healthwatch North Lincolnshire

BARRIERS TO ACCESSING CERVICAL SCREENING

AN INVESTIGATION REPORT

Contents

Contents

1 About Us

1.1 What is Healthwatch North Lincolnshire?

We are the independent champion for people who use health and social care services. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

In summary Healthwatch is here to:

- Help people find out about local care
- Listen to what people think of services
- Help improve the quality of services by letting those running services and the government know what people want from care
- Encourage people running services to involve people in changes to care

1.2 Why this Subject?

National targets for cervical screening coverage are set at 80%. Current coverage across England is at just 69.8% for those between 25 and 49 years old and at 76.2% for those between 50 and 65 years old. This shows that neither age group is reaching the national 80% target throughout England, and that coverage in the lower age group is substantially lower than in upper age groups.

C24b - Cancer screening coverage - cervical cancer (aged 25 to 49 years old) 2019 — Proportion - %

Export table as image | Export table as CSV file

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↓	7,129,579	69.8*	69.8	69.8
South West region	→	664,435	74.2*	74.2	74.3
North East region	→	321,758	74.2*	74.0	74.3
East Midlands region	↓	590,390	73.4*	73.3	73.5
Yorkshire and the Humber region	↓	674,543	72.8*	72.7	72.9
East of England region	↓	780,375	71.9*	71.8	72.0
South East region	↓	1,135,608	71.4*	71.4	71.5
North West region	→	908,191	71.3*	71.2	71.4
West Midlands region	→	702,979	69.6*	69.5	69.7
London region	↓	1,351,300	61.5*	61.5	61.6

Source: NHS Digital (Open Exeter) / Public Health England

(Figure 1: Cervical Screening coverage aged 25 – 49 years old, Public Health England[2])

C24c - Cancer screening coverage - cervical cancer (aged 50 to 64 years old) 2019 — Proportion - %

Export table as image | Export table as CSV file

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↓	3,792,408	76.2*	76.2	76.3
East Midlands region	↓	336,966	78.3*	78.2	78.4
Yorkshire and the Humber region	↓	374,971	77.8*	77.7	77.9
South West region	↓	399,317	77.0*	76.9	77.1
East of England region	↓	430,733	76.9*	76.8	77.0
South East region	↓	636,097	76.4*	76.3	76.5
North East region	↓	189,862	76.3*	76.2	76.5
West Midlands region	↓	386,956	75.7*	75.6	75.9
North West region	↓	495,873	75.5*	75.4	75.6
London region	↓	541,633	73.7*	73.6	73.8

Source: NHS Digital (Open Exeter) / Public Health England

(Figure 2: Cervical Screening coverage age 50 – 64 years old, Public Health England[2])

On 22 March 2009, Jade Goody, television personality, died from cervical cancer aged 27. Following the large media coverage at this time, cervical screening uptake increased dramatically with an estimated 370,000 extra attendances around the time of Jade's death. This increase of cervical screening uptake became known as the Jade Goody effect. The increase was seen most in the younger age group, but was still noticeable in the older age group, although this group had a generally higher uptake rate prior to the spike.[1]

After the initial spike, cervical screening in 2011 was at 73.7% for women aged between 25 and 49 and 80.1% for women aged 50 to 64. Since this time there has been a steady decline in the uptake of cervical screening of nearly 4% across both age groups.[2] Research completed by Jo's Trust[3] about declining cervical screening figures indicates that barriers could include; poor understanding about the test and its importance, lack of knowledge about the cause of cervical cancer, difficulties

[1] Lancucki L, Sasieni P, Patnick J, Day TJ, Vessey MP.(2012)
[2] PHE Fingertips
[3] Jo's Trust – Barriers to attending screening

making appointments around other commitments, lack of availability of accessible material and lack of accessible facilities or alternatives for those with physical disabilities.

Although the figures in North Lincolnshire are slightly higher than national averages, there has still been a noticeable decline over the last 8 years, with figures falling by around 3%. Public Health England report that in September 2019 coverage in North Lincolnshire was 74.7% for 25 to 49 year olds and 78.2% for 50 to 65 year olds[4]. This means that, as of 2019, there were around ¼ of women in North Lincolnshire, who were eligible for cervical screening, who did not attend their appointment.

In November 2019, it was reported to Healthwatch North Lincolnshire, by a local disabilities campaigner, that some women were facing barriers to accessing cervical screening. These barriers included women with physical disabilities being unable to be tested at GP surgeries due to them not having hoists available within practices.

Data from Public Health England regarding uptake rates for cervical screening does not differentiate between women with or without a physical disability; however data from NHS Digital suggests that only 20% of women registered at their GP with a learning disability in North Lincolnshire attend their cervical screening appointment[5].

[4] Public Health England
[5] NHS Digital

2 Background

2.1 Introduction

Cervical cancer develops when cells in the opening of the womb, known as the cervix, grow in an uncontrolled way. The abnormal cells build up and create a lump which can also be called a tumour.

HPV

During 2016, the screening process in England was changed to screening for high risk HPV before testing for abnormal cells during cervical screening. This was due to the fact that most cases of cervical cancers are caused by human papillomavirus (HPV) which is a common group of viruses which affect the mouth, throat and genital area. There are more than 100 subtypes of HPV and many people will contract some form of HPV throughout their lives. In most cases the infection will be cleared up by the person's immune system without the need for any further treatment. However, some high risk types of HPV can lead to the development of abnormal cells, which can become cancerous. HPV can be spread through skin-to-skin contact of the genital area, vaginal, anal or oral sex and sharing sex toys. As HPV can be transmitted without penetrative sex, it is advised that women should consider having cervical screening regardless of their sexual orientation or sexual history[6]. It is also advised that women who have had the HPV vaccine and those who have never been sexually active should also continue to have cervical screening as there is still a low level risk of developing cervical cancer.

Who is offered screening, and when?

Cervical screening is offered to all women and people with a cervix between the ages of 25 and 65, with patients receiving their first invitation around 6 months before their 25th birthday. Up to the age of 49 women should be offered screening every 3 years; this frequency reduces to every 5 years for women aged 50 to 64. All people with a cervix should be invited for screening by the national call and recall service or their individual GP surgery, depending on circumstances.

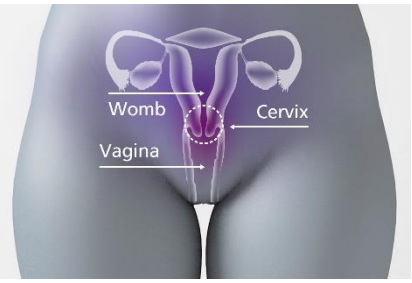
[6] NHS cervical screening: Helping you decide

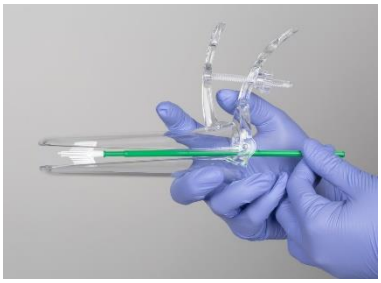
Reasonable adjustments

As outlined in the Equality Act 2010 reasonable adjustments should be made to ensure that disabled people do not face a disadvantage. As such, easy-read invitations and materials should be sent to women who require information in a more accessible format. It also states that no physical feature should put a person at a disadvantage, and steps should be taken to avoid such disadvantage. This means that if a women has issues around mobility, steps should be taken by service providers, such as GP practices, to ensure she can access the same screening service as a women who is not disabled. In terms of communication difficulties, it is reasonable for auxiliary aids to be provided to ensure no substantial disadvantage due to inappropriate communication methods.[7]

Process

The cervical screening process involves using a speculum to locate the cervix, so that a sample of cells can be taken using a soft brush (figure 3). The process is usually carried out by a female nurse or doctor who should explain what is happening throughout the screening and answer any questions or queries. The screening should take less than 5 minutes to complete and the whole appointment should be around 10 minutes. The nurse or doctor should explain what happens next in relation to possible after effects and the results process.





