, engagement and advocacy activities. This helped ensure the campaign's approach and recommendations were sensitive to survivors' experiences, responsive to their needs, and grounded in safety and empowerment.

Acknowledgements

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We are also deeply grateful to the organisations that supported and contributed to the campaign, including Nottingham Muslim Women's Network, Nottingham Ukrainian Cultural Centre, Nottingham Health Shop, Nottingham and Nottinghamshire Refugee Forum, and the University of Nottingham Health Service. Their insight and collaboration were instrumental in shaping and strengthening this work.

Above all, we offer our heartfelt thanks to the people who generously and courageously shared their experiences, insights, and personal stories with us. Their voices are at the heart of this report. We are profoundly grateful for their honesty and the trust they placed in us to listen to and represent their stories with care.

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Executive summary

Cervical screening is a vital part of preventative healthcare and one of the most effective ways to prevent cervical cancer. Yet, participation remains a concern, with screening coverage in Nottingham below the national average.[2] Increasing uptake is an important public health priority, but it requires a healthcare system that understands and responds to the practical, emotional, physical, and cultural barriers women face and ensures everyone receives consistently safe, respectful, and supportive care.

This report presents the findings of Nottingham Women's Centre's It's a Smear Campaign!, delivered as part of its wider Women's Health Matters campaign, in partnership with Nottinghamshire Sexual Violence Support Services (Notts SVSS) and funded by Rosa UK's Voices from the Frontline fund. The campaign sought to bridge the gap between how cervical screening is delivered and the needs, experiences, and barriers women themselves have identified. The overarching goal is to ensure that all women can access consistent, culturally sensitive, and trauma-informed cervical screening and gynaecological care.

Using a participatory, mixed-methods approach, the campaign gathered evidence through an anonymous survey and a series of drop-in and facilitated listening sessions across Nottingham and Nottinghamshire. The report is grounded in the lived experiences of people from diverse communities, including minoritised ethnic groups, Muslim and Ukrainian communities, transgender people, women experiencing homelessness, and women living in refuges. The campaign engaged 221 people - 155 through the anonymous survey and 66 through the listening sessions. Of the 147 respondents who rated their experience of cervical screening on the survey, an estimated **46% described it as positive, 44% as mixed, and 11% as negative.**

Cervical screening experiences

155 respondents rated their experience.

46% Positive	44% Mixed	11% Negative

221 people engaged through the survey and wider community activities.

Percentages are estimated and rounded: totals may differ from 100%

Key findings

1. Women want to be screened - the system must make it easier

> Due to my periods being irregular in length at the moment, it's tricky to make an appointment. After receiving my invite letter, I rang up and the first appointment available was 3 months away. I booked it in the hope that it would be mid-cycle, but when the date became nearer, I soon realised it would fall during menstruation. I therefore rang up and explained the situation and this time the next available appointment is another 3 months away and still a gamble as to when it will fall during my cycle. My worry is that this could potentially continue for many months and potentially years due to the significant lack of appointments…It feels hopeless - I desperately want to go as I have tested HPV positive in the past, but availability is a huge issue.



> I couldn't go with my little one who was not up to school age; neither could I pay for childcare and there was no offer for a quick childcare cover for the appointment.

The experiences women shared revealed that difficulties accessing suitable appointments can create a significant barrier to cervical screening. They described struggling to find appointments that fit around work and childcare, experiencing long waits with limited evening and weekend provision, difficulty coordinating appointments with menstrual cycles, uncertainty about whether they could attend another practice, and few alternatives to GP-based screening. Services should consider not only whether appointments are technically available, but whether women can access them quickly, conveniently and in a way that supports completion.

2. First screening experiences have a lasting ripple effect, shaping future engagement and influencing others through shared experiences

> It has taken me 7 years to book a second smear test - I haven't had this yet but I am still very apprehensive after my first experience.

> Better care at my first smear would've made all the difference.

Women's accounts suggest that the first cervical screening appointment is more than a single isolated clinical encounter. Cervical screening is not a one-off intervention; its effectiveness depends on women participating repeatedly at different stages of their lives. This influence can extend across generations, particularly from mothers to daughters, as family conversations pass down screening experiences and shape expectations, attitudes and confidence in accessing cervical screening. First-time screening should be recognised as a distinct and important point in the screening pathway.

3. Pain during cervical screening is often normalised rather than recognised and addressed

> I found it all too painful, so it had to be aborted. I missed the last 3 smear callings due to this.

> I've had many smear tests throughout my adult life and have always found them to be painful...

Accounts of pain emerged strongly across the findings and reveal a significant disconnect between how pain is communicated in statutory health information materials and women's experiences in practice, with many reporting unexpected discomfort that was inadequately acknowledged or minimised by healthcare professionals. Women's experiences of pain are not uniform, but are shaped by factors including race, menopause, age, sexual orientation, medical conditions, and experiences of sexual violence and trauma, which may intersect in ways that compound barriers to screening.

4. Gaps remain in how ongoing consent is translated into practice during cervical screening

> A bit of aggression at the beginning, did not know how to stop the procedure.

> I have vaginismus based on sexual coercion by previous partners and the two first smear tests I went to were not nice. The nurse did not stop when I started crying or ask me if I wanted to continue or offer different options such as a smaller speculum or to have support instead said I needed to 'speak to someone' about 'my problems'.

There were significant concerns about how consent is understood and respected during cervical screening. Some women described examinations continuing after they had withdrawn consent, while others reported crying, expressing pain, or asking practitioners to stop without feeling that their wishes were acknowledged.

These experiences underscore a fundamental principle: consent must be an active, ongoing process rather than a one-off procedural formality, with women retaining control, dignity, and bodily autonomy throughout the examination. A technically completed screening test cannot be considered a successful experience if a woman leaves feeling that she has lost control over what happens to her body.

5. Getting the right information, at the right time and in the right place, is essential

> I felt that I was left to figure things out for myself, a face-to-face or phone discussion with a 'person' ... perhaps a GP or a specialist would have improved the anxiety during this time and helped me to feel more informed about what my result meant and what the next steps would be.

> Would be really helpful to have more information about things that can help/options beforehand. Also, in reminder text/email, how to prepare, things to do afterwards, maybe a link to more information.

Women's accounts show that positive cervical screening experiences depend not only on the quality of care during the examination but also on how well women are informed, prepared, and supported throughout the screening pathway. Throughout the engagement, women consistently called for clearer information about the procedure, available choices and adjustments (including speculum sizes), the meaning of their results, and next steps. The findings suggest that providing information does not necessarily translate into meaningful preparation. Women described feeling rushed, finding the information too clinical and inaccessible, and having limited opportunities to raise concerns.

6. Positive cervical screening practices exist, but consistent care remains a matter of chance

> My most recent experiences at [surgery] have been really sympathetic and professional, so it really does depend on the surgery. But healthcare shouldn't be a postcode lottery, based on the mood of the practitioner conducting the smear.

> Little empathy, lack of reassurance or understanding when it does feel uncomfortable or painful. You get a harsh piece of paper towel to 'clean' yourself up with – it's just not very friendly when it's such an uncomfortable experience.

The positive experiences reported by women demonstrate that high-quality cervical screening is already being delivered within the NHS. Women described healthcare professionals who communicated clearly, anticipated discomfort, responded to concerns, protected dignity, and checked their willingness to continue. However, these experiences were not consistently reported, even within the same practice or screening location. This was explored within the context of pressures facing NHS services, where high workloads, time constraints, and limited resources can affect the ability of even experienced and compassionate healthcare professionals to provide the individualised care women need. Improving the quality of cervical screening requires not only strengthening professional practice but also addressing the structural conditions that enable consistent positive experiences.

7. Cervical screening services are not sufficiently equipped for the diversity of bodies they serve

> I experienced a traumatic birth at the Queens Medical Centre, causing irreparable damage internally and PTSD. A few years post birth a prolapse has occurred and therefore it is now more challenging for staff to take samples from the cervix and the tools required to carry out the smear test causes more discomfort and takes longer. At my most recent (2026) smear test the inference that the difficulties … in getting to the cervix to take the sample was partly due a problem with me (post childbirth) were not appreciated or helpful.

People accessing cervical screening represent a diversity of bodies and experiences, including variations in anatomy, disability, medical history, childbirth, pain, and trauma. These differences are a natural feature of the population served, rather than exceptional circumstances requiring special accommodation. The ways screening services recognise and respond to this diversity can determine whether participants complete screening successfully. For some participants, recognising bodily variation and adapting care prevented unnecessary pain; for others, it led to identifying and treating underlying conditions. Where neither occurred, some disengaged from screening altogether.

Recommendations for change

1. Commission neighbourhood-based cervical screening services through women's health and community hubs, offering flexible appointment options to women who face barriers to accessing screening through traditional GP settings.

2. Establish a national first-screening standard requiring everyone invited for their first cervical screening to receive accessible information alongside their invitation, opportunities for pre-screening consultation, and an assessment of individual support and adjustment needs.

3. Introduce mandatory pain assessment and management protocols for cervical screening and revise national clinical guidance and public information to accurately reflect women's diverse experiences.

4. Embed ongoing consent as a mandatory, assessable competency in trauma-informed cervical screening training, with clear practical protocols for maintaining choice and control throughout examinations, including agreed pause or stop signals.

5. Redesign cervical screening communications to prioritise meaningful understanding over information provision alone, using accessible, multilingual resources, peer educators, and trusted community networks to support confidence.

6. Scale positive cervical screening practices across NHS services through continuous professional development and investment in the systems and resources that enable consistent care.

7. Strengthen existing cervical screening audits to assess and improve provision for individual anatomical needs, including speculum choice, flexible positioning, and specialist referrals.

