

Cervical Screenings: Your Views and Experiences

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About Healthwatch Hertfordshire

Healthwatch Hertfordshire represents the views of people in Hertfordshire on health and social care services. We provide an independent consumer voice evidencing patient and public experiences and gathering local intelligence to influence service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

About the Hertfordshire and West Essex Integrated Care System

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services¹. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council².

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how it can further support people to attend cervical screenings.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years³.

Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care Board (ICB) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary
 Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement

¹ Integrated care systems: how will they work under the Health and Care Act? | The King's Fund (kingsfund.org.uk)

² Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)

³ Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)

- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented

Using patient and public feedback, this engagement project will focus on improving the relevant services within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From May to August 2023, the Director of Primary Care Transformation at the ICB has requested that Healthwatch Hertfordshire explore people's experiences and attitudes towards cervical screenings, including:

- People's experiences of cervical screenings
- Any practical barriers that people might face to attending a screening
- Any other reasons that might impact an individual's decision on whether to attend a screening

Background

National overview

Cervical screenings (previously known as smear tests or pap smears) check the health of a person's cervix in order to help prevent cervical cancer from developing. A cervical screening involves a small sample of cells from the cervix being tested for high-risk types of Human Papillomavirus (HPV) that can cause changes to the cervical cells and can lead to cervical cancer if left untreated⁴. This is why checking for HPV is so important for preventing cases of cervical cancer.

Cervical screenings have been offered in England since 1964, and the NHS has operated its cervical screening programme since 1988⁵. It is estimated that the programme saves around 5000 lives per year in England and deaths from cervical cancer have fallen by over 70% since the 1970s⁶. All women and people with a cervix aged 25-64 are invited to be screened regularly (either every 3 or every 5 years). If abnormal cells have been found, people may be invited to be screened more frequently.

HPV Vaccine

In 2008 the HPV vaccine programme was rolled out across England to help protect people against some forms of HPV and as a result, cervical cancer. Girls are offered the vaccine between the ages of 12–18 for free on the NHS and will often receive it at school. However, having the vaccine does not prevent all types of HPV and all women and people with a cervix are encouraged to be screened, even if they have been vaccinated⁷.

From September 2019 the vaccine has also been offered to boys between the ages of 12-18, since evidence has shown that the HPV vaccine helps to protect both boys and girls from HPV-related cancers⁸.

Home Tests

⁴ What is cervical screening? - NHS (www.nhs.uk)

⁵ <u>Cervical Cancer Screening in England – The journey so far | Synnovis</u>

⁶ Topic 2: background to cervical screening - GOV.UK (www.gov.uk)

⁷ Ten years on since the start of the HPV vaccine programme – what impact is it having? – UK Health Security Agency (blog.gov.uk)

⁸ Information on the HPV vaccination from September 2023 - GOV.UK (www.gov.uk)

Research has shown that embarrassment is often a key reason for not attending a cervical screening, as well as cultural barriers and fear about what the screening involves. To address this, in 2021 the NHS trialled at-home HPV tests in which people with a cervix can test themselves and the results are sent to their GP surgery. If the home test detects HPV, they will be invited to attend their GP practice for a standard cervical screening as a follow-up⁹.

HPV home-test kits can be purchased from specific retailers, however they are expensive and will require a follow-up by a clinician if the HPV is detected. However, evidence from Cancer Research UK suggests that some people would prefer a self-sample, providing reasons such as ease, convenience, reduced embarrassment and increased comfort¹⁰. Others would still prefer clinical sampling, stating they would have more confidence that it would be done correctly and would be more likely to trust the results. Regardless, home-tests kits have the potential to overcome several barriers, some of which are listed below, and may help reduce inequalities in cervical screening uptake in specific groups.

Common Barriers

Women and people with a cervix can face a variety of barriers to cervical screenings, some of which are practical while others are more personal.

As GP practices are serving increasingly large and complex populations, alongside staffing and resourcing strains, many people face difficulties in contacting their GP practice for a cervical screening and in getting an available appointment. This is often even more challenging for people with work and/or caring responsibilities as the times offered tend to be inconvenient. Other common practical barriers include having a disability and/or mobility issue, language and communication, and travel.

In regards to personal barriers, existing research suggests that factors such as embarrassment, anxiety and pain are some of the most common reasons preventing women and people with a cervix from attending cervical screening. Personal trauma such as sexual violence is also reported as a significant barrier to attending¹¹.

In contrast, some barriers relate to a lack of awareness and information, with people not understanding why cervical screenings are important. Others thought incorrectly that they do not think cervical screenings are relevant to them and/or they are not at risk either because they are sexually inactive, had the HPV vaccination, have been through the menopause, or have been in a monogamous relationship for many years¹².

Several studies have identified that some groups are less likely to attend cervical screenings, these include¹³:

- Younger women for some this is because they are worried the procedure would be painful or embarrassing, and were concerned about receiving their results. Anecdotally, some healthcare professionals are concerned that younger women may not attend because they have been vaccinated and no longer believe they are at risk.
- Women over 50 for some this is because they find smear tests more painful, especially since going through the menopause. For others, they no longer identify themselves as at risk.

⁹ https://www.england.nhs.uk/2021/02/nhs-gives-women-hpv-home-testing-kits-to-cut-cancer-deaths/

¹⁰ https://news.cancerresearchuk.org/2022/04/27/the-latest-on-self-sampling-for-cervical-cancer-screening/

¹¹ https://www.jostrust.org.uk/professionals/cervical-screening/barriers

¹² https://www.jostrust.org.uk/professionals/cervical-screening/barriers

¹³ https://www.gov.uk/government/publications/health-matters-making-cervical-screening-more-accessible/health-mattersmaking-cervical-screening-more-accessible--2

- Ethnically diverse communities this is often due to poor understanding about cervical screenings, as well as language and cultural differences.
- **Deprivation** people with less disposable income may find it difficult to attend cervical screenings.
- Women with learning disabilities Less than a third of eligible women with a learning disability are having a cervical screening¹⁴.
- Lesbian and bisexual women some incorrectly believe that because they do not have sex, or for bisexual women, may not have sex with men, they do not need to be screened.

