healthwatch Lancashire

healthwatch Blackburn with Darwen

Cervical Screening in Lancashire

June 2017

Report summarising feedback from people in Lancashire in relation to screening and immunisation services.

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Introduction

Healthwatch Lancashire is committed to listening to patients and members of the public in Lancashire and making sure their views and experiences are heard by those who run, plan and regulate health and social care services.

A need has been identified to undertake public and patient engagement to support potential changes to service delivery regarding screening and immunisation programmes, with the aim to increase uptake in identified community groups and geographical areas. This report seeks to supply providers with valuable information from women across Lancashire regarding access to the cervical screening programmes, including the Greater Preston, Blackpool, and Blackburn with Darwen areas.

This report summaries feedback collected from women across Lancashire. The main focuses are;

- Reasons given by women as to why cervical screening is not accessed and has a lower uptake than other screening and immunisation programmes.
- What women perceive the barriers to attending cervical screenings are.
- Recommendations from women of how to increase awareness and uptake of screening programmes.

Methodology

It is often those closest to the process who are best placed to give useful feedback on the way services work and how they can be improved. As patients and relatives are the ones who experience the process or service first hand, they have a unique, highly relevant perspective. Patient and relatives input into designing services can be invaluable as often seeing services from their point of view opens up real opportunities for improvement.

Representatives from Healthwatch Lancashire and Healthwatch Blackburn with Darwen visited community groups across Lancashire, encouraging members of the public to share their views and experiences of the cervical screening programme. During these engagement activities, we held structured conversations and recorded the feedback gained from the participants.

Healthwatch Lancashire also launched an online version of the survey to give as many people the opportunity to have their say as possible.

In total, we spoke to 245 people.

18 people shared their views during engagement activities in the community with Healthwatch Lancashire and Healthwatch Blackburn with Darwen at Lancashire Women's Centres in Preston, Blackburn and Blackpool.

A further 227 people chose to share their views online.

Acknowledgements

Healthwatch Lancashire and Healthwatch Blackburn with Darwen would like to thank all those who shared their views, experiences and took part in the activities along with representatives from Lancashire Women's Centres who supported our visit.

Demographics

The engagement activities took place during December 2016 and January 2017. The survey was available to complete online between November 2016 and January 2017. 245 people shared their views in total.

We asked: "How do you define your gender?"
(245 of the 245 answered)

Male	Female	Other
3%	96%	1%

We asked: "Does your gender match the gender on your original birth certificate?"
(190 of the 245 answered)

Yes	No	Prefer not to say
99%	0%	1%

We asked: "How would you define your sexual orientation?
(190 of the 245 answered)

Heterosexual	Gay	Lesbian	Bisexual	Other
86%	0%	2%	2%	10%

We asked: "What town do you live in?"
(245 of the 245 answered)

CCG Area	Percentage
Fylde and Wyre	6%
Greater Preston	15%
West Lancs	8%
Chorley and South Ribble	11%
East Lancs	42%
Lancs North	5%
Blackpool	5%
Other	6%
Unknown	2%

We asked: "What is your age?"
(205 of the 245 answered)

24-35	36-45	46-55	56-65
23%	20%	31%	26%

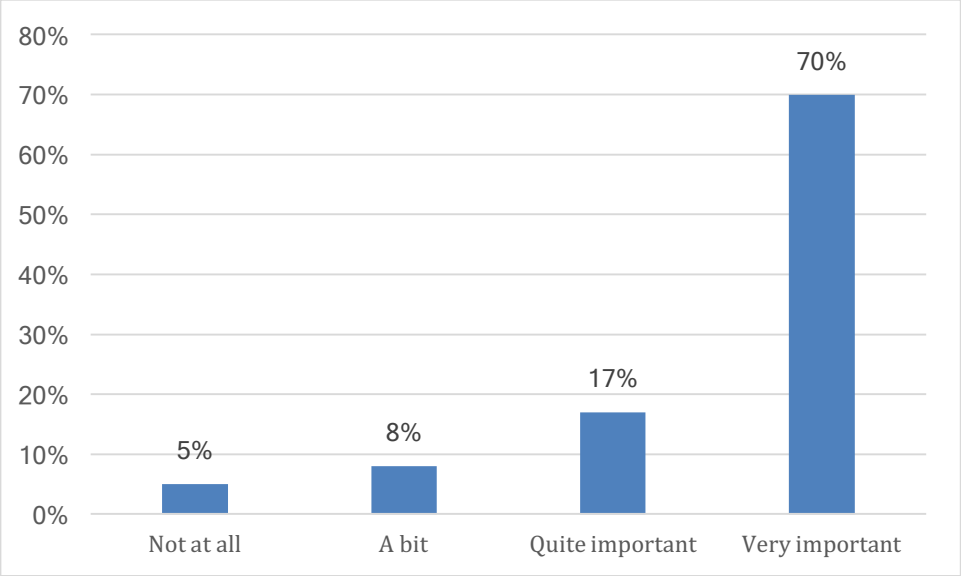
Results:

Section 1 - Value

1. We asked: "How important is cervical screening to you?"

(Have you or someone you know been affected by a screening e.g. early diagnosis, preventative treatment?)

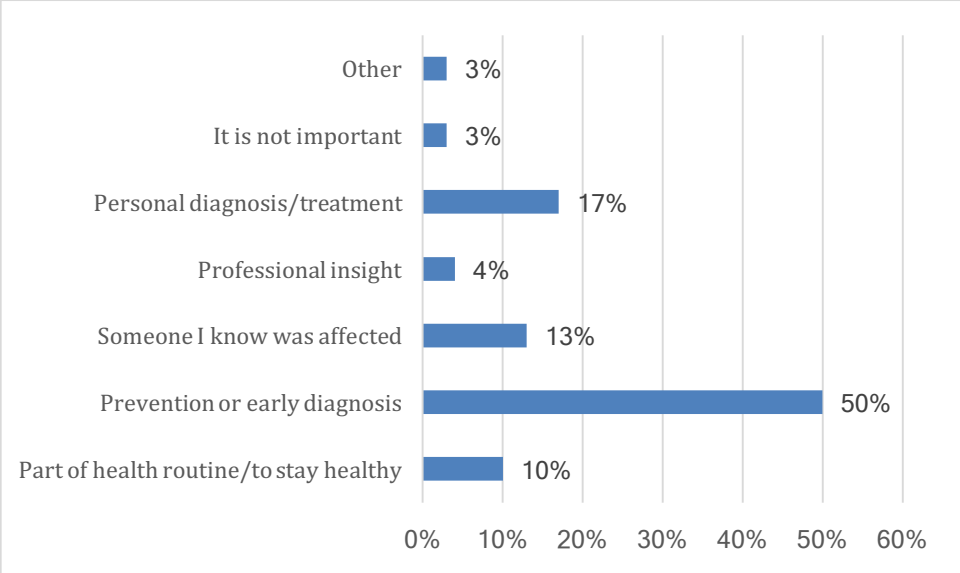
(198 of the 245 answered)



The large majority of women (70%) said that they felt cervical screening was very important to them.

2. We asked: "If you feel comfortable to say, please comment on why it is important to you."

(157 of the 245 answered)



50% of the women we spoke to stated that cervical screening was important to them because it acts as a preventative measure and can lead to early diagnosis. 17% of women stated that cervical screening was important them because they had been personally diagnosed or received treatment as a result of the screening.