Introduction

Cervical cancer is one of the most preventable and treatable forms of cancer, particularly when detected early and managed effectively.[3] However, it remains a significant global public health concern and a major cause of illness and death among women. Globally, cervical cancer is the fifth most diagnosed cancer in women, with approximately 604,000 new cases and 280,000 deaths in 2024.[4] Despite being largely preventable, the burden of cervical cancer is projected to increase without sustained and equitable prevention efforts. The World Health Organization (WHO) estimates that, without further action, annual cases could rise to 700,000 and deaths to 400,000 by 2030.[5] Countries worldwide have committed to the WHO's goal of eliminating cervical cancer as a public health problem. A key milestone towards this goal is achieving 70% screening coverage using a high-performance test by age 35 and again by age 45, as part of the WHO's 2030 elimination targets. [6] Australia provides an important example of progress towards this goal. By 2024, 85% of Australian women aged 35–39 had received at least one human papillomavirus (HPV) screening test, indicating substantial progress towards the WHO's 70% screening target.[7]

Its 2025 Cervical Cancer Elimination Progress Report also recorded no cervical cancer cases among women under 25 in 2021, marking the first time this had occurred since national records began in 1982.[8] In England, 76.9% of women aged 35–39 had undergone cervical screening before their 35th birthday in 2023/24.[9] Although these figures are not directly comparable with each other or with the WHO's specific screening targets, they provide useful indicators of progress towards cervical cancer elimination. However, these achievements sit alongside continuing challenges in screening participation. Despite Australia's achievements, declining screening participation remains a concern, demonstrating that these challenges are not unique to England but reflect a wider global public health issue.[10]

England

More than two people die from cervical cancer every day, and approximately 3,300 new cases are diagnosed annually in the UK.[11] In England, incidence has been reported to be 65% higher among women living in the most deprived areas than among those living in the least deprived areas.[11] Evidence indicates cervical screening saves 5,000 lives annually through the identification of high-risk HPV and abnormal cervical cell changes.[12]

Cervical screening in England is delivered through the NHS Cervical Screening Programme. Eligible women and people with a cervix aged 25–64 are routinely invited for screening every five years.[13] From 1 July 2025, those aged 25–49 who test negative for high-risk HPV moved from three-yearly to fiveyearly routine screening, bringing screening intervals into alignment across the 25–64 age range.[12] While the change is supported by clinical evidence, it has also raised questions about women's understanding, confidence and perceptions of risk. The government's equality impact assessment acknowledges that longer intervals could inadvertently reduce the perceived importance of screening if not communicated effectively.[14] In August 2026, NHS England began the national rollout of self-sampling for eligible people aged 30–65 who had not attended cervical screening following previous invitations. Nearly four million women are expected to be offered self-testing kits.[15] The initiative enables individuals to collect a vaginal sample privately at home and return it for high-risk HPV testing, with those receiving a positive result subsequently invited for further cervical sampling.[15]

Research suggests that self-sampling has the potential to address some of the practical, psychological, and personal barriers associated with conventional cervical screening and to improve access among people who are currently under-screened. During the campaign's engagement activities, women generally welcomed the option of self-sampling to improve choice and accessibility. However, some expressed uncertainty about whether they had followed the instructions correctly, which affected their confidence in the reliability of the results. Concerns were also raised about the potential difficulties of collecting a sample correctly, particularly for women with disabilities, limited mobility, or conditions affecting coordination, such as dyspraxia. While self-sampling offers a valuable alternative to clinician-led screening, our engagement highlights that it may not be suitable or preferable for everyone. Clear instructions, appropriate support, and continued access to clinician-led screening are therefore essential to ensuring that self-sampling expands choice rather than creating additional barriers.



Today, approximately four in ten cervical cancer cases in England are diagnosed through the screening route, demonstrating the continuing importance of screening in early detection and prevention.[16] Despite this, participation has declined. Recent data indicate that cervical screening coverage ranges from approximately 55.3% to 68.8% across the UK, based on the latest available national data from 2022/23 to 2024/25.[16]

In England, coverage also varies by age. In March 2024, coverage was 67.5% among women aged 25–49, compared with 74.9% among those aged 50–64. Significantly, none of England's 106 Sub-Integrated Care Boards achieved the programme's 80% coverage threshold in either age group.[17]

England has set an ambitious goal to eliminate cervical cancer by 2040, in line with the WHO elimination threshold. Achieving this ambition requires both HPV vaccination and cervical screening as complementary preventive measures. However, the effectiveness of screening as a public health measure also depends on women being able to access it. Declining participation and persistent inequalities in access risk slowing progress and leaving some women behind. Delivering on the 2040 ambition therefore requires not only improving screening coverage but also addressing barriers and ensuring care is consistently accessible, culturally sensitive, and trauma-informed.

Nottingham and Nottinghamshire

Participation in cervical screening is not evenly distributed across Nottingham and Nottinghamshire. Evidence shows a persistent geographical inequality between Nottingham City and the surrounding Nottinghamshire County. In 2024, only 60.5% of eligible women aged 25–64 in Nottingham City were up to date with cervical screening, compared with 75.7% in Nottinghamshire County - a substantial gap of 15.2 percentage points.[18] This is not a new inequality: screening coverage has consistently been lower in the city than in the county, and the gap has widened over time. Nottingham City also remains well below the England average of 68%.[19]

Understanding this variation is particularly important within Nottingham City, where deprivation and population diversity provide important context for the delivery of preventative healthcare. Nottingham City and Nottinghamshire County have different demographic and socioeconomic profiles, and screening coverage may vary considerably between local authorities, Primary Care Networks (PCNs), individual general practices and population groups. Nottingham is more deprived than approximately 94% of local authority districts in England.[20]

The Women's Health Needs Assessment[21] identifies poverty, caring responsibilities, discrimination, and difficulties accessing appropriate healthcare as significant determinants of women's health. Approximately 56.3% of women in Nottingham live in the poorest areas of the city, and women living in more deprived communities have lower participation in NHS screening services, including cervical screening[22] (Nottingham City Council, 2025). Local public data also identify particularly low cervical screening participation in areas including Hyson Green, Bulwell, and Strelley where higher levels of socioeconomic deprivation and wider health inequalities may contribute to barriers to accessing preventive healthcare services.

National evidence shows that women from socioeconomically disadvantaged and some minoritised ethnic groups are less likely to participate in cervical screening.[23] Nottingham's population reflects a wide range of ethnic, cultural, linguistic, and socioeconomic backgrounds, which can shape women's experiences of cervical screening and the barriers they face, highlighting the need for more than a universal, one-size-fits-all approach.

Participation in cervical screening is shaped by a combination of social, cultural and health-system factors, including age, ethnicity, socioeconomic circumstances, language and health literacy, cultural and religious beliefs, previous healthcare experiences, and practical barriers to accessing services.[24] These factors do not operate independently; for some women, several disadvantages may overlap and reinforce one another, making screening less accessible even where services are universally available. NHS England has recognised the value of examining how characteristics such as ethnicity and deprivation intersect and potentially compound disadvantage.[25] For Nottingham, this means looking beyond overall screening coverage rates to identify which communities face the greatest barriers, understand their experiences, and ensure that services respond to their specific needs.



This campaign sought to address these barriers by exploring them through community listening sessions and engagement with women from diverse backgrounds, particularly those whose experiences may be underrepresented in mainstream healthcare engagement. Conversations in Nottingham during the campaign highlighted that barriers do not end once a screening appointment has been made. The experience of the procedure itself is equally important. Cervical screening can leave women feeling vulnerable, and whether women feel listened to and their individual needs recognised can shape their screening experience and influence their willingness to complete the procedure and return for the next one. Their experiences may also shape how they talk about screening with friends, family, and others in their communities, potentially influencing wider perceptions of safety and trust in services.

Screening uptake and experiences of care are closely connected and should be understood as complementary measures of equity. While public health approaches have traditionally focused on raising awareness, improving knowledge and encouraging screening participation, these efforts alone cannot address the practical, cultural, emotional, and systemic barriers women face.

The healthcare system primarily measures progress through screening uptake and coverage rates, while women experience equity through how accessible, respectful, and responsive care is to their individual needs. Improving uptake without addressing inequalities in care risks overlooking the experiences that shape women's trust, confidence, and willingness to return for future screening. Achieving meaningful equity therefore requires attention not only to who accesses screening, but also to the quality and consistency of care they receive.

Methodology

The campaign used a mixed-methods approach to gather experiences of cervical screening from women and people with a cervix across Nottingham and Nottinghamshire. It combined an anonymous survey with listening sessions, and enabling the campaign to capture both broader patterns and more detailed accounts of people’s experiences of cervical screening. The engagement was designed to offer different ways to participate, recognising that cervical screening can be uncomfortable, distressing, or triggering, and that some participants may prefer to share their experiences anonymously or in a supportive face-to-face setting. Consent, confidentiality, and safeguarding were central to the design and delivery of the engagement.

The partnership with Notts SVSS provided an additional layer of specialist support, particularly for survivors of sexual violence and others who might experience distress or require further support as a result of the issues discussed. A separate quiet room was made available for anyone who needed privacy, additional space, or a calmer environment to participate.

The survey was open from June to July 2026 and was available electronically through Google Forms and the Notts SVSS website. The online survey was available in multiple languages to reduce language barriers, and translated paper copies were distributed as an alternative for women who may have faced barriers to accessing or completing the survey online.

The survey combined closed and open-ended questions. Participants were asked whether they had attended cervical screening and, if so, whether their experience had been positive, negative, or mixed. Open-text questions invited participants to explain what contributed to positive experiences and what could have improved negative or mixed experiences. Those who had not attended screening were invited to explain why, whether they might consider attending in the future, and what could help them feel more comfortable or able to attend.

Listening sessions were held as both drop-in and facilitated sessions. Nottingham Women's Centre hosted drop-in listening sessions over four weeks in June, where women could have informal conversations about their experiences with cervical screening.

The drop-in listening sessions created a space to talk openly about cervical screening, a subject that can still be considered sensitive or taboo. This helped to normalise conversations about cervical screening and promote wider dialogue about cervical health. Alongside the Centre-based drop-ins, facilitated listening and engagement sessions were held with women from Nottingham's Ukrainian and Muslim communities, the trans community, and women accessing refuge services. These helped broaden participation and provided additional opportunities to hear from people who might not otherwise have engaged with a general survey or attended the Women's Centre independently.



After the engagement period closed, the information was compiled and reviewed. Survey findings were summarised, while open-text responses and experiences shared through conversations were examined using thematic analysis to identify recurring themes. The analysis focused on patterns across accounts, including the factors that contributed to positive and negative experiences, barriers to attendance, unmet needs, and participant suggestions for making cervical screening more accessible, supportive, and responsive. The study also examined experiences and issues raised by people from different backgrounds and communities.

Rather than treating the survey and listening sessions as separate sources of evidence, findings were considered together. This enabled the campaign to identify where experiences and themes were repeated across different forms of engagement while retaining context.

