NHS England North West

Cervical screening – Insight work

Cheshire and Merseyside and Lancashire and South Cumbria

March 2024

Contents

1 Introduction

Despite being a well-established national screening programme, over the last decade the number of individuals coming forward across England for cervical screening has been steadily declining. Coverage fell from 73.5% in 2014/15 to 71.0% in 2019[1].

Work has been carried out nationally to understand the reasons why cervical screening rates are falling. However as the NHS England – North West (NHSE NW) Public Health Commissioning team, responsible for commissioning the NHS Cervical Screening Programme in Cheshire and Merseyside and Lancashire and South Cumbria, we were keen to hear directly from our population about the reasons why they were not coming forward. We also wanted to gain their views on what could be done to support more people to come forward for their screen.

We commissioned NHS Arden and Greater East Midlands Commissioning Support Unit and NHS Midlands and Lancashire Commissioning Support Unit to carry out insight work with our population on cervical screening. This work took place between July and October 2023. 2,935 individuals from across the North West shared their views with us via an online survey (including an Easy Read version) or at a face-to-face engagement session.

Our findings from this insight work are presented in this report. We have also included some direct quotes from respondents, which are a representative sample of the thousands shared (Appendix 5 also contains a selection of quotes grouped by theme).

Working with our partners across the North West, we will now look to act upon our findings to improve access and uptake of cervical screening across the North West.

This engagement work forms part of a suite of projects that NHSE NW is undertaking to improve access and uptake of all Section 7a Screening and Immunisation Programmes by North West residents including population groups known to experience health inequalities. Other projects are shown on the following page.

[1] Projected incidence and mortality of cervical cancer to 2040 | Jo's Cervical Cancer Trust (jostrust.org.uk)

NOTE: This report was carried out across the Cheshire and Merseyside and Lancashire and South Cumbria populations. Separate insight work has been carried out with the Greater Manchester population.

High impact interventions to reduce inequalities in screening 2023/24

CORE20 PLUS 5

Supporting the most deprived

- **Breast Screening – Improving Uptake Support Workers** – Targeted work with communities vulnerable to non-participation, expanding current work in L&SC and roll out project in C&M in 2023/24
- **Bowel Cancer Screening – Call for a kit** – Improving uptake with non-responders in low uptake areas – expanding current work in L&SC, implementing intervention in C&M during 2023/24.

Early cancer diagnosis

- **HMP Styal – Breast and Cervical Screening Programmes** – Review of current service provision to ensure continuous provision, improve access and uptake to achieve national targets for secure settings (April 2023 – March 2024)
- **Age extension (Age X) rollout – Bowel Cancer Screening** – Support providers to implement phased rollout of Age X in line with national timescales to extend screening from the 60 to 74 age group to 50 to 67. All programmes inviting people aged 54, 56 and 58 by end of Q1 2023/24.

Learning disabilities

- **Breast and Cervical Screening – Improved access and awareness for those with a learning disability or autism** – Work with system partners across C&M and L&SC to rollout learning from a two-year programme of work and five pilots undertaken during 2022/23 to reduce barriers to access, improve uptake and achieve better health outcomes (April 2023 – March 2024)
- **Bowel Cancer Screening – Flag initiative** – Work with Place Leads across C&M and L&SC to achieve full rollout and active use of digital 'flag' to enable people with a learning disability to be offered the appropriate support to improve access and uptake (April 2023-24).

NOTE: All initiatives will take place across Cheshire and Merseyside (C&M) and Lancashire and South Cumbria (L&SC) footprints unless specified.

Secure settings

- **Improved reporting of screening uptake against national targets** – Work with all stakeholders to implement recommendations following review of data quality/ flow for screening programmes in NW secure settings (April 2023-24).

Addressing wider inequalities

- **AAA Screening – Improving awareness, access and uptake** – Share findings of insight work on barriers to access and uptake for three population groups: ethnic minorities, individuals living in care homes/housing associations and gypsy traveller, to improve uptake rates (October 2023 – April 2024)
- **Breast Screening – Review of mobile screening sites in Liverpool, Sefton and Knowsley** – Ensure mobile sites meet the needs of the local population, share learning from the review with all NW Breast Screening providers (March – July 2023)
- **Cervical Screening – Understanding barriers to access** – Undertake insight work with the eligible population in areas with poorest uptake, share findings with system partners to inform ways to reduce unwarranted variation in uptake across the region (May 2023 – April 2024)
- **Diabetic Eye Screening – Health Equity Audits (HEA)** – All NW Directed Enhanced Service providers to complete HEAs and have plans in place to implement any recommendations (October 2023 – March 2024)
- **Supporting PCNs – Care Coordinator toolkit and Sharing Best Practice** – Share toolkit to support primary care networks (PCNs) to improve uptake rates across all screening programmes and share with learning from engagement and targeted initiatives to improve uptake by certain population groups undertaken by C&M and L&SC PCNs during 2023 – (May 2023 – March 2024).

High impact interventions to reduce inequalities in immunisation 2023/24

Supporting the most deprived

- **Flu – children aged 2 and 3 –** Support targeted initiatives in areas of high deprivation and low uptake for children aged 2 and 3 including School Aged Immunisation services offering flu vaccine to nurseries attached to schools, GP endorsed letters including Easy Read images
- **Flu –** Continue promotion of delivery model for people with HIV attending test and treat centres and Drug and Alcohol Team (DAT) services
- **School Aged Immunisations – College Pilot –** Working together with Wirral Community Trust, implement a college pilot in Wirral to improve uptake in 16-18 year-olds who missed vaccination in the school setting in most deprived wards in Wirral April 2023 onwards
- **0-5 Immunisation programme –** Targeted interventions/services in areas of low uptake and high deprivation:
  - Review of targeted immunisation teams in Liverpool and Knowsley
  - Commission an increasing immunisation uptake team to target areas of low uptake, provide support and training for PCN staff.

CORE20 PLUS 5

Addressing wider inequalities

- **Measles, mumps and rubella (MMR) –** Continue to implement initiatives – MMR Pre School Letter and MMR Postcard – to support prioritisation of key vaccinations in areas of low uptake; MMR Dose 2 and pre-school booster
- **Human papillomavirus (HPV) –** Work with providers to ensure catch up of unvaccinated (HPV) children across all eligible cohorts and develop communications to parents regarding forthcoming changes to the HPV programme schedule (September 2023)
- **Secure Settings –** Support delivery and recording of flu vaccination across NW secure settings through provision of tailored resources for healthcare teams and eligible individuals
- **Looked After Children –** Ensure pathways to support access to School Aged Immunisation (SAI) Services for protected groups including looked after children and children with education, health and care plans (EHCPs) in place
- **Supporting PCNs –** Use the latest data to work with partners to agree an offer of targeted support to improve uptake of immunisations in 'hotspot' PCNs
- **Best practice –** Share resources to support high quality provision/best practice across the NW; Google Drive resources, training slide packs and top tips for clinical and non-clinical staff
- **Reducing barriers –** Utilise data to identify areas of low uptake, work with system partners to understand reasons/barriers and solutions.

Maternity

- **Hep B –** Ensure a standardised approach across all providers for the neonatal Hep B vaccination programme and roll out targeted Hep B dried blood spot (DBS) testing in C&M
- **Flu –** Share educational material and information on maternal flu to non-clinical maternity colleagues to enable them to provide accurate information to pregnant women
- **Pertussis –** Work with healthcare professionals to produce positive media content to promote maternal flu and pertussis immunisations.

Severe mental illness (SMI)

- **Flu –** Working with mental health units and other secure settings to improve access and uptake.

Chronic respiratory disease

- **Adult immunisations –** Review current delivery models of adult immunisations including shingles and pneumococcal vaccinations in care homes to procure best practice and reduce hospital admissions.

NOTES: All flu-based initiatives are active during flu season (September to February). All initiatives will take place across Cheshire and Merseyside and Lancashire and South Cumbria footprints unless specified.

On 15 November 2023, NHS England outlined its ambition to eliminate cervical cancer by 2040 in line with World Health Organisation targets.[2]

Two public health programmes are key to preventing cervical cancer: the HPV Vaccination Programme and the Cervical Screening Programme. High participation rates and equitable uptake of both programmes is needed to reduce the diagnosis of cervical cancer and ultimately support the elimination of cervical cancer in the UK.

This report presents the findings from insight work undertaken in 2023 to understand why so many of our residents across Cheshire and Merseyside and Lancashire and South Cumbria are not coming forward for cervical screening.

National engagement work has shown that reasons, including embarrassment, poor knowledge of the procedure and worry about the results can influence an individual's view of cervical screening, but it was important for us to understand whether these are the same views held by our population.

The North West has some of the lowest uptake rates in the country for cervical screening across both age cohorts (25-49 and 50-64 year-olds). We need to change this situation.

We have now heard the views of nearly 3,000 people across the North West and we are extremely grateful for their openness and willingness to share their experiences with us.

As a next step, we will work with regional colleagues and ICB and Place colleagues including local authorities to agree how collectively we can act upon these findings and test some of the ideas shared with us to understand if they improve access and uptake in the programme. During 2024/25, the NHSE NW Public Health Commissioning team will be reaching out to our system and Place-based colleagues for support with this work.

[2] NHS England » NHS sets ambition to eliminate cervical cancer by 2040

I would like to take this opportunity to thank each and every person in the North West who took the time to complete the survey – the response was fantastic. I would also like to thank all of our healthcare professionals in primary care, sexual health, NHS Trusts and other providers and system colleagues including local authorities, ICBs and Places, third sector organisations and Cancer Alliances for your support with this work.

If you have any questions about this project or you are implementing service changes to improve access and uptake of Section 7a screening and immunisation programmes in the North West, please do let us know. We are very keen to hear from you and you can email us at: **england.cmphadmin@nhs.net**

Andrew Bibby

Regional Director of Specialised Commissioning and Health and Justice

NHS England – North West

> "Cervical screening is so important in early detection of HPV and cervical cancer. For all our service users who are eligible for cervical screening, I would encourage you to come forward when called. I understand that some may find the experience uncomfortable and embarrassing and I also recognise that we need to ensure clinic times are flexible and accommodating to all and we are working to address this. Your cervical screening could save your life… please do not miss the opportunity."
>
> **Dr Paula Cowan, Medical Director for Primary Care, NHS England North West Region and GP partner**

Acknowledgements

We would like to say a huge thank you to everyone who has supported us with this work – particularly our residents who generously took the time to complete the survey. Your willingness to share your views, your very personal experiences of cervical screening and ideas for how we can encourage more people to come forward for screening is invaluable.

Also, our healthcare and system colleagues (Please see Appendix 1 for who you are) who met with us, helped us to shape this survey and then supported us to reach so many of our population – your support was hugely appreciated.

We would also like to thank Andrea Clark and Ajey Sharma, our colleagues at NHS Arden and Greater East Midlands Commissioning Support Unit and NHS Midlands and Lancashire Commissioning Support Unit for all your work, invaluable advice and support throughout this commission – we have learned a lot from you.

Helen Dickinson, Kathryn Hayes, Kathryn Jones, Kath Lewis and Carolyn Wake

Cervical Insight Programme team – NHSE – North West

2 Background

2.1 A national picture

The NHS Cervical Screening Programme aims to reduce the incidence of and mortality from cervical cancer by delivering a systematic, quality assured population-based screening programme for the eligible population. It is estimated that the NHS cervical screening programme saves around 5,000 lives a year.

Cervical screening is offered to women and people with a cervix aged 25-49 years old every three years and those aged 50-64 years every five years. The national coverage target is for 80% of eligible individuals to have a cervical screen within 3.5 (25-49 year olds) or 5.5 years (50-64 years).

Despite being a well-established screening programme, cervical screening coverage is decreasing, and uptake is lowest in women and people with a cervix who may already be experiencing disadvantage.