(Figure 3: NHS[8])

Results

[7] Equality Act 2010
[8] NHS: What happens at your appointment

Following the screening process results should be received in the post within 14 days, however they can take longer.

There are four possible results:

1. **HPV negative -** If you test negative for HPV then no further testing will be completed at this time. It is considered that there is very little risk of abnormal cells which can lead to cervical cancer without the presence of HPV.
2. **HPV positive: no abnormal cells -** If a sample is found to contain HPV it will then be tested for abnormal cells. If in the case that HPV was found but with no abnormal cells, screening may be required earlier than recall frequency to ensure the immune system is dealing with the infection.
3. **HPV positive: abnormal cells found** – This result indicates that both HPV and abnormal cells have been found. Some abnormal cells are more serious than others and an explanation will be given in the letter. Following this result a colposcopy will be required.
4. **Inadequate result** – Occasionally a laboratory is unable to test a sample due to a technical problem. If a sample is declared as inadequate further screening will be completed in 3 months' time.

2.2 Services/Pathway

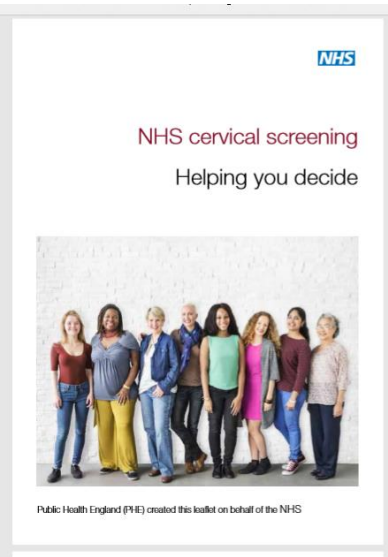
In England, Public Health England and the NHS work together to oversee and deliver population screening, such as cervical screening. All women who are eligible for screening should be given the opportunity and access if they decide this is right for them. Cervical screening should be offered to all women and transgender men who have a cervix, unless they have been ceased or deferred from the process.

Call and Recall

The current patient pathway for accessing cervical screening is the call and recall service. The pathway starts with prior notification lists, detailing women due to be screened, GP Surgeries review the list to cease or defer any women as necessary. All remaining women will be sent invitations to attend screening by the Cervical Screening Administration Service. A reminder letter is sent to anyone who does not

attend screening within 12 weeks and after a further 14 weeks, if screening has still not taken place, the individual is recorded as a 'non-responder'. After this they may receive further letters of invitation from their GP practice and will be recalled by the call and recall service in either; 3 or 5 years for routine screening and 1 year following an early repeat or suspended screening[9].

With the invitation to attend cervical screening all women should receive the leaflet 'Cervical screening; Helping you decide' (figure 5). This leaflet should give accurate and up to date information highlighting the process for cervical screening alongside the associated benefits and risks. This should assist anyone considering whether cervical screening is right for them, in making an informed choice. The publication is available in a number of languages and an easy read format to make it accessible to a wide range of women.



(Figure 5: Public Health England[10])

When a woman who is registered as having a learning disability fails to attend for cervical screening, GP practices should access available resources to ensure information is provided for these women in an accessible format. Public Health England provide a number of easy read letter templates including letters to invite for screening, reminders about screening and results letters. There are also easy read booklets, a photo story and a short film, designed and made by women with

[9] PHE – Cervical Screening: guidance for call and recall administration best practice
[10] PHE: Cervical Screening: Helping you decide

learning difficulties, to help support decision making around this subject. Guidance is also available for decisions in relation to capacity to consent to screening and how to proceed if a lack of capacity is established.

Deciding to attend screening

After a woman receives her invitation for cervical screening and makes the decision to be screened, she is then required to make an appointment with her GP practice. A professional at the GP practice will take a sample at the appointment and send this to be tested. Laboratories test the sample for the presence of HPV and other testing, as required, and then send a results letter to individuals informing them of the next steps; either return to normal screening interval or information regarding possible further investigation.

Ceasing and Deferring from Call and Recall

GP practices can remove (cease) an individual from the screening process for reasons such as:

- If a woman makes in informed personal choice
- Voluntary withdrawal
- Individual circumstances (Female genital mutilation, vaginismus, cervical stenosis, physical conditions and disabilities, terminal illness, mental capacity)
- Age
- Absence of cervix
- Radiotherapy

Individuals may delay (defer) testing for such reasons as:

- Recent test complete (within last three months)
- Pregnancy
- Under care of colposcopy
- Under treatment
- Personal choice

GP practices are able to cease screening for reasons of age or the absence of a cervix and defer screening for 6, 12 or 18 months, without an individual's explicit consent.

Although there are reasons for those with a cervix to be removed from screening, they cannot be removed without just cause, and without following processes to ensure that all attempts have been made to allow individuals the opportunity to make an informed choice[11].

Local Pathway

Locally, women are able to access cervical screening through their GP practice. However, cervical screening can be provided by the local Sexual Health clinic commissioned by the Local Authority, for individuals who choose not the access this in their own GP practice. Usually, if an individual is attending cervical screening routinely (such as having received a reminder for cervical screening) or opportunistically (such as at another appointment) they do not need to attend their own GP practice before accessing screening at the Sexual Health clinic. However, if an individual is concerned about any symptoms they have, relating to cervical screening, they should in the first instance attend their own GP practice.

Women who have physical needs should access cervical screening at their usual GP practice. Though there does not appear to be any GP practices with hoisting facilities, it is reported through CCG North Lincolnshire that, they are generally able to manage the mobility needs of their patients using adjustable examination beds and supporting the individual with moving and handling, to be positioned in order for cervical screening to take place. If the individual cannot be assisted into the required position for cervical screening to take place, due to significant physical disability, a referral to the hospital may be required.

GPs should regularly undertake health-checks for individuals who have been diagnosed with a learning disability. The CCG provides GP Practices with resources to help them invite and encourage people with learning disabilities to attend these health-checks. In North Lincolnshire, 59% of people with a learning disability who were eligible for a health check actually had one in 2018 – 2019. This is slightly higher than the national average of 56%[12], but is still considerably lower than the

[11] PHE: Call and Recall cease and defer
[12] NHS Digital

target of 75% by 2020. GP practices should provide individuals with easy read information about the health-check, which should include information about additional tests, such as cervical screening, as required. At the end of each health-check, an individual Health Action Plan should be produced which gives the opportunity for the individual to agree actions they will take, which may include attending for cervical screening.

2.3 Approach

We collected information for this report using (5) different methods:

General Survey

We produced a general survey to gather findings from a wide range of women at engagement events held at:

- The Ironstone Centre
- The Pods
- The Arc
- UCNL

We also promoted the survey on our social media pages such as twitter, Instagram and Facebook, including a targeted promotion to women in North Lincolnshire within the screening age range. The survey was also made available to women opportunistically whilst attending other events attended by Healthwatch North Lincolnshire between 20 January 2020 and 28 February 2020 inclusively.