Who we heard from

Overall, the campaign engaged 221 people through the survey and wider community engagement activities. Participants represented a diverse range of communities, identities, circumstances, and life stages across Nottingham and Nottinghamshire.

This included women from Black and Asian communities, Ukrainian and Muslim communities, younger and older women, women with disabilities, women experiencing homelessness, people with English as a second language, and trans and gender-diverse communities. This breadth enabled the campaign to hear from people whose experiences of cervical screening may be shaped by different cultural, social, economic, linguistic and accessibility factors. Protecting participants' privacy and confidentiality remained a priority throughout the engagement; detailed demographic breakdowns are therefore not reported.

Summary of community engagement

Community groups were offered flexible ways to support participation in the campaign, either by facilitating survey completion or by co-facilitating a listening session. The survey was also shared with the Women's Organisations Network,[26] a network of over 80 local women's groups, to encourage wider participation through trusted networks.

Women living in refuge (Sycamore Centre) wanted to complete the survey in their preferred language. Participants were supported to access the survey hosted by Notts SVSS, which offered translation. This approach helped reduce language barriers and provided a more accessible and inclusive way for women to share their experiences.

This section presents findings from facilitated listening sessions held in collaboration with women from the Muslim, Ukrainian, and transgender communities.

Women from Muslim communities

A facilitated listening session was held in collaboration with grassroots organisation Nottingham Muslim Women's Network. Participants shared a range of positive and negative screening experiences. Positive experiences were often linked to healthcare professionals who were supportive, reassuring, and took time to explain the procedure, helping women feel heard and involved in decisions about their care. Participants also recognised the value of cervical screening in protecting women's health and identifying potential concerns early.

One participant with clinical experience shared an example of a GP practice that organised a cervical screening awareness event in response to low uptake, demonstrating a proactive approach to engaging women and addressing potential barriers to participation.

Conversely, fear and anxiety emerged as significant barriers to cervical screening, particularly in relation to invitation letters and uncertainty about the procedure. Some women described feeling frightened by references to cancer in screening invitations, while others found the language overly clinical and lacking clear, reassuring explanations. Participants emphasised the importance of feeling mentally prepared before attending appointments, noting that uncertainty about what to expect and the meaning of screening results could heighten anxiety.

Discussions also highlighted how fears and negative healthcare experiences can be passed between generations. One participant described how witnessing a parent's distressing experience had shaped their own perceptions of screening, with the potential for these concerns to influence the next generation. This is particularly significant for women who rely on family members to translate or explain healthcare information.

In these circumstances, information about screening may be filtered through relatives' own experiences, beliefs or anxieties, potentially reinforcing fears or limiting access to clear, impartial information. Reliance on family members may also make it more difficult to discuss sensitive concerns openly and confidentially. These experiences highlight a wider equity issue: providing the same information to everyone does not ensure that all women have an equal opportunity to understand it, ask questions, or make informed choices. Women facing language barriers or limited access to independent information may be disproportionately disadvantaged, particularly when navigating intimate or sensitive healthcare. Without accessible information and appropriate professional interpretation support, existing inequalities in knowledge, confidence, and access to screening may be reinforced. At the same time, some women may be able to communicate verbally in English but struggle to read or understand written medical information. While information may be available, participants noted that these (NHS App, website information) were difficult to navigate. Medical terminology was often viewed as overly clinical, and while translation could support access, differences in dialect could make information less accessible.

Consent also emerged through the discussion, with concerns raised about procedures being carried out without adequate explanation or women feeling that meaningful consent had not been obtained. One participant described attending a repeat smear test where the nurse's manner left her feeling as though she had done something wrong. She experienced pain and distress, which affected her confidence. Another participant recalled being told that, having previously experienced labour, she should be able to tolerate cervical screening. Participants felt these comments were dismissive and failed to recognise individual experiences, concerns, and levels of discomfort. Some participants felt that self-sampling could be a beneficial option; however, their lack of understanding about the process created uncertainty and increased feelings of fear and anxiety.

Cultural beliefs, stigma, and embarrassment were identified as further barriers. Participants discussed how sexual and reproductive health can remain a taboo subject within some communities, particularly among older generations where conversations about intimate health may be associated with shame. Cervical screening was sometimes linked to sexual activity or sexually transmitted infections, potentially creating confusion or discomfort, particularly for women who have never been sexually active.

Participants also highlighted sensitivities within some Muslim communities relating to modesty, privacy, and intimate examinations. They emphasised the importance of addressing these concerns respectfully, without making assumptions about women's beliefs or experiences.

The session also highlighted gaps in awareness and understanding of cervical screening, HPV, and the HPV vaccine. Participants felt that women were not always adequately informed about the purpose of screening, what to expect during the procedure, or what their results might mean. There was also concern about the limited information available to younger people and parents about HPV vaccination. Participants stressed the importance of providing age-appropriate education that helps young people understand vaccination and participate meaningfully in decisions about their health.

Finally, participants reflected on the wider pressures affecting women's engagement with preventive healthcare. Women described frequently prioritising the needs of children, families, and others above their own health. This, combined with fear, cultural expectations, and negative healthcare experiences, could contribute to delayed or missed screening appointments.

Participants called for more accessible, culturally appropriate, and reassuring information about cervical screening. One example is the successful Medical English course delivered by Nottingham Muslim Women's Network, which has supported several women in developing their understanding of basic medical and clinical terminology through accessible, easy-to-understand language.[27] The course has helped participants build confidence, navigate healthcare services more effectively, and feel empowered to make informed decisions and take greater control of their health and wellbeing. Suggestions included reviewing the wording of invitation letters, providing pre-screening consultations, using demonstrations to explain procedures, and offering opportunities to ask questions before appointments. Greater emphasis was placed on compassionate communication, informed consent, and ensuring women feel comfortable, respected and in control throughout their screening experience.

Participants also recommended developing information in different languages and formats, including videos, podcasts and spoken explanations, while recognising variations in dialect and literacy. Community-led awareness sessions, trained community champions and education programmes for younger women were suggested as ways to address stigma, increase understanding of HPV and cervical screening, and encourage informed participation.

Women from the Ukrainian community

A facilitated listening session was held in collaboration with Nottingham Ukrainian Cultural Centre to explore experiences of cervical screening and wider healthcare services. Appropriate language interpretation enabled participants to engage fully in discussions, share their experiences, and express their concerns. Participants reported mixed experiences. Positive experiences were generally associated with pain-free, straightforward examinations where women felt comfortable with the procedure. In contrast, negative experiences included perceptions of rough or insensitive treatment, uncertainty about their right to pause or stop an examination, and difficulties communicating pain, discomfort, or concerns due to language barriers.

Language emerged as a particularly significant barrier, affecting women's ability to understand health information, communicate with healthcare professionals and navigate NHS services. During the session, an NHS cervical screening information video was shown in a language accessible to participants, providing an opportunity to improve understanding and encourage discussion.

Participants recognised cervical screening as an important preventive health measure. They compared their experiences with Ukraine, where they reported undergoing screening more regularly, often alongside other routine women's health checks.

Participants also highlighted differences in screening practices between the UK and Ukraine, particularly regarding the use of metal and plastic specula. Some women expressed greater familiarity with plastic specula, which they reported were more commonly used in their home country, and described perceived differences in comfort during examinations. These discussions highlighted how previous healthcare experiences can shape expectations, preferences, and confidence when accessing screening in a different healthcare system.

Beyond cervical screening, participants raised broader concerns about accessing women’s healthcare in the UK. They described difficulties understanding how the NHS operates, identifying appropriate services, and knowing where to seek advice or support. Some expressed frustration about the perceived lack of access to comprehensive women’s health checks, which they reported were more routinely available in Ukraine. They also raised concerns about the accessibility and availability of healthcare support for older women, highlighting the need for clearer information and signposting across life stages.

Overall, language accessibility, familiarity with healthcare systems, previous screening experiences and differing expectations of preventive healthcare all influence women's confidence and ability to engage with services. These findings reinforce the importance of providing accessible, translated information, professional interpretation, clear explanations of screening procedures and patient rights, and culturally responsive support. They also highlight the value of working with trusted community organisations to help women navigate NHS services, understand the support available and make informed decisions about their health.

Trans Community

Access to gender-affirming healthcare has been subject to significant uncertainty, against a backdrop of long waiting times, difficulties accessing shared-care prescribing arrangements and changes to specialist service pathways. Wider developments, including the 2024 Cass Review[28] of gender identity services for children and young people in England and the temporary suspension of gender-affirming surgical referrals in Wales in August 2026, have also contributed to a changing healthcare landscape.[29] These circumstances highlight the importance of accessible, inclusive and trusted healthcare services for trans and gender-diverse people.

While trans-specific healthcare is based on gender, cervical screening is based on sex assigned at birth. This has obvious implications where a person's lived gender is different to their assigned sex.

Nottinghamshire Sexual Violence Support Services led engagement with the trans community. Survey respondents, while showing a mixture of experiences overall, did point to some practitioner awareness of trans bodies, including how gender-affirming hormones and hormone blockers can impact testing. Positive experiences highlighted the importance of respectful, inclusive care, with participants praising nurses for not misgendering them, explaining each stage of the procedure to help them feel in control, and offering reassurance.

One positive account involved a non-binary participant with vulvodynia and vaginal atrophy who described an appointment during which the speculum broke. The nurse then referred them to hospital, where screening could be done with gas and air for pain relief.

> They just gave me what I would need to make it go okay, not the bare minimum to make it happen painfully.

The hospital also, without prompting, suggested they have the last appointment of the day to ensure they would not be in a waiting room surrounded by women as a trans-masc[30] person.

> I didn't have to ask for any of it, it felt like it was 'standard' for me as a trans person.

Another respondent, experiencing vaginal atrophy due to testosterone, noted:

> The GP arranged for the exam and the smear test to take place in the same appointment at my request, which made it easier to attend as I didn't have to emotionally prefer for a dysphoria-inducing appointment twice.

However, there were some reports of negative experiences, particularly where concerns and expressions of pain were dismissed. One respondent described an appointment where the clinician continued the procedure despite being asked to stop:

> … I felt severe pain and audibly screamed multiple times. She talked to me, gently telling me it was almost at the right spot, I said she could continue. But then the pain got worse and I asked her to stop, however she kept pushing.