Comments about health:

"It is a way of preventing ill health in the future."
"I want to keep healthy as long as possible and want to catch any problems earlier rather than later."
"It is important because I believe that everyone should do what they can to protect themselves for a longer happier life!"

Comments about prevention and early diagnosis:

"It's an excellent screening to pick up early cancerous or precancerous changes. If done well the test is minimally invasive."
"You hear about more people having it now (cervical cancer). If you have got anything it can be sorted out."
"Because you don't know what might be underlying and it's more treatable. They're awful though, it is the worst."

Comments about professional insight:

"I used to work within a Gynaecology Department and so I understand the importance of early diagnosis."
"As a retired GP I have taken hundreds of smears, and followed up positive smears, mostly with curative treatment. Sadly, some were too advanced and died."

Comments about knowing someone who has been affected:

"My mum has had pre-cancerous cells identified and removed."
"Two of my three closest friends have had abnormal smear tests which has resulted in further interventions."
"I know three women that have been diagnosed with cervical cancer. One was only 25 on her initial first ever smear, she was diagnosed and required a hysterectomy. I lost a friend to cervical cancer 18 months ago."
"My sister has been diagnosed with cervical cancer at 58. She has been treated but it is a concern to make sure we are tested regularly."
"Because I've had a sister that has died of cancer. I go for anything. It was still important before that but now I make an appointment, I make sure I do."

Comments about non-importance:

"It is NOT important to me and I decline all screening."
"Screening is NOT important to me. I think too many women are treated and feel bad effects from that, when the odds are that they would ever develop cancer is very low. Also, I think doctors push for surgeries that are unnecessary."
"I don't like them."

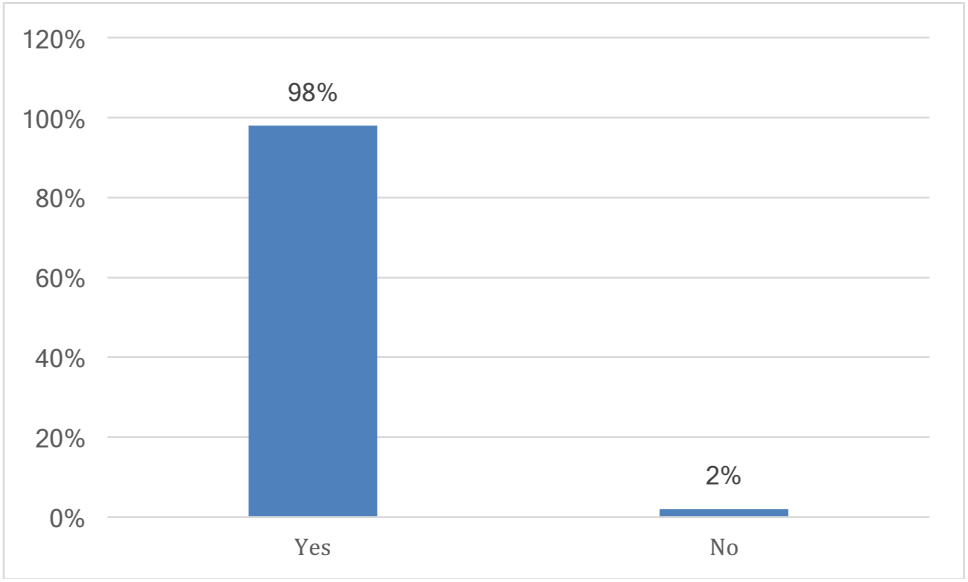
Comments about personal diagnosis and/or treatment:

"By having screening in 2001 it identified cervical cancer. Within six weeks, I had a radical hysterectomy and after I was given the all clear with no more treatment necessary. I count myself very lucky, without the screening this would not have been diagnosed as I wasn't experiencing any problems. I encourage all women I know to have regular screening including young women."
"I had an abnormal smear and needed treatment about 15 years ago. Regular screening has since prevented anything more serious developing."
"I never had a screening until I was 24 and by the time I did I had a lot of precancerous cells and needed tests and treatment. If I hadn't gone who knows what would have happened. I wasn't pushed to have a screening but I wished I'd had one sooner."

Section 2 - Knowledge

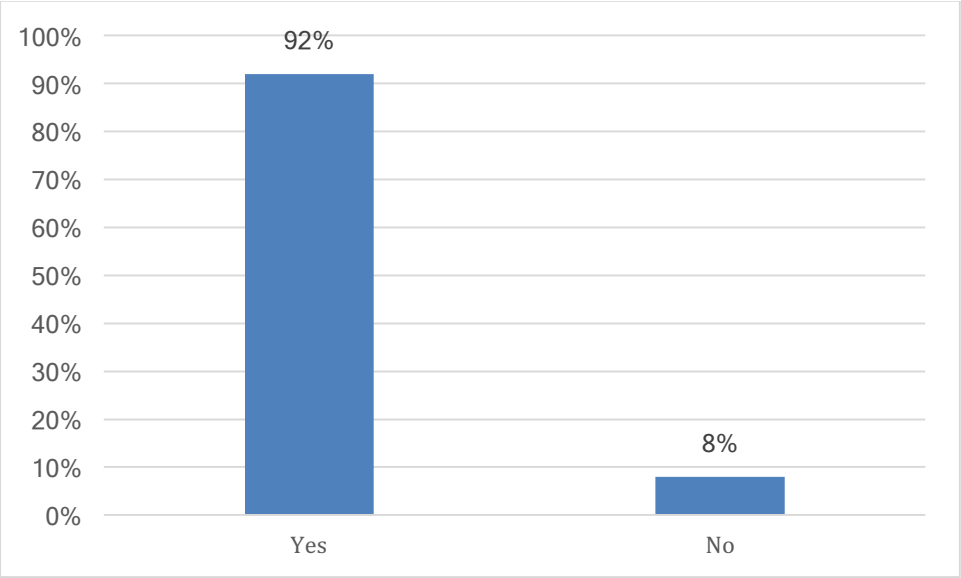
1. **Screening can detect precancerous/abnormal cells so that they can be treated to prevent the occurrence of cancer. Having regular cervical screening offers the best protection against developing cervical cancer (www.nhs.uk).**

We asked: "Were you aware that this is the purpose of a cervical screening?"
(192 of the 245 answered)



Some of the comments shared:
"I know, but I think many people don't, and if people don't know the true purpose then they won't think the risks apply to them."
"This is explained to me each time I have visited for a screen"
"I just thought it was for S.T.Ds"

2. **We asked: "Do you know where to get information about cervical screenings?"**
(192 of 245 answered)