- A third more of ethnic minority women of screening age report to have never attended a cervical screening appointment, compared to white women and only 28% of ethnic minority women said they would feel comfortable talking to a male GP about cervical screening[3]
- Lesbian and bisexual women over the age of 25 were twice as likely to have never had a cervical screen compared to all women over the age of 25[4]
- 34% of women with learning disability have a cervical screen compared to 75% of those without[5].

The impact on the health of women and people with a cervix as a result of declining uptake rates cannot be underestimated.

[3] Jo's Cervical Cancer Trust. The differing understanding of cervical screening among white women and women from a Black, Asian and Minority Ethnic (BAME) community. Available from www.jostrust.org.uk/sites/default/files/bme_research_2011_final.pdf [Accessed 3rd April 2018].

[4] Stonewall. Prescription for Change. Lesbian and bisexual women's health check 2008. Available from: www.stonewall.org.uk/sites/default/files/Prescription_for_Change__2008_.pdf [Accessed 9th October 2017].

[5] NHS Digital. Health and Care of People with Learning Disabilities, Experimental Statistics: 2018 to 2019 [PAS] [Internet]. NHS Digital. 2020 [cited 2020 Sep 2]. Available from: digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019

Unless the situation changes, the incidence of cervical cancer over the next 20 years will be dominated by women and people with a cervix currently in their 40s and 50s, as individuals born after 1991 have benefited from the introduction of the HPV vaccination programme (2008) and more effective HPV primary screening.

- Incidence among 50-54 year-olds will increase by 50% (from 177 cases in 2015 to 265 cases in 2040)
- Incidence among 60-64 year-olds will climb 54% (from 144 cases in 2015 to 222 in 2040) and mortality 109% (from 79 to 165 deaths a year)

While diagnoses will fall among women and people with a cervix aged 25-29 from 412 cases a year to just 104 cases in 2040, this does not mean that we can become complacent about screening for this age group – another study reports that this age group has a disproportionate risk of high grade cervical abnormalities.[6]

- Nationally, research has been carried out to understand the reasons why individuals are not coming forward for cervical screening
- A study of people aged 25-29 in 2016 showed reasons for not taking up the offer of screening included simply just putting it off, being too embarrassed to attend and not thinking cervical screening reduced the risk of cervical cancer[7]
- Another study of those aged 50 – 64 showed that while all women had heard of cervical screening, many felt they had poor knowledge of the procedure and reasons for non-attendance were wide-ranging and included discomfort and embarrassment, negative perceptions of health professionals, worry and trust in the results.[8]

[6] NHS Cervical Screening Programme in England 2016-17 digital.nhs.uk/catalogue/PUB30134 NHS Digital 2017

[7] Barriers to cervical screening among 25-29 year olds | Jo's Cervical Cancer Trust (jostrust.org.uk)

[8] Barriers to cervical screening among older women from hard-to-reach groups: a qualitative study in England | BMC Women's Health | Full Text (biomedcentral.com)

2.2 The North West picture

Uptake rates of cervical screening across the North West reflect the national downward trend (See Appendix 2 for coverage figures by ICB and Place for 2019/20 to 2022/23 noting that these figures may have been impacted by behaviour change due to COVID-19).

Table 1 below shows the latest data available prior to the North West insight work.[9]

Improving uptake and reducing unwarranted variation in uptake rates across Places and different population groups is a key priority for NHSE NW.

We have worked closely with our 13 local authorities and sexual health providers to ensure cervical screening is available in community sexual health clinics (we have provided funding for up to 8,152 screens per year) to support patient choice. PCNs across the region (that have practices not achieving target uptake) have been offered funding to implement local initiatives to encourage more of their registered patients to attend their cervical screen.

In 2023 we completed a two-year programme of work to improve uptake of both breast and cervical screening by individuals who have a learning disability. We heard from more than 40 of our residents (via an Easy Read questionnaire and focus groups) who have a learning disability about the barriers they face accessing cervical screening.

Table 1 Q1 2022/23 coverage rates across Cheshire and Merseyside and Lancashire and South Cumbria

Age range	England	North West	C&M Place range	L&SC Place range
25-49	67%	67.4%	Liverpool 60.9% Cheshire 73.1%	Blackburn with Darwen 61% Chorley and South Ribble 74.4%
50-64	75%	73.8%	Liverpool 67.7% Cheshire 76.9%	Fylde and Wyre 69.8% Blackpool 77.3%

They told us:

- Reasonable adjustments are not always offered
- Easy Read materials were not always received with the appointment letter
- Most individuals had no understanding of what would happen during a screening appointment. They said that if they were able to speak with someone who had knowledge of the process, they would feel more confident to attend
- Some felt afraid or concerned about what would happen at a screening appointment, which was linked to misunderstandings or limited knowledge
- Some said they found it difficult using the appointment systems – especially when changing appointment dates.

[9] Cervical screening: quarterly coverage data reports 2023 - GOV.UK (www.gov.uk)

We will be working with our partners across the region throughout 2024 to implement recommendations from this work to support more individuals who have a learning disability to take up the offer of cervical screening[10].

In addition to work we have done, we are also aware of interventions being undertaken at practice level (including text message reminders and additional clinics) and by regional partners to improve cervical screening.

The Women's Health and Maternity (WHaM) Programme, Cheshire and Merseyside Health and Care Partnership (as part of a project funded by the Cheshire and Merseyside Cancer Alliance) engaged with 120 individuals along the maternity pathway during 2023. One-to-one interviews, group sessions and a 'quick' questionnaire to understand reasons why people were not coming forward for cervical screening were conducted.

[10] Report_NHSE NW_Improving Access to Breast and Cervical Screening for Individuals with a Learning Disability.pdf - Google Drive

The five key themes identified through the WHaM work explaining why individuals are not having their cervical screen were:

Embarrassment

Not sure what would happen at appointments, feeling embarrassed as it's intimate.

Language used – smear vs cervical screening

Is cervical screening different to the smear?

Difficult to make an appointment

Can't get through to see a GP or even get an appointment.

Lack of information

Might hurt, don't understand why we need it.

Fear

About the size of equipment and also didn't know they could request a female to undertake cervical screen or scared to find out something is wrong.

Important points raised included in one-to-one and group discussions during the WhaM work included:

- Limited understanding of whether cervical screening is required if someone has not been sexually active or, they have had the same partner for life
- In some cultures, females who are not married or sexually active are worried the screening would make them no longer a virgin
- Females may like to attend screening with husband and children. Special consideration of culture, religion, previous trauma or other triggers
- Some countries don't offer cervical screening which could potentially lead to confusion about why someone should attend and fear they may be charged for the service
- Asylum seekers face difficulties accessing their screen when moving to another area
- Many people remember Jade Goody and the campaign for cervical screening (especially those with children) and stated 'you wouldn't want that to happen to you' and this still drives them to go for cervical screening, however most people under the age of 30 did not know who Jade was'
- HPV vaccine – misunderstanding with many younger individuals saying they 'don't need to go for a smear as I've had the HPV vaccine' and a lack of understanding about what the vaccine is and if it effects fertility.

Suggestions for how we can help more people to attend cervical screening were:

- Show the equipment used, normalise it somehow amongst adult females
- Option to have an informal conversation with a health practitioner to ask questions
- Increase awareness of cervical screening from a younger age in schools/colleges, etc.
- Better appointment availability like a clinic just for cervical screening
- More understanding around the HPV vaccine and what it means for smears
- More talking about cervical screening; advertisements; referring to it as 'cervical screening also referred to as a smear
- Promote in different languages or different communities
- More venues as alternatives to GP surgeries – appointment availability outside of 'normal' GP hours and more clinics in the community.

3 NHSE NW insight work – cervical screening

NHSE NW commissioned Arden and GEM Commissioning Support Unit (AGEM CSU) and NHS Midlands and Lancashire Commissioning Support Unit (MLCSU) to undertake insight work on the subject of cervical screening with the North West population.

From the outset, close collaboration with our partners across the North West was key. Meetings were held with local authorities, Primary Care Networks, GP practices, third sector/community groups, Cancer Alliances and NHS provider trusts to gain their input, support and ideas on how best to engage with local residents – particularly those less likely to take up the offer of screening.

It was decided that a standard questionnaire (and an Easy Read version) would be used for the insight work. A draft of the questionnaire was shared with partners for review and comment prior to being finalised.

We were keen not to just focus on the barriers people felt they faced in accessing screening, but also on what they thought needed to change to encourage them to book and attend their screening appointment.

The survey used a combination of 'open' free-text questions for respondents to make written comments, and 'closed' questions where respondents 'ticked' their response from a set of pre-set responses.

The questionnaires were then made available online and used in face-to-face sessions (link to questionnaires below):

future.nhs.uk/NWPublicHealthCommissioning/view?objectID=45388912&done=-OBJChangesSaved

Links were shared to the online survey with partners for wider distribution (See Appendix 3 for the social media advertisement and emails circulated to partners).

The survey was live between 10 July and 1 October 2023 and 2,935 individuals took part (141 completed the Easy Read questionnaire). The engagement period was extended until October as we wanted to engage with community groups who did not meet during the school summer holidays.

On the basis of postcodes provided, 40% of respondents were from Cheshire and Merseyside and 52% from Lancashire and South Cumbria (4% did not provide a postcode and 4% were living out of area). Appendix 4 provides the full demographic breakdown of respondents.

16 face-to-face engagement sessions took place with communities across the North West.

At these meetings, attendees completed the survey to feedback their views. The venues included:

- Halton Women's Centre
- Bangor Street Community Centre, Blackburn
- Tomorrow's Women – Chester
- Tomorrow's Women – Birkenhead
- Venus Centre, Bootle
- The Strand Shopping Centre, Bootle
- Palatine Library, Blackpool
- Palatine Leisure Centre, Blackpool
- Moor Park Library, Blackpool
- Moor Park Leisure Centre, Blackpool
- Blackpool Sports Centre
- Eagle Bridge Health and Wellbeing Centre, Crewe
- Northgate Arena Leisure Centre, Chester
- Blackburn Central Library
- Harris Museum, Art Gallery and Library, Preston
- Health and Wellbeing Mela, Burnley.

The CSU also worked in partnership with the Women's Health and Maternity (WHaM) Programme team to engage with communities across Cheshire and Merseyside – using the Living Well Bus. As part of this, 35 face-to-face events were attended. Venues visited included:

- Mulgrave Street Mosque, Liverpool
- Wirral Deen Centre
- Multicultural Centre, Birkenhead
- Refugee Womens Connect, Liverpool
- World Café, Southport
- Warrington Maternity – Meet the Midwife (homebirth Team)
- Womens health event African Caribbean Centre, Liverpool
- International Café, Bootle Library, Sefton
- Koala Northwest Family event, Birkenhead
- Singing mama's event – Liverpool Museum.