Participants who reported negative experiences emphasised the need for greater honesty about potential pain, empathy and respect for patients' decisions throughout the procedure. This highlights a real issue around consent and whether sample collection is being prioritised over patient comfort. These factors correspond with some experiences reported by cisgender women.

Additionally, trans people may be unaware that they are eligible for cervical screening. This can be further compounded when an individual changes the gender marker on their NHS records, potentially creating additional confusion about eligibility and access to screening services.

While there is a considerable amount of information available online, guidance on cervical screening for trans people is not always clear. Generally, the following applies:

- **Trans men and those assigned female at birth** are recommended to attend cervical screening if they have not had a full hysterectomy. However, people who are registered as male with their GP will not routinely be called.
- **Trans women and those assigned male at birth** do not need to attend cervical screening but may still be invited for screening that they do not need if they are registered as female with their GP.

The survey illustrated the importance of this issue when a male respondent described how a supportive nurse asked whether he was still receiving invitations to smear tests, which led him to undergo screening.

> Nurse was friendly and approachable and only mentioned my trans identity when she was asking if I had been invited for a smear. At no point did she make me feel uncomfortable for having a different body shape to other patients.

Although it's possible for trans people to opt in and out of screening, wider concerns about their access to healthcare - including how the Equality and Human Rights Commission (EHRC) Code of Practice[31] might be applied in different healthcare settings - may make accessing screening not feel like a genuine or safe option.

While adjustments such as using lubricant or a smaller speculum are sometimes mentioned, less information exists on other ways to make the experience more manageable, supportive, and affirming.

Proactive engagement with trans communities is therefore important, particularly to reassure people about the screening process, confidentiality, and the adjustments or support that may be available. It is also important to recognise that, for some trans people, undergoing cervical screening without a general anaesthetic may not be possible. This highlights the need for a more individualised and sensitive approach that recognises different needs and circumstances.

> Absolutely not a chance would I cope or let someone see or touch that area.



Summary of survey findings

Cervical screening experiences

155 respondents rated their experience.



221 people engaged through the survey and wider community activities.
Percentages are estimated and rounded: totals may differ from 100%

A total of 155 people responded to the survey, providing valuable insight into their knowledge and experiences of cervical screening. The overwhelming majority of eligible respondents reported that they had previously attended screening. Two eligible respondents reported that they had not attended, while three respondents were under 25 but approaching their first appointment. People aged 18–24 were intentionally included in the survey, despite not yet being eligible for routine cervical screening, to explore awareness, knowledge, and perceptions of cervical screening among younger people.

When asked to describe their experience of cervical screening as positive, mixed or negative, 46% of respondents reported a positive experience - fewer than one in two women.

By comparison, 44% - more than two in five women - described their experience as mixed, while 11% - around one in nine women - reported a negative experience. Essentially, 54% of respondents - more than one in two women - described their experience as either mixed or negative. The relatively high proportion reporting mixed experiences is noteworthy, suggesting that screening experiences are not uniform. These findings highlight the importance of looking beyond uptake alone and considering the quality of people's experiences.

The next sections explore these experiences in greater depth, drawing on participants' accounts to identify the key factors that shaped their experiences of cervical screening.

Word cloud from survey: Experiences of cervical screening

This section highlights the words and phrases respondents most commonly used to describe their experiences of cervical screening. The size of each word reflects its relative prominence within the responses rather than the statistical significance or importance of a particular theme. It is interpreted descriptively and considered alongside the more detailed findings presented below.

Positive experiences



Fig. 1.1

The most prominent words, such as friendly, comfortable, and kind, suggest that healthcare professionals' interpersonal approach was an important feature, particularly in feeling reassured, heard, and supported throughout the procedure.

Communication also emerged as a key theme. Terms such as explained, checked, and consent suggest that women valued being kept informed about what was happening and having the opportunity to ask questions.

References to speculum size, option, and chaperone indicate the importance of personalised care.

Words such as efficient, professional, and experienced point to positive perceptions of staff competence and the organisation of screening. Overall, the word cloud suggests that a positive experience was strongly associated with kind and non-judgemental staff, clear communication, reassurance, respect for consent and individual preferences, and efforts to make women feel comfortable and at ease.

Negative and mixed experiences

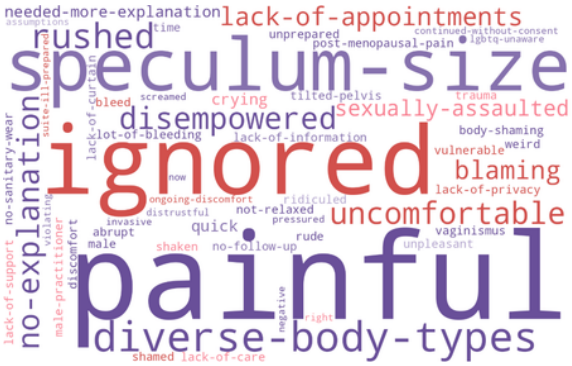


Fig. 1.2

The most prominent terms included painful, ignored, blamed, and lack of appointments, suggesting that negative experiences extended beyond physical discomfort and included concerns relating to communication, consent, dignity, accessibility, and the extent to which individual needs were recognised.

References to discomfort, bleed, post-menopausal pain, and vaginismus indicate that pain was a significant concern. The prominence of speculum size alongside diverse body types may also suggest that women felt greater consideration should be given to individual anatomy and making appropriate adaptations during screening.

Terms such as no explanation, lack of information, pressured, and continued without consent indicate instances when respondents felt insufficiently informed about and involved in decisions about their care. Words such as abrupt, unprepared, and no follow-up further suggest that the manner and pace in which care was delivered can negatively affect the screening experience.



Our Findings

This section explores the six key findings emerging from respondents' open-ended survey responses, capturing the full range of experiences.

1. Women want to be screened – the system must make it easier

Services should consider not only whether appointments are technically available, but whether women can access them quickly, conveniently, and in a way that supports completion. The experiences shared revealed that difficulties accessing suitable appointments can create a significant barrier to cervical screening. They described struggling to find appointments that fit around work and childcare, experiencing long waits, limited evening and weekend provision, difficulty coordinating appointments with menstrual cycles, uncertainty about whether they could attend another practice, and few alternatives to GP-based screening.

What women told us:

> I delayed my smear test as I couldn't go with my little one who was not up to school age; neither could I pay for childcare and there was no offer for a quick childcare cover for the appointment.

> I have put off my smear test for ages as the appointment times don't fit in with my work schedule and they no longer do saturday appointments at my surgery. I would be more inclined to keep and make appointments if they were more flexible.

> It feels hopeless - I desperately want to go as I have tested hpv positive in the past, but availability is a huge issue.

Some accounts reveal how practical and emotional barriers reinforce one another. Waiting times that appear administratively acceptable may have a very different impact on someone already anxious about screening.

> “When you've worked up the courage to ask for an appointment, it’s then months later that you have to build up the courage to attend… the wait makes it worse.”

Women experiencing homelessness

For women experiencing homelessness or other forms of disadvantage, these barriers were often more pronounced. Research shows that women may experience less visible forms of housing insecurity, including sofa surfing, staying temporarily with friends or family, living in insecure or temporary accommodation, or adopting other strategies to avoid sleeping on the streets.[32] Homelessness can make attending healthcare appointments particularly challenging when immediate priorities, unstable accommodation, and other competing demands take precedence. Unstable accommodation can also disrupt the practical mechanisms on which routine screening programmes depend, including receiving correspondence, maintaining contact details, registering with and engaging consistently with primary care, and attending appointments at a fixed time and place.

NHS England’s assessment of HPV self-sampling notes that people experiencing homelessness are less likely to attend cervical screening and cites evidence that only 54% of eligible homeless people had accessed cervical screening in the previous three years, compared with 70% of the general population.[33] Although women in this situation may be signposted to specialist services, referral alone does not necessarily guarantee that screening will be accessed. A woman may still face significant barriers between receiving a referral and successfully attending and completing screening. Where support services operate separately, women with the most complex circumstances may also be required to navigate multiple systems at the point when they have the least capacity to do so.

While national guidance suggests that sexual health clinics and walk-in centres can provide an alternative for women who experience difficulties accessing their GP, this choice is considerably more limited locally (NHS, 2025). Following changes to sexual health provision across Nottingham and Nottinghamshire, the current Sexual Health Services Nottingham and Nottinghamshire guidance states that the service ‘does not routinely offer cervical screening’ and directs people who are due for screening to their GP practice.[34]

Specialist services such as Nottingham's Health Shop provide an important route into healthcare for some groups who experience barriers to mainstream services. However, specialist provision cannot substitute for a widely accessible network of screening locations. For most women in Nottingham, cervical screening is now accessed through primary care rather than through the wider network of sexual health clinics.[35]

This is particularly timely in the context of current NHS reform. The Government's 10 Year Health Plan sets out a clear ambition to shift care from hospital to community and from sickness to prevention, with neighbourhood health services designed around local population need.[36] Cervical screening provides a tangible opportunity to put these ambitions into practice: bringing prevention closer to communities, reducing barriers to access, and reaching women who are currently underserved.

Changes to the commissioning landscape create further opportunities for local action. NHS England's proposed approach to cervical screening recognises that local commissioning can enable Integrated Care Boards to 'diversify the provider network according to local need', including cervical sample taking through primary care, sexual health services and opportunistic settings.[37]

This creates scope to move beyond a predominantly one-size-fits-all model and consider where, when, and how screening is offered in response to the needs of local populations.

This flexibility is particularly important in Nottingham, where cervical screening coverage remains below the national average and significant health inequalities persist. 55% of residents in Nottingham City live in areas ranked among the 20% most deprived nationally.[38] Nottingham also ranks 8th in England for the prevalence of Severe Multiple Disadvantage (SMD).[39] These inequalities intersect with the city's diverse cultural and linguistic needs. The Care Quality Commission reports that 8.9% of Nottingham households have no resident who speaks English as their main language at home.[40] People from ethnic minority groups are also overrepresented in areas of higher deprivation; Nottingham's 2025 Pharmaceutical Needs Assessment further illustrates this diversity, reporting that Asian ethnic groups account for 24% of residents in the Radford and Mary Potter Primary Care Network area.[41] Together, these factors highlight why a standard invitation-based approach may be insufficient to ensure equitable access to cervical screening. For women experiencing deprivation, homelessness, language barriers, cultural concerns, trauma or competing life pressures, receiving an invitation does not necessarily mean being able to access screening.