In total 260 responses were received. 161 were completed online and 99 paper responses were returned, of these responses, 20 had to be discounted due to being out of area. Ages ranged from 21 to 75 years old with 68% of results coming from women between 25 and 49.

Easy Read Survey

We worked with Cloverleaf Advocacy to develop an easy read version of the general survey which was distributed within a 'Do Something Different' session at the Pods, which is a session for adults with learning difficulties. Two members of Healthwatch North Lincolnshire attended this event and engaged with the women

within the age range for cervical screening, alongside the people there in a support capacity. Not all women wished to take part in the survey and one chose to take the survey home to look at with family; this woman was given a freepost envelope to return the survey in.

In total three women were spoken to; one completed the survey with the help of Healthwatch staff and her personal support assistant, one person took the survey home to complete with family and one person decided she did not wish to participate.

Focus Group

We used a mixture of group activities working in groups of two or three and one to one work to gather the views and experiences of the participants. We then used the information gathered to summarise each section as a whole group. Each group had a facilitator, who was a member of the Healthwatch North Lincolnshire team, who would focus the group discussion and record views and experiences on paper. Question prompts were provided to facilitators to ensure that each group focused on similar aspects which were relevant to the information required as part of the project. There was occasional need for Lincolnshire House staff to interpret responses for the facilitator. The facilitator would then read out the responses and share them with the group, with the project leader drawing the collective responses together on to a central whiteboard which was visible to all participants.

Eight people participated in the focus group and covered a range of ages, needs and abilities. We had five participants who were sharing their own experiences and three participants who were sharing perspectives from a caring point of view. Three participants had severe mobility issues requiring the use of a wheelchair and two participants required walking frames. Four participants experienced difficulty with communication.

Interview with women with learning disabilities

We attended a supported living provider for people with learning disabilities to speak with the women who lived there about their experiences of cervical

screening. The session was kept very informal and was run in conjunction with Cloverleaf Advocacy, a representative of which was present at the session. We asked a range of open and closed questions, allowing the women to speak freely about their experiences. After the session the verbal results were collated and written up to be used in the report and the easy read surveys were collated with the others of their kind.

Three ladies attended the session but only two were willing to complete the easy read survey and discuss the matter in more detail.

GP Surgery Survey

A GP surgery specific survey was created to gather information about facilities and adaptions available to minimise the impact of barriers to accessing cervical screening. The survey link was sent to a member of the CCG who distributed the survey amongst GP Practice Managers and also emailed directly to practices, for the attention of the Practice Manager.

There are nineteen GP Practice in North Lincolnshire and eleven of these have responded to the survey.

3 Findings

3.1 GP Survey

At the beginning of our investigation we conducted an initial contact with GP Surgeries via telephone. We asked surgeries in the area if they had a hoist available to use if an individual required this to transfer onto an examination bed. We discovered throughout this process that no surgeries in the area had hoist facilities. This was later confirmed through our GP Survey which was sent out to practice managers via email. Responses to our GP Survey confirmed that no surgeries in our area have a hoist to enable individuals who require this to transfer to an examination bed.

When asked how they conduct cervical screening (and other examinations) on patients who cannot transfer themselves independently, three surgeries indicated that they utilise the adjustable examination bed and support using moving and handling techniques. This was also confirmed by CCG North Lincolnshire who advised this was the correct procedure and that services do not identify any issues with this process. They further advised that if transfer is not possible in the surgery a referral to the hospital may be required. One practice identified this process on our survey.

With consideration around assisting people with learning difficulties to access cervical screening; three practices identified that they utilised resources such as easy read leaflets and offering longer appointments. One practice also stated they aim for continuity with the same nurse each time and access support from the learning disabilities team as necessary.

We also asked about how GP practices ensure the cervical screening needs of transgender patients are met. In response to this two practices identified that this had not yet happened and would discuss this with the practice manager when the time arose. One practice stated they were aware of resources that were available

to assist with this when they are needed. Another practice reinforced that staff are trained in equality and diversity and treat every patient with the same courtesy. They also appreciated that the nursing team would need to be considerate that the patient wasn't made to feel uncomfortable in any way, during discussions about this sensitive issue and that all leaflets and promotional material is now worded to state 'women and anyone with a cervix' instead of being aimed solely at 'women'.

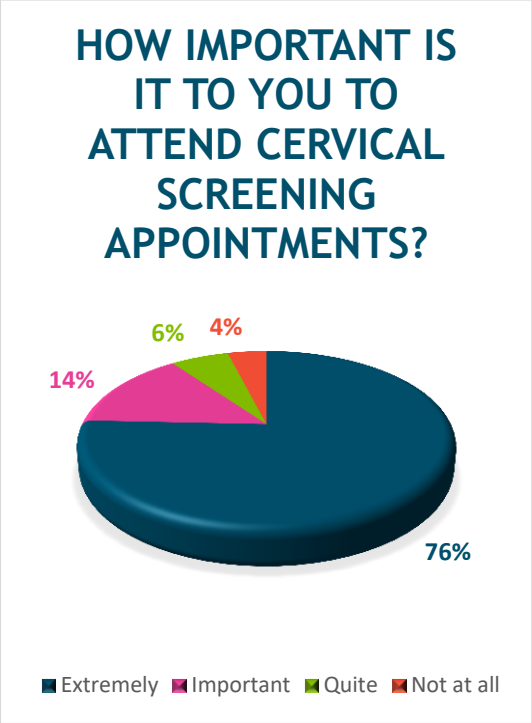
Finally, we explored how GP practices engaged with people who do not respond when offered cervical screening. Responses varied and included such measures as sending SMS messages, personal letters, and telephone calls from nursing staff and opportunistic discussions. We explored the process GP practices follow if an individual makes the decision to withdraw from the call and recall service, and no longer wished to be called for cervical screening. Responses again varied. Whilst some responses seemed to line up with guidelines, others differed slightly. Most indicated that they would discuss the decision with individuals and attempt to identify any reasons which may be addressed. However some practices follow the guidelines fully in assisting individuals to remove themselves from the call and recall system fully, informing them they can return to the system at a later date, if they are still eligible. Whereas others would remove them on this occasion but then recall them either the following year or when the screening should be due again in the future. This shows some inconsistency in this process across practices.

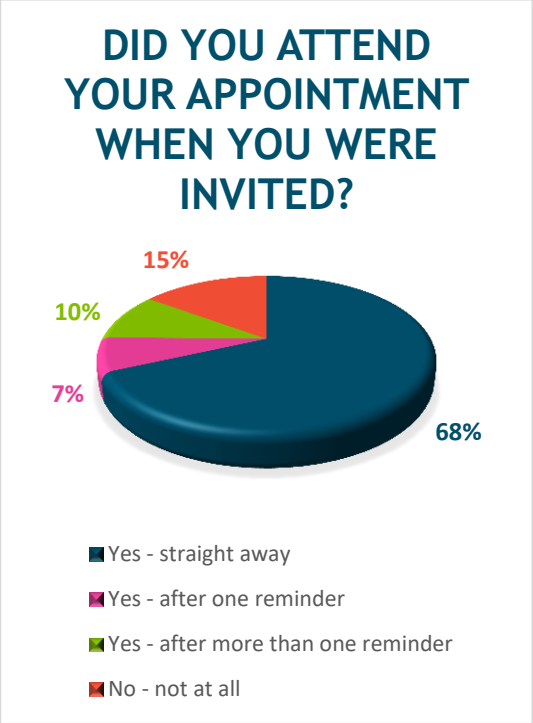
3.2 General Survey

In total 260 responses to our general survey were received; 161 were completed online and 99 were collected as paper copies through participation at our events or through partner distribution. Most responses were received by women who were within the age range for cervical screening although 8 responses were from women under 25 and 9 were from women over 65. Over half of all responses came from women between the ages of 40 and 60.