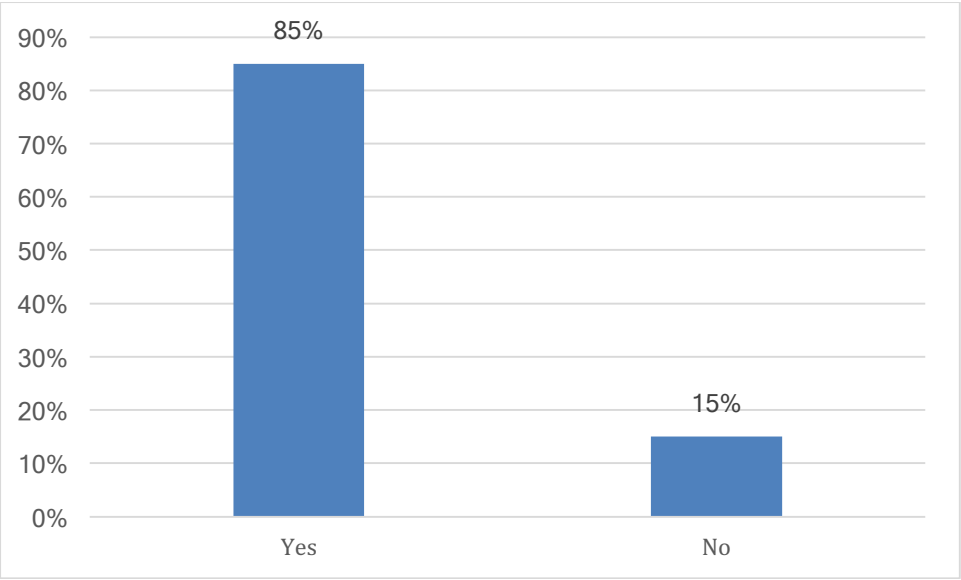


Some of the comments shared:

"My GP, online, the NHS, or cancer research."
"The doctor's surgery has loads of pamphlets."
"I think so, I would contact CaSH (Contraception and Sexual Health clinic) and/or my GP."

3. **Women aged 25-49 will be invited to screenings every three years, women aged 50-64 will be invited to screenings every 5 years (www.nhs.uk).**

We asked: "Did you know previously how often you will be invited for a cervical screening?"
(195 of the 245 answered)



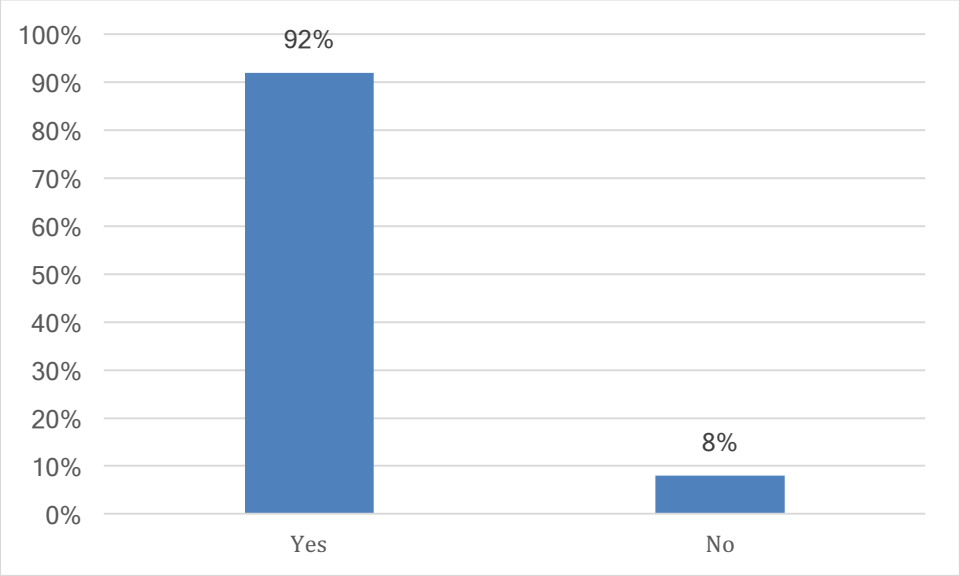
The large majority of the women we spoke to (85%) knew how often they would be invited for screening. 15% of the women were not aware of the frequency.

Some of the comments shared:

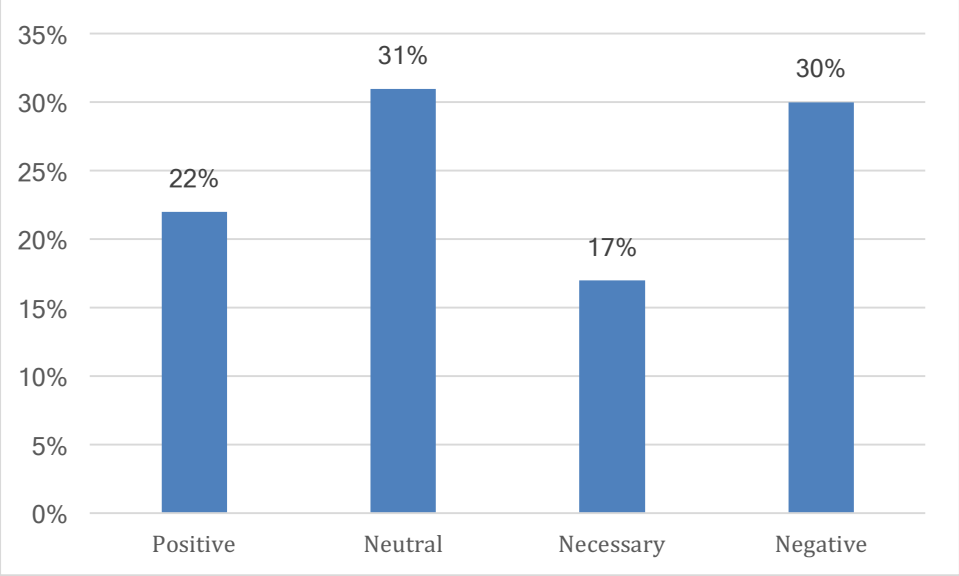
"I think screenings should start younger. There would be no point in educating girls at such a young age for them to then wait 10 years for it to be brought up again, they're not going to think it's important if there's no outcome."
"I knew the age of 25 - 49 was three yearly, but was unaware that 50 - 64 was five yearly."
"Yes, this was explained by the nurse at the time of the screening appointment."
"It is scary to know that once you reach 65 you are considered not worth worrying about."
"The age of 25 before people can have screening is too high. I am 100% convinced that the amount of deaths would decrease even further if the age limit was lower."
"I would like it to be more often or at least to have the option to have it more regularly even if I had to pay for it."
"I thought it was every year."

Section 3 – Experience

1. **We asked: "Have you been invited for a screening?"**
(196 of the 245 answered)



We asked: "If 'yes', how did you feel when you received the information?"



22% of the women we spoke to reported that they felt a positive about receiving their cervical screening invitation. The majority of women (48%) reported that they had a neutral reaction to the invitation or that they felt it was a necessary appointment. 30% of women reported that they had a negative response to receiving their invitation.

Positive comments:

"Pleased to receive the invitation, but not looking forward to the experience."
"I receive regular invitations for smear tests. It is reassuring to know that I can have these tests and always take this up."
"I was terrified but I knew I had to do it. I did it and thankfully everything was fine. I won't be scared to do it again, it's scary to think about but it was actually not that bad."
"Information received was very comprehensive."
"Very pleased I received an invitation and that I did not have to rely on my memory of date of last screening."

