

## ***“Why Me?”: Women’s Views of Cervical Screening in Greenwich***

### **Introduction:**

The NHS Cervical Screening Programme invites women between the ages of 25 and 64 for regular cervical screening. In England, cervical screening prevents 70% of cervical cancer deaths (estimated). Improved screening uptake could result in more lives being saved.<sup>1</sup>

Screening checks for a virus called high-risk HPV and cervical cell changes. It is not a test for cancer but aims to detect abnormalities within the cervix that could, if undetected and untreated, develop into cervical cancer. 99.8% of cervical cancer cases in the UK are caused by HPV infection<sup>2</sup> and thus 99.8% of cervical cancer cases in the UK are preventable.<sup>3</sup>

### **Aim of the study**

To understand the views and experiences of cervical screening amongst non-attenders – i.e., women who had not attended for their cervical screening tests in Greenwich.

### **Methodology**

Greenwich Public Health recruited women to take part in one of two focus group discussions at the end of November and early December 2022. Healthwatch Greenwich provided a facilitator and note-taker for each focus group.

Focus group discussions were held on two weekend mornings in community spaces in Greenwich. Discussions were recorded, with verbal consent from participants.

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<sup>1</sup> NHS England

<sup>2</sup> <https://pubmed.ncbi.nlm.nih.gov/29567982/>

<sup>3</sup> Cancer Research UK

None of the women requested an interpreter or required communication assistance, and everyone participated in English.

A topic guide was used to steer the discussion and reveal experience and insight. The topic guide was divided into the following themes:

- Association - words/emotions associated with cervical screening
- Awareness of cervical screening and information sources
- Knowledge/assumptions about the screening procedure
- Challenges/barriers to cervical screening attendance

A total of nine women participated who each received a £30 voucher. Leaflets about cervical screening were made available and a representative from Greenwich Public Health was present to answer queries about the screening procedure at the end of the discussions.

## Limitations

The group did not exclusively consist of women who had not attended for cervical screening. Two women had received cervical screening tests. Of these, one was a recent migrant and had the test in her country of origin. However, the views summarised in this report are overwhelmingly of women who had never attended (when offered the opportunity to do so) for a cervical screening test.

We do not have access to demographic information on participants collected by Greenwich Public Health. While the group was diverse in ethnicity, we do not know how diverse participants were with regards to other protected characteristics. As such, discussions captured here may not reflect a wide body of views or experience.

All participants were of reproductive age, and we do not therefore capture the views and experiences menopausal or post-menopausal women.

## Findings

### Association—words/emotions linked to cervical screening

We started the discussion by asking women to write down three words they associate with cervical screening. Whilst not all women wrote down three words, everyone wrote down two or more words.

A total of 21 words were recorded. The most common word used was *“pain”*<sup>4</sup>. The second most common word was *“worried”*<sup>5</sup>. The third and fourth common words were *“discomfort”*<sup>6</sup>, and *“sexual transmission”*<sup>7</sup> respectively.

Participants were invited to explore why they had chosen particular words or feelings.

### Pain

There were two main reasons participants associated pain with cervical screening.

- **Peer group** – some had heard or spoken to women they knew who said the procedure was painful.

*“Painful. That’s what I’ve heard from people. It may not be true, but that is what I have been told by friends. Haven’t asked the specifics and I don’t know if it’s during or after.”*

- **Invasive** – others said the thought of *“something going inside”* made them think the procedure must, by definition, be painful.

*“Is this going to go inside me? I can already feel it’s going to be painful. Oh God this is going to be painful”*

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<sup>4</sup> Includes associated words/terms like “painful”, “is it painful?”