Accommodations

A cervical screening is an intimate procedure, so it is important that patients feel supported and as safe as possible. Patients can request a number of different accommodations that might support them to feel more confident and comfortable during the appointment. These include:

- Requesting a female practitioner to conduct the screening
- Requesting a chaperone in the room with the patient (either someone they know or another trained member of staff)
- Requesting a longer/double appointment
- Requesting pessaries or creams to help with vaginal dryness
- Requesting a smaller speculum (the tool that is inserted in order to be able to see the cervix)

Offering such accommodations can help address some of the barriers patients may face, however evidence has shown that patients are often not aware that they can ask for such support and adjustments¹⁵.

Local picture

Statistics

In Hertfordshire, between October-December 2022, 70% of eligible 25-49-year-olds were screened, and 77% of eligible 50-64-year-olds were screened. This indicates that older women are slightly more likely to be screened but these percentages fall within the average for England.

Initiatives

Some local councils in Hertfordshire are running cervical screening initiatives, to help increase the uptake. People who have missed their latest cervical screening are being phoned and offered to make an appointment on the spot. Outcomes have been positive so far, and this method appears to work around some of the most common barriers – making and finding time for an appointment.

Aims

To gather lived experience to feed directly into the Integrated Care Board (ICB) Primary Care Workstream.

- To explore the uptake of cervical screenings and whether people feel well-informed about cervical screenings
- To understand people's experiences of having a cervical screening
- To identify the barriers people may face in accessing a cervical screening

¹⁴ Mencap's response to today's publication of Health and Care of People with Learning Disabilities statistics for 2017/18 | Mencap

¹⁵ Our cervical screening tips | Jo's Cervical Cancer Trust (jostrust.org.uk)

• To propose recommendations to the Integrated Care Board Primary Care Board

Methodology

The aims were explored through an online survey directed at women and people with a cervix living in Hertfordshire, whether or not they had ever attended a cervical screening. The survey ran from August to October 2023. The survey link and a digital flyer was shared with the NHS, other statutory services, and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to distribute via their networks, contacts and social media channels.

Respondents were given the opportunity to request support with completing the survey, or to complete a hard copy but these were not requested at any point.

Findings

Demographics

233 Hertfordshire residents completed the online survey¹⁶.



1% were aged 24 years old¹⁷
17% were aged 25-34 years old
26% were aged 35-44 years old
24% were aged 45-54 years old
26% were aged 55-64 years old
5% were aged 65-74 years old



100% were female



80% were of a White British background17% were from an ethnically diverse background¹⁸



15% are a carer7% had a disability8% had a long-term condition



70% stated that they had a little or a lot of disposable income **15%** had either just enough, or not enough money for basic necessities

Trans and non-binary people who have a cervix are eligible for cervical screenings. However, as we only had those who identify as a woman filling in this survey, so the term 'woman' has been used throughout this report.

¹⁸ Ethnicities engaged with included: Indian, Arab, Bangladeshi, Asian and White, Caribbean, African, Black Caribbean and White, other mixed/multiple ethnic backgrounds, Irish, Polish, Italian, other White backgrounds, and other ethnic backgrounds not listed.

¹⁶ Please note that percentages do not always add up to 100% due to some respondents choosing not to answer, or preferring not to say.

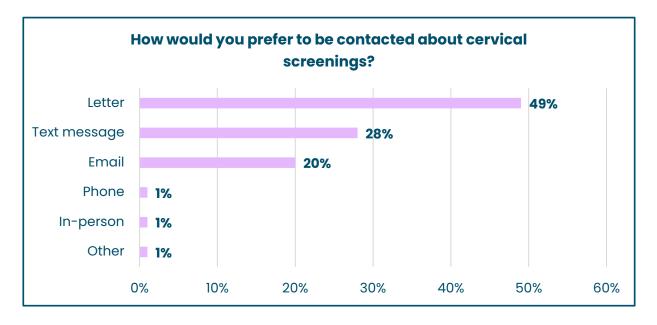
¹⁷ Please note that respondents under the age of 24 were not engaged with as women and people with a cervix are not invited to a cervical screening until they are 25 years old.

Invitation to Screening



At **97%** almost all respondents had received an invitation to attend a cervical screening. Just **3%** said they had not, and **one** person was not sure or could not remember whether they had been invited.

Normally, invitations to cervical screenings are sent by letter. Of the respondents, **49%** said they would prefer to be contacted via letter, though **28%** would prefer to receive a text message and **20%** said their preference would be via email.



At **33%** respondents aged 24–44 were slightly more likely to prefer a text message, in comparison to those aged over 45, of whom **25%** would prefer to receive a text. Slightly lower than the average, **13%** of 24–44 year olds wanted to be contacted by email, compared to **25%** for those aged over 45 years old.

Just 1% would prefer to be contacted via a phone call, and 1% would prefer an in-person invitation. The remaining respondents had no preference, or would prefer not to be contacted at all.

Information

Positively, **95%** said that the reasons for cervical screenings had been explained in their invitation. Only **3%** said the reasons had not explained and **2%** were not sure or could not remember.

Also encouraging is that **88%** of respondents felt they had received enough information about cervical screenings. Just **10%** felt they had not received enough information, and **1%** said they had not received any. Interestingly, Asian respondents were more likely to feel they had received enough information.

Respondents from a Black background and those aged 24-44 were slightly less likely to say that they had received enough information at **80%** and **84%** respectively. Respondents with less disposable income were also less likely to feel they had received enough information at **75%**.

92% of Asian respondents said they had received enough information. "I do feel that more information could be given in advance, for those who do have any concerns and may wish for support in terms of knowledge/information."

There was particular concern from respondents about younger women having enough information to feel confident to attend.

"I think first appointments can be scary for young ladies, from my experience there was no extra information given or taken during my appointment, it would have been nice to have a better overview of why it's being done, what the outcomes could be etc in person before the actual swab, I also think it would have been good to be asked a few questions related to cervical health too. My appointment felt very rushed."

As mentioned in the literature review, the HPV vaccine was made available to all girls and women aged between 12–18 from 2008¹⁹. Although the vaccine helps to protect against cancer-causing HPV infections, it does not eliminate all infection and all women are still recommended to have a cervical screening. Given this, some respondents were concerned that, as the first cohort of vaccinated women are invited to be screened, there needs to be more information about the importance of cervical screenings, even if you have had the vaccination.