A neighbourhood approach creates an opportunity to connect screening more effectively with the places and services women already use and trust, while ensuring that pathways remain clinically safe, coordinated, and responsive. Success should therefore be measured not only by how many women are invited for screening, but by whether women have a realistic, timely, and acceptable route to participate - and whether those routes reach communities where coverage remains lowest.

Peterborough provides a practical example of how screening can be embedded within a wider, neighbourhood-based model of care, bringing preventative healthcare closer to women through services designed around their wider health and support needs. Rather than relying solely on women accessing conventional primary care pathways, Peterborough developed a multi-agency model bringing together community outreach, a specialist primary care clinic, a women-only wellbeing hub, and supported housing. The model was designed to engage women who were often hidden from mainstream services and experiencing multiple disadvantage, including homelessness, substance use, poor physical and mental health and sexual exploitation.

At the centre of the approach is the Wildflowers Clinic, which provides cervical screening alongside GP registration, contraception, sexual health services, drug and alcohol treatment, and wider health promotion within a safe, non-judgemental environment. Importantly, provision does not stop at offering a screening test. A dedicated colposcopy clinic was subsequently established to provide continuity for women requiring further investigation. Women have also helped shape the service through ongoing feedback and engagement. According to the case study, cervical screening uptake among the women reached by the service increased from 19% in 2019 to a striking 95% in 2024.[42] Liverpool also provides a dedicated women's health hub that brings together a range of services in one accessible setting, offering another example of integrated, person-centred care that could inform the development of similar provision in Nottingham.[43] While this experience should not be assumed to be directly transferable to every locality, it demonstrates what can be achieved when services are designed around the circumstances of women who may not be effectively reached through conventional pathways.

Recommendation

Commission neighbourhood-based cervical screening services through women's health and community hubs, offering flexible appointment options to women who face barriers to accessing screening through traditional GP settings.

2. First screening experiences have a lasting ripple effect, shaping future engagement and influencing others through shared experiences

Women's accounts suggest that the first cervical screening appointment is more than a single isolated clinical encounter. Cervical screening is not a one-off intervention; its effectiveness relies on women engaging with screening at recommended intervals throughout different stages of their lives.

This influence can extend across generations, particularly from mothers to daughters, as experiences of screening are passed down through family conversations, shaping expectations, attitudes, and confidence in accessing cervical screening.

Respondents described markedly different first experiences. Some recalled nurses who listened to their concerns, explained what would happen, checked their comfort, and helped them feel at ease.

Others described feeling unable to ask questions, having fears dismissed, experiencing significant pain, or feeling insufficiently prepared for the procedure.

What women told us:

> Better care at my first smear would've made all the difference.

> It has taken me 7 years to book a second smear test - I haven't had this yet but I am still very apprehensive after my first experience.

> I attended my first ever smear last year. There were some difficulties inserting the speculum and this was really painful. They offered some techniques such as putting my hands under my hips to tilt myself up but when this didn't help they struggled with alternative suggestions. It would have been better to have more guidance of how to make the procedure more comfortable.

> I was left waiting in the room for ages, with no explanation as to why. The nurse barely spoke to me and made 'alarming' noises, again without explaining why. Fortunately, this was not my first smear, otherwise it might have affected my attitude to future smears.

These accounts are consistent with wider evidence. NHS England guidance recognises that a negative cervical screening experience can contribute to anxiety about the procedure and may discourage women from attending future screening appointments. [44]

A systematic review by Chorley et al. (2016) also found that previous screening experiences influenced willingness to re-attend and that, for some women, a single negative experience was enough to prevent subsequent attendance, even when they had previously had positive experiences.[45]

The latest detailed national statistics available show that cervical screening coverage in England was 68.8% in March 2024.[46] However, coverage among those aged 25–49 was substantially lower, at 66.1%, compared with 74.3% among those aged 50–64. [47] This is significant because many women in this age group are at the beginning of their screening journey: their early encounters with the programme have the potential to influence attitudes towards screening over many years.

Our engagement with women approaching their first invitation revealed a lack of knowledge about cervical screening.

> I am only aware of smear test because my mum is a nurse.

> I know nothing.

Research examining women approaching their first invitation found low awareness of both the purpose and procedure of cervical screening and reported that accounts of negative experiences could discourage participation.[48] More recent UK research similarly identified important knowledge gaps among young women, alongside anticipated pain, embarrassment and anxiety, and practical difficulties accessing appointments.[49] Women who experienced their previous test as painful subsequently held more negative views about a future screening test.[50]

First-time screening should therefore be recognised as a distinct and important point in the screening pathway. Women should be supported to understand what to expect before attending, given sufficient opportunity to ask questions and discuss concerns about pain or anxiety, and informed about the choices and reasonable adjustments available to them. Consent should be actively maintained, and women should feel able to pause or stop at any point. Screening practitioners should also have the skills, time and appropriate equipment - including access to different speculum sizes - to respond sensitively when screening is painful, difficult, or cannot be completed.

Improving the quality of first screening experiences should form part of the wider approach taken by NHS England, Integrated Care Boards, and Public Health to support England's ambition to eliminate cervical cancer by 2040.

Recommendation

Establish a national first-screening standard requiring everyone invited for their first cervical screening to receive accessible information with their invitation, opportunities for pre-screening consultation, and an assessment of individual support and adjustment needs.



3. Pain during cervical screening is often normalised rather than recognised and appropriately addressed

Pain was a recurring theme in our findings, and, for most women, this appeared to be unexpected, inadequately acknowledged, or minimised by staff. Several women described feeling unprepared because public messaging or previous information had led them to expect screening to be quick and painless, yet their experience differed substantially from these expectations. This increased their anxiety about returning. Women also reported that lubrication was not consistently offered, with concerns about potential interference with the cervical sample appearing to influence its use.

What women told us:

> I found it all too painful, so it had to be aborted. I missed the last 3 smear callings due to this.

> …all the campaigns (and people having tests on TV, etc, at the time) made me think that it should be quick/painless and then because my experience was not the same, it has made me very anxious about the whole thing.

> When I was having my first few smear tests I had severe pain during the process. Nobody believed me. One nurse even chastised me for expressing pain.

> I've had many smear tests throughout my adult life and have always ground them to be painful.

For women with vaginismus, describing cervical screening simply as "uncomfortable" underestimates the real barriers they faced. Vaginismus causes involuntary tightening of the vaginal muscles in response to attempted penetration and can produce burning or stinging pain; the NHS specifically identifies cervical screening as one situation in which this response can occur.

Women told us:

> I have vaginismus so can't as it wouldn't "go in".

> It isn't because I don't want it but because I can't have it- and treatment takes time for vaginismus; I have vaginismus based on sexual coercion by previous partners and the two first smear tests I went to were not nice. The nurse did not stop when I started crying or ask me if I wanted to continue or offer different options such as a smaller speculum or to have support instead said I needed to 'speak to someone' about 'my problems.

Vaginismus should also be considered in the wider context of sexual violence and trauma. Sexual violence does not inevitably lead to vaginismus, nor should vaginismus be interpreted as evidence that a woman has experienced abuse.

Nevertheless, evidence suggests a clear association. A systematic review and meta-analysis found a statistically significant association between a history of sexual abuse and a diagnosis of vaginismus, based on 12 studies (OR 1.55, 95% CI 1.14–2.10).[51] This finding is particularly relevant in the context of the prevalence of sexual violence against women in England and Wales. According to the Crime Survey for England and Wales (year ending March 2025), approximately one in four women (25.6%) have experienced sexual assault, including attempts, since the age of 16.[52] This suggests that a substantial proportion of women attending cervical screening may have experienced sexual violence, regardless of whether this history has been disclosed to, or is known by, the healthcare professional conducting the examination. Current NHS cervical screening guidance requires sample takers to check relevant screening history and obtain appropriate clinical information. However, reviewing medical records alone cannot reliably identify women who have experienced sexual violence, as such experiences may never have been disclosed or documented. This reinforces the importance of adopting a trauma-informed approach to all cervical screening appointments, rather than relying solely on recorded medical history to identify those who may need additional support.

Furthermore, vaginismus is often underdiagnosed, suggesting that the number of women affected may be substantially higher than those with a formally recorded diagnosis.[53] Some women may have vaginismus without a history of sexual violence, some survivors of sexual violence may experience severe distress during penetration without meeting diagnostic criteria for vaginismus, and some women may experience both. Given the intimate and penetrative nature of cervical screening, these figures strengthen the case for trauma-informed practice to be embedded routinely within screening services.[54]

In an English exploratory study of women who had experienced sexual abuse, only 48.5% of eligible respondents reported cervical screening within the previous five years, compared with a national screening figure of 78.6%.[55] A survivor described how, despite feeling apprehensive about attending cervical screening, she was determined to participate. For her, attending screening represented an important way of taking control of her health and ensuring that the impact of the abuse she had experienced did not extend to this aspect of her life.

What women told us:

> I was able to advocate for myself, I have experienced sexual violence and the process was a trigger. I made the nurse aware of this trigger. The nurse met me with compassion and sensitivity and had a good understanding of trauma.

> My early experiences of smear tests were excruciatingly painful. I had been sexually abused throughout my childhood, and undergoing a smear test led to what I now understand to have been an anticipated pain reaction.

> Although I told GPs and Nurses performing the smear tests, I don't think they were fully appreciative of the trauma. At the time, there was no obvious support available, so trying to put myself through a smear test required massive motivation in the knowledge that it would be extremely painful.

Pain can also present differently for women who are peri- or post-menopausal. Reduced oestrogen levels can contribute to vaginal dryness and atrophic changes, making speculum insertion considerably more uncomfortable or painful. However, menopause is not a homogenous experience. Evidence suggests Black and Asian women not only experience menopause earlier but also a greater and longer burden of some menopausal symptoms.[56]

> Difficulties and discomfort experienced due to perimenopause were not taken into consideration and I thus avoided the smear test for several years, due to trauma caused. Once I found a nurse who was able to be compassionate, gentle and understand my requirements (small speculum and course of vaginal hormone) the procedure was far more tolerable.