3.1 Demographic breakdown of respondents

98% of respondents were female, but other genders were represented including males, trans-men, non-binary and gender-non-conforming

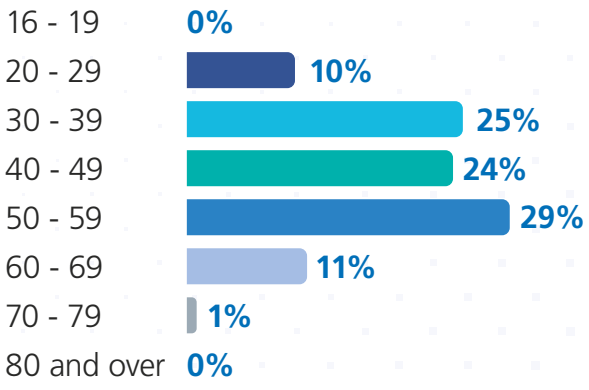
54% were married

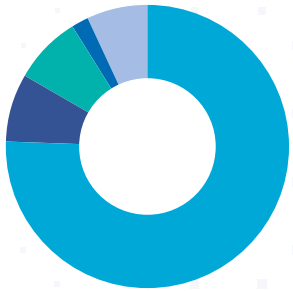
14% single

18% lived with a partner

22% were carers for other people (children or adults)

Most respondents were within the eligible age range for the cervical screening programme (25 to 64)

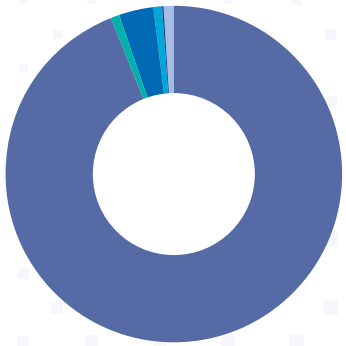




- **78%** had no level of disability
- **8%** had a mental health need
- **8%** had a physical or sensory disability
- **2%** had a learning disability
- **7%** had a long-term illness

The majority of respondents identified as white British

Just over **3%** as Asian/Asian British (Indian, Pakistani or Bangladeshi)



- **93.9%** White (British/Irish/Gypsy or traveller/Other)
- **1%** Mixed: (White and Black Caribbean/ Black African/Asian, Other)
- **3.2%** Asian/Asian British: (Indian/Pakistani/ Bangladeshi/Chinese/Other)
- **0.8%** Black/Black British: African/ Caribbean/Other
- **0.1%** Other ethnic group
- **1%** Preferred not to say

A full breakdown of the survey demographics is available in Appendix 4

4 Findings

4.1 Experience of cervical screening

Respondents were asked if they had previously attended for cervical screening, and the majority of respondents had (94%).

Respondents were then asked when they last attended. The majority had attended screening within the last three years (where a date was given) – See graph 1.

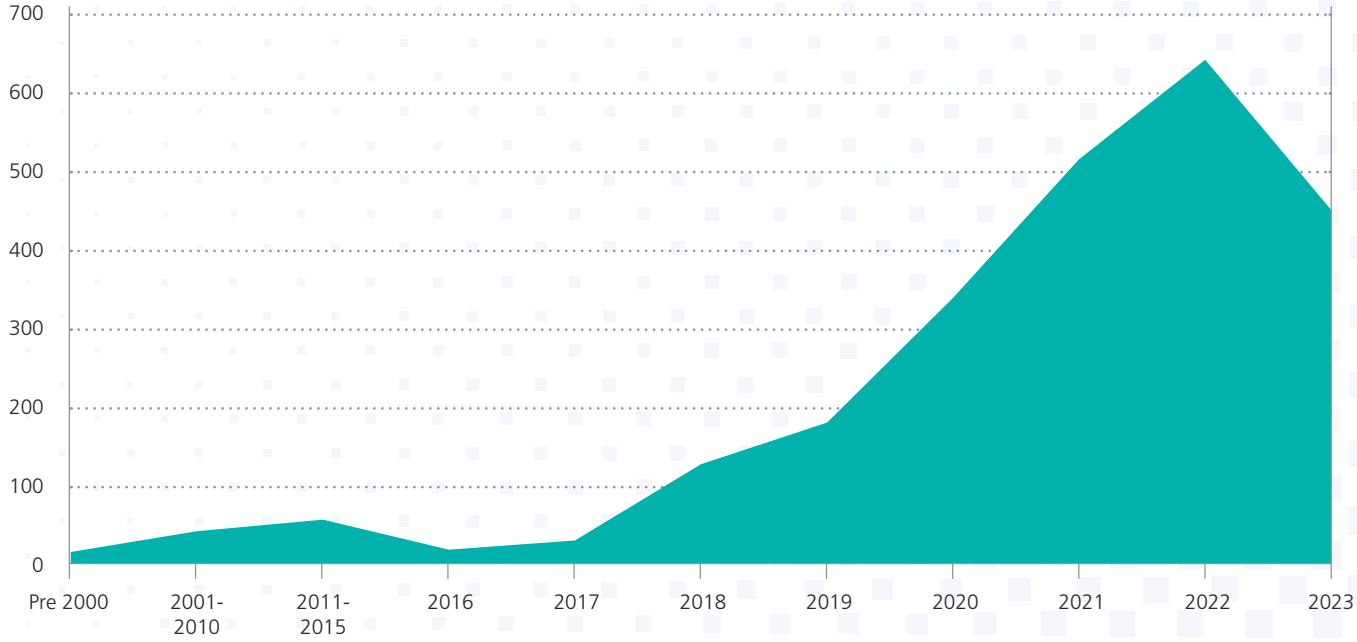
Many of those who hadn't attended for some time explained this was due to having had a hysterectomy or because they were above screening age.

Of those who had attended an appointment previously, the majority believed that cervical screening was important and felt knowledgeable about the programme and why they should attend.

As evidenced in our uptake/coverage statistics, the survey reflected that those aged over 50 were more likely to attend than those in younger age groups. (96.5% of respondents over 50 had attended compared to 92.2% of those under 50).

Those that hadn't previously attended for cervical screening were asked why they hadn't. Approximately 10% of these were below the age of eligibility and a further 10% were eligible, but hadn't yet received their first invitation or had their first appointment booked in the near future.

Graph 1 – Year of last cervical screen (where given)



Of the remaining respondents, there were two common themes that emerged as to why they hadn't attended yet:

- **Anxiety about the procedure itself.** A third mentioned fear of it being painful or uncomfortable, that is was too invasive or they felt embarrassment due the nature of the screening. For a few who had previously suffered trauma from sexual assault or rape this was particularly acute
- **Difficulties getting appointments**. One in five respondents mentioned they were unable to get appointments at all or at times that were suitable – a particular issue for those who worked or had pre-school children. Some had had appointments cancelled due to staff shortages, but had had no new appointment offered.

Approximately 10% felt they didn't need to attend as they were not sexually active.

This is a misconception, whilst someone who has never been sexually active is at lower risk they are not at no risk. If an individual has had any sexual contact in the past they should be advised to attend for screening.

Quotes

"I changed my first appointment due to work and said I'd call back, but became anxious and couldn't go."

"Struggling to have the courage for one – feels too invasive."

"The dates for the clinics are once a month and line up with my period, not ideal."

"Due to the availability of appointments. There needs to be more time slots available for people that work 9-5. When I have checked there were no morning or later in the day appointments. All appointments are carried out during the working week and people can't afford to be taking time off just for an appointment."

4.2 Knowledge and beliefs around cervical screening

Respondents were asked whether they felt knowledgeable or not about cervical screening and if they believed it would prevent them from becoming ill with cervical cancer or not.

Four out of five respondents stated they felt knowledgeable about cervical screening, just under half (45%) also stated they believed cervical screening would prevent them from becoming ill with cervical cancer.

One in 10 stated they didn't believe cervical screening would prevent them from becoming ill with cervical cancer.

When asked "Is screening important to you as part of looking after your health?", 95% said yes.

Although the number of respondents who hadn't previously attended for screening was small, it is worth noting that only 76% of them felt screening was an important part of looking after their health and so this may be a contributing factor in their decision not to attend.

Similarly, only small numbers of respondents identified their sexual orientation as other than heterosexual but again this group were slightly less likely to believe screening was important (90%) – potentially because they believe they are at lower risk.

Just over 2,000 of the respondents went on to give their reasons for why they felt screening was important (or not).

Although the responses were free text answers, the majority were on the same theme – that they considered cervical screening important for early diagnosis and/or treatment and to 'stay healthy'.

Just under 10% mentioned they felt it was important because they had previously had abnormal cells detected, and 7% attended due to family history of cancer.

Negative views were small in number but again referenced a fear the screening would be painful, that it was invasive, that screening can seem intimidating and made them anxious and attending appointments is inconvenient. A few were concerned the test didn't detect cervical cancer or cell changes (but tested for HPV).

Quotes

"I have always gone for my cervical smears when invited as I feel it is very important to attend for early detection of anything abnormal."

"It is an early detection for cervical cancer and also the HPV virus. It's good that younger generations now have access to an injection that protects against the HPV virus, which was not available to my generation."

"I want to be proactive about my health."

"I didn't have a smear until 28 due to bleeding whilst pregnant. When my son was born it was found i had cancer on the cervix I've since had treatment and a full hysterectomy i was so foolish for not getting a smear at my first available opportunity."

"I do think its important but personally find it a traumatic experience."

"Very important as the previous smear test i had to have treatment for HPV. The last one was all clear thank god."

4.3 Why might someone not attend for cervical screening?

Respondents were given a list of 17 reasons someone may have for not attending their cervical screening and asked to pick all those they thought were true. They could also give their own reason.

The top 10 reasons chosen in order of popularity were:

1. Too embarrassed to go (76%).
2. Feel uncomfortable that someone they don't know is going to undertake such an intimate procedure (73%)
3. Too busy working/family commitments/both (52%)
4. Feel afraid (52%)
5. Appointments offered are at inconvenient times (46%)
6. Don't know what happens when you go for cervical screening (39%)
7. Can't get an appointment (32%)
8. Not sexually active (24%)
9. Appointments offered are at an inconvenient location (24%)
10. Have been in or are in an abusive relationship (23%)

Those aged under 35 were more likely to give answers 1 and 2 than the older age groups.

Those who gave their sexual orientation as other than heterosexual were more likely to include answers 4 and 10, and 9% felt that their sexual orientation was a reason for not attending.

Access issues were slightly more prevalent in the answers of those that lived in Cheshire and Merseyside than those that lived in Lancashire and South Cumbria.

Although not making it into the top 10 answers, 17% selected 'Have had the HPV vaccination so do not need cervical screening'. This is a misconception. Although the vaccine is very effective, it is not 100% effective. The vaccine offers protection against a number of HPV types (of which there are more than 100) and includes the two most common types that cause cervical cancer. However the HPV vaccine does not offer protection against all types of HPV that could cause cancer, which is why cervical screening is important even for those who have received a HPV vaccination.

4.4 How can we help more women and people with a cervix to attend cervical screening?

Moving the focus away from why individuals don't attend, the next section of the survey asked respondents about what would make it easier for them (or other people) to attend for cervical screening. Again, respondents were given a list of suggestions and asked to tick all those that applied to them.

The two most popular answers both relate to access and were:

1. Offer cervical screening in the evenings and weekends (2,214 responses/77%)
2. Allow people to book online for their cervical screening (2,022 responses/70%)

The next popular answers related to information and were:

3. Tell people that a female doctor or nurse will carry out the test (2,005 responses/ 69%)
4. Explain why cervical screening is important (1,721 responses/ 60%)
5. Give people more information about what happens when you go for cervical screening (1,662 responses/ 58%)

The next five most popular answers reinforced these two themes:

6. Have more appointment times (1,613 responses/56%) – **access**
7. Give people an opportunity to talk to a health professional about cervical screening (1,393 responses/48%) – **information**
8. Offer cervical screening in more places e.g. children's centres to help people with young children (1,307 responses/45%) – **access**
9. Offer mobile screening closer to people's homes e.g. clinic room on a health bus, in screening units similar to blood donation clinics or breast screening (1,178 responses/41%) – **access**
10. Let people do a self-sample test at home which they then send off to a laboratory (1,162 responses/40%) – **access**

Alongside the tick box options, 965 respondents provided their personal views on how uptake may be improved via a free text answer option.

Many responses in this section included personal stories of their own experiences, some good and some worryingly poor.

There were many comments made on the theme of improving access. There is an obvious frustration that in this day and age, appointments are not routinely available to book online and having to ring a GP practice was often cited as a specific barrier.

Timing of appointments was also key, with respondents requesting routine availability outside of the traditional working hours of Monday to Friday, 9am to 5pm. They also wanted a greater choice of venue.