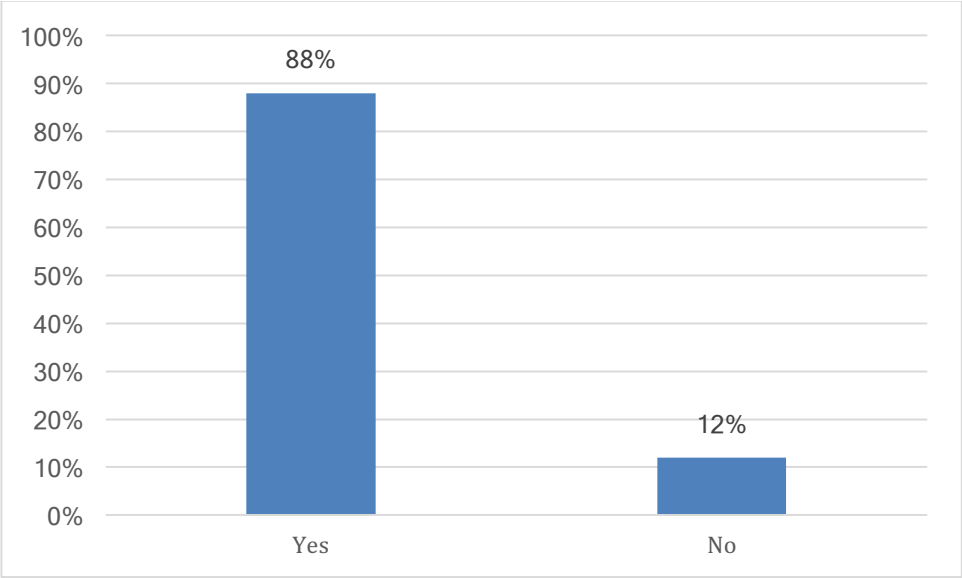
Neutral comments:

"Squeamish more than anything, luckily I had a female friend who had just been and she shared her experience with me, which made me more confident to book it."
"It was interesting because I am a lesbian and was told many years ago that I did not need screening. I had to sign to say that I was not going to attend. I then received a phone call from my surgery to say that they had new information and I should attend."
"I just felt that it is peace of mind to make the appointment and have the screening done."
"Same as any medical check; inconvenient but essential."
"In the past I did not relish going but this is a free test for females and very important to look after our health."

Negative comments:

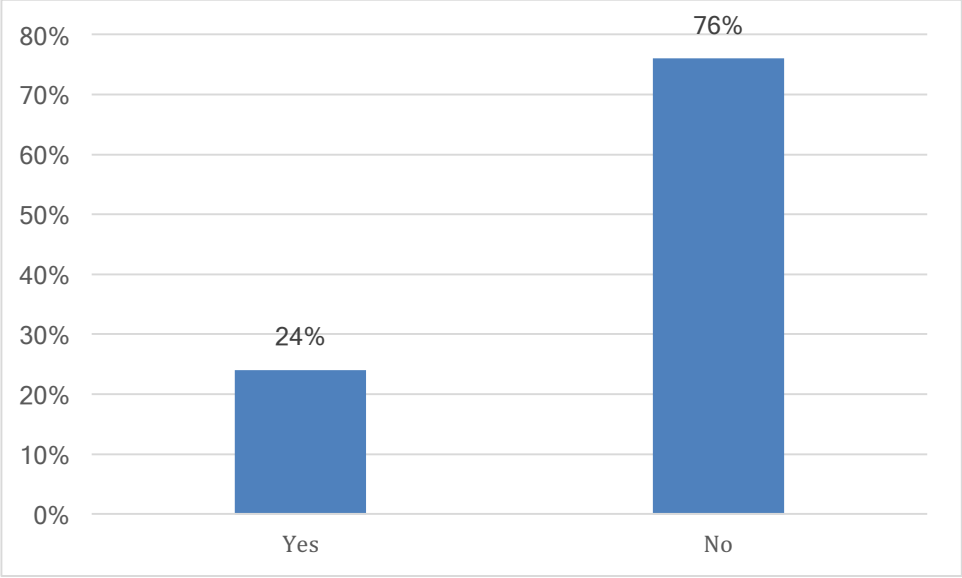
"Frustrated when I had trouble booking an appointment – that could put people off."
"I felt the information was biased towards having the screening and did not allow me to make an informed decision to decline the invitation."
"Slightly apprehensive knowing what the test involves."
"Upset, scared and worried."
"Nervous, not a pleasant procedure."

2. **We asked: "Have you attended a screening?"**
(197 of the 245 answered)



The large majority of the women we spoke to (88%) had attended a cervical screening.

3. **We asked: "If 'yes', was there anything about your experience that would prevent you from going again?"**
(147 of the 245 answered)



The large majority of women we spoke to (76%) reported that there was nothing about their experience of cervical screenings that would prevent them from going again.

Of the women who reported that their experience would prevent them from going for another screening, 12% stated that this was due experiences with staff and poor environments (that did not provide adequate privacy and dignity) whilst 7% stated that they experienced pain that would prevent them from going again.

Comments shared by women who stated they had an experience that would prevent them attending another cervical screening:

- **Comments about the staff:**

"There was a male doctor who was present whilst the nurse did it which made me feel uncomfortable."
"On one occasion the nurse undertaking the screening said she was unable to take a swab and made me go into a position on all fours which was high degrading. I will never be put in that situation again."
"Definitely. I have only been three times in my life. Only once did the nurse understand and make allowances for my absolute fear. After the last one I was so upset that I decided I'd rather die from cervical cancer than go through that again."
"The practice nurse remained in the room while I got undressed with no screen or partition. I had to ask for a sheet to cover myself over."
"Painful, disengaged staff - a bit accusatory that I had 'missed' the first appointment because the invitation went astray in the post."

- **Comments about the environment:**

"Everything, it was one of the worse experiences of my life and so painful. I don't think they should be carried out in a doctor's surgery if they don't have the proper chair."

- **Comments about practical difficulties:**

"Very difficult to get an appointment which fits in around work. Even difficult to get an appointment for the repeat test which was required."
"I don't agree with screening."

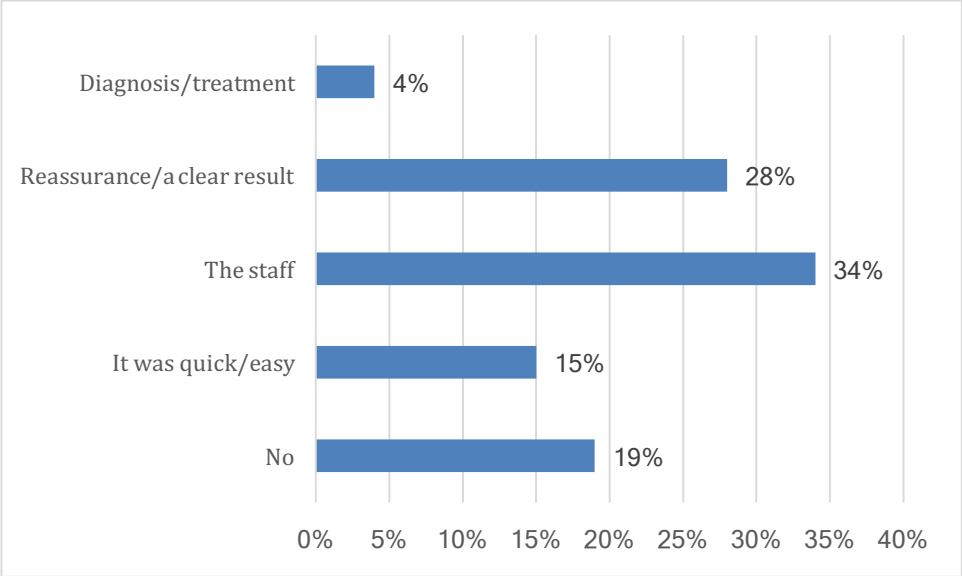
- **Comments about pain/discomfort:**

"Yes - it was EXTREMELY uncomfortable. I didn't respond to the most recent call to be screened. As a postmenopausal woman who has been celibate for over a decade I believe my personal risk is negligible."
"Because the procedure the last time I went was so painful I have not attended the recent reminder to say that I am due for another."