"One other thing that could be helpful to include is information about the impact of the HPV vaccine and why you can still have the virus even if you were fully vaccinated as a teenager."

"Promotional communications need to make it clear that these appointments are for women. Young women have a false sense of security having had the HPV jab but it doesn't cover ALL strains."

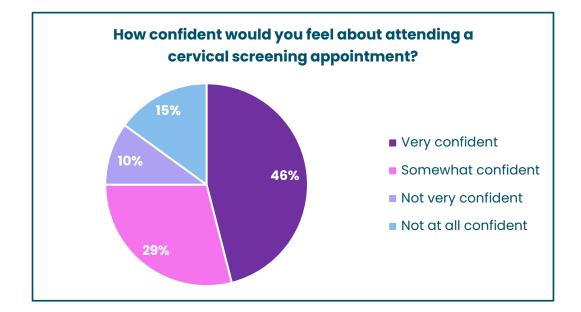
Other respondents also shared the importance of having open conversations and positive communication about cervical screenings from an early age to help encourage women to attend.

"The main reason I attended cervical screening as a young woman is because I remember my mum attending them as a child and actively talking to me about it. At school when discussions and lessons were given on health and common cancers the focus was on breast cancer for women- there was nothing on cervical cancer. Open conversations and educating young women at school I think is key in normalising the procedure and ensuring women attend."

Confidence to Attend

75% of respondents said they would feel either very or somewhat confident attending a cervical screening, while **25%** said they would not feel confident to attend.

¹⁹ Ten years on since the start of the HPV vaccine programme – what impact is it having? - UK Health Security Agency (blog.gov.uk)



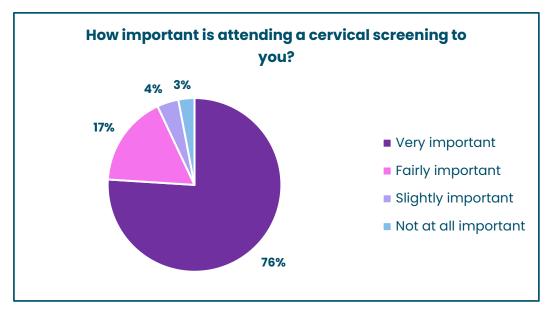
People who had previously attended a cervical screening showed more confidence in attending, with **78%** feeling very or somewhat confident, in comparison to just **31%** of people who had never attended before. Concerningly, Black respondents were far less likely to feel confident about attending at just **50%**.

50% of Black respondents said they were not confident in attending.

Confidence also varied between participants in different financial circumstances – with **65%** of people with less disposable income feeling confident to attend, while **36%** were not confident about attending a cervical screening. This relates back to earlier findings in which people with less disposable income were also more likely to say

they had not received enough information about cervical screenings, which would likely lead to lower confidence.

Nevertheless, **76%** of all respondents said that attending a cervical screening is very important, and a further **17%** said it was fairly important to them. Only **7%** said it was slightly important, or not important at all.



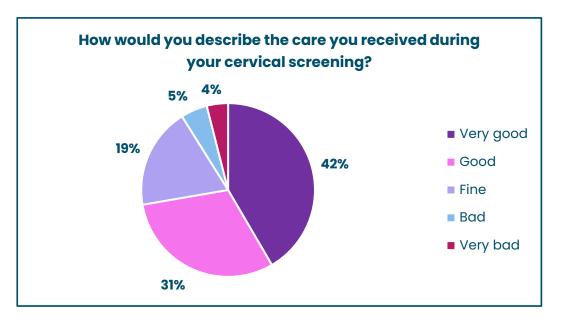
Respondents aged 24-44 years old were slightly more likely to consider cervical screenings to be important at **97%** - this figure drops slightly for those aged 45 years old to **92%**. For Black respondents, this was even lower at **80%**.

Experiences of Screening

Positively, **94%** of respondents had attended one or more cervical screening appointments, and their experiences are detailed in this section. Barriers to attending cervical screenings and reasons for not attending are explored later in this report.

Standard of Care

Overall, **73%** described the care they received at their cervical screening as either good or very good, **9%** said it was either bad or very bad, and **19%** described their experience as fine.



For those who had a positive experience, the majority of respondents said this was because the healthcare professional conducting the cervical screening was kind, sympathetic, reassuring and treated them with respect and dignity.

"It was quick and I had privacy and felt comfortable."

"Lovely nurse, personable, explained everything, took her time, listened."

"I received great care from my nurse. She was respectful and kind."

"Nurses performing the screening were very kind, gentle and I was made to feel at ease in what can be a very sensitive situation."

Some respondents commented that the healthcare professional helped them to feel comfortable, at ease and were accommodating of their needs.

"I experienced pain as the procedure was attempted – so I was prescribed a cream to be used for a month and a new appointment was booked which was successful – nurses very kind and understanding." "All questions answered, was allowed to bring my mum for support, nurses have all done everything they can to make me feel comfortable."

"I've always been offered for someone else to be in the room. Been made to feel comfortable and at ease."

Other respondents said the healthcare professional was knowledgeable and professional, and clearly explained the procedure and answered any of their questions or concerns.

"Nurse was very polite and talkative, talked through the whole procedure so I knew exactly what was happening as it happened."

"The nurse was kind, relaxed, explained everything clearly so I could understand and informed me of the next steps."

"I have had 2 cervical screenings so far, and both times from what I recall the nurses have been very friendly, explained the process and what they were doing. I felt relaxed in the room and I had nothing to worry about."

Lastly, some respondents praised the healthcare professional for being quick and efficient, without feeling rushed.

"My appointment last month with the practice nurse was the quickest, most efficient and painless procedure during a smear test I've ever encountered!"

"The nurse explains what they're doing and are as fast as possible (I find it very uncomfortable)."

19% of respondents described their experience as fine and for the majority, this was because they have had a mixture of both positive and negative experiences – and often this was dependent on the healthcare professional conducting the cervical screening.

"Mostly very good but I have had one example which was quite poor and I found the person doing the appointment rude and discouraging."

"I've been to many over the years since my 20s, some people are OK, some are not, this was the average."

"One time I was yelled at – with an angry raised voice – to 'relax' because the nurse couldn't get in. This caused me anxiety and physical pain. Other times I have been treated well."

For some respondents, they recognised that their experience was unpleasant and/or painful simply due to the nature of the procedure, rather than due to any fault of the healthcare professional.