Please note that throughout this report the amount of question responses may differ from the total number of completed surveys, due to people skipping questions.

A large majority of women felt that cervical screening was important by some degree, with only 4% of women saying that they felt it was not important at all. Yet 15% stated they had been unable to attend their most recent cervical screening appointment. This suggests that there are women who would like to be screened but have faced barriers to accessing this.



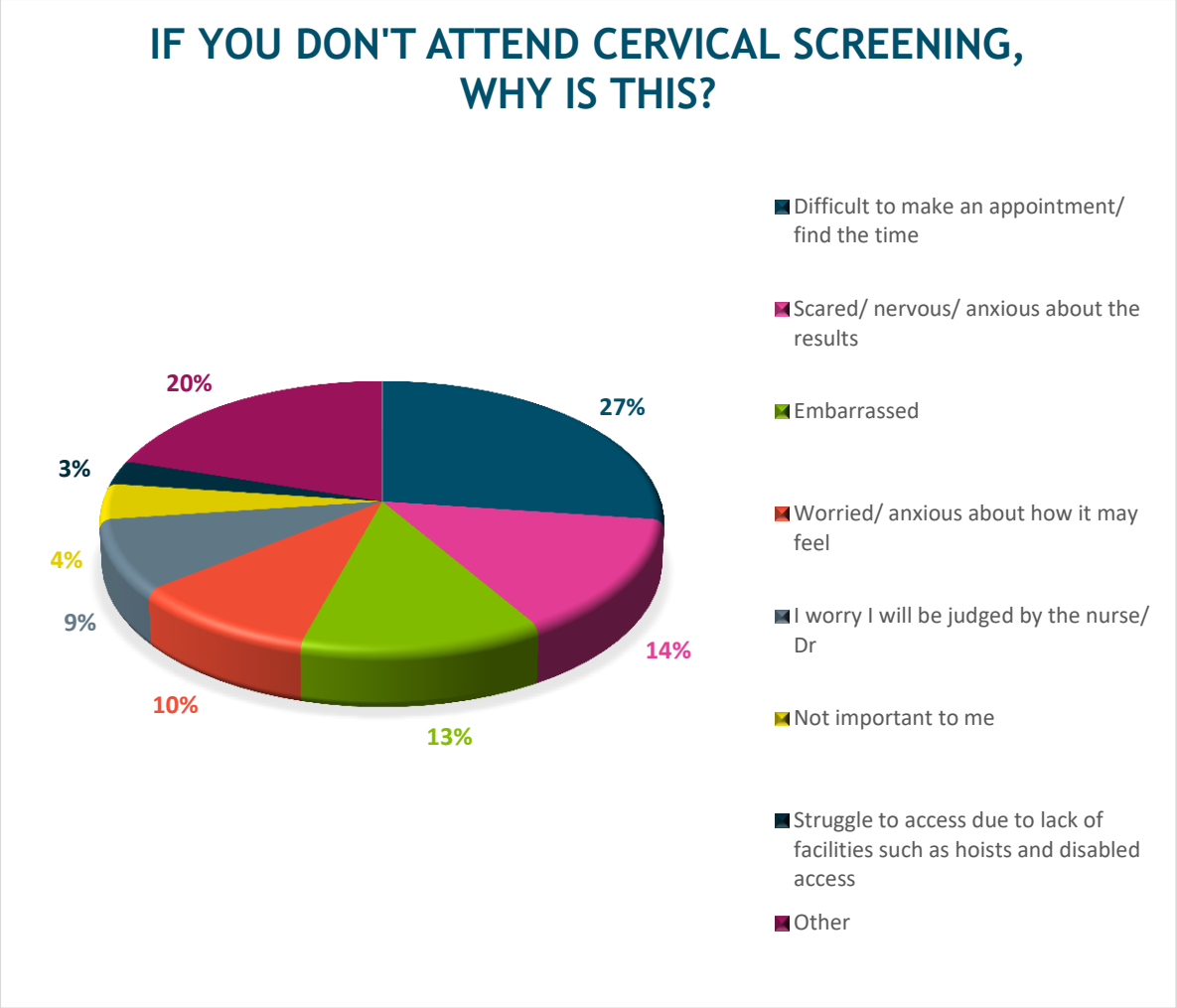


The most common reason women gave on the general survey, for why they did not attend cervical screening, was that it was difficult to make an appointment or find the time. Comments included:

"Availability was a problem."

"I have tried to book an appointment at GP and have been unable to get one out of work hours"

"Difficult when working full time"



Emotional Barriers

Amongst our general survey participants, the majority of reasons given for not attending cervical screening were due to emotional factors, such as:

- Feeling scared, nervous or anxious about the results
- Embarrassment
- Being worried or anxious about how it may feel
- Worry about being judged by the nurse or Doctor

The most common reasons given for having these feelings were:

Abuse

It is estimated that 7.5% of adults between the ages of 18 and 74 years experienced sexual abuse before the age of 16[13], and 20% of women in England and Wales have been subjected to sexual assault since the age of 16[14].

As these offences are not always reported, the actual figures are expected to be higher. Researchers have found that women who have been sexually abused are less likely at access cervical screening[15].

Within our survey six people indicated they had been subject to sexual abuse at some point in their life. The uptake of cervical screening within this group was low and only one respondent reported having attended their screening straight away, and more than half the respondents (4) did not attend at all. It also appeared that these individuals considered cervical screening to have a low importance to them with 80% saying they either do not always or never attend these appointments.

This supports claims that, women who have been subject to abuse are less likely to access cervical screening. Comments we received about the reasons for this include:

"Sexual assault survivor and couldn't face the idea of someone looking let alone touching an intimate area. Felt panicky, anxious and terrified every time I thought about going."

"N chose not to attend her appointment as she is scared of (males) from abuse as a child"

Vaginismus

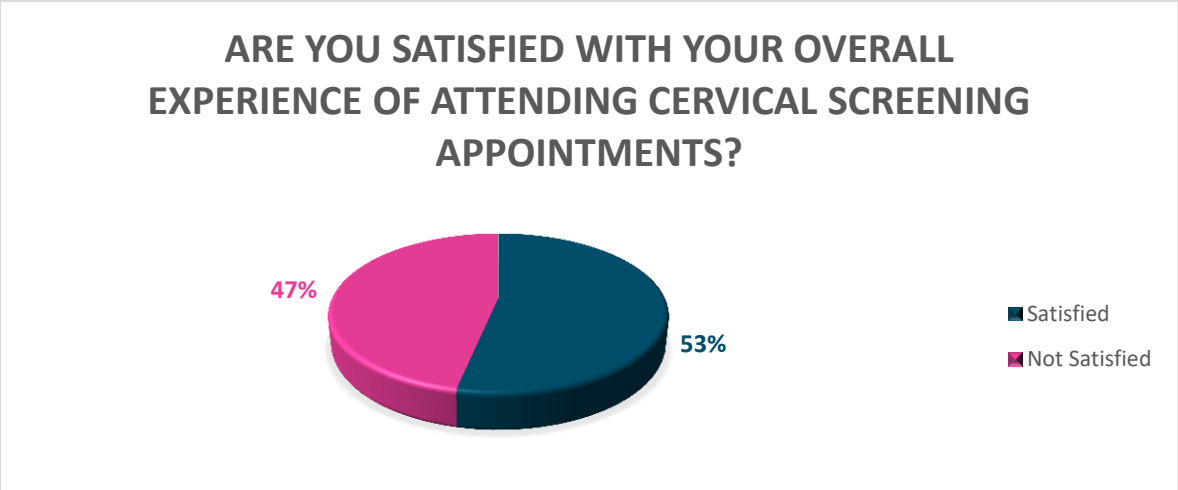
Vaginismus is when the vagina suddenly tightens up when you try to insert something into it; this can be painful and distressing. It is difficult to estimate the amount of women in the UK who suffer from vaginismus but studies have found

[13] Office of national statistics
[14] Office of national statistics (1)
[15] Cadman et al 2012

that around 10% of women find sex painful[16] and it is thought that many women will experience it at some point in their life[17].