The following were the most frequent suggestions to improve access and therefore uptake:

- Ability to book online. Trying to ring a GP was often cited as an impossible task – and when they did get through, appointments were often not available. This process was often described as inducing anxiety and therefore led to putting off booking
- Evening and weekend appointments to avoid the need to take time off work and to help accommodate caring or childcare responsibilities
- Drop-in clinics to avoid the need to book ahead and offer flexibility of choice – it was pointed out that irregular periods meant booking an appointment weeks in advance was a lottery and often meant they had to cancel at the last minute
- Wider choice of venues including at their sexual health clinic which they were familiar with using
- Hospital staff able to access cervical screening at their workplace
- Offer workplace appointments so people can attend during the day
- Appointments in venues where childcare is available
- Appointments where it is possible to book with a friend so they can go together for moral support, or appointments where partners were able to be in the room, again for moral support
- Specialist clinics for those who have experienced trauma or sexual violence
- Reminders of appointments to be sent
- Ability to choose the clinician doing the procedure – to avoid someone you know or to book appointments with someone from the same cultural background.

Respondents feedback

"For me, childcare has always been a big issue. I work part time, so my health appointments are always allocated to my days off. Once my child was a toddler I was no longer able to bring her to for example my cervical screen and had no one to look after her so relied on just putting the appointment off until I had a day off or my husband was around. I typically attended my local sexual health service, however I was unable to book my screening appointments so had to attend the open clinics which involved long waiting times."

"It has been difficult in the past for me to get an appointment, as I have a condition that makes my periods irregular, I'm often not able to know far in advance any period where I am or am not likely to be on my period, and often there aren't any available appointments for weeks, so more flexibility in appointments would be beneficial."

"Booking online would make it easier as impossible to get through to surgery by phone and no appointments available when you do."

"For me attempting to book via my doctors clinic was problematic, appts in the day making it difficult to get time off work, or surgery not booking more than a few weeks ahead, so i could not book in advance and give employer enough notice. Walk through clinics were an alternative pre-covid, but now they are no longer a walk-in clinic you have to book an appt. Online booking is always a good idea now for busy people."

"Flexibility of times and locations is the biggest thing that would help."

"I work at a local Hospital and think that if a screening service was available for staff it would be used by many. It would save trying to get an appointment at your GP practice and would be more convenient and accessible for working women."

"I think inconvenience is the BIGGEST thing. SO many of my friends say "I've got my letter, I just haven't got round to it." It can take HUGE amounts of time to get through to someone at the doctors to book an appointment, to then be told that there's only availability during working hours. I, for example, am a teacher. am carrying the HPV virus so have to go for 12 monthly screening checks. When I phoned last year, I was told that there were simply no appointments available around my working day. Not in the near or distant future. When I really pressed the matter and the importance of me having it, I was offered a weekend appointment. As people feel uncomfortable about screening checks anyway, it CANNOT be made into an inconvenience for them. People only need one excuse to go "I'm not bothering then"."

"Woman used to be able to get smears at sexual health clinics, this was a much better service, more convenient hours, staff had more expertise and it addressed womans health needs in a holistic way."

Prior to booking the screening appointment, many wanted the opportunity to talk through the procedure with a health professional.

> Allow people to talk through their individual needs with someone before booking an appointment e.g can it be done with sedation, how is it done for people with mobility issues who can't position themselves as needed, seeing the room and meeting the screener in advance for autistic people.

> Have a nurse phone a person beforehand and form a relationship with them as Specialist Screening Practitioners do with the Bowel Screening Programme.

> Chance to discuss concerns before appointment.

> I have been involved in a project booking women in for screening & have found giving someone time to talk about their worries or booking them in to chat with a health professional has been helpful.

Another common theme revolved around the issue of pain. There were some very strong views on this subject, some being contradictory. Those who found the test not to be painful felt this should be emphasised as a 'selling point' but those who experienced pain felt very strongly that this must be acknowledged and communications material claiming otherwise was interpreted as insulting. The impact of menopause making the procedure more painful was also frequently mentioned.

For those that did experience pain during the screening process, a number requested that pain relief should be available. They also wanted better training of staff to both ensure their worries and concerns were acknowledged but also how the test may be carried out in a way to minimise pain.

> Explain that it's less painful than an IUD, you can take a loved one with you if you're nervous or uncomfortable. You can have them in the room if you would prefer.

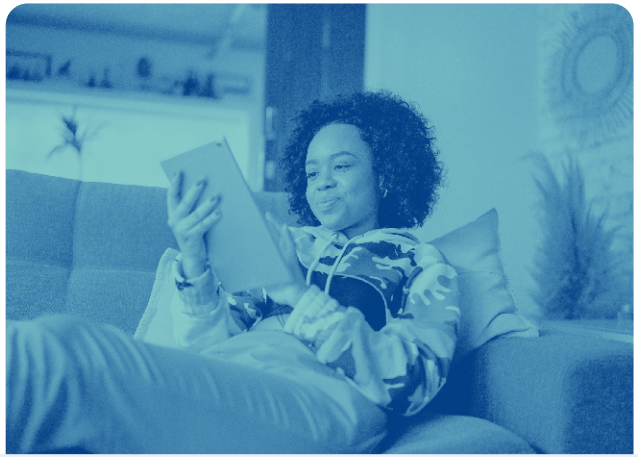
> Specific information for menopausal/post menopausal people, especially those affected by vaginal atrophy. It can be very painful to have a smear test and lead to bleeding afterwards as i know from experience. Also, using a trauma-informed approach – you have a domestic violence tickbox in an earlier question but nothing for survivors of sexual assault/ rape.

> At no point in this questionnaire have you given us the option to state that the reason some people don't have a smear test is because it is painful. The communication and PR around smear tests is that is not painful. This is a lie. I personally haven't had my |smear test in over 4 years because it is excruciatingly painful, and my local health professionals have given me no support in this. I was told to tilt my hips differently. Made no difference yet I was not then offered any other help. Sedation should be offered for those who find the procedure painful. And please please please stop promoting that it is not painful when it bloody well is.

Train medical staff better! Previous screenings have been very painful and staff have not been at all patient or compassionate.

Stop gaslighting people who have extreme pain associated with the procedure by telling them during the screening that 'it's not supposed to hurt'.

I have endometriosis and found my smear very painful, not just at the time but causing a deep ache for days afterwards. Don't dismiss the fact that smears can be more than "a little uncomfortable" but make the benefits clear so people still understand that it's worth doing.



There were other comments too about the language used or behaviour of staff during a procedure and individuals wanting more control over the procedure as a way to feel more in control.

Staff training to help feel comfortable
Longer appointment slots so not as rushed
Measures to reduce discomfort – positioning, speculum size.

Train staff better to know what things are appropriate to say and which not. Personally I've had an unpleasant experience at XXXXXX centre when a lady performed procedure and caused pain and therefore bleeding, then commented that I started bleeding profusely and that I should get checked out cause something seems wrong. Long story short, nothing was wrong and the profuse bleeding was a drop or two after going to the toilet post procedure.

Change it from something that is happening to you to something you actively participate in. Make it normal for women to be able to select size of speculum and insert it themselves if they want to. A lot of nurses will allow you if you ask but it makes you feel like a nuisance having to ask. More information on what happens if you need further tests is essential. I was referred for colposcopy (not due to a screening result). I was given no information at all from my GP or the hospital. The information on the internet especially tiktok is terrifying, in particular in relation to cervical biopsies and LEEP. People may be put off attending screening so they they are not referred for colposcopy.

Promotion of screening, better education and awareness by the public and normalising talking about cervical screening was another theme that emerged, with many suggesting that boys and girls should be taught about the screening process in schools and why it was important.

Many felt greater use of social media including TikTok was needed to break down barriers and promote both the importance screening but also increase understanding of what happened during appointments. Jade Goody was mentioned a number of times and the effectiveness of her story in promoting screening.

Some felt that the change in the test from looking for abnormal cells to one testing for HPV meant people trusted the test less and/or having the HPV vaccine meant they didn't need to attend for screening.

> Train hair and nail people in the little salons to open and have the discussion in a friendly/knowledgeable way.

> Get comments from real women who have been for the screening and promote it on the letter when sending the appt letter out. Stress how quick the appointment is.

> Perhaps educating females from high school age, going into schools to show what happens at a smear test and telling them the benefits.

> Should be part of health sessions at school for girls and boys to understand how important it is.

> Use more simple language, Possibly have Health professionals linking in with schools – many mums are there twice a day during the term – this could be a good opportunity to spread the word, also engage with younger people.

> Address needs of some BAME populations where the husband will not allow his wife to attend due to his lack of knowledge and understanding of importance of screening.

> I was told that HPV was a sexually transmitted disease. This is not true and a lot of younger women have the same perception.

> I think people may also not trust the screening now as the test has changed and only tests for HPV and no further testing is undertaken if HPV is not found.

> Promote at events. I recently went to the royal show and they had a stall form prostrate cancer, lot of men stood talking to them.

"I work with adults who have a learning disability often cared for by older parents or carers. It has ben said to me that due to the fact that the person with the disability does not have sex then they do not need a smear test. Targeted information around this would be useful in partnership with disability services, day services and Shared Lives (PSS for example)."

"This area has a large South Asian majority, where the women may not be too familiar with the concept or benefit of cervical screening. And generations of women in their circle have most likely never undergone cervical screening therefore they see no benefit to it. I think awareness and clear knowledge on cervical screenings needs to be given. Also, many females who have never been sexually active or only ever had 1 sexual partner may feel it doesn't apply to them. Again, it should be made clear whether it does or does not. For instance, I have never been sexually active and some nurses have told me I don't need to get it done until I become sexually active and others have said I should, which left me quite unclear on my decision."

Reference to gender and the language used in the promotion of the screening programme was raised by a number of respondents. As a national screening programme, NHSE NW follows the national guidance on the use of language which ensures consistency across the country. Currently the agreed wording to use in the promotion of the programme is 'women and people with a cervix'.

The new Cervical Screening Management System, due to be introduced during 2024/25, will include GP Opt-in for Trans/ non binary people who are not currently automatically invited for screening.

Respondents also mentioned that a new test was needed. The subject of self-sampling, which was given as one of the suggested options for improving uptake, generated considerable interest. There was broad support for this option, although some mistakenly assumed that it was the same technique used at the GP practices and therefore had concerns about how well they could perform this at home. Given that self-sampling is a much simpler technique and potentially feeling less invasive, this may be one solution for those who find the traditional test painful or who are hesitant to attend due to triggering abuse experiences.

> Acknowledge that trauma from sexual assault is a barrier to screening and ensure there is trauma informed care in place, including allowing people to self-test. The current procedure is incredibly disempowering and invasive.

> A self sample would be good as long as it was sure that people did it properly.

> Develop a way of them doing them at home and sending off for testing instead of someone doing it to them. Bit like the pregnancy tests they do now.

> I think the self sample test is a fantastic idea and I think this would increase the uptake.

> home testing is a great idea for procedures that are intimate and embarrassed.

> The fact that i saw the last choice (self sampling) made me breathe a sigh of relief. If this became a possibility, or even to carry out the procedure yourself within the medical practice i would do it no problem at all. Its just SO invasive and actually a really traumatic experience.

NOTE: More quotes are included in **Appendix 5**.

4.5 The importance of cervical screening in the prevention of cervical cancer

The programme aims to reduce the number of women, developing and dying from cervical cancer. It is estimated that the NHS Cervical Screening Programme saves around 5,000 lives a year.

Unfortunately, in this area, the number of women booking their cervical screening appointment is decreasing and cervical cancer is increasing.

Despite the potentially life-saving benefits of cervical screening, fewer than seven in 10 people in the North West attended their appointments in the year to December 2022.

This section presents the feedback from the following questions:

- How did you feel when you read this information?
- Please tell us the reason for your answer and any other comments you may have.

A large proportion of respondents (62%/1,703 responses) said this information concerned them and they didn't know that fewer individuals were attending and more were getting cervical cancer. Many went on to express surprise at the numbers not attending and reiterated previous assertions as to why this might be.

A further 19% said they were surprised and felt informed as they did not know about the benefits of the screening programme.