"It is not their fault but every time has been very painful and bleeding sometimes to the extent it has to be repeated as the cells can't be seen because of the blood."

"All done very professionally but I find it to be quite an unpleasant and uncomfortable experience."

"It was as ok as it can be! Not a nice process but appreciate the importance of it."

In contrast, a few respondents commented that booking an appointment can be difficult, noting that appointment times offered are not always convenient, and problems getting through to their GP practice to initially book the screening.

"Technical process (taking of the sample) was fine. Making the booking for the test is more time consuming, and appointments are not at convenient times."

"Difficult to obtain an appointment in a reasonable timeframe (waited weeks)."

For the **9%** of respondents who described the care they received as bad or very bad, for the majority this was a result of the healthcare professional performing the cervical screening. Respondents commented that the healthcare professional was insensitive and lacked compassion, while some felt their poor experience was due to the clinician's inexperience or lack of training.

"The nurse said I had an oddly shaped cervix. She wasn't warm or welcoming and didn't try to put me at ease or make me feel comfortable."

"I felt uncomfortable and not at ease, it hurt, the nurse made comments during it that I felt were inappropriate."

"I'd taken my underwear off and got into the position with my legs wide open on the bed. Another nurse walked into the room to get something out of the cupboard, without knocking. I was mortified and I haven't been back since!"

Other respondents commented that their appointment was rushed, their needs were not appropriately accommodated for, and that they did not feel listened to by the healthcare professional.

"Nurse was running late and was abrupt, to her I was just a number not a person."

"All smears I've had have been very, very uncomfortable. Nothing explained, not discussed how ladies of a certain age when we lose oestrogen down there smears are much harder, not offered a smaller instrument to take smear." "I find the process very painful but get very little sympathy like I'm just making a fuss."

Several respondents raised that they did not feel the healthcare professional conducting their cervical screening was sufficiently informed or understanding of the menopause and the impact that it can have on screenings. Genitourinary Syndrome of Menopause (GSM) as referred to below can cause dryness and irritation of the vagina, making the screening procedure particularly painful.

"Painful, embarrassing, hate the feeling of a metal speculum inside me opening up, I've had two children and I still hate smear tests. Painful due to vaginal dryness from menopause not recognised."

"GP's nurses not knowledgeable about menopause."

"Nurses were completely uneducated about GSM and the pain it causes."

For a few respondents, their experience was so poor that they are reluctant to ever attend a cervical screening again.

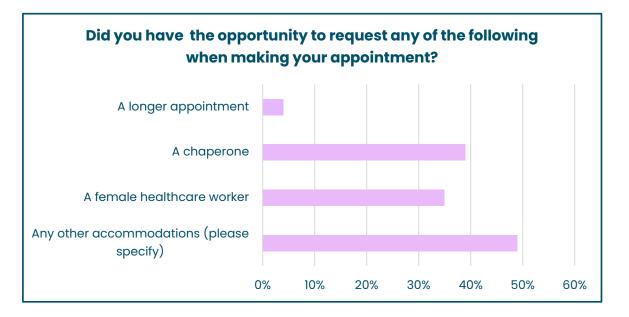
"Nurse at my practice who had never met me before. I'm post-menopausal and she made no allowances for that (e.g. with size of speculum). She kept pushing and pushing, hurting me so much I actually screamed out loud. Eventually she went to get a GP who also tried and said there was so much blood now she wouldn't be able to do the smear. I had to wear sanitary towels for three days after. Prescribed oestrogen pessary and returned to GP to do - she couldn't do it again. Ended up going to GP practice who are the gynae lead for GP group. She got the smear no problem. Said the difficulties were basically because I'm post-menopausal, fat and not having sex currently. Needless to say I don't plan on returning for any future smears."

"The nurse at the GP surgery was not competent – it made for an extremely traumatic experience. It hurt and I experienced pain a good few days later. Never had another one and never asked why or reassured it wouldn't happen again."

There were slight variations in the care experienced by different demographic groups. Those aged over 45 were slightly less likely to report the care they received as good or very good at **68%**. Black respondents and Asian respondents were even less likely to describe the care they received as good or very good, at **66%** and **50%** respectively.

Accommodations

Cervical screenings are an intimate procedure, so it is important that women feel in control and comfortable during the appointment. The screening will usually be performed by a female healthcare professional, and women can also request further accommodations, such as a chaperone, to help them feel more secure.



Of all the respondents who had attended a cervical screening, **35%** had the opportunity to request a female healthcare professional, **39%** could request a chaperone, and **4%** could request a longer appointment.

For those who selected "Other" – many said they did not need to ask for any accommodations as they are automatically given a female practitioner. Although if this was not the case, they would have asked for one or at least a chaperone.

"At my practice it is automatically a female healthcare worker carrying out the procedure."

"It may have been that the chaperone and female healthcare worker would have been offered if the person doing the appointment wasn't female but that has always been the case for me, so far."

Some respondents said they were not offered any accommodations, but they did not feel the need to request them and/or they were not required.

"Didn't need to request these, appointment length was appropriate, was with a female."

"I don't recall having that opportunity but as I didn't require any of those options, I would not have looked for it."

In contrast, **13%** of respondents said they were not offered the opportunity to request any accommodations and for some, they would have liked to have been aware of what additional support was available. When accommodations are not offered or widely known about, it is up to the individual to research and advocate for their needs and rights.

"I have never been given the opportunity to have any of the above, I have in fact been advised of the opposite (not allowed to have the option!)"

"I've never been offered any accommodations whatsoever!"

"I wasn't offered any of the things mentioned. I went most recently in February 2023, and even though I had researched and found that I am able to request a smaller speculum and bring one person of my choice into the exam room with me, I completely forgot all of it and just got on with what is a painful procedure (for me) on my own."

One respondent said that the clinician was not very accommodating of her partner's presence in the appointment, while another would have liked a longer appointment to enable time to recover afterwards.

"I have my husband if he can attend as my carer/chaperone and I ask not to close the curtain but I get overridden. I want to have his support, have my hand held but the nurses don't like it."

"It would be good to be given some down time after. As a sufferer of endometriosis this is very painful and courses a lot of pain and cramping and trying to just get up and WALK home right after can be VERY difficult."