Comments shared by women whose experience would not prevent them from attending another cervical screening:

"I can understand why people don't go for them as they are invasive and can be upsetting but it wouldn't prevent me from going because of how important it is to have them."
"The only bad experiences I have had were when my smear was left out at the GPs so could not be tested. I then had to repeat the process."
"It's not the most pleasant experience but I understand the importance of the test so I will continue to go for screening."
"It was uncomfortable and I didn't like the nurse performing the procedure. But it wouldn't stop me going for my next one."
"No, the staff are lovely and put you at ease, it's not a scary experience for me, I feel relieved to be having it."
"It was painful but I will still attend."
"Nothing at all. Simple straightforward procedure."

4. We asked: "Were there any positives of your experience?"
(141 of the 245 answered)



34% of the women we spoke to reported that the staff had contributed to a positive cervical screening experience. 19% of women reported that there were no positives of their experiences.

Comments shared by women who had a positive experience:

- **Comments about staff:**

"The nurse was very calm and chatty, gives you a bit of distraction when they show some interest, even just little things like "where are you off to after here?"

- **Comments about efficiency:**

"My appointment was dealt with quickly, professionally, explaining the process well. They also explained about possible letters if the outcome was not as expected. A professional service."
"The relief knowing I'd done it and only took 10 minutes."

- **Comments about reassurance/results:**

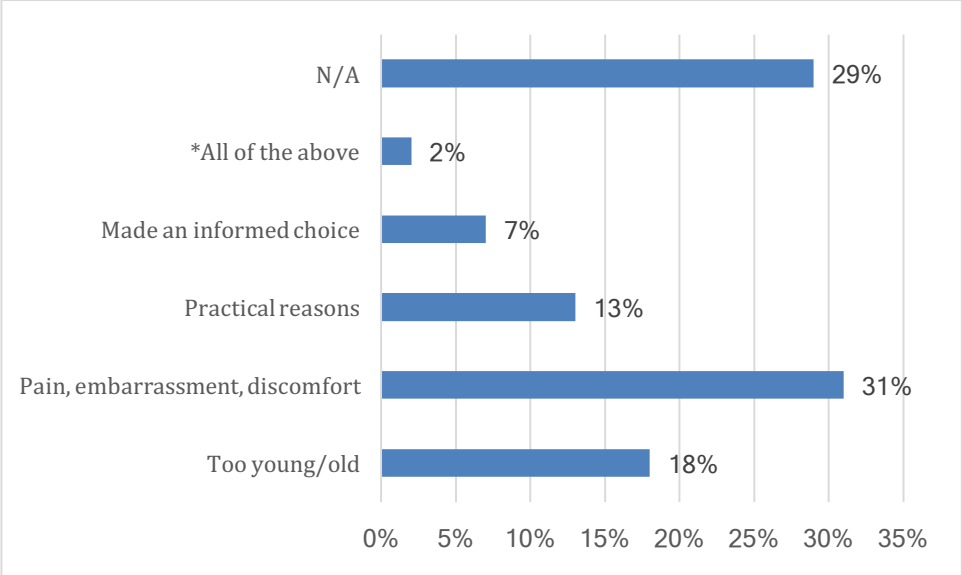
"Knowing that you have had the screening and that you are trying to remain healthy and that if abnormal cells were detected you would hope that this was done in time to receive the best outcome."
"It was good to know things were fine - peace of mind."
"The knowledge that I was doing what I could to potentially save my life."
"Yes, knowing all was well when I got the results."

Comments shared by women who had a negative experience:

"The doctor laughed and said I was being silly."
"It was awful and like being tortured."
"It can depend on the person doing it and some put you more at ease than others and appear more at ease themselves. Some staff are obviously not that comfortable doing it."

Section 4 - Barriers

1. **We asked: "If you have not attended, what are the reasons behind this?"**
   *(*worried it's going to be painful, embarrassing, scared of results, too long of a wait?)*
   (45 of the 245 answered)



The majority of women (31%) reported that the reason they had not attended a screening was due to fear of pain, embarrassment, or discomfort. 13% of women reported that there were practical reasons for not attending (such as difficulty booking an appointment) whilst 7% said that they had made an informed decision not to attend.

Comments about pain, embarrassment, and discomfort:

"I did delay because all my screenings have been very painful."
"I'm embarrassed about going. I am also busy at work so I find it difficult to find a convenient time to go."

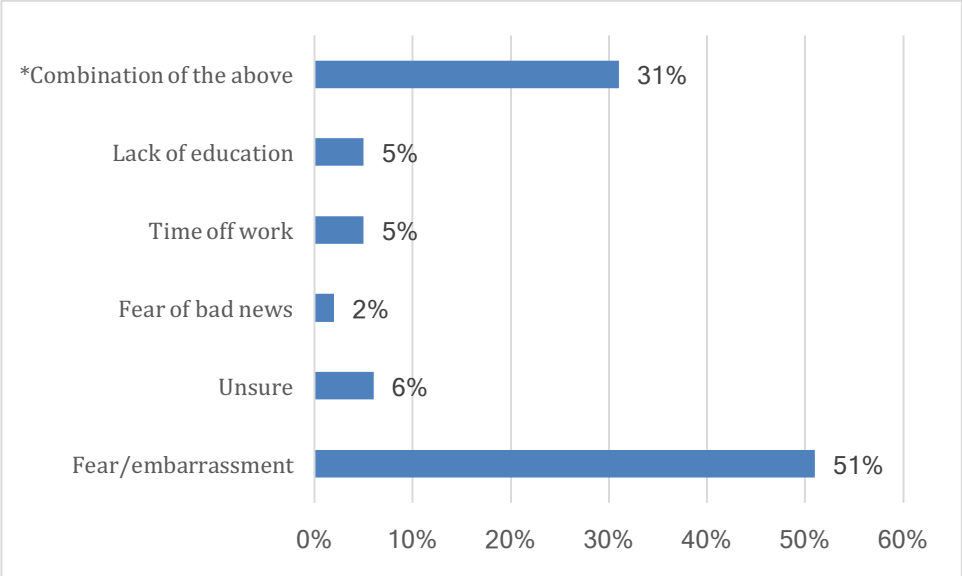
Comments from women who had decided not to screen:

"I think cervical cancer is very rare."
"I go for enough medical appointments/tests and have enough medical problems already."

Comments about practical difficulties:

"I was overdue for this smear because of the difficulty in booking an appointment. My GP surgery only books appointments three weeks ahead. Each time I tried to book an appointment all the slots were booked and I was told to ring back in three weeks. I didn't always remember to call back in exactly three weeks, and when I got round to calling again, the same thing would happen and all the slots were booked. This went on for many months. I eventually got an appointment because I attended the Practice Nurse for a routine review for other medical conditions, and it flagged up that I was overdue a smear, so she booked me an appointment as a priority that week."

2. **We asked: "What do you think the main barriers are for women attending cervical screenings?"**
   *(*fear, embarrassment, literacy, language, unable to take time off work?)*
   (179 of the 245 answered)



The large majority of women we spoke to (51%) reported that the main barriers for women attending cervical screenings are fear and embarrassment.