The remaining respondents were either not concerned about the statement or stated they already knew this information.

4.6 How cervical screening can prevent cervical cancer

Cervical screening doesn't test for cancer, but it can prevent cancer by spotting abnormal cells early, so they don't have chance to turn into cervical cancer.

- During the screening appointment, a small sample of cells will be taken from your cervix
- The sample is checked for certain types of human papillomavirus (HPV) that can cause changes to the cells of your cervix. These are called 'high risk' types of HPV
- If these types of HPV are not found, you do not need any further tests
- If these types of HPV are found, the sample is then checked for any changes in the cells of your cervix. These can then be treated before they get a chance to turn into cervical cancer.

This section presents the feedback from the following questions:

- How did you feel when reading this information?
- Please tell us the reason(s) for your answer.

Half of the respondents (1,379/50%) felt knowledgeable as they already knew the purpose of cervical screening was to prevent 'high risk' cells becoming cancer, and 888 (32%) felt reassured as they always attended their cervical screening appointments.

4.7 Women and people with a cervix not attending cervical screening

Your local NHS is concerned as in the North West, we have high numbers of women not attending for cervical screening. In total more than 1 million women in the North West have not attended their cervical screening appointment up to December 2022. If things don't change, more women in the North West may go on to develop cervical cancer.

Statistics tell us that:

- In both Liverpool and Cheshire areas more than 50,000 women haven't attended their cervical screening appointments
- West Lancashire has the highest number of women who attend their cervical screening appointments, but even in that area more than 7,000 women did not attend their screening appointments
- Women living in Southport and Formby also attend more frequently than most other areas, but still more than 8,500 women did not attend
- We also know that people are less likely to have ever attended a cervical screening appointment if they are from a Black, Asian and Minority Ethnic background (according to a study by Jo's Trust, the UK's leading cervical cancer charity)
- The same study also found there was lower awareness among Asian women that screening is a test to check cells from the cervix to find pre-cancerous abnormalities – 70% of Asian women aged 20-65 knew this, compared with 91% of white women of the same age.

This section presents the feedback from the following questions:

- How did reading this information make you feel?
- Please tell us the reason for your answer(s)
- After reading the information in section B, have your views about cervical screening changed?
- Please tell us the reason for your answer.

Just over half of respondents (52%) stated they were aware that a lot of individuals did not attend cervical screening. 39% were not concerned as they always attended their appointments. 6% were concerned as they never attend their cervical appointments.

Regarding whether this information had changed their minds, 2,128 (78%) respondents confirmed that they would attend their cervical screening appointments in the future.

A further 299 (11%) stated they are now more likely to attend a future cervical screening appointment.

268 (9%) were unpersuaded and stated they would still not attend a future screening appointment.

Of those that stated they had not previously attended a cervical screening (172 people), 107 of them (62%) said they would definitely attend or were more likely to attend after reading these statements. 51 (30%) said they would still not attend a future screening appointment. Individuals who identify their sexual orientation other than heterosexual emphasised the need for information and engagement to help them overcome the barriers and stereotypes they experienced.

Respondents who are limited in their day-to-day activities would still not attend a future cervical screening appointment due to the lack of access and appointments.

5 Conclusions

This report offers an insight into almost 3,000 people's views of cervical screening and the barriers that exist. It is clear from the responses that the reasons individuals across the North West do not come forward for cervical screening are complex and varied.

The views obtained from this survey will be used alongside those obtained from other local engagement work carried out recently across the region, presented in Section 2.2 The North West picture.

Importantly the findings of this survey also provide important insight into what our North West population want and need in order attend for screening in the future. They present us with a very real opportunity to improve the health and wellbeing of females across the North West, and in turn contribute to the achievement of the ambition of eliminating cervical cancer by 2040.

As we look to implement change, it is important to acknowledge the context in which recommendations from this insight work should be considered.

Cervical Screening – the wider context

The cervical screening pathway is complex and incorporates a number of services. It involves five key stages provided by different providers and each has separate commissioning arrangements.

Service	Provider	Commissioner
Call/Recall Service (sending out of invitations/reminders and results and Prior Notification Lists to GP practices)	Cervical Screening Administration Service	NHS England holds a national contract
Sample taking	Primary care including Extended Access Services, community sexual health services in 13 local authority areas, colposcopy services (difficult smear clinics) and gynaecology services	ICBs are the commissioners of primary care, colposcopy gynaecology services. Local authorities are commissioners of community sexual health providers. With the support of local authorities, NHSE NW has agreed local contracting arrangements with providers of sexual health to deliver a level of cervical screening activity
Sample screening	North West HPV laboratory – Manchester University Hospitals NHS Foundation Trust	NHS England North West, Greater Manchester Care Partnership and NHS England – North East and Yorkshire
Colposcopy	11 NHS trusts across C&M and L&SC	ICBs NHSE NW are responsible for the screening element of colposcopy but funding sits with ICBs
Histopathology	9 NHS Trusts across C&M and L&SC (including 1 in Midlands)	ICBs as commissioners of pathology

In order to achieve the maximum impact, it is recommended that a joined up and collaborative approach to improving access and uptake in the North West is adopted by partners working across the pathway. A pilot approach to testing possible interventions to improve access and uptake should be adopted prior to any widespread rollout. Appropriate consultation, communication and involvement of providers delivering services along the cervical screening pathway is fundamental to ensure that capacity is available to meet the potential increase in demand for services.

Cervical screening is a national screening programme and must be delivered in line with the national service specification and to established national service standards. The NHSE Screening Quality Assurance Service should be included in any improvement work/ development of interventions to ensure all relevant requirements of the programme continue to be met.

In line with recommendations included in the Professor Sir Mike Richards review in 2018,[11] work is being undertaken at a national level to improve and modernise cervical screening.

This work includes:

- The decommissioning of the National Health Application and Infrastructure Services (NHAIS) Open Exeter system. This will be replaced with a new Cervical Screening Management System – due to be introduced during 2024/25. The new IT system will include GP Opt in – for Trans/ non binary people who are not currently automatically invited for screening
- A self-sampling pilot has been undertaken and work continues to evaluate this work to inform a wider rollout
- Potential changes to screening intervals
- Revised invitation/reminder letters now have QR code to signpost individuals to GOV.UK website information on screening.

NOTE: The content of invitation letters and reminders is set nationally and cannot be modified. Easy Read and letters in different languages are available

- Examining how NHS Notify can be used to improve communication and correspondence with individuals in terms of invitations and reminders
- An evaluation of work undertaken in London and the East of England has been commissioned to better understand how to maximise the use of text messaging
- A review of colposcopy services – including workforce.

NHSE NW Public Health Commissioning team can provide further updates on national workstreams as these develop, but it is recommended that pilots implemented in the North West do not duplicate any work underway at a national level.

[11] Report of The Independent Review of Adult Screening Programmes in England

6 Recommendations

Based on the findings of this insight work, NHSE NW and partners should look to take forward the following recommendations:

Establish a NW-wide cervical screening steering group led by NHSE NW

Given the breadth and complexity of the cervical screening pathway, a group including representatives from across the pathway and system should come together to consider the report and agree a whole system approach to improving access and uptake of cervical screening. This group should develop and retain oversight of the implementation and evaluation of the programme of work (including pilot projects) that will be implemented across different settings.

Improve information/ understanding of the HPV vaccination and cervical screening

Work is required to ensure that there is a clearer understanding across the population of the HPV vaccine and why it is important for both girls and boys to have it.

There is a need to communicate the importance of cervical screening to detect for HPV and how it can help people stay healthy from a young age (starting at school). This message to all eligible age cohorts, so that cervical screening becomes a normal part of looking after one's health.

Improve information about the procedure

Individuals want to have more information about the procedure – what will happen at the appointment.

Dispel misconceptions

There is a need to address misconceptions/ myths about who needs to come forward for cervical screening. This includes individuals:

- who have had HPV vaccination
- who are not sexually active
- who are lesbian
- who are trans men/non-binary
- who have a learning or physical disability
- are older and who have had several clear screens.

Address embarrassment and anxiety

There needs to be greater acknowledgement of the embarrassment and anxiety individuals feel towards cervical screening – particularly for younger cohorts. Better communication is needed about the procedure and offering individuals (across the two age cohorts) the opportunity to talk with a health professional about their concerns prior to their appointment could help alleviate concerns.

This would offer the chance to reassure individuals that it would be a female clinician doing the test (where this is true) and a friend/chaperone/partner could accompany the individual for support.

Send reminders

Busy lives mean that although individuals receive an invitation, they frequently forget to act upon it – so reminders (through various media) are helpful.

Acknowledge pain

Greater consideration needs to be given to the real issue of pain, experienced by many individuals during the procedure in communications (both written and verbal) at the appointment. Amongst the older age cohort, the impact of menopause (including vaginal atrophy) which can make the procedure more painful – should be recognised and solutions discussed.

Failure to acknowledge, minimise or 'brush off' the idea that it's painful claiming otherwise – particularly if this is by the health professional carrying out the screen – may be interpreted as insulting, lead others to listen more closely to hearsay and deter individuals from having their screen.

Healthcare staff carrying out the test are key to supporting individuals, discussing concerns about pain with those who find the procedure painful and suggesting how the test may be carried out in a way to minimise pain.

Improve access

Improving access to screening is fundamental – this could include:

- Offering appointments out of hours – evenings and weekends, walk-in clinics
- Increased choice of venues – where childcare options exist, where a large number of eligible individuals work (e.g. hospitals), where it is easier to book (e.g. sexual health)
- Sexual health services/genitourinary medicine (GUM) clinics – so individuals can have their screen at the same time they are attending the service, health bus
- Online booking system for appointments – there is an obvious frustration that in this day and age, appointments are not routinely available to book online and having to ring a GP practice often cited as a specific barrier.

NOTE: Although cervical screening is available in sexual health clinics, many individuals are not aware of this.

Offer specialist support/clinics for individuals who have experienced trauma/sexual assault

Individuals who have experienced trauma and sexual assault are particularly vulnerable to non-participation and would benefit from a specialised service delivered by clinicians with experience of supporting these individuals. Additional training for sample takers could help more healthcare staff in all settings to support individuals who have experienced trauma or sexual assault to come forward and have a positive experience of screening.

Provide additional training and support for sample takers

Many individuals commented about the language used or how they felt they were treated during a procedure. To raise awareness of the themes identified through this insight work, training in the form of a workshop or webinar for sample takers could support them in their work (e.g. how to support individuals who find cervical screening painful, supporting individuals who have experienced trauma to have their cervical screen).

Address specific barriers relating to gender, culture and disability

Greater awareness is required of the specific barriers some people may face. Targeted communication and reasonable adjustments (where appropriate) need to be considered to ensure that individuals who may be particularly vulnerable to non-participation are encouraged to come forward for screening.

The insight work has highlighted how by using non inclusive language (e.g. only referring to 'women' in communications can have a significantly detrimental effect on other people with a cervix).

An appreciation is needed of possible cultural sensitivities and differing levels of awareness of cervical screening within certain population groups (e.g. the South Asian community) and an acknowledgement of the barriers faced by individuals who have a disability – learning or physical.

NHSE NW will work with partners to roll out learning from pilots implemented during 2023 to improve access and uptake of cervical screening by individuals who have a learning disability.

Self-sampling

While many respondents suggested self-sampling would support more individuals to take up screening (as outlined in Section 4), work is underway nationally on self-sampling and several areas in the North West have acted as pilot sites (both in primary care and colposcopy units). It is recommended that NHSE NW remain abreast of developments in this area and identify any further opportunities for the North West to participate in this work.

Ongoing feedback

Any pilot work undertaken to improve access and uptake should include a process for people to feedback on the changes made. This will ensure that these improvements meet the needs of the population prior to any wider rollout.