Communication during the Screening

Respondents were asked if they felt able to share any concerns and feel listened to during their cervical screening. Positively, **68%** said yes while a further **16%** said no. Other respondents shared more nuanced feelings and reasons as to why they felt that way.

For those that had a positive experience, respondents commented that the healthcare professional conducting the cervical screening listened to their concerns and provided reassurance, and were kind, caring and accommodating to their needs.

"I was really nervous and was put at ease."

"I also felt that my concerns were anticipated by the clinicians and that they proactively enabled me to raise them."

"They made time to reassure me."

Some respondents did not personally have any concerns, but felt confident that if they did, that they would have been listened to and addressed by the healthcare professional.

"I didn't have any concerns but I know I would have felt able to share any concerns at any of my appointments."

"I didn't have any concerns but I think I would/could have raised if I did."

For those who had a more negative experience, some respondents shared that they did raise concerns or fears with the healthcare professional but they were not adequately responded to or acted upon, and in some cases were neglected entirely.

"I have tried to share my concerns. Sometimes I am listened to, other times I am utterly dismissed."

"I can share concerns but they are not really listened to."

"I explained that I always find smears painful & that I have never had children. However, no alternative was ever given so just had to proceed."

In particular, pain during the screening was sometimes unacknowledged, dismissed or ignored by the healthcare professional.

"Care was adequate but little understanding of the pain I feel when having the smear."

"I expressed I was nervous at the start which the nurse was understanding about. When the procedure was incredibly painful and had to be abandoned, the nurse dismissed the pain as being related to my nervousness/ lack of sexual activity. I have since had further investigations with a pelvic health physio who has identified that there are other issues including possible endometriosis. I am not happy that the nurse did not think it worth exploring my pain further."

"I shared that the procedure was extremely painful, but was not listened to at all. The nurses told me I just needed to relax."

Some respondents said there was not enough time to raise concerns during the appointment, and that they felt they had to simply "get on with it".

"The appointment is quick so not much time to talk about things. I do think I'd be listened to but it was hard to find an opening to discuss issues."

"Not really - it's felt a 'get on with it' kind of approach. You're told to relax - usually impossible!" Lastly, other respondents shared that although they have never needed to raise a concern, they are not sure whether it would be listened to, indicating some lack of trust in healthcare professionals.

"I didn't have any concerns. Don't know if I'd have been listened to."

"I don't feel like I would be listened to! It feels like I am "Just another task" to get through."

Test Results

85% of respondents said they were automatically informed of their cervical screening results, and **4%** followed the results up themselves. Only **5%** were not informed, and **7%** cannot remember or were not sure if they had been informed.

Some respondents said that their results could have been delivered more sensitively and that they did not receive an adequate explanation or reassurance following a positive HPV result. This sometimes led to respondents looking independently for information, rather than receiving it from a trusted source which caused undue stress and anxiety.

"Improve the way results are given. I was told via letter that I was HPV positive. You are almost never given health results via letter so this was extremely disconcerting as I didn't have anyone to discuss this with and the supporting leaflet was less than helpful and made me concerned about potential impact on my health and my partner. As I work in the healthcare sector I was able to discuss this with colleagues but would be concerned about the impact receiving this information in the post could have on someone younger or with less access to supporting information."

"I was very anxious attending my third cervical screening as I was told I had HPV despite being vaccinated. I didn't feel I had enough information to know if it was a high-risk strain, low risk, if I'd had it before or if it was new. I had only had one partner for 10 years, and all the information was on HPV being passed sexually. Did this mean he'd been unfaithful between my smear tests? I found myself on Google and trying to find information on forums like Mumsnet."

"The letter to say you have HPV does not include information for people who were vaccinated as young teenagers and for whom have been told they have immunity to HPV. The letter did not make clear when you may have contracted HPV and where. It does not include information on different strains (in the appointment the nurse had told me about all the different strains)."

Linked to this, a few respondents said they did not have enough understanding or information about what the process or advice should be following a positive HPV result, again often causing distress and anxiety.

it might be useful to say what will likely happen if you have a positive HPV result 3 years in a row, which is what my situation might be next year. Do they automatically send you for a colposcopy at that point? I really hope not as that would be really horrible and difficult for me. :(I feel very worried about this."

"I have HPV which was picked up in 2021 and I still had it at my last smear in 2022. My GP letter said if I experienced any bleeding to contact them. I did and the GP didn't seem concerned. I've had bleeding on and off for months, a sign of abnormalities but nothing is being done. I'm worried it's a sign of cervical cancer but the GP is dismissing it at something else."

Although one respondent did share that they were saw a consultant after testing positive for HPV, which provided them with much needed reassurance.

"I had a positive HPV and a follow up with a consultant who did an ultrasound. it was very reassuring to hear all was fine."

Lastly, a few respondents had faced delays when waiting for their results, and noted that this could result in increased anxiety and puts additional responsibility on the patient to follow up.

"Don't make me wait too long for results like my one before last where it was five months plus and two samples given and every week chased to find out the result."

Barriers and Concerns

Non-attendees

Only **6%** of respondents had never attended a cervical screening appointment. **33%** were aged between 25-34 years old – the most common age category for not attending. **20%** were aged 35-44, and **20%** were aged 45-54 – indicating that younger women are slightly more reluctant to attend their cervical screening.

Women aged **25-34** were the most likely to have never attended a cervical screening.

25% of Asian respondents and **20%** of Black respondents had never attended a cervical screening. Women will less disposable income were also more likely to have not attended at **10%**.

However, it is important to note that the above findings are only based on a small number of respondents and we would encourage the Hertfordshire and West Essex ICB to conduct targeted engagement with people who have never attended a cervical screening to gather further insights.

27% of those who had never attended also stated that they have never received an invitation to be screened, which is concerning but could explain their non-attendance.

Interestingly, **47%** of those who have never attended said that receiving a text message would be their preferred method of invitation – this is significantly higher than the average of **28%**. **40%** said they would prefer to receive a letter, which is just below the average of **49%**. Given the younger age demographic of non-attendees, it is perhaps the case that being contacted by letter is less reliable or suitable, given they could move house or GP surgery and letters could easily be missed.

53% of non-attendees said that they have not received enough or any information about cervical screenings – again this is much higher compared to the **11%** average. Likewise, **27%** said the reasons for cervical screenings had never been explained to them, in contrast to the **3%** average.