Out of the 31% of women who gave more than one example in their answer, the most common factors that were not listed in the question itself were:

- **An "it won't happen to me" culture – 32%**
- **Being unable to see the right clinician (a female) – 22%**
- **Fear of getting bad results – 14%**

Other answers included; religious beliefs, not enough advertising, not knowing where to go, complacency or forgetting and continuous pregnancy.

Comments about fear and/or embarrassment:

"It can feel scary when going for one, and having to get undressed. People who may have been abused or victims of domestic violence, may be put off going due to the implications of going back into an abusive relationship." (This quote pertains to a person's historic and personal experience of an abusive relationship)
"Embarrassment for sure, I think some people are misinformed about male doctors carrying out the screening, or put off from hearing horror stories. I do think there's some logistics mixed in with misunderstanding around it too, lack of education means many women undervalue the importance of this screening, and so it seems irritating to them that they have to find time out of their full-time career/parenting life to make an appointment. Perhaps this would change with a lift of those preconceptions."
"I honestly believe it's fear that it will be painful and embarrassing for people. I still feel like that every time but I wouldn't want the alternative outcome and that's why it's so important as it literally does only take a few minutes."
"Pain, embarrassment, previous medical treatments and attitudes of staff."
"Probably fear of the pain and embarrassment. Also for those who don't have regular periods it can be the case that you are on your period when you're supposed to be at the appointment and are embarrassed to rearrange."

Comments about lack of knowledge:

"Ignorance - from no fault of their own. I don't think they advertise it in the correct manner and say 'this is for you'. I think there should be more education."

Comments about appointments:

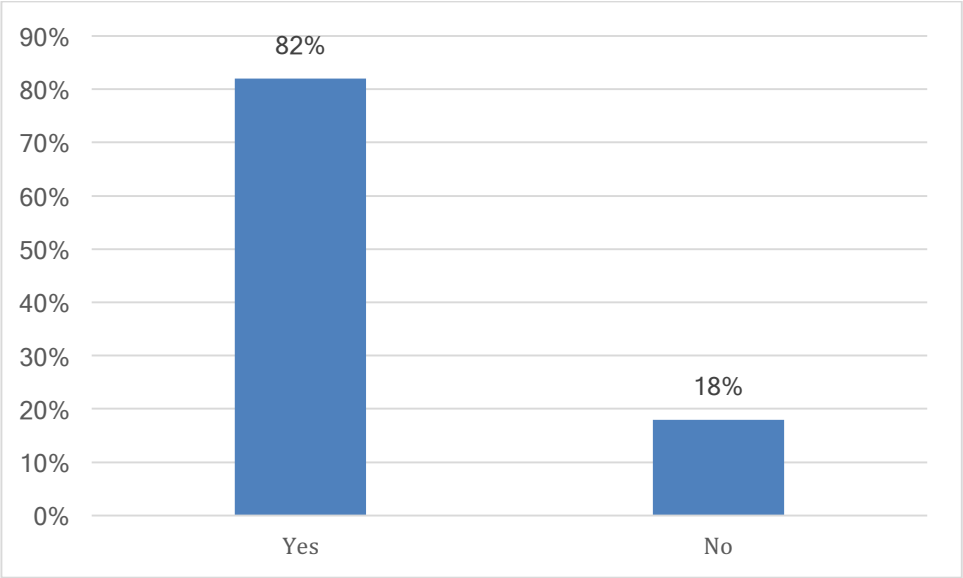
"Apart from the obvious reasons, pain, embarrassment. I often feel the appointments are rushed and I don't have confidence that the results will be screened accurately, due to past issues with poor recognition of pre-cancerous cells."
"Appointments being lost in the post (has happened to me twice now, but not in the same year). Lack of engagement with attendees - you feel as though you are being 'processed.' It can be a painful experience and embarrassing."
"Most of them do not want it, hate it. Also, they tend to make these appointments in the middle of the day so the woman must take a half day off work. For some that means no work and no pay."

Comments that cite a combination of barriers:

"Poor education, fear, time off work, cultural beliefs, male members of staff doing screening."
"Embarrassment, mainly talking to other women this seems to be the most talked about rationale. There is also a culture of 'it won't happen to me' attitude."
"Embarrassment. People with anxiety. People who are scared for the results. Not knowing if they look normal. Not knowing who is going to look at you!"
"I would imagine embarrassment is the biggest barrier, fear, language - many ladies do not have English as their first language, and literacy."
"Time/childcare/fear/embarrassment/don't know what a smear is for. I feel not enough is communicated to them in school about HPV and the need to attend for smears when they are old enough."
"Fear and embarrassment are probably the main factors and the thought that 'it won't happen to me, I have no symptoms'."
"It could be embarrassment, it could be getting time off work. There could be language problems. Some do not know the importance of these screenings."
"Embarrassment and also a fear of the results. Fitting appointments in around work in general are also a barrier."
"I think all of the above are a true reflection. I do feel that a designated smear clinic would be more appealing to women i.e. before or after work hours and those who struggle with English speaking to have someone there to help with the language barriers."

Section 5 - Recommendations

1. **We asked: "Is there anything that could be done to encourage more women to attend a cervical screening?"**
   (184 of the 245 answered)



The large majority of the women we spoke to (82%) felt that there are ways to encourage women to attend cervical screenings. Some of the most common suggestions are as follows:

- 4% of women suggested that cervical screenings are 'tagged on to' or discussed during existing health care appointments, and that the GP should follow up non-attendees with a phone call.
- 19% of women suggested that uptake can be increased via the media. This included social media campaigns, TV advertising, demonstrations/videos of the procedure and other readily available advertising materials such as leaflets.
- 15% of women suggested that awareness is raised through more education and availability of information around cervical screening.
- 11% of women suggested targeting younger women in high schools in order to prepare them for cervical screenings in the future.
- 8% of women suggested a greater availability of appointments (e.g. evenings and weekends to accommodate for those who work during the week).
- 8% of women suggested utilising patient stories, case studies, statistics and positive messages in order to promote cervical screening.
- 3% of women suggested introducing a 'buddy system' by which women are able to take someone with them into the appointment for reassurance and comfort.
- 4% of women suggested targeting large work places and/or utilising mobile units to make it easier for women who work to access cervical screenings.
- 3% of women suggested offering a choice of staff and ensuring that a female healthcare professional is always available to undertake the procedure.
- 4% of women reported that a new method of screening would encourage more women to attend.

Comments about GPs:

"When visiting the GPs perhaps they could bring it up during the consultation to encourage women who won't go."
"Being more proactive in educating and talking to patients who continually don't book appointments, or who have never had screening, I have a neighbour who had never had a smear at 40 years old, I'm an oncology nurse so explained the importance of them, and encouraged her to have it done, thankfully she took my advice, I believe education works in most cases, but we don't always give it in the right way to patients."
"When I was a practice manager in a GP surgery, it became apparent that some women saw it as a painful procedure, some as a pointless procedure. As a surgery, we then starting offering an appointment with the practice nurse to come and discuss such issues before the actual smear. We were even going to approach the mosques and ask if we could speak to the women to engage them in the importance of attending routine smears. Instead of letters for our frequent non-attenders my receptionists actually took the time out to contact these ladies and invite them in."