NOTE: As mentioned in Section 4, the new IT system will include GP Opt in – for Trans men/non-binary people who are not currently automatically invited for screening. Work is also underway with groups representing Trans men/non-binary people to understanding the appropriate and inclusive wording to be used in material and communications on cervical screening. Jo's Trust have also advice and information available on their website.[12]

[12] Cervical screening for trans men and/or non-binary people | Jo's Cervical Cancer Trust (jostrust.org.uk)

Appendix 1: Partners who supported us with this work

Dr Yasara Naheed, GP Partner, Clinical Director Burnley East Primary Care Network

C&M and L&SC local authorities – particularly Blackburn with Darwen, Liverpool and Knowsley

Blackpool South and Central PCN

Lancaster PCN and Bay PCN

Pendle West PCN and Hyndburn Central PCN

One Knowsley and their social prescribers

Living Well Sefton and their social prescribers and Community Connectors

Liverpool University Hospitals NHS Foundation Trust – Sexual Health Service

Cheshire and Merseyside Women's Health and Maternity (WHaM) Programme team

Appendix 2: C&M and L&SC data for cervical screening

Cheshire and Merseyside ICB

Cervical Screening Coverage: aged 25 to 49 years old												
	2019/20			2020/21			2021/22			2022/23		
Sub ICB	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage
01F – Halton	21,829	16,121	73.9%	21,747	15,652	72.0%	21,787	15,528	71.3%	21,769	15,057	69.2%
01J – Knowsley	27,853	20,785	74.6%	28,078	20,132	71.7%	28,633	20,712	72.3%	28,990	20,449	70.5%
01T – South Sefton	24,548	17,919	73.0%	24,656	17,356	70.4%	24,812	17,296	69.7%	25,036	16,792	67.1%
01V – Southport and Formby	16,773	12,634	75.3%	16,694	12,160	72.8%	17,391	12,574	72.3%	17,451	12,266	70.3%
01X – St Helens	29,629	22,394	75.6%	30,992	22,467	72.5%	31,382	22,472	71.6%	31,476	21,876	69.5%
02E – Warrington	35,986	27,452	76.3%	35,761	26,511	74.1%	36,317	26,575	73.2%	36,816	26,447	71.8%
12F – Wirral	50,547	37,933	75.0%	51,682	37,790	73.1%	51,813	37,551	72.5%	52,262	36,863	70.5%
27D – Cheshire	116,685	88,786	76.1%	119,639	89,536	74.8%	121,267	90,553	74.7%	123,410	90,173	73.1%
99A – Liverpool	93,275	62,312	66.8%	94,894	61,052	64.3%	97,586	61,351	62.9%	100,849	61,417	60.9%
Cheshire and Merseyside ICB	417,125	306,336	73.4%	424,143	302,656	71.4%	430,988	304,612	70.7%	438,059	301,340	68.8%
England	10,351,734	7,256,331	70.1%	10,453,561	7,093,073	67.9%	10,405,524	7,142,114	68.6%	10,586,146	7,097,011	67.0%

Source: PHE Fingertips Cancer Services – OHID (phe.org.uk)

Cheshire and Merseyside ICB

Cervical Screening Coverage: aged 50 to 64 years old												
	2019/20			2020/21			2021/22			2022/23		
Sub ICB	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage
01F – Halton	11,992	8,834	73.7%	12,217	8,842	72.4%	12,367	8,922	72.1%	12,440	8,875	71.3%
01J – Knowsley	15,517	11,378	73.3%	15,748	11,323	71.9%	15,872	11,340	71.4%	15,718	11,187	71.2%
01T – South Sefton	15,161	10,792	71.2%	15,211	10,548	69.3%	15,428	10,670	69.2%	15,468	10,681	69.1%
01V – Southport and Formby	12,080	9,202	76.2%	12,278	9,122	74.3%	12,917	9,631	74.6%	12,863	9,487	73.8%
01X – St Helens	17,002	12,916	76.0%	18,111	13,451	74.3%	18,789	13,900	74.0%	18,916	13,777	72.8%
02E – Warrington	20,258	15,709	77.5%	20,694	15,873	76.7%	21,193	16,150	76.2%	21,555	16,389	76.0%
12F – Wirral	31,281	23,096	73.8%	32,492	23,712	73.0%	32,885	24,099	73.3%	33,193	24,386	73.5%
27D – Cheshire	71,552	55,691	77.8%	75,033	57,562	76.7%	76,783	58,995	76.8%	77,872	59,881	76.9%
99A – Liverpool	43,846	30,684	70.0%	44,517	30,384	68.3%	44,965	30,468	67.8%	45,008	30,481	67.7%
Cheshire and Merseyside ICB	238,689	178,302	74.7%	246,301	180,817	73.4%	251,199	184,175	73.3%	253,033	185,144	73.2%
England	5,083,078	3,867,196	76.1%	5,233,098	3,904,400	74.6%	5,314,074	3,986,392	75.0%	5,389,582	4,037,949	74.9%

Source: PHE Fingertips Cancer Services – OHID (phe.org.uk)

Lancashire and South Cumbria ICB

Cervical Screening Coverage: aged 25 to 49 years old												
	2019/20			2020/21			2021/22			2022/23		
Sub ICB	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage
00Q – Blackburn with Darwen	28,556	19,771	69.2%	28,668	18,687	65.2%	29,821	18,940	63.5%	30,199	18,428	61.0%
00R – Blackpool	25,629	18,365	71.7%	25,732	17,932	69.7%	26,750	18,105	67.7%	27,070	17,409	64.3%
00X – Chorley and South Ribble	28,547	22,302	78.1%	29,502	22,598	76.6%	29,508	22,415	76.0%	29,850	22,221	74.4%
01A – East Lancashire	60,738	44,881	73.9%	61,712	43,526	70.5%	62,235	43,056	69.2%	62,961	42,278	67.1%
01E – Greater Preston	34,311	24,094	70.2%	35,113	23,986	68.3%	35,956	24,014	66.8%	37,198	24,473	65.8%
01K – Morecambe Bay	48,449	35,550	73.4%	49,599	35,071	70.7%	50,063	34,718	69.3%	50,272	33,807	67.2%
02G – West Lancashire	16,209	12,358	76.2%	16,122	12,237	75.9%	16,326	12,238	75.0%	16,642	12,175	73.2%
02M – Fylde and Wyre	23,628	18,632	78.9%	23,509	18,359	78.1%	23,586	18,203	77.2%	23,753	17,550	73.9%
Lancashire and South Cumbria	266,067	195,953	73.6%	269,957	192,396	71.3%	274,245	191,689	69.9%	277,945	188,341	67.8%
England	10,351,734	7,256,331	70.1%	10,453,561	7,093,073	67.9%	10,405,524	7,142,114	68.6%	10,586,146	7,097,011	67.0%

Source: PHE Fingertips Cancer Services – OHID (phe.org.uk)

Lancashire and South Cumbria ICB

Cervical Screening Coverage: aged 50 to 64 years old												
	2019/20			2020/21			2021/22			2022/23		
Sub ICB	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage	Number Eligible	Number Screened	% Coverage
00Q – Blackburn with Darwen	13,260	10,142	76.5%	13,540	10,094	74.5%	14,286	10,525	73.7%	14,544	10,466	72.0%
00R – Blackpool	15,603	11,252	72.1%	15,809	11,209	70.9%	16,506	11,623	70.4%	16,610	11,594	69.8%
00X – Chorley and South Ribble	16,442	12,770	77.7%	17,544	13,388	76.3%	17,926	13,729	76.6%	18,191	13,893	76.4%
01A – East Lancashire	32,610	25,034	76.8%	33,745	25,393	75.2%	34,383	25,716	74.8%	34,777	25,792	74.2%
01E – Greater Preston	17,445	13,503	77.4%	17,995	13,757	76.4%	18,527	14,030	75.7%	18,898	14,254	75.4%
01K – Morecambe Bay	30,748	23,667	77.0%	32,527	24,565	75.5%	32,999	24,922	75.5%	33,185	24,917	75.1%
02G – West Lancashire	10,506	8,211	78.2%	10,787	8,287	76.8%	11,062	8,481	76.7%	11,296	8,627	76.4%
02M – Fylde and Wyre	18,125	14,235	78.5%	18,549	14,409	77.7%	18,939	14,658	77.4%	19,123	14,775	77.3%
Lancashire and South Cumbria	154,739	118,814	76.8%	160,496	121,102	75.5%	164,628	123,684	75.1%	166,624	124,318	74.6%
England	5,083,078	3,867,196	76.1%	5,233,098	3,904,400	74.6%	5,314,074	3,986,392	75.0%	5,389,582	4,037,949	74.9%

Source: PHE Fingertips Cancer Services – OHID (phe.org.uk)

Appendix 3: Social media advertisement and emails sent to partners to share questionnaires

Title: Social media – share your views on cervical screening across Cheshire, Merseyside, Lancashire and South Cumbria

Twitter/Facebook

Image	Supporting copy
	Share your views on Cervical Screening across Cheshire, Merseyside, Lancashire and South Cumbria. www.nhs.welcomesyourfeedback.net/rn9qyx
	We want to understand why the uptake of Cervical Screening appointments is declining and see what we can do to encourage more people to be screened, share your views. www.nhs.welcomesyourfeedback.net/rn9qyx
	Cervical screening across Cheshire, Merseyside, Lancashire and South Cumbria, share your views. www.nhs.welcomesyourfeedback.net/rn9qyx
	NHS Cervical Screening saves around 5,000 lives a year. Cervical screening is decreasing and cervical cancer is increasing. Help us to understand your views. www.nhs.welcomesyourfeedback.net/rn9qyx

LinkedIn

Image	Supporting copy
	Share your views on Cervical Screening across Cheshire, Merseyside, Lancashire and South Cumbria. We are asking women and people with a cervix aged between 25-64 to share their views by taking a short online survey **www.nhs.welcomesyourfeedback.net/rn9qyx**
	NHS Cervical Screening saves around 5,000 lives a year. We want to understand why the uptake of Cervical Screening appointments is declining and see what we can do to encourage more people to be screened. Help us to understand your views. **www.nhs.welcomesyourfeedback.net/rn9qyx**

Title: Have your say on NHS cervical screening – letter

The NHS Cervical Screening Programme aims to reduce the incidence of and mortality from cervical cancer by delivering a systematic, quality assured population-based screening programme for the eligible population. It is estimated that cervical screening – also known as a 'smear test' – saves around 5,000 lives a year.

Cervical screening looks for high-risk types of the **human papillomavirus (HPV)** which can cause abnormal cells on the cervix and is offered to women and people with a cervix aged 25-64 years old.

However, despite being a well-established screening programme, cervical screening coverage is decreasing, fewer than 7 in 10 individuals in the North West attended their appointments in the year to December 2022.

At a regional level, there is considerable variation in uptake across Cheshire and Merseyside and Lancashire and South Cumbria with some areas falling far below both the England and North West averages, accounting for 6 of the 10 poorest performing areas for 25-49 year olds, and 7 of the 10 poorest performing areas for the 50-64 year olds.

The NHSE North West Public Health team, supported by with the Midlands and Lancashire CSU, want to understand what needs to be done to encourage people to attend cervical screening and has produced a questionnaire to capture people's views. An easy read version of the questionnaire is also available.

If you would like to have your say, please go to **www.nhs.welcomesyourfeedback.net/rn9qyx** by Sunday 20th August 2023 – or via the QR codes – to complete the questionnaire. This will take about 15 minutes to complete.

Title: Have your say on NHS cervical screening – email

Good morning/afternoon,

Please could you take a few minutes to help us understand why the number of women attending their cervical screening appointment is decreasing and cervical cancer is increasing in this area.

We want to understand what needs to be done so more women attend cervical screening. We need your help to get this right!

Why do you think more people are not attending? Do you have any ideas on what would make it easier to attend?

Please complete a short questionnaire by visiting xxxxxxxxxxxxxxxx. It will take about 15mins to complete the questionnaire (the questionnaire closes on Sunday 20 August 2023)

Thank you for your time.