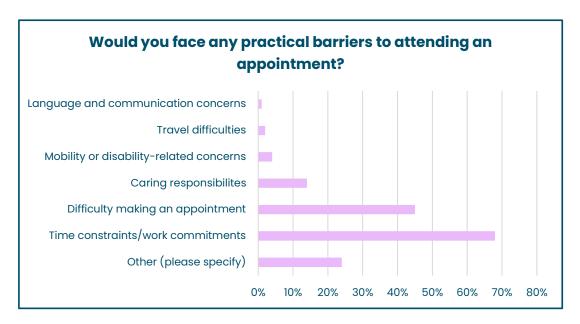
Perhaps unsurprisingly, **69%** of non-attendees said they would not feel confident attending a cervical screening appointment which is much higher compared to the **25%** average. Despite this, **61%** still said cervical screenings were still very or fairly important to them, with only **8%** stating they are not important.

However, those who have never attended a cervical screening faced barriers beyond a lack of information or missed invitation. Other barriers and reasons for non-attendance are detailed below, alongside challenges faced by women who have previously attended cervical screening appointments.

It is also important to note that the above findings are only based on a small number of respondents and we would encourage the Hertfordshire and West Essex ICB to conduct targeted engagement with people who have never attended a cervical screening to gather further insights.

Practical Barriers Identified by Respondents

Across the board, many respondents experienced practical barriers which discouraged or prevented them from booking and attending a cervical screening appointment – with only **10%** stating they did not face any barriers at all.



The most common barrier was time constraints, including work commitments, which **68%** of respondents reported. For those who had never attended a cervical screening this was even higher at **80%**. At **82%**, those aged 24-44 were also much more likely to cite time constraints as a barrier. As a result, many respondents called for greater availability of appointments, including evening and weekend slots.

"Make it easy to make an appointment at a convenient time please."

"Really need access to screening at weekends and evenings."

"I was fortunate during COVID that the practice offered evening appointments, be good if this continues."

45% of all respondents said they faced difficulties making an appointment, although only **20%** of nonattendees cited this factor as a barrier, possibly indicating that other challenges meant they had not necessarily got to the stage of trying to book an appointment.

Women with less disposable income and those aged 24-44 were more likely to face difficulties making an appointment at **53%** and **59%** respectively. Respondents shared their frustrations about long waiting times on the phone, lack of available appointments, and not being able to book a cervical screening online.

"More support for attending. It's very hard to make an appointment which is off putting and it's already a hard thing to ring up and arrange. I would prefer the chance to book online so I can plan my day around it."

"I was recently contacted to book my next smear test. When I contacted my surgery in early Sept, they didn't have ANY appointments available this month and next month's calendar isn't open yet."

"Booking the appointment is the reason I haven't been recently. For working people being in a queue on the phone is not practical."

Linked to this, a few women shared that it was difficult to accommodate both the available appointments with their own menstrual cycle and again emphasised how valuable online booking would be.

"Fitting in an appointment around your period is sometimes tricky. Would be nice to be able to book online rather than phone up and negotiate a date."

"Online booking for this service would be much more convenient as can take time checking calendar and cycles to get appropriate appointment."

14% said that their caring responsibilities hindered their ability to attend cervical screening appointments – this was slightly higher for those who had never attended at 20%. This figure was even higher for Black and Asian respondents at 25%, and for those aged 24-44 years old at 26%. Women in this age category are more likely to have dependent children and may not be able to easily find childcare, making attendance at appointments more difficult.

"I am not keen to take my three-year-old with me."

4% of respondents faced mobility or disability-related concerns and **2%** faced difficulties related to travelling to their appointment. Only one person faced language and communication barriers. However, women with less disposable income were more likely to have mobility or disability-related concerns at **10%** and **7%** would also face difficulties travelling to appointments, possibly due to the cost of fuel and/or public transport.

"I don't drive so my local GP surgery would be best."

"I am autistic, ADHD and dyslexic. I also have Ehlers Danlos Syndrome which causes chronic pain and fatigue amongst many other issues. I find it difficult sometimes to attend appointments alone, and struggle with miscommunication and emotional dysregulation and frustration from being misunderstood or when people do not explain things enough for me to understand. My husband often attends appointments but taking time off work costs him £200 or more in income. And being autistic, one of the things I dislike is being touched especially by strangers. This is VERY difficult for me to do."

Other Barriers

Alongside practical barriers, respondents noted other concerns about attending their cervical screening. One of the most common concerns was pain – with respondents commenting that they find the procedure extremely uncomfortable and either physically or emotionally painful.

"Pain, it is extremely painful for me which is always ignored by my GP or nurse."

"Pain, always pain. I have endometriosis so this is always very painful."

"Worried about it being painful."

Unfortunately this is sometimes made worse by the lack of understanding or compassion from the healthcare professional conducting the screening, with respondents commenting that their pain and discomfort is ignored.

"Pain and the feeling of it being dismissed by the nurse."

"Just the understanding from the nurse that some women find the entire procedure very uncomfortable so do not find it easy to relax quickly."

Some respondents commented that they cervical screenings embarrassing and awkward, largely due to the intimate nature of the procedure.

"The main thing is embarrassment. It's an intimate matter having such a test."

"Always slightly embarrassing by nature of the examination, and uncomfortable."

"Embarrassing, undignified, I feel very vulnerable during smear test."

Other respondents said they feel incredibly anxious about cervical screenings, and this was often closely related to feelings of embarrassment and concerns about pain and discomfort.

"Anxiety – the process is too intrusive."

"I do feel apprehensive leading up to a screening as I do tend to feel pain during and after."

Despite concerns about pain and feelings of anxiety and embarrassment, the majority of respondents said these challenges would not deter them from attending a cervical screening, with many accepting the importance and necessity of cervical screenings. Respondents also commented that healthcare professionals do their best to make you feel at ease, comfortable and reassured.

"It's always an anxious appointment but I've never had a bad experience."

"The idea of going is always worse than the actual procedure. The intimate nature of the test always feels embarrassing but the nurses are always amazing at putting you at ease."

"I do find them awkward and embarrassing which causes slight anxiety but this is outweighed by knowing it's important to go."

"I find it uncomfortable and unpleasant but I will always attend if invited."