The National Institute for Health and Care Excellence (NICE) recognises that people from some ethnic minority groups may experience menopause at a younger age.[57]

A Black woman experiencing menopausal vaginal changes at a younger age may not be identified by healthcare professionals as requiring menopause-related adjustments if assumptions about pain and vaginal atrophy are based predominantly on chronological age. These differences should not be interpreted as simply biological consequences of race. Menopausal experiences are shaped by an interaction of biological, psychological, socioeconomic, and social factors. Research has raised the possibility that cumulative exposure to social and economic disadvantage and structural racism may contribute to disparities in reproductive aging. Overlapping inequalities relating to ethnicity, access to healthcare and reproductive health, alongside the physiological effects of menopause.

Pain was also apparent in the experiences of LGBTQ+ women and women who were not sexually active.

> For me, I am not sexually active it's very painful. It makes me bleed. If you're not sexually active it doesn't seem like there is much point. They reckon you can still get cervical cancer even if you're not sexually active.

Research also confirms that the experiences of women with disabilities identify difficulties with the examination couch, adopting required positions, and insufficient staff support as barriers.

> I have Multiple Sclerosis and both my mobility and muscles are really effected. However, the Nurse was so expert and understanding the whole experience was very positive and didn't hurt anywhere near as much as I thought it would and had in the past.

Our survey findings suggest a significant gap between what is communicated about pain and what women experience in practice. NHS cervical screening guidance recognises that women may experience pain or discomfort during cervical screening and that services should respond when this occurs.[58] The NHS Professional guidance advises women to tell the sample taker if they experience pain and identifies practical adjustments that can make screening more comfortable, including different positioning, lubrication, a smaller speculum, and, for some women, the option of initially inserting the speculum themselves.[59]

However, many of these measures are currently discussed within guidance on accessibility, disability, or circumstances requiring additional support. UK research has repeatedly identified pain and anticipated pain as barriers to cervical screening. A recent UK survey involving more than 700 people highlights the wider challenges associated with vaginal access procedures, including cervical screening, IUD fitting, hysteroscopy, and biopsy.[60] A population-based study of women in England found that fear of pain was reported as a barrier by 14% of respondents, while subsequent UK research identified pain and discomfort among the most commonly reported and influential barriers to screening.[61] An international 2023 scoping review drawing on 18 qualitative studies internationally identified speculum pain and discomfort as one of four recurring categories of negative experience associated with cervical screening.[62]

Evidence suggests that pain should be considered as a routine quality-of-care issue for everyone undergoing cervical screening, not only as a reasonable adjustment for those with an identified condition or additional need. A woman should not need to have a diagnosed condition, identify herself as requiring a reasonable adjustment, or know in advance which adaptations to request before steps are taken to minimise avoidable pain.

Nor should access to a more comfortable examination depend on her confidence to advocate for herself once an intimate procedure has begun. Pain-aware care should be the starting point for every cervical screening examination, with additional or specialist adjustments available where individual needs require them.

Given the evidence that pain and fear of pain can influence participation, this should be regarded not simply as an issue of comfort, but as an issue of quality, accessibility, and screening equity. Pain prevention should be built into the cervical screening pathway as a core component of high-quality care. Current practice should move beyond responding to pain once it occurs towards routinely anticipating, preventing, and managing it. This should be reflected not only in clinical practice, but also in the information women receive before screening. Public health communications should acknowledge that experiences of pain vary and provide realistic information about what patients may experience, the options available to make screening more comfortable, and their right to pause or stop the procedure.

Crucially, a proactive screening approach should not depend on a woman identifying herself as requiring a reasonable adjustment, having a particular diagnosis, or knowing which adaptations to request.

Nor should women have to advocate for pain relief or adjustments once an intimate examination is underway. The screening service should routinely create the conditions for the most comfortable examination possible, with further adaptations or specialist support provided according to individual need. This requires a shift from seeing pain primarily as something to respond to, towards recognising pain prevention and management as a universal standard of good screening care. Existing measures - including appropriate speculum choice, lubrication, alternative positioning, clear communication, sufficient time, and maintaining consent throughout - should be proactively considered and communicated rather than relying on women to know these options exist.

Health communication is equally important. Pain should be acknowledged as a legitimate and variable experience. Communication that focuses predominantly on ‘discomfort’ may leave women who experience significant pain feeling that their experience is unusual, unexpected, or something they are expected to tolerate.



Honest and balanced communication can better prepare women, support informed consent, and make it clear that experiencing pain is a reason to pause, adapt, or reconsider the examination - not simply to endure or avoid it. Minimising or failing to acknowledge the possibility of pain risks undermining trust, particularly when women's experiences differ from what they were led to expect. Our evidence shows that negative screening experiences can discourage future attendance. Therefore, the aim should not simply be to encourage women to attend screening once, but to build the confidence and trust needed to support continued participation in subsequent screening appointments.

Recommendation

Introduce mandatory pain assessment and management protocols for cervical screening and revise national clinical guidance and public information to accurately reflect women's diverse experiences.



4. Gaps remain in how ongoing consent is translated into practice during cervical screening

Consent strongly emerged as a theme across the listening sessions and the survey. Some participants described examinations continuing after they had withdrawn consent. Others described crying, expressing pain, asking practitioners to stop, or attempting to advocate for themselves without feeling that their communication was adequately recognised.

Women told us:

> … I felt severe pain and audibly screamed multiple times. She talked to me, gently telling me it was almost at the right spot, I said she could continue. But then the pain got worse and I asked her to stop, however she kept pushing.

> I was sexually assaulted by a GP during my first smear test. I did not understand what had happened until much later on in my life although I knew something hadn't been right, especially when I had my second smear which was so different.

> Friendly nurse, good communication and consent for student asked without student present.

> I have vaginismus based on sexual coercion by previous partners and the two first smear tests I went to were not nice. The nurse did not stop when I started crying or ask me if I wanted to continue or offer different options such as a smaller speculum or to have support instead said I needed to 'speak to someone' about 'my problems'.

> A bit of aggression at the beginning, did not know how to stop the procedure.

The experiences shared underline a fundamental principle: consent should be treated as an active, ongoing process, not a one-off administrative step. It must be maintained throughout the examination, preserving control, dignity, and autonomy at every stage. Some women described experiences that left them feeling that 'something was done to them', signalling a loss of agency.

Current NHS guidance states that sample takers explain what will happen and what patients should expect, obtain and document consent, and recognise a decision not to proceed - or distress during the procedure - as a valid choice.[63] It states that patients remain in control of the examination and can ask for it to stop at any time.[64] However, the experiences shared suggest that there can be a gap between these requirements and how consent is experienced in practice. Maintaining consent requires more than obtaining initial agreement; it involves ongoing communication, sensitivity to verbal and nonverbal signs of distress, and a willingness to pause or stop when needed. This is crucial for women, particularly those who have experienced sexual violence or abuse.

Cervical screening involves intimate contact, insertion of a speculum, and physical vulnerability, which may trigger feelings associated with previous trauma.

This is supported by a UK study which found that intimate gynaecological examinations can be particularly difficult for women who have experienced sexual abuse, with loss of control, power differences, and physical sensations potentially echoing aspects of previous trauma.[65] Evidence from a 2026 systematic review further highlights the importance of trust, communication, choice, and control in supporting more positive screening experiences and engagement. [66]

A trauma-informed approach addresses these challenges by embedding safety, choice, and shared control throughout the screening process. In practice, this means explaining each stage of the examination, seeking permission before proceeding, agreeing how women can signal that they wish to pause or stop, and respecting these decisions without requiring explanation or disclosure of previous trauma. Where screening cannot be completed, women should be supported to explore their options and return when they feel ready. A woman should consent to the procedure with an agreement that, if she wishes to halt it, that choice will be respected. These principles are important for all patients, regardless of whether they have experienced or disclosed trauma.

A technically completed screening test should not, on its own, define a successful screening experience if a woman leaves feeling that she lost control over what happened to her body. Such experiences risk undermining trust in healthcare services and discouraging future participation. Although existing NHS guidance recognises the importance of consent and responding to distress, there is an opportunity to strengthen how these principles are translated into consistent, demonstrable trauma-informed practice. Embedding these skills more explicitly within cervical sample-taker training and assessment could help ensure that women experience consent not simply as a procedural requirement, but as a meaningful and continuing choice.

Recommendation

Embed ongoing consent as a mandatory, assessable competency in trauma-informed cervical screening training, with clear practical protocols for maintaining choice and control throughout examinations, including agreed pause or stop signals.

5. Getting the right information to women, at the right time and in the right place, is essential

Accounts show that positive cervical screening depends on whether women arrive informed and prepared, have sufficient time to discuss their concerns, and remain supported and in control throughout the screening pathway. Across the survey, women repeatedly expressed the need for clearer information about what would happen, what choices were available (such as speculum sizes), what they might experience afterwards, what their results meant, and what would happen next.

Women told us:

> Being informed what was going to happen at the beginning of the appointment, and why it was happening.

> Would be really helpful to have more information about things that can help/options beforehand. Also, in reminder text/email, how to prepare, things to do afterwards, maybe a link to more information.

> The health practitioner performing the smear prepared me for the procedure and gave me the option to pause/stop if I felt uncomfortable at any time.

The above accounts raise the question not simply of whether information should be provided, but whether the information adequately prepares women for the examination. NHS England guidance states that people should have sufficient information to make an informed choice about screening, including why screening is offered, what happens during the test, its benefits and risks, and potential outcomes.[67] Clear explanations, opportunities to ask questions, and reassurance that a woman can pause or stop the examination are relatively simple interventions, but they can fundamentally alter the experience of an intimate procedure.

For cervical screening, good communication should do more than encourage attendance: it should prepare women for the examination, support informed choice, and give them the knowledge and confidence to exercise control throughout.

This is significant because cervical screening communication has shifted from a predominantly paper-based system to a digital-first approach. In England, invitations are now issued initially through the NHS App; if they are not opened within 72 hours, an SMS is sent, followed by a paper letter if the digital communication is not accessed.[68] NHS England has described this transformation as a way to make communications faster, more accessible, and more efficient; however, receiving a notification does not, in itself, ensure that women feel adequately prepared for an intimate examination. A sample of a cervical screening invitation sent by a GP practice to a participant via text message stated: “Dear [Name], our records show you are due for your routine smear test. For more information, visit [link]. We are holding a clinic on [date], and you can book your appointment using the following link.”

While women welcomed the link to further information, they felt the message itself provided insufficient detail about the support and adjustments available during screening.