Please feel free to share the above information with friends and family members across the North West (as many of the people you know as possible).

If you require this information in another language or another format or would like support completing this survey, please email us on **mlcsu.involvement@nhs.net**.

Title: Email sent to stakeholders asking for support once live

Good afternoon/morning,

The cervical screening engagement project in now live. Please visit (insert link) to find the online questionnaire (there is also an easy read version available at the same link).

Thank you for all the information and ideas shared at our meetings and via email communications. This has been really helpful for the initial planning phase of the engagement project and development of the questionnaire.

Now that the six-week period of patient and public engagement has launched (Monday 10 July to Sunday 20 August 2023), we would really appreciate if you please could you help in any or all of the following ways:

- Cascade information on the project and link to the questionnaire to your contacts.
- Let us know of any existing opportunities to engage in your local community.
- Share information about the cervical screening engagement programme and link to the questionnaire on your website.
- Share information about the cervical screening engagement programme via social media such as your Facebook/Instagram page or whatsapp groups.
- Include your PPAGS in cascading information and getting people to complete the questionnaire.
- Include cancer champions/community champions/social prescribers in getting feedback or helping us to reach people.
- Can any of your staff identify contacts or opportunities to reach people e.g. breast feeding groups, well woman clinics, weight management groups? Do they have contact with communities we don't often hear from such as Gypsy/ Travellers; those with severe mental health illness, those living in areas of high social deprivation/ ethnic minority groups. Any other communities you know have a low attendance rate for cervical screening. Please let us know.

To assist you in reaching as many people as possible. Please see attached a description of the engagement project; email content; copy for newsletter/website, social media content.

Please do let us know of any activity you undertake to help us reach as many people as possible.

We can then include this in a section on how Primary Care and other systems partners were involved in our final report.

For example, how you have promoted the questionnaire, how you have helped to identify opportunities for face to face engagement and anything else you have done to promote the project.

If you have any further ideas on how we may reach people, please do not hesitate to contact us.

Thank you for your invaluable support – it is very much appreciated.

Appendix 4: Demographic breakdown of respondents

Ethnicity	No.	%
White: British	2,635	90%
White: Irish	30	1%
White: Gypsy or traveller	3	0.1%
White: Other	81	3%
Mixed: White and Black Caribbean	6	0.2%
Mixed: White and Black African	4	0.1%
Mixed: White and Asian	15	1%
Mixed: Other	5	0.2%
Asian/Asian British: Indian	21	1%
Asian/Asian British: Pakistani	62	2%
Asian/Asian British: Bangladeshi	3	0.1%
Asian/Asian British: Chinese	3	0.1%
Asian/Asian British: Other	5	0.2%
Black/Black British: African	16	0.5%
Black/Black British: Caribbean	5	0.2%
Black/Black British: Other	2	0.1%
Other ethnic group: Arab	-	-
Any other ethnic group	3	0.1%
Prefer not to say	28	1%
Base	2,927	-

Age category	No.	%
16 – 19	-	-
20 – 24	22	1%
25 – 29	259	9%
30 – 34	344	12%
35 – 39	379	13%
40 – 44	369	13%
45 – 49	335	11%
50 – 54	435	15%
55 – 59	419	14%
60 – 64	300	10%
65 – 69	39	1%
70 – 74	15	1%
75 – 79	6	0.2%
80 and over	2	0.1%
Prefer not to say	18	1%
Base	2,942	-

Religion	No.	%
No religion	1,136	39%
Christian	1,562	54%
Buddhist	8	0.3%
Hindu	3	0.1%
Jewish	2	0.1%
Muslim	97	3%
Sikh	-	-
Any other religion	33	1%
Prefer not to say	78	3%
Base	2,919	-

Sex	No.	%
Male	7	0.2%
Female	2,877	98%
Trans-Men	3	0.1%
Trans-Women	-	-
Non-binary	16	1%
Gender-non-conforming	4	0.1%
Other	2	0.1%
Prefer not to say	19	1%
Base	2,928	-

Sexual orientation	No.	%
Heterosexual	2,630	91%
Lesbian	47	2%
Gay	6	0.2%
Bisexual	84	3%
Asexual	20	1%
Other	16	1%
Prefer not to say	88	3%
Base	2,891	-

Relationship status	No.	%
Married	1,589	54%
Civil partnership	50	2%
Single	420	14%
Divorced	155	5%
Lives with partner	533	18%
Separated	42	1%
Widowed	42	1%
Other	40	1%
Prefer not to say	53	2%
Base	2,924	-

Pregnant currently	No.	%
Yes	65	2%
No	2,835	97%
Prefer not to say	24	1%
Base	2,924	-

Recently given birth	No.	%
Yes	38	1%
No	2,857	98%
Prefer not to say	21	1%
Base	2,916	-

Health problem or disability	No.	%
Yes, limited a lot	192	7%
Yes, limited a little	366	13%
No	2,357	81%
Base	2,915	-

Disability	No.	%
No disability	2267	78%
Physical disability	177	6%
Sensory disability	58	2%
Mental health need	235	8%
Learning disability or difficulty	51	2%
Long-term illness	202	7%
Other	41	1%
Prefer not to say	78	3%
Base	2,912	-

Carer	No.	%
Yes – young person(s) aged under 24	290	10%
Yes – adult(s) aged 25 to 49	68	2%
Yes – person(s) aged over 50 years	284	10%
No	2,254	78%
Prefer not to say	48	2%
Base	2,909	-

Armed services	No.	%
Yes	35	1%
No	2,876	98%
Prefer not to say	18	1%
Base	2,929	-

Appendix 5: Quotes from respondents by theme

The following quotes are a selection of the thousands received, organised by theme.

Experience of Cervical Screening – Why haven't you attended to date?

"It's invasive and humiliating and more painful than it needs to be (according to people I know who go)."

"I changed my first appointment due to work and said I'd call back, but became anxious and couldn't go."

"Struggling to have the courage for one – feels too invasive."

"The dates for the clinics are once a month and line up with my period, not ideal."

"ring to book appointment, limited availability during week with work."

"I have had similar invasive tests before and it was extremely uncomfortable and painful. I recently booked a smear test and the doctor's' surgery cancelled it due to staff availability without offering me a new date, so my motivation is low to try again."

"Due to the availability of appointments. There needs to be more time slots available for people that work 9-5. When I have checked there were no morning or later in the day appointments. All appointments are carried out during the working week and people can't afford to be taking time off just for an appointment."

Is cervical screening an important part of looking after your health?

"I have always gone for my cervical smears when invited as I feel it is very important to attend for early detection of anything abnormal."

"It is an early detection for cervical cancer and also the HPV virus. It's good that younger generations now have access to an injection that protects against the HPV virus, which was not available to my generation."

"My best friend has just recovered from stage 1 cervical cancer caught early by her smear."

"I put off having a smear for a year after it was due, I had always had all clear and assumed there would be no problems but this time there were and I need to go for a colposcopy."

"I want to be proactive about my health."

"I want to give myself the best chance if I get cancer."

Its free and although unpleasant, a simple enough check that might just save you from developing the disease.

I didn't have a smear until 28 due to bleeding whilst pregnant. When my son was born it was found i had cancer on the cervix ive since had treatment and a full hysterectomy i was so foolish for not getting a smear at my first available opportunity.

I do think its important but personally find it a traumatic experience.

I'd do it but it's too painful.

Very important as the previous smear test i had to have treatment for HPV. The last one was all clear thank god.

It helps with not being able to see if anything is wrong inside.

I'd rather die that relive that experience, it was painful and humiliating.

How can we help more women and people with a cervix to attend for cervical screening?

Quotes by theme

Access:

For me, childcare has always been a big issue. I work part time, so my health appointments are always allocated to my days off. Once my child was a toddler I was no longer able to bring her to for example my cervical screen and had no one to look after her so relied on just putting the appointment off until I had a day off or my husband was around. I typically attended my local sexual health service (Southport), however I was unable to book my screening appointments so had to attend the open clinics which involved long waiting times.

I WORK at a hospital – why can't I do it there?

I work at Whiston Hospital and think that if a screening service was available for staff it would be used by many. It would save trying to get an appointment at your GP practice and would be more convenient and accessible for working women.

I WORK IN THE LIVERPOOL WOMENS AND IT WOULD BE GREAT IF THERE WAS A TEAM HERE THAT COULD DO THE TEST FOR STAFF MEMBERS.

Booking online would make it easier as impossible to get through to surgery by phone and no appointments available when you do.

Allow a choice of clinician. I live across the road from a practice nurse from my local health centre and it would be my biggest nightmare to have her do an intimate procedure.

Drop in sessions that don't require pre-made appointment.

make far easier and convienant and mass adtvertise allow work places to book so can be attebded during work – like the flu jab offer some employers provide.

Booking online will help. The anxiety and time needed of having to call (and wait for ages) to speak with the receptionist at a GP can be very much a barrier to even making an appointment. Plus you need to have a very regular and predictable menstrual cycle to be able to make an appointment at the time offered (which is often many weeks in advance) that fits with work/childcare and will not be when on period. (Plus factoring in the time for a shower/waxing (for those who do this) beforehand).

I struggle with phone calls and would prefer to book online. But my surgery only allows doctor appointments online, not nurse appointments. I want an appointment but forget and procrastinate booking because I have to make a phone call.

for me attempting to book via my doctors clinic was problematic, appts in the day making it difficult to get time off work, or surgery not booking more than a few weeks ahead, so i could not book in advance and give employer enough notice. Walk through clinics were an alternative pre-covid, but now they are no longer a walk-in clinic you have to book an appt. Online booking is always a good idea now for busy people.

Flexibility of times and locations is the biggest thing that would help.

Just have more locations available.

A walk in clinic would help for people who cant attend during normal hours.

childcare is a huge issue in the modern day. Myself and friends with children have aging parents who dont live nearby and lack childcare. So our own health appointments dont take precedent.

Don't become annoyed when there is no alternative but to bring child/ren to the appointment.

I think inconvenience is the BIGGEST thing. SO many of my friends say "I've got my letter, I just haven't got round to it." It can take HUGE amounts of time to get through to someone at the doctors to book an appointment, to then be told that there's only availability during working hours. I, for example, am a teacher. I am carrying the HPV virus so have to go for 12 monthly screening checks. When I phoned last year, I was told that there were simply no appointments available around my working day. Not in the near or distant future. When I really pressed the matter and the importance of me having it, I was offered a weekend appointment. As people feel uncomfortable about screening checks anyway, it CANNOT be made into an inconvenience for them. People only need one excuse to go "I'm not bothering then".

It would also be good to have my cervical screening history on the NHS app as I use this for other healthcare reasons. Screening could also be undertaken if women attend maternity clinics at the postnatal appointment. many women may have recurrent pregnancies which increases the gap of screenings.

Previously in my area you could attend a sexual health clinic which offered later appointments and staff who regularly did those examinations, this was great.

It has been difficult in the past for me to get an appointment, as I have a condition that makes my periods irregular, I'm often not able to know far in advance any period where I am or am not likely to be on my period, and often there aren't any available appointments for weeks, so more flexibility in appointments would be beneficial.

I do think mobile vans are a good idea. A Walk in clinic would be ideal in the evenings or weekends. Possible adult smears run at children centres where the child is safely at school or looked after by a person trained and crb checked while the mum is at the appointment.

If possible for cultures such as Asian women, have Asian women practitioners and Drs to undertake the procedure.

It was much easier in warrington when sexual health clinics and the old family planning clinics were open for these procedures.

Definitely feel on-line booking would help with lower age group uptake, younger people not going to hang on the phone endlessly trying to book an appointment, need appointments to be readily available and not weeks and months off.

someone in the room with you to put your mind at rest and make you feel more comfortable – hold your hand etc.

Offereing tests at GUM clinics when women are attending anyway.