Within our survey two people shared that they suffered from vaginismus. Neither respondent went to their last cervical screening appointment nor did they consider cervical screening to be important at all. Although this was a very small sample of people, there were fourteen other respondents who described that the process had caused them pain. Within this group there was a higher percentage of people (31%) who did not attend their latest screening appointment. Although the majority of the groups still saw screening as very important there was a high percentage (23%) who did not view it as important at all.

Overall from this group there was a high rate of dissatisfaction with the overall experience of cervical screening.



Choices about who completes the smear

We also received comments about having choice over who completes cervical screening, such as:

"Its not great when you see the lady that has just done your test in the local Co Op straight after!"

"usually see same lady doctor but last time had to see a different one so set my ptsd off so wasn't that good"

[16] Mitchell et al n.d.
[17] HSE

"Its not a great experience, I always think if there was a way to do 'at home' testing it would be a lot more popular."

These comments show that women should be given greater choice about who completes their smear testing to enable them to feel comfortable with the process.

Physical Barriers

There were 26 people on our general survey who identified themselves as being physically disabled, with ages ranging from 26 to 75. Most of these women had attended their cervical screening appointment when invited with more than half (64%) doing so straight away. However, when you consider that 96% of these women stated that the test was important in some degree, it does suggest that there are women who are facing barriers to access who wish to be screened. Further to this, one third described that their disability had affected their ability to attend cervical screening appointments, suggesting there are additional barriers to access within this group. Comments made included:

"I would need support to attend"

"I need an appointment when I am at my best as the physical activity of getting to the doctor's getting undressed etc is very exhausting for me"

The first comment highlights how some women require personal support from friends/family/paid carers to access cervical screening. For these women, arranging cervical screening can be difficult due to having to negotiate a time when someone can support them in accessing/attending the appointment. The second comment indicates that there needs to be better availability and flexibility of appointments to suit personal needs. These comments support the general findings, which show women are not attending cervical screening due to difficulties in making appointments.

Other comments, within this section of the survey, indicate that there is a lack of facilities for women with physical needs, which impacts on their ability to access appointments. Some of the comments included:

"Although I don't as yet need a hoist, I do require a room large enough to get in with my electric wheelchair and manoeuvre round the room to get on the exam bed"

"My own GP surgery doesn't have a height adjustable bed, and I use a wheelchair full time, my husband has to transfer me onto the examination bed"

These comments highlight how without adequate facilities, women with physical needs can experience difficulty in accessing cervical screening. They require facilities such as, suitable space and access for wheelchairs and equipment to aid transfer onto the examination bed. Although, these women do not require a hoist as yet, there is the suggestion, that without a hoist being available, there may be a point in the future where they become unable to access screening without this equipment.

Cognitive Barriers

Within our general survey 14 participants indicated they considered themselves to have a learning disability. We considered these responses alongside those collected through our easy read survey and also with the information gathered in our informal interviews. Of this group around 66% attended their most recent screening and 78% considered cervical screening was important by some degree. From this information you can see that more people consider the screening to be important than are regularly attending the appointment to be screening. With this in mind some of the reasons people gave for not attending this appointment were:

"Due to lack of understanding of the importance"

"Don't fully understand why it's needed. Painful and make me tearful"

"Do not understand all the letter - gave to support worker"

This lack of understanding was brought up several times, with some women indicating that they either did not understand the letter or required help from someone else to read the letter. During our interviews we asked whether invitations were provided in an accessible or easy read format and it was identified that this had not been the case. We also asked whether women understood why they were invited to attend screening. Across our general and easy read survey 22% of women indicated they did not understand why they had been invited for cervical screening. The support worker confirmed that they understood the importance but

did not fully understand why they had screening (smear) or what it was testing for. One woman explained that she knew the test was important because it helped to test for cancer, whilst the other did not know what the test was for. Although, there were also instances where time had been taken to ensure understanding, one comment in relation to this was:

"the lady was supported by her support staff and a health and well being coordinator from the LD team. A lot of preparation work was carried out."

"needed to do a lot of work, i.e. reasonable adjustments, to ensure the lady understood and consented"

These comments show that support is available, but appears to be sporadic and not consistent across all settings. This is further evidenced with 50% of this group being happy/satisfied with their experience of cervical screening, and 22% stating they were unsatisfied and 23% did not answer the question. This shows that there appears to be an inconsistency in approach with half of women having positive experiences and around 25% having less positive experiences. Comments made in relation to being satisfied/happy with their appointment were:

"Pleased once it was over proud that I'd attended"

"Nurse explained what she was doing Test for cervical cancer"

Differing beliefs

Throughout our survey we encountered a variety of different people, with many different views about cervical screening. We encountered a number of recurring themes in relation to miscommunication or misunderstanding of information and wanted to try to throw light on any myths and clarify some key issues.

"I have never been sexually active therefore cannot have HPV"

"I am asexual so there is no chance I can have HPV"

As HPV is most commonly passed through sexual contact, many people believe that if they have never been sexually active, or have not been sexually active for a long period of time, they are at no risk of contracting HPV and as such developing cervical cancer. However, it is important to note the following information when making a decision to not be screened on this basis. There is evidence that HPV is able to survive on surfaces for a number of days and common household disinfectants are ineffective in neutralizing it, meaning it is potentially possible it

can be spread through means other than sexual contact[18]. It is also possible to contract it through any type of sexual contact to the genital area, not just from penetrative sex. A woman may also have HPV for a long period of time without knowing it, as such if you have had any form of sexual contact, regardless of how long ago it was, there is still a potential risk of having HPV.

"I had a hysterectomy 3 years ago but was still called for appointments"

There are different types of hysterectomy, some of which do not remove the cervix as such cervical screening would still be offered and is still relevant. You should discuss this with your GP to ensure that you are clear about whether cervical screening is still relevant for you after a hysterectomy.

"I always think if there was a way to do 'at home' testing it would be a lot more popular"

"Should be a home kit"

Many people commented on how home testing kits may be useful and encourage more women to participate in screening. Currently, in the UK, home testing kits are not available. However, the move to primary HPV testing has opened the door to the possibility that self-testing at home may be possible in the future and it is hoped that pilots and further research will help understand how this will work in practice[19].

"Personally I think the age should be lowered when you get offered to have screening."

"I am not sure why the age limit, my sister-in-law developed symptoms in her seventies and I would always attend if offered irrespective of age."