Comments about sharing stories and messages:

"Keep mentioning the positives. We are all the same underneath and we all get embarrassed but it's worth having the smear."
"Perhaps some statistics to show how beneficial it has been for people whose screening led them to being referred for further tests or some statistics on how effective cervical screening is for young women overall."
"Interviews with real people such as YouTube videos interviewing people before and following the procedure. I think those who have not had children may be a gap, as they may never have had this kind on 'intrusion' before and are more likely to be fearful. Please note that I am solely basing this on my daughters first smear and the encouragement I needed to give her. She couldn't believe what all the fuss was about afterward!"
"Hard hitting campaigns using real life people affected by cervical cancer."
"People should be aware of the reasons for screening and why it's important however there are a lot of women who are unclear. I think it could do with further promotion and awareness raising, perhaps some hard-hitting facts and personal experiences of people who have caught cervical cancer in time as a result of the screening - these stories tend to hit home more with people."

Comments about media:

"Smash the stigma, release a 'myths about cervical screening' campaign. Get some TV/YouTube advertising going. Offer a 'buddy system' that allows women to bring a friend with them to the appointment."
"Media – the 'Jade Goody' campaign proved that. Clinics that are accessible after work."
"Media campaigns, education within schools and colleges. Leaflet explaining the procedure prior to attendance so that any questions or concerns may be addressed."

Comments about targeting younger women:

"Go into schools. They go to school to give them the HPV vaccine but they don't tell them what it is for. They don't have the knowledge, consequences of having sex, not having screening. They don't know what to expect."
"Targeting advertising towards young people/ colleges/universities about the necessity of the screening. Screening done at an earlier age could build the pattern for life. Even a couple of years earlier when at University could save some lives, and reduce fears/embarrassment."
"Give accurate facts and highlight how important they are. Start the process at an earlier age, so young girls get used to doing it, then it won't be so daunting later on in life."
"More awareness, make campaigns more tailored to the different age groups, especially the younger women."
"There needs to be more public awareness about smear tests, including what's involved and why it's important to attend. Maybe targeting college/university pupils. Most women who attend my colposcopy clinic have never heard of HPV and the risks associated with cervical cancer. Maybe the practice nurses need to be giving clearer information to the women participating in smears also."

Comments about appointment availability:

"More publicity and regular invites and follow up for those that do not attend possibly due to working hours. Some night appointments for people on unsocial hours."
"Perhaps a follow up phone call/text message urging those that do not attend to do so."
"Possibly look at mobile screening similar to the breast cancer facilities and maybe target large organisations and use their car parks to encourage more women to come along."
"If there was somewhere convenient that I could just pop in and know that I could just get it over and done with within a few minutes and then pick up my results the following week or month I might go."
"More flexibility about appointment times. Evening and weekend appointments might help?"

Comments about screening 'buddies':

"Maybe allow a close friend in the room for those who are too nervous."
"I know it sounds odd but I think something like women sitting together whilst waiting to go in the treatment room. Maybe a nurse/facilitator sat with women before they go in the room. The waiting is the worst bit. Relaxing music and aromatherapy. Make it feel more pampering."
"A video to watch prior so women feel fully informed of the process and know exactly what to expect. A screening 'buddy' who can talk someone through the process from personal experience."

Comments about finding new methods:

"Find a less invasive way of doing it - gynaecology is still medieval and needs investment to modernise."
"Find a different way of screening."

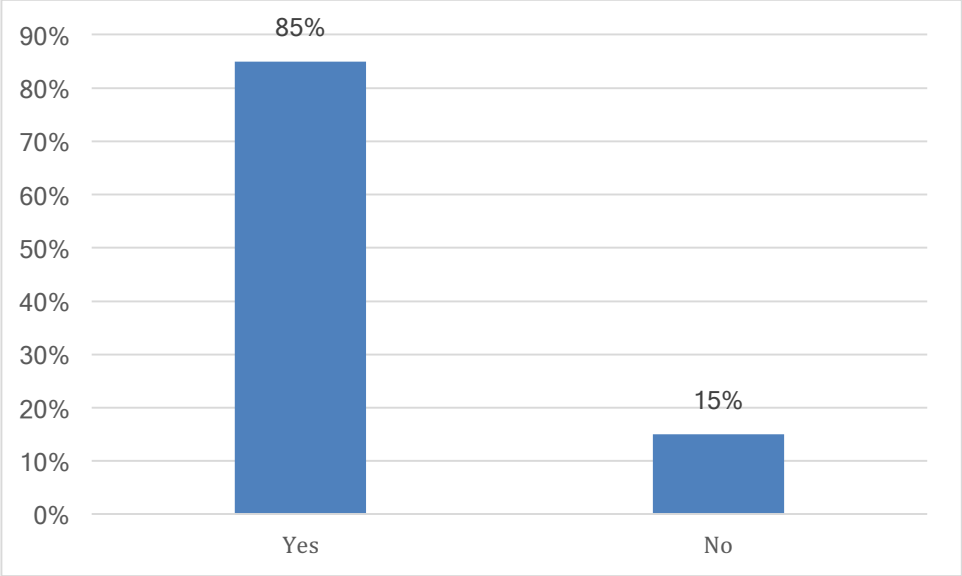
Comments from those who feel nothing more can be done:

"I don't think so; all the information is out there so can't think of anything to encourage anyone. It's a personal decision."
"From my experience, I don't think that anything further could be done."
"I can only speak for women in my socio-economic, educational, belief etc. group - but I believe the women already know what they need to know. If they choose not to attend, it will be an informed decision."
"Not sure anything else could be done as it is already extensively advertised and encouraged. Short of dragging women in off the street there is little else to do. A woman ultimately has to take responsibility for her own health."
"Not sure as I don't understand women not taking up the service and I have told friends, family and colleagues to make sure they go"

Other comments shared:

"Maybe put a class on (as you do for expectant mothers) with a pelvis demonstrating with the tools that are going to be used for the cervical screening, then it's not so daunting then at least women know what to expect and what it entails."
"A phone line to speak to someone about any concerns."
"I would suggest a Well Woman clinic attached to local GP surgeries where there could be a drop in say once every so many varied weeks. Or same day appointments (obviously, this would need to be limited service but even by providing a few appointments for hard to target people would be an advantage). Text message results if good? The waiting is horrible. There was a short video on the procedure at the NHS England event that would be good to show on TVs in waiting room, on all targeted cancers to include cervical tests and bowel cancer. These videos were animated and inoffensive so nobody could be offended and small children would not know what it was."
"Ensure literature available in different languages in all clinics surgeries and discussed by all health professionals."

2. We asked: "Would it help to have the procedure explained first?"
(192 of the 245 answered)



The large majority of the women we spoke to (85%) said that it does help to have the procedure explained, however, 15% felt that this would not be helpful.

Comments from those who feel it would help:

"Show a short video clip to show how its performed especially for women that are having it done first time."
"I think if it's done in a light and breezy manner, emphasising the benefits of getting it done and taking out all jargon, that may help."
"I think a leaflet explaining the procedure in a plain English way, even down to what items of clothing to be removed, as silly as it sounds. I prefer to wear a skirt for example as I don't feel quite as exposed. How long the procedure will take, what will be asked of you as the patient during the process. Simple but reassuring information."
"Explanations are always helpful, but I think something should be done before the lady even comes for the test to educate more ladies about the importance of the test and to reduce embarrassment. In the case of ladies with language barriers, the community as a whole could be involved."

Comments from those who feel it would not help:
"I personally prefer not to know."
"Maybe. Could put some people off. Perhaps give people the choice, obviously the first time can be a bit daunting, perhaps ask if they want a companion to accompany them."