Woman used to be able to get smears at sexual health clinics, this was a much better service, more convenient hours, staff had more expertise and it addressed womans health needs in a holistic way.

I found it difficult to get an appointment due to availability, lots of dates full. I needed to plan this around work and childcare, but also didn't want to attend my GP as I work closely with them and felt embarrassed.

I would appreciate an annual text message (or email or letter) to remind me when my next screening is due. I struggle to remember how long ago it was and get anxious about being forgotten and not invited again.

Keep sending reminders! Sometimes I ignore the first reminder but always make my appointment when the 2nd one comes.

Reminder letters each year to people over 25. Very busy lifestyles & having children means we do very easily forget about ourselves. I have not received any letter regarding this since I was 25, I'm now 27 and completely forgot about it for 2 years.

Pain:

Explain that it's less painful than an IUD, you can take a loved one with you if you're nervous or uncomfortable. You can have them in the room if you would prefer.

Specific information for menopausal/post menopausal people, especially those affected by vaginal atrophy. It can be very painful to have a smear test and lead to bleeding afterwards as i know from experience. Also, using a trauma-informed approach – you have a domestic violence tickbox in an earlier question but nothing for survivors of sexual assault/ rape.

At no point in this questionnaire have you given us the option to state that the reason some people don't have a smear test is because it is painful. The communication and PR around smear tests is that is is not painful. This is a lie. I personally haven't had my smear test in over 4 years because it is excruciatingly painful, and my local health professionals have given me no support in this. I was told to tilt my hips differently. Made no difference yet I was not then offered any other help. Sedation should be offered for those who find the procedure painful. And please please please stop promoting that it is not painful when it bloody well is.

Train medical staff better! Previous screenings have been very painful and staff have not been at all patient or compassionate.

The main barrier for me is the knowledge that it will hurt.

Provide pain relief options! This is a very painful and uncomfortable procedure and so pain relief needs to be provided. I am shocked that this is not an option.

Try listening to patients when they tell you its hurting and not just carry on saying it wont take another minute.

I do not like the procedure maybe calming down methods or painkillers to get rid of awkwardness and discomfort. I often get told if you can have baby then this test is easy but i disagree the smear test is random and not a procedure like child birth. The device is metal and cold not like a delicate baby.

Offer pain relief for people who find it very painful, but this is always brushed off by clinicians.

Stop gaslighting people who have extreme pain associated with the procedure by telling them during the screening that 'it's not supposed to hurt'.

many women i know do not like going because it hurts. Doctors always say it doesn't hurt but it does for some people.

As you get older a smear gets very painful and it puts you off having them.

it has been very painful for me the past few times i had it. i am not sexually active and even though i have requested a number of times for appropriate lubrication to be used – none has been used. This has scared me from going for another smear test.

I have endometriosis and found my smear very painful, not just at the time but causing a deep ache for days afterwards. Don't dismiss the fact that smears can be more than "a little uncomfortable" but make the benefits clear so people still understand that it's worth doing.

Have staff trained in trauma-informed approaches. Nurses should not be shocked that a patient finds screening difficult. – Invest in the self testing options which are proven to be as sensitive and accurate. – Don't lie to women about the experience. It CAN be painful. Bin any material that tells people it won't or shouldn't hurt. I was unprepared for the pain and bleeding because no one told me it could happen.

Given that 80% of women will experience vaginal atrophy as part of peri/menopause and only 8% seek treatment for it (source Dr Louise Newson) many women will find the procedure too painful or impossible. And there is no acknowledgement of this issue in your survey.

Pre-appointment information/ support:

Allow people to talk through their individual needs with someone before booking an appointment e.g can it be done with sedation, how is it done for people with mobility issues who can't position themselves as needed, seeing the room and meeting the screener in advance for autistic people.

Chance to discuss concerns before appointment.

have a nurse phone a person beforehand and form a relationship with them as SSP's do with BCSP.

I have been involved in a project booking women in for screening & have found giving someone time to talk about their worries or booking them in to chat with a health professional has been helpful.

Improving patient experience and staff training:

Staff training to help feel comfortable Longer appointment slots so not as rushed Measures to reduce discomfort – positioning, speculum size.

Train staff better to know what things are appropriate to say and which not. Personally I've had an unpleasant experience at XXXXXX centre when a lady performed procedure and caused pain and therefore bleeding, then commented that I started bleeding profusely and that I should get checked out cause something seems wrong. Long story short, nothing was wrong and the profuse bleeding was a drop or two after going to the toilet post procedure.

Change it from something that is happening to you to something you actively participate in. Make it normal for women to be able to select size of speculum and insert it themselves if they want to. A lot of nurses will allow you if you ask but it makes you feel like a nuisance having to ask. More information on what happens if you need further tests is essential. I was referred for colposcopy (not due to a screening result). I was given no information at all from my GP or the hospital. The information on the internet especially tiktok is terrifying, in particular in relation to cervical biopsies and LEEP. People may be put off attending screening so they they are not referred for colposcopy.

Move away from the narrative that you don't need to shave or you don't need to be embarrassed. We're not embarrassed, we're busy, we're nervous due to previous trauma, we've had deeply negative experiences at cervical screenings in the past. It's patronising and it's minimising to suggest women aren't accessing lifesaving interventions due to fears that our labia are wonky or our pubic hair is untrimmed. The issues are deeper than this and they are valid concerns. Meet us with respect and empathy.

Its not just convenience of appointments its about helping women manage their anxiety of examinations of an intimate nature that make them feel vulnerable. Staff become desensitised to these examinations and women's discomfort because they do them everyday but to that women its a big deal. I'm afraid to go now and admit I've never had one as. I also found cervical examinations during childbirth excruciating so dread the thought of a smear, services really need to be more attuned to this fear and how to help and manage it rather than ignore. I know how smears are performed but nothing is ever mentioned about the examination will be made more comfortable and pain free.

Painful experience previously, nurse poor bedside manner, abrasive manner, put me off to attend other appointments.

Provide more aides for people who are disabled such as a wedge cushion instead of being told to put fists under bottom. Don't shame larger people by going on about their weight, weighing them, or complaining you can't see their cervix easily and definitely do not assume they need a large/long speculum.

Kinder, non patronising staff who feel it is their right to tell you off for not attending sooner. Im here now! And more professional staff – inappropriate comments re need a new speculum, sigh, you have a ling vagina! (2 smears , 2 bad experiences ...) Aged 51 ...total 2 smears! Health care professional..yes! Should know better – yes! Experience bad events like none health care professionals ..yes!

More recognition and understanding of pain for some women during screening. How can this be prevented, minimised or relieved? My last screening was incredibly painful and staff were completely dismissive. Would put me off going again if i didn't have such high personal motivation for going.

Educations and normalising screening conversations:

Train hair and nail people in the little salons to open and have the discussion in a friendly/ knowledgeable way.

Get comments from real women who have been for the screening and promote it on the letter when sending the appt letter out. Stress how quick the appointment is.

Perhaps educating females from high school age, going into schools to show what happens at a smear test and telling them the benefits.

Should be part of health sessions at school for girls and boys to understand how important it is.

Use more simple language, Possibly have Health professionals linking in with schools – many mums are there twice a day during the term – this could be a good opportunity to spread the word, also engage with younger people.

Address needs of some BAME populations where the husband will not allow his wife to attend due to his lack of knowledge and understanding of importance of screening.

Social media, influencers to promote like a product.

Social media campaign with videos Pre-appointment chat (like with an IUD insertion, opportunity to ask nurse questions).

I was told that HPV was a sexually transmitted disease. This is not true and a lot of younger women have the same perception.

There are some historical beliefs – with gay women – as a result of information given by health professionals/GP's in the past that they do not require smear tests – as they are not in a sexual relationship with men. The message to lesbian women needs to be very clear in order to dispel this myth.

Talk more about vulvas and vaginas. Talk about hair/no hair, smells, discharge. I think lots of people are embarrassed as we don't talk about what's normal enough. Use real imagery.

Make it less taboo to discuss – advertise on TV at prime soap opera time. Men need to know about it as well.

I think people may also not trust the screening now as the test has changed and only tests for HPV and no further testing is undertaken if HPV is not found.

Promote at events. I recently went to the royal Lancashire show and they had a stall form prostrate cancer, lot of men stood talking to them.

I work with adults who have a learning disability often cared for by older parents or carers. It has ben said to me that due to the fact that the person with the disability does not have sex then they do not need a smear test. Targeted information around this would be useful in partnership with disability services, day services and Shared Lives (PSS for example).

If the person hasn't had the screening done on a number of occasions could this trigger a meeting with the GP or Nurse so that they can talk to the women and understand her reasons? A friend has never been in over 20 years because of her weight, the issues she went through in child birth and embarrassment. I'm sure if a doctor spoke with her directly it would possible sway her to have one done. I also think it would help having a friendly face. Nowadays you seem to see someone different every time you go.

This area has a large South Asian majority, where the women may not be too familiar with the concept or benefit of cervical screening. And generations of women in their circle have most likely never undergone cervical screening therefore they see no benefit to it. I think awareness and clear knowledge on cervical screenings needs to be given. Also, many females who have never been sexually active or only ever had 1 sexual partner may feel it doesn't apply to them. Again, it should be made clear whether it does or does not. For instance, I have never been sexually active and some nurses have told me I don't need to get it done until I become sexually active and others have said I should, which left me quite unclear on my decision.

Self-sampling:

Acknowledge that trauma from sexual assault is a barrier to screening and ensure there is trauma informed care in place, including allowing people to self-test. The current procedure is incredibly disempowering and invasive.

A self sample would be good as long as it was sure that people did it properly.

Develop a way of them doing them at home and sending off for testing instead of someone doing it to them. Bit like the pregnancy tests they do now.

I think the self sample test is a fantastic idea and I think this would increase the uptake.

home testing is a great idea for procedures that are intimate and embarrassed.

The fact that i saw the last choice (self sampling) made me breathe a sigh of relief. If this became a possibility, or even to carry out the procedure yourself within the medical practice i would do it no problem at all. Its just SO invasive and actually a really traumatic experience.

Change the procedure, find another way of identifying cervical cancer without an uncomfortable procedure.

Alot of people feel ashamed of the way their bodies are and uncomfortable showing it to others.

At home testing would be crucial to me wanting to take the test.

Allowing people to do a test at home kit would be beneficial, it is an intimate procedure and feels very uncomfortable allowing a stranger to do it. This has stopped me from having anymore than one screening.

I think if this can be done at home by yourself there will be a huge uptake and save costs of a healthcare professional undertaking the test.

Be able to offer it home for people who are housebound with agoraphobia.

I think you need to look for an alternative method of screening. I imagine the main reason why people don't go is because it can be extremely uncomfortable and so it is not something that people want to undergo.

Provide a self screening test, as had happened in the covid testing, women know their bodies, and I'm sure if they were given a chance to test at home privately it would make a huge difference.

Test at home is a great idea I think it would encourage lots more women to do the test.

This shouldn't be done at home due to the risk of it going wrong/not being done correctly and then needing to be redone resulting in money being wasted.

Home kits would help people who are having irregular periods due to menopausal changes. Cannot plan an appointment at the right times due to this.

Self testing would be amazing but only if it is actually going to be accurate and explained thoroughly.

I think a home kit that we can do in the comfort of our homes would be the answer.. there are a lot of kits coming out now for ie bowel cancer etc cervical screening kits would be a huge endorsement..I would prefer to do mine at home.

Home testing would be the way forward I feel.

Come up with a different way to do it. It's a horrible experience and no amount of information in a pamphlet or celebrity promotion will change my mind. I don't know how anybody could reliably swab their own cervix at home either so I'm not sure how successful that option would be.

For women who don't want a stranger in their private part. Create a video/ instructions of how to get someone you are comfortable with a trust to do it for you.. 'like a at home kit' or at the doctors with their supervision without looking at their private are.