Many people commented that they would like to see the screening age lowered. Screening used to be completed for women under 25 and was raised in England in 2003. Reasons behind this change were that there was a higher chance of abnormal cells in younger women correcting themselves. This meant that there was a higher number of unnecessary gynaecological procedures, for abnormal cells which may have cleared up on their own. As these follow-up procedures also held some risk or further complications, it was therefore decided that women under 25 should only be screened if they develop symptoms[20]. As for the upper age limit, women over

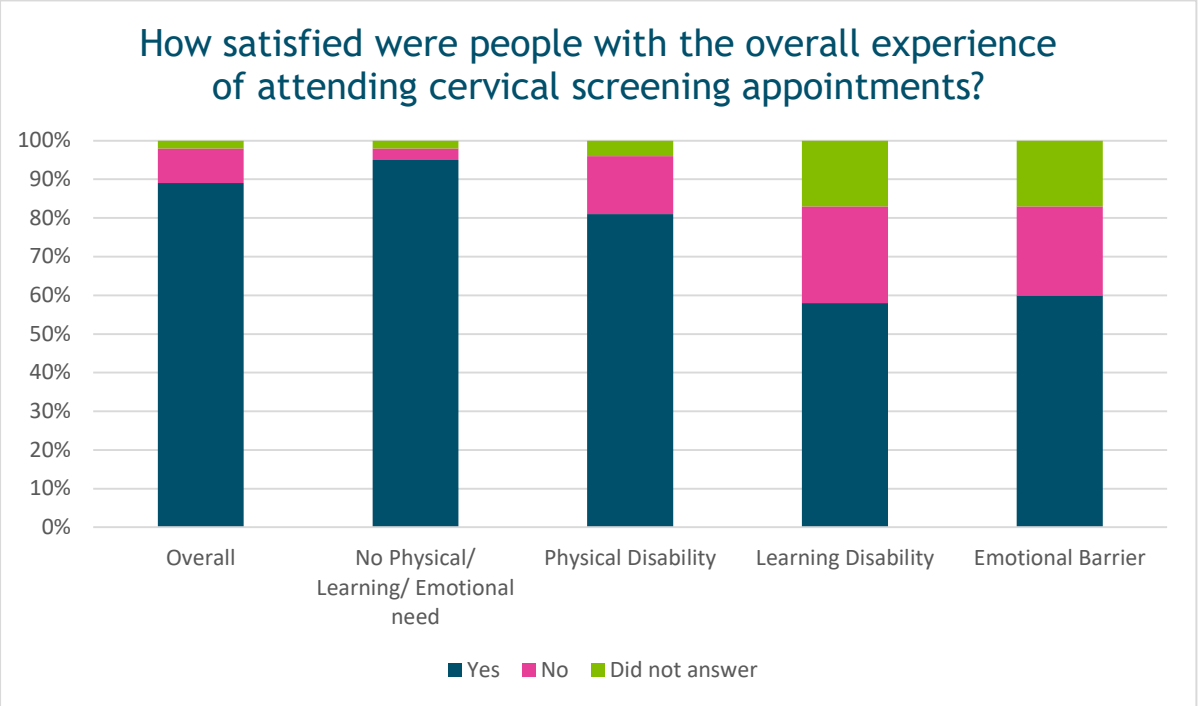
[18] Ryndock and Meyers (2014)
[19] Public Health England: HPV
[20] Cervical cancer consultation Q & A

65 will only have further screening if it is a follow up of abnormal cells; this is because the benefits of cervical screening are lessened as you get older[21].

Screening satisfaction

Overall, most women are satisfied with cervical screening with a majority of women (89%) stating they are satisfied with the overall experiences of attending cervical screening appointments. Just 9% of respondents overall, indicated they were dissatisfied with cervical screening. However, when the group is broken down into groups results begin to show some difference.

Of women who experienced emotional barriers to cervical screening, 23% indicated they were dissatisfied with the overall experience of attending cervical screening appointments. There were 15% of women who have a physical disability who were unsatisfied with their overall experience of cervical screening. Further to this 25% of women with learning difficulties were also dissatisfied with the process.

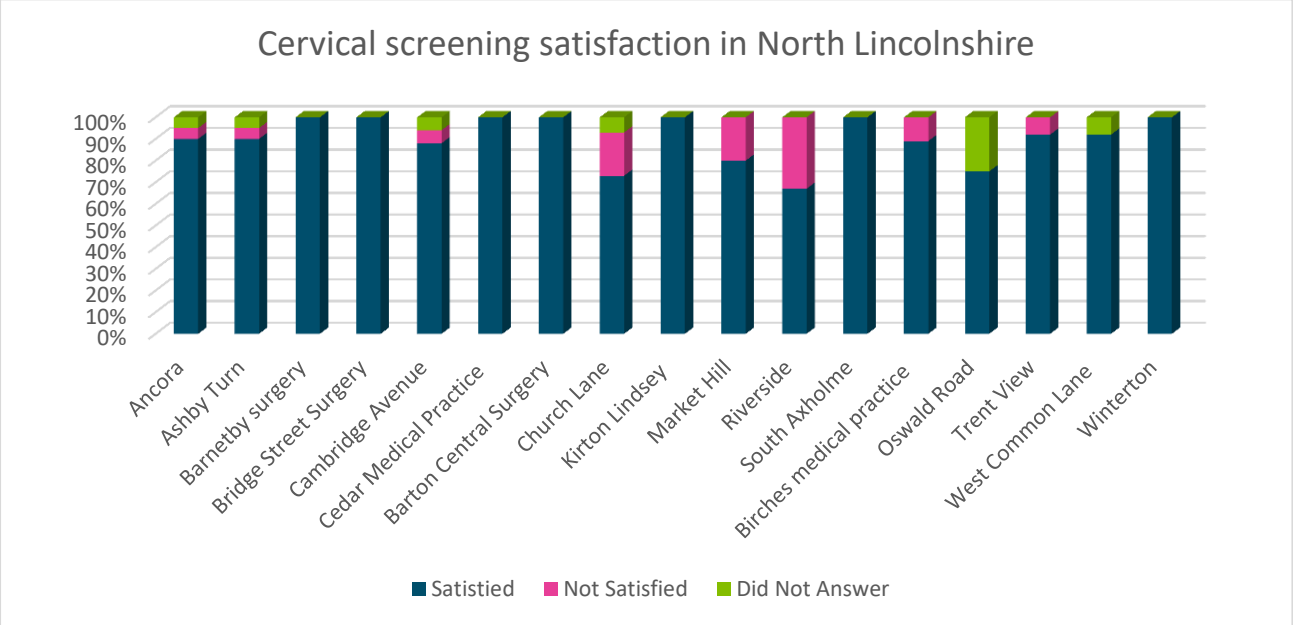


The disparities between the overall results and the broken down groups show that although on the whole people are satisfied with the cervical screening process, those who have additional needs for accessing this service are not as satisfied as those who do not. In fact when the respondents are broken down to the group

[21] Jo's Trust: Cervical screening aged 65 and over

which has no physical disabilities, no learning disability and did not indicate any emotional barriers to screening, just 3% were dissatisfied with the cervical screening process. This further highlights the differences experienced for those with additional needs.

Satisfaction with screening also varied depending on which GP practice the patient used;



Disclaimer - This chart is for information only, and as the number of responses received varied from practice to practice, cannot be used for true comparative purposes. Each GP surgery will receive a breakdown of patient satisfaction related to their practice in addition to this report.

3.3 Focus Groups/Interview

During our focus group and interviews it emerged that some women did not recall receiving any invitations for cervical screening and they do not remember it being raised at any other appointments. This was very frustrating and upsetting for the women who felt the choice to have cervical screening had been taken away from them. It was highlighted by staff that in the past, letters had been received from

GP practices to inform them that some women were being removed from the cervical screening process, due to not being sexually active. This information had never been confirmed with service users by their GP practice. Many participants felt that if they had been invited, they would have attended. They felt that everyone deserves to be invited and given the choice whether they would like at attend or not. One participant said:

"Why single me out?"