In contrast, a few respondents had a previous poor experience which has negatively impacted their feelings about attending future cervical screenings. Concerningly, a couple also said they had been removed from the contact list following a previous negative experience.

"Stop making those with anxiety after a bad experience feel worthless and taken off contact lists without finding out full reason why they don't attend and offer assurance - I don't even know if I can have one now, and don't want to call doctors in case refused."

"It hurt and I experienced pain for few days later. Never been contacted or asked why I won't go again. Just informed, by letter, I'd be taken off the contact list!"

"Explained before, negative experiences with poorly qualified staff."

In addition, a few respondents had concerns about cervical screenings because of personal trauma they had experienced.

"I was raped and sexually assaulted as a child so I have a lot of issues with being screened in this intimate way."

"Too humiliating - past assault probably affects me - so not wanting to think about it or plan ahead."

For a few respondents, their main concern about cervical screenings was a fear of receiving a positive test result.

"It's not a pleasant procedure and anxious about the results."

"The test to be painful and getting bad results."

Lastly, although all respondents identified their gender as female, one respondent did express their concerns for people who are trans and the barriers they may face to attending cervical screenings.

"I am a cis female, but my trans male friends are often overlooked for cervical screening, and face barriers to attending appointments as they face being misgendered."

Future Attendance

75% of respondents said they were planning to attend their next cervical screening, while **25%** said they were not.

Of those who **had never** attended a cervical screening before, only **25%** said they will attend and **75%** said they would not. For some, this was because they were worried about the potential pain they might experience during the screening.

"Worried it will hurt."

For a couple of respondents, previous experiences of trauma and assault meant they did not feel comfortable attending.

"I was sexually abused as a child and can't face uncomfortable screening."

Lastly, a few respondents had made a decision that the appointment was not relevant to them, or sometimes that the pain was not worth it, in comparison to their self-perceived low risk.

"It seems very painful and scary and I am so self-conscious of myself and have sensory problems due to being autistic so I avoid it. Plus I am gay so I believe I don't really need one as much."

"As I am a virgin, I have not attended any cervical screening appointments"

For those **who had** attended a cervical screening before, the percentage of those planning to attend was slightly higher at **78%**, but there were still **22%** who said they were not planning to attend again.

Of the **22%** of respondents who were not planning to attend their next cervical screening, approximately **23%** said this was because they no longer have a cervix and/or had surpassed the age bracket for eligibility. However, some expressed that they would like the opportunity to continue having cervical screenings despite being past the age bracket.

"I have since had my cervix removed when I had a hysterectomy."

"I don't need them now as I have had a full hysterectomy."

"Think I am considered too old now, but would if I could!"

"If I'm able to, as I had a letter saying as I'm 62 I'm not going to be asked to attend but I've read here the age limit is 64 so I'm unsure?"

In contrast, some respondents said they found their previous cervical screening so painful that they no longer want to attend their next appointment.

"I have never been sexually active so I understand that my risk level is very low. Currently the procedure is too painful and I would not attend until the pain has lessened."

"I have received an invite but I haven't booked yet as I'm worried it will hurt again."

"I've not attended for years despite knowing I should and receiving reminders. I am not afraid of the results but the actual procedure itself I find absolutely excruciating, frankly unbearable. It is so uncomfortable and almost painful for me. I cried at my last appointment and the nurse couldn't complete the procedure. She was extremely compassionate so I was grateful for that."

Similarly, some respondents shared that they felt too anxious to attend a cervical screening again, particularly due to their previous experience.

"My sister doesn't attend these appointments because she would rather chance it than to go through what feels traumatic each time." "I am extremely anxious about having the procedure."

As mentioned earlier, another common reason for people who have previously attended to not re-attend is due to having had a poor experience and/or negative interaction with the clinician at their last cervical screening.

"Negative, painful, uncaring previous appointments have rendered me with pure fear of going to another one."

"Unless this smear has changed in any way from the old version, I cannot say I will be attending."

"Last time I attended I needed hip surgery due to damage to my hip and the need to get in an awkward position! I feel that I am at higher risk of getting a long standing hip problem than I am of having cervical cancer."

Suggestions and Improvements

Appointments

As mentioned, many respondents would feel more encouraged to attend cervical screenings if they were made easier to book. Respondents shared that they have difficulties getting through to their GP practice due to long waiting times, and others commented that they have contacted their GP practice only to be told there are no appointments available.

"I am planning on attending but phoned the surgery today to make an appointment and there are none available."

"I haven't booked because of the difficulty making contact with GP."

"My work schedule fills at least 3 months in advance and there is no facility to book beyond 6 weeks in advance at my practice."

Others said that due to their work and/or caring responsibilities, the ability to access evening or weekend appointments would enable easier access to cervical screenings.

"Making sure there are appointments after work or in the evenings is key."

"Only offered one date, and I'm working."

A few respondents suggested that providing walk-in clinics could address some of the practical barriers faced.

"The whole process is awful. It would help if you could go to a drop in centre not book through GP appointments."

"Walk in clinics, without having to plan ahead would help around erratic periods. Evening appointments better for working age, reassurance female staff only."

Facilities

A few respondents had concerns about the facilities of GP surgeries, and suggested that they could be better equipped to conduct cervical screenings.

"Please ensure surgeries have the proper set up for carrying out meaningful tests."

"I feel like my surgery is not set up for cervical screenings. The nurse was very nice and professional but the facilities didn't even have anything for me to put my legs in. I question how useful the screening was compared to others I've been to in my home country. They were more thorough and felt more meaningful. The ones I've had here were very fast and I wonder if they got a proper sample."

Training

Some respondents suggested that healthcare professionals could have some more training, both on cervical screenings specifically and gynaecology issues more generally.

"I am concerned that general practice staff don't have enough training in gynaecology issues so if I had not requested further investigation, my condition would have been missed. I know that the level of pain I experienced was not normal but the nurse did not pick up on it so I am concerned that other things could be missed and that I would not be understood or believed."

"Yes, please get all GP practice nurses trained properly on procedures."

"Maybe like breast screening this needs to be done by a nurse/doctor that does a large number a week, so is skilled and confident."

Self-testing

Several respondents suggested distributing self-testing/home-testing kits, commenting that this would be more accessible, comfortable and offer greater privacy and dignity. This has been trialled by the NHS in some areas, but not in Hertfordshire.