Participants highlighted that not everyone has reliable internet access or the confidence to navigate online information. They suggested including key information, such as the availability of additional support and options to discuss concerns before booking, directly in the text message. Providing this information at first contact, rather than relying on links, could help address uncertainties, reassure women, and encourage informed participation.

A 2025 qualitative study on communication needs around cervical screening found that people wanted information to support informed decision-making and recommended communication strategies that provide clear, accessible, and tailored information at appropriate points in the screening pathway. 69 Women also described feeling rushed during the examination, which limited their opportunity to ask questions and receive adequate explanations.

> “I appreciate that the appointments are quick but when it feels rushed it can then be more painful.”

> I received an ‘abnormal result’ after my first smear test and didn't feel as though much information was given in the lead up to my follow up appointment (colposcopy). I received an information leaflet but it was very top line and I had to carry out my own research, it was an anxious experience. The experience would have been improved with more contact/ reassurance/ detailed information. I felt that I was left to figure things out for myself, ‘a face to face or phone discussion with a ’person’ perhaps GP or a specialist would have improved the anxiety during this time and helped me to feel more informed about what my result meant and what the next steps would be.

Practitioners cannot meaningfully give explanations, answer questions, address discomfort, or maintain ongoing consent if the appointment structure does not allow enough time.

These findings raise an important question: does the current design of cervical screening appointments give practitioners enough time to deliver the quality that national guidance expects? NHS information describes the cervical screening test itself as taking less than five minutes and the whole appointment as approximately 10 minutes, although this should not be interpreted as a nationally mandated appointment-slot length.[70] NHS England guidance for people facing barriers also recommends longer appointments where appropriate, obtaining consent at every stage, and giving the individual control to stop the examination.[71] Within a short appointment, the practitioner may need to check relevant information, explain the purpose and limitations of screening, answer questions, support informed consent, allow the woman to undress and dress in privacy, undertake the examination, respond to pain or discomfort, make adjustments where necessary, explain what happens next, and complete the associated clinical and administrative tasks. The real question then is whether sufficient time is routinely available, or whether access to a longer appointment depends too heavily on an individual recognising and disclosing needs in advance.

Time and information may therefore be interdependent components of screening quality.

International comparisons of publicly stated cervical screening appointment durations[72] suggest that cervical screening appointments typically last around 10–15 minutes,[73] allowing time not only for the procedure itself but also for explanation, questions, and reassurance. [74]

There is an economic case for considering slightly longer appointments. Based on the 2026/27 NHS Agenda for Change Band 5 salary range of approximately £32,000–£39,000, an additional five minutes of nurse time would cost approximately £1.33–£1.67 per appointment, excluding employer on-costs and overheads.[75] This modest investment should be considered alongside the wider costs of missed or unsuccessful appointments, repeat screening attempts, rebooking, reminder letters, follow-up calls, and additional clinical time required to support distressed patients. The longer-term costs of cervical cancer are also substantial, with previous research estimating average healthcare costs of £12,721 per patient in England and government modelling suggesting treatment costs for later-stage disease may reach £25,000.[76] On an illustrative comparison, these amounts correspond to providing approximately 7,600–9,500 screening appointments, respectively, with an additional five minutes of nurse time.

While these comparisons do not demonstrate direct cost savings or establish that longer appointments prevent cancer, they illustrate the relatively modest additional staffing investment involved. For local commissioners, evaluating longer, trauma-informed appointments against the costs of repeat attendance, follow-up activity, screening completion, and longer-term outcomes could help establish clinical and economic value. [77]

An alternative approach would be to introduce a standard but optional pre-screening consultation as part of the cervical screening pathway. This would provide an opportunity to discuss the screening procedure in advance and identify any individual needs or reasonable adjustments that could make screening more acceptable and accessible.

This could be beneficial, as barriers to cervical screening are not limited to patients with a formally recognised disability or previously documented need for reasonable adjustments.[78] Rather than relying on women to disclose their needs during the screening appointment, healthcare professionals could identify potential barriers beforehand and agree adjustments collaboratively.

A more flexible model for pre-screening consultation would make the offer universal while letting women choose whether, where, and how they access it. For many women, clear information accompanying the invitation and sufficient time during the appointment will be enough. For others, this could include a face-to-face, video, or telephone conversation, or support delivered closer to home through trained community and voluntary-sector organisations. Some may find a group information session or conversation in a familiar cultural or community setting more acceptable than an additional appointment in general practice. Women with more complex needs - including previous traumatic or painful experiences, severe anxiety, disability, or requiring reasonable adjustments - could be offered an extended clinical pre-consultation before deciding whether and how to proceed. The NHS app could provide national screening information with short multilingual videos, opportunities to ask questions, interpreter-supported telephone consultations, and a simple mechanism for women to indicate before attending that they would like more time, a smaller speculum, a female practitioner, an interpreter, support with disability, or another reasonable adjustment.

There is already a foundation for this approach. NHS England guidance for community partners encourages collaboration between GP practices and community organisations, including training community members as peer educators or screening advocates and facilitating peer-led discussions and support groups.[79] The opportunity is to move beyond seeing these activities primarily as awareness raising and consider how trusted community partners could become a more systematic part of the ‘pre-screening support pathway’. Appropriately trained community health workers, link workers, peer advocates, or bilingual health workers could explain what screening involves, discuss screening choices, identify concerns or required adjustments, and help women prepare questions for their screening appointment.

Some international programmes provide practical examples of how cervical screening can be delivered through more flexible and culturally appropriate models. In Aotearoa New Zealand, the national cervical screening programme explicitly allows women to choose between conventional general practice and other community spaces such as Māori, Pacific, and women's community health centres.[80] Australia similarly promotes community engagement, including working with bilingual health educators and Aboriginal and Torres Strait Islander health workers to improve access for underserved communities. [81]

These examples highlight the potential for England to adopt a more flexible, tiered approach to pre-screening support, without requiring every woman to attend an additional consultation. By offering different levels of support according to individual need and drawing on trusted community organisations and existing healthcare services, such an approach could help address barriers to participation while making effective use of available resources.

Recommendation

Redesign cervical screening communications to prioritise meaningful understanding over information provision alone, using accessible, multilingual resources, peer educators, and trusted community networks to support confidence.



6. Positive cervical screening practices exist, but consistent care remains a matter of chance

Women should not have to hope that they get the 'right' practitioner to receive a comfortable, compassionate and professional cervical screening experience. For the healthcare professional, inserting a speculum and taking a sample may be routine. For the patient, it requires removing clothing, exposing an intimate part of their body, and undergoing an invasive examination that may cause embarrassment, anxiety, discomfort or pain. Our findings demonstrate striking differences in women's experiences. Some described healthcare professionals who were calm, gentle and reassuring, explained what they were doing, anticipated discomfort, and regularly checked that the woman was comfortable continuing. Others described feeling rushed, exposed, dismissed, or treated as simply the next procedure in a busy clinic. These differences must be understood in the context of the considerable pressures facing NHS services and staff.

High workloads, time constraints, and limited resources can affect the ability of even experienced and compassionate healthcare professionals to provide the individualised care women need. Improving screening quality therefore requires attention not only to professional practice, but also to the working conditions in which care is delivered.

Women told us:

> Little empathy, lack of reassurance or understanding when it does feel uncomfortable or painful. You get a harsh piece of paper towel to 'clean' yourself up with – it's just not very friendly when it's such an uncomfortable experience.

> Have medical professionals have empathy training. I know women who have been screamed at by nurses because they were scared to have one and it hurt and then they never wanted to go back for another smear test.

> Nurse … got annoyed at me for crying when she physically tore me open with the speculum. Struggle to attend appointments now.

> Some empathy, compassion and not made to feel like the nurse is bored, ticking a box or that we aren't human!

These accounts highlight an important distinction between the routine nature of screening for the practitioner and the personal significance of the experience for the patient. Familiarity with a procedure should improve clinical expertise; it should not diminish recognition of its intimate nature.

Women's experiences were influenced not only by the person carrying out the examination but also by the environment in which it took place. Respondents described cold examination couches, clinical or unwelcoming rooms, and inadequate paper coverings. Others suggested relatively modest improvements: appropriately sized coverings or blankets, warmer rooms, privacy curtains, comfortable examination couches, and suitable tissues or wipes after the procedure.

These may seem like small details, but during an intimate examination they can make a substantial difference to whether a woman feels exposed or protected and cared for.

Some accounts raised privacy concerns, including instances where another person entered the room during screening. Although NHS Cervical Screening Programme guidance already sets expectations for a safe, private, and respectful environment, women's accounts suggest that these standards are not always consistently met. The challenge is therefore not simply to establish good practice, but to ensure it is reliably delivered across all screening settings.

Women also reported substantial differences in the technical proficiency of sample takers and linked these differences directly to pain and discomfort:

> My most recent experiences at [the surgery] have been really sympathetic and professional, so it really does depend on the surgery. But healthcare shouldn't be a postcode lottery, based on the mood of the practitioner conducting the smear.

> Skill of nurse / doctor doing the screen varies wildly. And therefore so does the pain/experience.

Several accounts illustrate how relatively simple clinical adjustments transformed experiences.

> It was a few years ago, in my twenties, I always found smears to be uncomfortable until one that a lovely nurse did for me. I was lay down on the bed, ready to have the smear, we were chatting about past smears, I said I find them uncomfortable, like they are being pushed into me, when she looked at me and said "oh okay you need the longer speculum!". I asked what she was talking about. She went on to say "well look at you, you are long, long legs, arms, body, even eyelashes. You're long so it stands to reason you need the longer speculum as you will be longer everywhere, including there" I found her manner to be so lovely and caring and as she was older than me, I found a comfort in. [cont.]

> [cont.] We did the exam with the longer speculum and it was a complete different experience, not uncomfortable as it has been. From then on I always said to the nurse that I need a longer speculum and each exam has been without discomfort. A game changer. So simple and was something I'd never even known was an option.

> I have had 3 screenings — all three have been positive experiences, particularly the first as the nurse knew it was my first and took time before hand to explain the whole process to me, what would happen and why and made sure I understood and was comfortable before starting. Even when returning for the next the nurses have always explained the process even though it's not the first time. I've had smears at more than one GP practice as well so positive experiences across multiples doctors surgeries.