"I don't want this to happen to anybody else"

One participant explained how there is a lack of support for women with caring responsibilities as well as those who required care support, in accessing cervical screening. When making appointments it can be difficult to arrange appointments around caring responsibilities and needs. During one interview it was highlighted that they often had to arrange them around other activities or schedules which could be challenging and mean they were postponed for a while.

For those who had received letters, these were not always in a format which they found accessible. For some women with learning difficulties, letters were not provided in an easy read format, this meant that they required support to access the information. Some participants were unsure of why they had received them and did not understand the importance of having cervical screening, showing a lack of accessible information.

"I just ignore the letters now"

It was also discussed how the standard letter is not easy to read and the information is not provided in a useful way. One participant commented:

"It looks very formal with too much medical speech"

Participants described how they had felt scared because they had not understood what cervical screening was. Little explanation was given to the women, even when it was brought up by medical staff in other appointments, and it was not fully explained leaving them scared and worried. The information provided about cervical screening should be clear and relevant and there are plenty of easy read documents available to help women with learning difficulties to understand the

cervical screening process. This does not appear to be being used effectively to enable women to make informed choices about their health.

Participants who use a wheelchair, also indicated that some GP surgeries are still not accessible to them in general; lacking ramps, widened doors/corridors and rooms too small to navigate in a wheelchair. The lack of hoist facilities available in GP Practices and other medical settings has also impacted on the ability to access some procedures. One participant made the following comment in relation to attending appointments but being unable to complete procedures due to lack of accessible facilities:

"You're wasting your day"

Participants felt that there could be improvements in the way medical staff speak to them too; citing that they can feel patronised because they are in a wheelchair or have communication difficulties. Participants felt they should be spoken to directly and given time to understand and respond themselves.

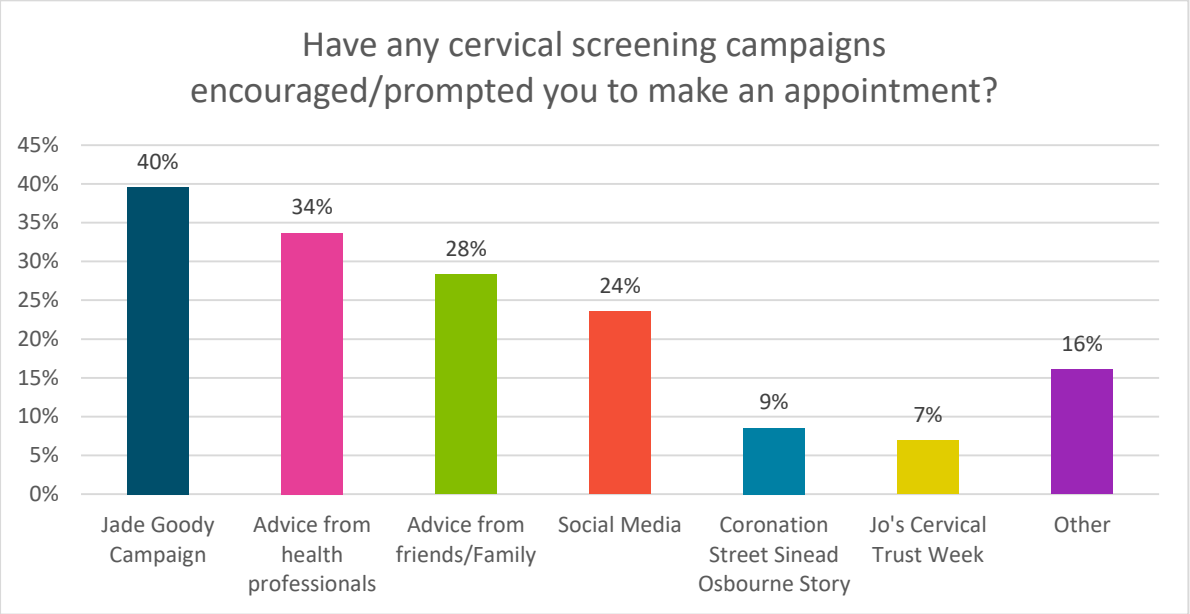
During discussion in our focus group, many participants expressed a lack of understanding of the process. It appeared that time had not been taken to ensure that women fully understood what cervical screening was, how and why it is completed and what the results of cervical screening mean. One participant who had accessed cervical screening recalled how it was never explained to her what the process involved or was for, it was just something she had done.

During one of our interviews an individual was able to describe what she needed to do during a cervical screening (getting undressed), however, she had little understanding of what the test was for. Both interviewees did not understand how the test worked and what the results mean.

3.4 Influences

Earlier in this report we discussed the Jade Goody effect, which was the increase in cervical screening uptake during 2009 following the death of TV personality Jade Goody. Within our survey we asked what influenced women to be screened and it is clear that although the Jade Goody Effect may have fallen, it is still a big

influence for many, with 40% of women saying it had encouraged or prompted them to be screened. Another big influence was advice from health professionals which had encouraged 34% of women to attend screening.



4 Conclusion

Cervical screening is an important public health intervention to detect the development of pre-cancerous cells that can lead to cancer, and although most of the women we surveyed consider this to be important, there are barriers that are preventing women from receiving this vital test. These barriers are causing inequity of access across North Lincolnshire.

Disabled women, specifically those who use a wheelchair and cannot transfer themselves independently onto the examination table are particularly disadvantaged due to the lack of hoists available in GP practices. Although these women can be referred to the hospital if needed, this is time consuming and doesn't allow the patient the same choice as able bodied women. The lack of hoisting facilities also means that both women and men who require any kind of intimate examination are disadvantaged.
Women have expressed that GP practices are not wheelchair accessible which makes attending an appointment in the GP practice difficult, and can be a barrier for accessing screening. GP practices do not appear to be making reasonable adjustments for these women to ensure that have the same access to screening as those who are able bodied.

NICE guidelines on cervical screening clearly state that all women between the ages of 24.5 – 65 should be offered cervical screening, at varying intervals depending on age. However, information gathered during our focus groups suggested that some GP practices are ceasing offering appointments to disabled women who they consider do not require screening due to either assumptions or disclosures of not being sexually active. All women should be given the choice over whether they attend or not, and GP practices should enable and empower women to make an informed choice by providing all the relevant information needed to make this decision.

There is an inconsistent approach to providing accessible information across GP practices for women with a learning disability or difficulty. Some practices are taking the time to support women to understand the importance and process of screening, and are providing easy read information to reinforce this. Those women who felt supported reported a higher level of satisfaction in the process.

However, some women with a learning disability are not accessing cervical screening appointments due to lack of understanding of, and importance of attending regular screening. This is contributing to fears over attending the appointments. Information provided to patients is not accessible enough, and GP practices are not supporting women with a learning disability to understand the process, despite a plethora of easy read and accessible information available.

The low uptake of learning disability health checks in North Lincolnshire means that some GP practices are missing opportunities to engage with women who have a learning disability to discuss future screening appointments and promote understanding of the process.

Some women find the prospect of cervical screening daunting, due to range of issues such as beliefs around screening, fear, embarrassment and previous negative experiences, including abuse. This means that some women are avoiding attending screening and are ignoring reminders to have this important test undertaken.