"Provide options to do it at home in your own comfort or at least an opportunity to choose where to go and get it done. This would offer a variety of choices to choose from and more participation."

"Please find other ways of doing it. Places in Australia have simple small swabs and more sensory friendly ways than the current way. Like the Self-Collection method. Info: It's quick, easy, private and just as accurate as a test done by a healthcare provider using a speculum and a small brush."

"I'd like someone to work out a way we can test ourselves, or have a partner test us so that it is not such a traumatic event each time. I've burst into tears on many visits to intimate things like this or a vaginal ultrasound, bladder biopsy etc."

Less Invasive

Linked to this, some respondents wondered if cervical screenings could be made a less painful and/or less invasive procedure.

"If there is a non-invasive / painful way of doing it, I would go."

"Just wish the whole procedure could be done in another way as it is still Victorian in its way, I have an extremely low pain threshold and each time I have been has been excruciating and humiliating."

"If there was an easier way/less painful then I would get another one done."

Frequency of Screenings

Some respondents said that cervical screenings should be more frequent and offered annually, rather than every 3-5 years.

"Frequency of appointments. I feel a cervical screening should be offered at least once a year."

"I think that they should happen more frequently than 3/5 years."

"I'd like them to be more frequent. Early detection is very important."

Linked to this, respondents said they would like to be able to request a cervical screening if they have concerns and/or any symptoms.

"Should be allowed to have one when your concerned and not have to wait a year or two."

"Would like this to be every 3 years and easy to make an appointment if you raise any concerns between screening assessments."

"To have extra screening available in case of any symptoms, extra screenings are declined regardless of reason."

Age Limits

Another common theme from respondents was regarding both the lower and upper age limit restrictions of being invited for a cervical screening. Many respondents felt that the first screening should occur much earlier, at 18 years old rather than at 25 years old²⁰.

"I think the minimum age is too old, I had precancerous cells at 22 years old - if I hadn't had a smear this would have gone undetected for a couple of years."

"I started having cervical screenings when I first went on the contraceptive pill at 17 and thereafter every 6 months. I have a daughter of my own, now in her 30s who has had cervical screenings but not regularly enough and they only began at age 25. I firmly believe that once a female is sexually active and using the pill they should have regular smear tests and I have felt this is a huge mistake only offering them from age 25."

"I feel the age of 25 is still too high, and needs to be lowered. Many young women go through puberty much earlier so detecting cancers early is key."

Likewise, older women felt that being screened continued to be of importance to them past the age of 65, and that there should not be an upper age limit²¹.

"At my last screening I was told I would not be called for further screening due to my age. I would like to continue screening opportunities as evidence suggests it is wise to continue. I think discontinuing at age 65 is unfair and should continue for longer than 65 years of age. Please review this point."

"I will no longer be invited which is disappointing. I have a cervix so why no more opportunity to be screened?"

²⁰ According to NICE, cervical screenings are not offered to those aged under 25 because cervical cancer is very rare in this age group, and cervical screenings have not been shown to reduce the number of cervical cancers in under-25s, and cervical abnormalities are common in this age group. ²¹ Again, according to NICE people aged 65 and over should only be invited to a cervical screening if a recent cervical cytology sample is abnormal and/or if they have not had a cervical screening test since 50 years of age and they request one. This is because the risk of cervical cancer is very low.

"Why is there an age limit? Is it true that women are more unlikely to have cervical cancer as they age or is it simply a cost cutting exercise. There are limited resources so I'd prefer to be told the truth about this with an opportunity to pay privately if necessary."

Summary

Overall, respondents shared some very positive experiences when having a cervical screening, commenting that clinicians were kind, reassuring and professional. The survey also highlighted a good level of confidence in women attending their appointment, and there was a high level of importance placed on having cervical screenings. Though, it is important to recognise that confidence levels were lower amongst some demographic groups, including Black respondents and those with less disposable income.

Some women told powerful stories about the negative experiences they have had, which could have been improved by increased compassion and understanding from the clinician conducting the screening. Pain was dismissed at times, needs were not accommodated for, and not everyone felt comfortable to raise issues or concerns during their appointment – and we found that these experiences were more common amongst older women and Black and Asian respondents. The findings also highlighted how having a poor experience can prevent women from attending again. Given that cervical screenings are such an intimate procedure, with many women feeling anxious and/or embarrassed ahead of their appointment, it is imperative that clinicians are sensitive to each individual's needs and feelings.

A large number of respondents also faced barriers to attending cervical screenings. For most, these were practical barriers such as work and/or caring responsibilities, lack of available appointments and difficulties getting through to their GP practice to book the screening. Other barriers included pain, anxiety, previous poor experiences, and personal trauma. Some demographic groups were more likely to have faced barriers, particularly younger women, those with less disposable income, and Black and Asian respondents.

To conclude, it is important that the experiences and challenges conveyed within this report are assessed and addressed to help people feel able to attend either their first or next cervical screening with confidence and reassurance. Particular attention and further engagement should be given to typically underrepresented groups, as this survey has shown they are more likely to face barriers to attending.

Recommendations

Based on the findings of this research, we advise the Hertfordshire and West Essex ICB Primary Care Board to consider and implement the following recommendations to improve experiences of and access to cervical screenings.

Information

1. Provide invitations to cervical screenings in a range of formats, including letters, text messages and emails.

- 2. Ensure women receive enough information about cervical screenings and why they are important, even if you have been vaccinated.
- 3. Consider targeted engagement with ethnically diverse communities, younger women and those with less disposable income to improve confidence and attendance.

Access

- 4. Enable cervical screenings to be booked online.
- 5. Provide appointments for cervical screenings outside of typical working hours, including evenings and weekends. This could also include the provision of walk-in clinics.
- 6. Support and promote any trial or roll-out of self-sampling at-home HPV tests.

Experience and Training

- 7. Ensure effective training and awareness for practitioners on cervical screenings, and particularly about the impact menopause can have on this procedure.
- 8. Consider providing double appointments to women who are presenting for their first screening and/or have shared they experienced pain or anxiety at a previous screening. This is to ensure there enough time for reassurance and for information to be given.
- 9. Advise reception staff to mention available accommodations at the point of booking cervical screenings.