For some women, however, persistent pain was not resolved by changing equipment or technique. Listening to the woman and investigating why screening was painful sometimes revealed underlying clinical problems. Difficulty completing cervical screening should not automatically be treated as reluctance or non-compliance. It may itself be clinically useful information. Asking why a woman has found screening difficult - or why she has stopped attending - may identify pain, previous trauma, anatomical differences or an underlying condition requiring a different approach or further investigation.

The positive experiences reported demonstrate that high-quality cervical screening is already being delivered within the NHS and can be replicated. Women described healthcare professionals who communicated clearly, worked gently, anticipated discomfort, answered questions, protected dignity, and regularly checked that they were comfortable proceeding. The challenge is to make these experiences the expected standard, rather than something dependent on individual practitioners or the pressures within particular services. Achieving this requires understanding that screening quality is more than successful sample collection.

Training, service planning, and quality assurance should give appropriate weight to women's experiences, clinical technique, communication, pain management, trauma-informed practice, privacy, dignity, and continuous consent. Healthcare professionals also need sufficient time, appropriate equipment, and the flexibility to respond to individual needs. Systematically gathering feedback could help identify good practice to share, as well as areas where services need additional support or improvement.

This matters for England's ambition to eliminate cervical cancer by 2040. More invitations and better access are essential, but coverage alone does not tell us what happens once a woman walks through the door. A poor experience can influence how someone approaches future screening, while a practitioner who listens, adapts, and responds appropriately can transform an examination that was previously painful or distressing.

Women should be able to expect a consistent minimum standard of clinical competence, compassion, dignity, and responsive care every time they attend cervical screening, regardless of where they live or which healthcare professional carries out the examination.

Recommendation

Embed and scale effective cervical screening practices across NHS services through continuous professional development and investment in the systems and resources that enable consistent care.

7. Cervical screening services are not sufficiently equipped to accommodate the diversity of bodies they serve

Cervical screening is delivered to a population with enormous variation in anatomy, disability, medical history, childbirth experiences, pain, trauma, and individual needs.

These factors may make cervical screening more complex, but how that complexity is recognised and managed can make the difference between a successful screening and a positive experience. Our findings suggest that cervical screening services are often not equipped to respond to those differences.

> The first time I had a smear test it was very painful. I kept telling the nurse it was really painful but she didn't listen. The next time I went for a smear (having moved to a different area) I told the nurse how painful it had been. She had a look and told me I had a tilted womb, so she used a different speculum. I felt no pain at all. From then on, whenever I was with that nurse she used the different speculum. If somebody else was doing the test, I would tell them about me needing a specific speculum, because I had a tilted womb.

> There seems to be little preparation for diverse body types here.

> I usually have to interrupt the nurse to highlight that I need a smaller speculum, which can be embarrassing. I also have pelvic pain due to endometriosis which makes the screening painful.

Variation should be a basic design assumption of the programme, not an unexpected complication in the examination room. For some women, the result was unnecessary pain or embarrassment. For others, screening had to be abandoned. Some did not return when next invited for screening.

At the same time, pregnancy and childbirth can change people's bodies, and women described how those changes affected cervical screening.

> I experienced a traumatic birth at the QMC, causing irreparable damage internally and PTSD. A few years post birth a prolapse has occurred and therefore it is now more challenging for staff to take samples from the cervix and the tools required to carry out the smear test causes more discomfort and takes longer. At my most recent (2026) smear test the inference that the difficulties … in getting to the cervix to take the sample was partly due a problem with me (post childbirth) were not appreciated or helpful.

A body that has changed following pregnancy, childbirth, trauma, or a medical condition should not be treated as an inconvenience or abnormality. The survey also identified people for whom screening could not be completed because use of the speculum was extremely painful due to a narrow vagina.

Respondents described the value of being asked about previous difficulties before a screening began. For some, a previous painful experience had revealed useful information about their body - for example, the position of their cervix or uterus, or the need for a smaller speculum. Once they knew this, they could often tell future sample takers what worked. Subsequent screenings could be considerably easier and, in some cases, pain-free. But this placed much of the responsibility on patients to remember, disclose, and advocate for what they needed.

These accounts raise important questions about how consistently national cervical screening guidance is implemented in practice to accommodate the diversity of women's bodies and individual anatomical needs. NHS Cervical Screening Programme guidance specifies that sample takers should have access to a range of speculum sizes, adapt examination techniques and positioning to individual needs, and ensure appropriate referral pathways for women requiring specialist support.

However, women's reported experiences suggest potential gaps between these established expectations and their consistent delivery.[82] This highlights the need to examine whether screening services are adequately equipped, whether staff are supported to make appropriate adjustments, and whether women are routinely informed of the options available to them.

Above all, the findings suggest that women should not be expected to fit the screening procedure; the screening service should respond to them. For some participants, that flexibility was the difference between a painful and a pain-free procedure. For others, being listened to led to diagnosis and treatment. Where neither happened, some women stopped attending.

Recommendation

Strengthen existing cervical screening audits to assess and improve provision for individual anatomical needs, including speculum choice, flexible positioning, and specialist referrals.



Conclusion

The findings of this report demonstrate that improving cervical screening participation is not simply about encouraging attendance, but about ensuring services are accessible, culturally sensitive, trauma informed, and responsive to meet diverse needs. Women's experiences highlight persistent gaps between national guidance and everyday practice, particularly around pain, informed consent, communication, and individual adjustments. While examples of positive care exist, these are not consistent. Cervical screening is not a one-off intervention; its effectiveness relies on women engaging with screening at recommended intervals throughout different stages of their lives, as their bodies, circumstances, and support needs change. Trust is therefore fundamental to sustained participation. Each screening experience can strengthen or undermine that trust, influencing not only women's willingness to return but also the decisions of others through shared experiences.

As a community-led charity, we have seen the value of creating trusted spaces where women feel safe to share their experiences, challenge existing practices, and shape solutions. Their voices demonstrate that meaningful change requires more than information campaigns; it demands practical improvements in how screening services are designed, delivered, and experienced.

The report's recommendations offer NHS commissioners, policymakers, and healthcare providers an opportunity to partner with women and community organisations to build a more equitable, compassionate, and person-centred screening system. Success must be measured not only by increased uptake, but by patients' experiences of care, their confidence in screening services, and their willingness to return. Ultimately, everyone should feel informed, respected, supported, and in control throughout their screening journey.

Recommendations

1. Commission neighbourhood-based cervical screening services through women's health and community hubs, offering flexible appointment options to women who face barriers to accessing screening through traditional GP settings.

2. Establish a national first-screening standard requiring everyone invited for their first cervical screening to receive accessible information alongside their invitation, opportunities for pre-screening consultation, and an assessment of individual support and adjustment needs.

3. Introduce mandatory pain assessment and management protocols for cervical screening and revise national clinical guidance and public information to accurately reflect women's diverse experiences.

4. Embed ongoing consent as a mandatory, assessable competency in trauma-informed cervical screening training, with clear practical protocols for maintaining choice and control throughout examinations, including agreed pause or stop signals.

5. Redesign cervical screening communications to prioritise meaningful understanding over information provision alone, using accessible, multilingual resources, peer educators, and trusted community networks to support confidence.

6. Scale positive cervical screening practices across NHS services through continuous professional development and investment in the systems and resources that enable consistent care.

7. Strengthen existing cervical screening audits to assess and improve provision for individual anatomical needs, including speculum choice, flexible positioning, and specialist referrals.

Appendix A: Community learning resource – My Cervical Screening Checklist (pilot version)

As part of the campaign's commitment to empowering women, we developed a pilot version of the Cervical Screening Checklist. The checklist aims to strengthen women's knowledge, confidence, and ability to navigate cervical screening by providing clear, accessible information on the support available before, during, and after appointments. The checklist will undergo a structured process of piloting, evaluation, and refinement. We will gather feedback from women, community groups, and relevant healthcare stakeholders to assess its usability, cultural appropriateness, and practical application. Findings from this evaluation will inform evidence-based revisions to the resource and ensure the final version is both fit for purpose and responsive to the needs of the women it is intended to support.

Designed as a standalone, printable resource, the checklist can be piloted across community and healthcare settings to support wider engagement and extend the campaign's reach and impact beyond the publication of this report.

My Cervical Screening
CHECKLIST



This checklist was developed by women from the 'It's A Smear Campaign!' Steering Group, drawing on their lived experiences and informed by the key findings and insights gathered throughout the campaign.

Who is this for?

For women and anyone with a cervix who has been invited for NHS cervical screening, is preparing for an appointment, or wants to understand the options available.

Why screening matters:

Cervical screening saves around 5,000 lives each year in the UK. It checks for high-risk HPV so it can be treated before cancer develops. You should still be screened even if you have had the same partner for years or have not been sexually active.

How to use this checklist:

Read it before your appointment. Tick what you feel confident about and circle anything you would like to discuss. You can bring it to your appointment or share it with your GP or nurse beforehand.

More information + support

NHS: cervical screening: nhs.uk/conditions/cervical-screening/
Eve Appeal: Ask Eve: 0808 802 0019 | nurse@eveappeal.org.uk

Nottingham Women's Centre come on in
NOTTS SVS SERVICES LISTEN BELIEVE SUPPORT
IT'S A SMEAR CAMPAIGN
ROSA THE UK FUND FOR WOMEN AND GIRLS

Before my appointment:

- I understand that screening checks for high-risk HPV to help prevent cervical cancer
- I know what will happen and can ask questions
- I have asked about adjustments I need (e.g. extra time or smaller speculum)
- I know I can bring someone for support or ask about a chaperone

During my appointment:

- I have had the chance to ask questions and understand what will happen
- I feel ready to proceed and know that screening is my choice
- I know how to ask for the examination to be paused or stopped at any time
- I can tell the clinician if I feel pain, discomfort or anxiety

Before I leave:

- I know when and how I should receive my results
- I know who to contact if I have questions about my results or next steps

Questions or adjustments I want to discuss:

_____

_____

_____

To book your screening or discuss results, please contact your GP practice.
This checklist supports conversations; it does not replace NHS screening information.

Local advice + signposting

Nottingham Women's Centre
0115 941 1475
Sexual Health Services Nottingham and Nottinghamshire
0300 131 7010

Please note, this is a pilot verison of this resource. Please use the QR code to leave your feedback on how we can improve it.

Nottingham Women's Centre come on in
NOTTS SVS SERVICES LISTEN BELIEVE SUPPORT
IT'S A SMEAR CAMPAIGN
ROSA THE UK FUND FOR WOMEN AND GIRLS

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