Although the sample size from GP practices is relatively low, it is clear that some GP practices are making a concerted effort to engage with women who do not attend appointments. However, it is unclear to what extent this engagement is, and whether or not the women are given the opportunity to express their concerns and discuss their fears in detail.

Women are finding attending appointments difficult due to caring responsibilities, work commitments etc which indicates a general inflexibility of GP practices to accommodate these needs.

Generally, women in North Lincolnshire have expressed a high level of satisfaction over their cervical screening appointments, however, it is clear from our investigation that there are many women who's individual needs are not being met, which is leading to gaps between the most able and the least able.

Although this report is highlighting the issue around cervical screening for disabled women it is important to understand that the issues around access and lack of hoists and disabled facilities in GP practices has far reaching implications for all women and men who require hoisting for other intimate examinations. Therefore the findings within this report should also be considered within a wider context of all people with profound physical disabilities and the issues they may face within the GP practice setting.

5 Recommendations

The North Lincolnshire Clinical Commissioning Group (CCG) should;

1. Implement a more defined referral pathway for patients who require use of a hoist which takes into account patient choice about their preferred setting for this examination. These options should include the patient's home, a different GP practice with a hoist, or the hospital.

2. Implement a more defined pathway to improve consistency in approach to non-responders and ceasing patients.

The North Lincolnshire Clinical Commissioning Group should work with all GP practices in North Lincolnshire to ensure they implement the following measures;

3. GP practices should install a hoist to enable disabled patients to transfer independently on to the examination table. In surgeries where this is not

possible, practices should consider offering screening within the home environment or at an alternative GP practice with a hoist.

4. Where it may not be possible for hoists to be available in every GP Practice, primary care networks should ensure that there is at least one hoist available in each network that all patients can access.
5. GP practices should revaluate the accessibility of their buildings in partnership with disabled patients to enable them to share their lived experiences of accessing services, including their ability to manoeuvre around consultation rooms. GP practices should make any simple adjustments necessary to ensure freedom of movement for wheelchair users. Where more major adjustments are required, GP practices should consider these in any planned renovations.
6. GP practices should always enable patients to make an informed choice about cervical screening before removing them from the register. This should include providing further relevant information and exploration of the options with the patient and/or patient representative where the patient does not have capacity. Exploration should also include enquiring about any additional needs people may have to enable them to access services.
7. GP practices should continue to promote the use of LD Health checks with individuals registered as having a learning disability, as a way to involve this group in decisions about their health, including cancer screening.
8. Women with learning disabilities should be provided with easy to read and clear information about the cervical screening process by the GP practice staff. This should be provided face to face where possible to allow the patient to ask any questions, and remove any communication barriers.
9. GP practices should review the approach taken to engage with women who are not responding to reminder letters by allowing the women the opportunity to discuss their concerns without fear of judgement.
10. GP practices should refer patients who are profoundly affected by previous abuse or trauma to support services to help them overcome these barriers. Jo's Trust provides a helpline on their website https://www.jostrust.org.uk/get-support/helpline

11. GP practices to should take a more flexible approach to cervical screening by offering more out of hours and weekend appointments for those who cannot attend during usual office hours.

North Lincolnshire Council Public Health team should;

12. Regularly engage with GP practices and use practice level data to identify the groups of women who are not attending screening, and use this intelligence to run targeted, local public health campaigns to encourage better screening uptake.
13. Ensure that all members of staff supporting people as part of the Healthy Lifestyle Service are trained as cancer champions to increase their understanding of the importance of cancer screening, and use this opportunistically to encourage uptake amongst people who use their service.

6 Next Steps

The report will be sent to:

- All GP practices within North Lincolnshire
- North Lincolnshire CCG
- North Lincolnshire Council Public Health team

*GP practices will also receive an overview of patient satisfaction related to their surgery with their copy of the report.

All services will have 20 days in which to respond to the recommendations within this report.

Our report will also be available for public view on our website, and will be shared with the CQC (care quality commission) North Lincolnshire Health Overview and Scrutiny panel, and other relevant partners across the Health and Social Care system.

7 Acknowledgements

We would like to thank everyone who contributed to this piece of work:

- Lorna Fillingham, a local disability rights campaigner who brought this issue to our attention.
- Staff and service users at Lincolnshire House, for their hospitality and assistance and contribution to our focus group.
- Cloverleaf Advocacy, for facilitating our interviews with women with learning difficulties and for helping to create our easy read survey.
- North Lincolnshire council public health team who supported our launch event.
- The GP practices that completed the survey
- Every member of the public who shared their experiences with us

8 References

Cadman et al (2012) 'The effects of childhood sexual abuse on women's lives and their attitudes to cervical screening'
https://srh.bmj.com/content/38/4/212

Cervical cancer consultation Q & A
https://legacyscreening.phe.org.uk/cervicalcancer-qa

Equality Act 2010
http://www.legislation.gov.uk/ukpga/2010/15/section/20

HSE
https://www.hse.ie/eng/health/az/v/vaginismus/

Jo's Trust - Barriers to attending screening
https://www.jostrust.org.uk/professionals/health-professionals/nurse-gp/screening-barriers

Jo's Trust: Cervical screening aged 65 and over
https://www.jostrust.org.uk/information/cervical-screening/cervical-screening-over65

Lancucki L et al (2012) 'The impact of Jade Goody's diagnosis and death on the NHS Cervical Screening Programme.'
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3385661/

Mitchell et al (n.d.) 'Painful sex (dyspareunia) in women: prevalence and associated factors in a British population probability survey. BJOG 2017; 124: 1689–1697.'
https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.14518

NHS Cervical Screening: Helping you decide
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/862008/Cervical_screening_helping_you_decide_HPV2.pdf

NHS Digital
https://app.powerbi.com/view?r=eyJrIjoiNTYyNDM4MGYtZDRmYi00NTAxLTkzY2QtMjcwZTY2YTQ0MzNkIiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMiIsImMiOjh9

NHS: What happens at your appointment
https://www.nhs.uk/conditions/cervical-screening/what-happens-at-your-appointment/

Office of national statistics (1)
https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/adhocs/008805crimesurveyenglandandwalesestimatesofsexualassaultanddomesticabuseexperiencedbyadultsaged16to59

Office of national statistics
https://www.ons.gov.uk/peoplepopulationandcommunity/crimeandjustice/articles/childsexualabuseinenglandandwales/yearendingmarch2019

PHE – Cervical Screening: guidance for call and recall administration best practice
https://www.gov.uk/government/publications/cervical-screening-call-and-recall-administration-best-practice/cervical-screening-call-and-recall#invitations-reminders-and-non-responders

PHE Fingertips
25-49 Percentages https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/4/gid/1000042/pat/6/par/E12000003/ati/202/are/E08000016/iid/93560/age/299/sex/2

50-64 Percentages https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/4/gid/1000042/pat/6/par/E12000003/ati/202/are/E08000016/iid/93561/age/273/sex/2

PHE: Call and Recall cease and defer
https://www.gov.uk/government/publications/cervical-screening-removing-women-from-routine-invitations/ceasing-and-deferring-women-from-the-nhs-cervical-screening-programme#contents

Public Health England: HPV
https://phescreening.blog.gov.uk/2020/01/23/significant-landmark-as-primary-hpv-screening-is-offered-across-england/

Public Health England
https://www.gov.uk/government/publications/cervical-screening-quarterly-coverage-data-reports-2019

Ryndock and Meyers (2014) 'Susceptibility of High-Risk Papillomavirus Type 16 to Clinical Disinfectants'
https://pubmed.ncbi.nlm.nih.gov/24500190/