Healthwatch Lancashire Summary of Findings:

Here is a summary of findings from the visits to the groups and the online survey:

- Of the women we spoke to in targeted areas, 10% specified that they were from Blackburn, 15% from Greater Preston and 5% from Blackpool. The remaining 70% were from other areas across Lancashire.
- 70% of women said that cervical screening is very important to them. 5% said it is not at all important.
- 49% of women said that the reason cervical screening is important to them is because it acts as a preventative measure and can provide early diagnosis. 17% reported that it was due to being personally diagnosed or treated, and 10% because it was a part of their regular health routine.
- 98% of women said that they were aware of the purpose of a cervical screening.
- 92% of women said that they know where to get information about cervical screenings.
- 85% of women said they know how often they would be invited for a cervical screening. 15% of women reported that they were not aware of this.
- 92% of women had been invited for a cervical screening.
- Of those who had been invited, 22% said they felt positive when they received the invitation. 48% of women reported feeling neutral or that they felt it necessary to book the appointment. 30% of women reported negative responses to receiving their cervical screening invitation.
- Of those who had been invited, 88% had attended a cervical screening whilst 12% of women had not.
- Of those who had attended, 76% of women reported that there was nothing about their experience that would prevent them from going again, whilst 24% said their experience had put them off.
- 34% of women who reported that their experience was positive said that this was due to staff, 28% due to receiving reassurance from a clear result and 15% due to it being a quick or easy process.
- Of those who had not attended, 31% reported that this was due to fear of pain, embarrassment, or discomfort, 13% due to practical reasons (such as difficulty booking an appointment) and 7% said they had made an informed decision not to attend.
- 50% of women reported that the main barriers to attending a cervical screening were fear and embarrassment. 31% gave a combination of barriers, the most common being an ‘it won’t happen to me’ culture.
- 82% of women feel that more can be done to encourage others to attend cervical screenings whilst 18% feel that there is nothing more that can be done.
- 85% of women feel that it would be beneficial to have the procedure explained first, whilst 15% feel that it would not be beneficial.

Additional comments from organisations:

The report was sent to representatives at Lancashire Women's Centres for additional comments. Representatives said that although they had no specific comments to add they had found the report to be very interesting.

Response from provider:

"The NHS has a critical part to play in securing good population health and disease prevention. NHS England has a specific role to commission the public health services. Screening and immunisation programmes have an important role to play in improving public health outcomes, reducing health inequalities, and contributing to a more sustainable public health, health and care system. NHS England North (Lancashire and South Cumbria) asked Healthwatch Lancashire to carry out this work on our behalf, in order to develop a better understanding of the barriers to people taking up screening and immunisation. We would like to thank Healthwatch Lancashire for producing this report, which will be used to learn lessons and improve the delivery of screening and immunisation services for residents of Lancashire and South Cumbria."

- Response from NHS England

Appendix – Share your views and experience

We asked the 245 women we spoke to: "Do you have any views you would like to share from experiences with female friends, family and loved ones who have attended a cervical screening?"
(81 of the 245 answered)

"I really struggled to encourage my wife to attend an appointment for cervical cancer screening. The main reasons why she didn't want to were that she didn't feel comfortable ringing and booking an appointment as you have to ask for it and she said that she would prefer it if they rang you because this would avoid an awkward phone call. Once she had the appointment she attended because she never cancels appointments but her initial apprehension was with the appointment booking."

"My sister however never had a smear test and discovered about age 50 (due to heavy bleeding) she had cervical cancer, she has had to endure chemotherapy and radiation therapy. She also refused to tell anyone because of the stigma surrounding the term 'cervical cancer' i.e. that it is sexually transmitted. Perhaps a campaign to allay these myths would be helpful, after all you may only have had one partner but still get it."

"Most of the ladies I know who do not go for regular screening do not do so due to embarrassment, despite understanding the importance of the test. Others simply do not make the time to go as they have a 'it won't happen to me' psychology."

"My sister was lucky. She should have gone for screening but didn't attend. She nearly lost her life and now has no bladder as a result. She could have stopped this as it could have been diagnosed earlier. She regrets not having had a test. When women don't attend, they are not looking after themselves and too busy but then it can be too late especially when you are older because you are only tested every 5 years."

"I know a lot of my family are too scared to attend cervical screening, but it is vital every woman gets checked regularly."

"This is the reason for completing the survey. Experiences locally for both my daughter and my friend's daughter have been less than satisfactory. The attitude of some of the staff has been less than friendly, this would have been helpful through difficult cervical procedures. In my daughters case the female doctor showed no empathy did not explain the procedures which caused further upset in a difficult situation. The long wait for test results also causes further distress and worry. In my friend's daughters case, mistakes were made, things were missed and as a result she lost her life at the age of 27."

"Both my daughters attend regular screening. They have never commented in a negative way about their experience. I think it is something they need to have on a regular basis, to help keep them well."

We asked the 245 women we spoke to: "Please share with us your experience of having a cervical cancer screening."
(110 of the 245 answered)

"When I went for laser in 2000 the staff were lovely. On the ceiling there was a picture of George Clooney and they had a box of other celebrity cut outs to change if you weren't that keen on George. This did help take your mind off the procedure and made me relaxed."

"I attended my GP practice, had to wait in the normal waiting area for quite a long time as the nurse was busy. I think if you have an appointment time then it should be on time. The room is off the main waiting area which is not really suitable."

"I was nervous whilst sitting in the waiting room, but as soon as I went in the nurse put me at ease. She knew it was my first screening and talked me through everything before the procedure. And then she distracted me throughout the procedure with different questions. It didn't hurt, it was just a bit uncomfortable. But a few seconds of discomfort is nothing if it can help with early diagnosis!"

"Undignified and slightly embarrassing examination but abnormal cells were detected and treated at a very early stage, and so prevented anything more serious developing. An absolute must for all woman of any age."

"At my doctors, we are able to go behind a screen and cover ourselves with a blanket so nothing too embarrassing at all. I do not find the test embarrassing or painful. There are things I would rather be doing, like going shopping, but it really isn't that bad! The hardest part is fitting in the appointment with work and family commitments."

"The last one was extremely painful, I have only previously experienced discomfort and no reassurances of what I could do the next time (to prevent this), if anything at all."

"My experience has been fine, when I was younger I found them more difficult/embarrassing, but as I have got older they have become part of life, similar to going to the dentist, and they are done so quickly they are not a problem."

"It was so bad I don't want to think about it, I was crying, I was in pain and the doctor just coerced me into putting up with it. It was like being sexually abused all over again. This is a huge problem. For women who have suffered sexual abuse, being in this vulnerable and submissive state is appalling. I will not put myself through that. I don't know if there are a higher number of survivors amongst lesbians but I'm certain this contributes to us not getting cervical screening."

"I feel deceived, cheated, violated, misled, bullied and coerced into a test I don't want, need & will never have again."

"If I hadn't attended screenings I would probably have got cancer."

"Painful throughout, blood everywhere, no support when I was upset."

"The very first one I had was very painful and frightening as the nurse only had a large apparatus and didn't explain anything. The ones in recent years have been a lot nicer."

"Increasingly stressful, after attending my first two with no issues I then had poor results on my third. Not enough cells were collected and I had to return to my nurse for three more attempts before being referred to colposcopy. However, this would not prevent me from going again."

"Quick/professional service."

"As you would expect it be, over and done within 5 minutes."

"Only had one but there was nothing too horrific about it. The feeling when it's over is better than having the weight of booking the appointment on your shoulders."