<sup>5</sup> Includes words like “afraid” and “anxiety”

<sup>6</sup> Some used synonyms like “awkward”

<sup>7</sup> Includes words specifying being sexually active – like ‘having sex’ and STIs

And: *when they call they make it sound like it's not something serious. We know it's invasive and going to be painful"*

All the women associated pain or discomfort with cervical screening tests: *"It is painful. There is no way around it... It's painful."*

Pain was at the top of women's minds, but said it's not generally mentioned or discussed by healthcare professionals when talking to women about the test. *"No one ever tells you about the pain. You do not know about the pain..."* Another said: *"is it like a pin prick or like giving birth or like getting bloods done."* One woman said the pain *"has become almost mythical."*

## Worry

Women who noted "worry" as one of their words said this was the first thing they thought of when they got a call or letter asking them to attend for an appointment because *"there must be something wrong with me". Why me? Why now? I don't have any symptoms like itching or discharge"*

Other women echoed this sentiment: *"I was on the couch watching TV and I get a call - "can you come for cervical test?" It was like police knocking on the door - out of nowhere! I was not sick - why was I being called? I called a friend - did anybody call you? Are you sure? I have got a call, so I know I am sick."*

Again from another woman: *"From my experience, if you get a letter, you are in deep shit!"*

Others shared similar sentiments: *"Never feel sick so why is there a need?"*

Worry about the results of the test was also a concern: *"What if results are not going to be positive?"*

Other women had similar concerns: *"Waiting for the results is going to be stressful."*

And: *"I have been for blood tests before and they don't tell you about the outcome. There is probably nothing wrong, but you don't know... they should tell us when we can expect the results"*

## Discomfort

As women spoke about discomfort, they expressed both being touched in an intimate area by a stranger in addition to concerns that the person carrying out the procedure might be a man. *"I really don't like being touched by strangers anyway, so from that perspective I'm already feeling ill at ease"*

Another woman shared: *"I am concerned about who is going to do the test - male or female? The idea of a man doing it makes me feel uncomfortable."*

One woman said since the test was going to cause discomfort, she wanted to do it herself: *"I thought why can't I do it myself? I do the COVID test on my own - insert it up my nose. When I saw images [online] I saw it has to go into the cervix - it has to go FULLY in, and that is when it registered why I can't do it on my own."*

Another said: *"When they call you they are so nonchalant-as if it's something ordinary. I know it's going to be invasive. There are other less invasive procedures like ultrasound, but it's not offered."*

## Sexual transmission

A few women associated the screening with being sexually active and felt those who were not having sex, did not need the test: *"They just assume all young people are having sex. It's not the case. Just because we are in a certain age group they assume things about us. If we haven't had [sexual] relations, they shouldn't push us for the [cervical] test. It's for people who are sexually active. Every young person is not [sexually] active"*

Another said: *“My daughter is 16, and I want her to have the test when it is time. But I don’t know if it only after she has been with someone. That is what I want to know”*

Some women also said the test could check for sexually transmitted diseases – and therefore not needed if the person was not sexually active.

### **Awareness and information sources**

Most women had no previous awareness of the test and heard about it for the first time after receiving a letter, text, or call offering an appointment. Some reached out to women (family and friends) in their social circle for information. *“I asked my sister-did you get a letter? Sister said it’s normal, and she has got it done as well. After talking to her I felt reassured”*

Another woman said: *“I talked to my support worker - you must go she said. If you need a woman you can ask for it. I felt more confident after speaking to her.”*

A few women confirmed that speaking to other women increased their confidence: *“I got the call when I was at work... I went and spoke to my colleague who is very good with these things. She said it’s really important. “I did it when I was young-a tumour was found. It was in its early stage and was removed. I wouldn’t be here if today if I didn’t have the test.” It did help to reassure me.”*

Whilst some got reassurance from those they knew, others did not, and conversations heightened anxiety. *“Spoke to my friend, but she is a drama queen. She has zero tolerance for pain. The way she spoke I already got scared”*

Some went online to find information *“I went on Google. But there is so much information there.”* and others said they received a booklet with their appointment letter, but they didn’t read it. *“I got a booklet with the letter but I didn’t read it...the information is there but you still have to read it. It would be better if they just tell you.”*

Receiving a text was also unsatisfactory: *“The text is brief and just tells me to book a test. It doesn’t allay any concerns. If I had a phone call from someone... and they say ‘we notice you haven’t had it [cervical test] before, is there anything that is worrying you?’, I would like that. It doesn’t have to be a GP, just a medical professional because I don’t feel comfortable speaking to a receptionist about intimate things”*

## Why have a cervical test?

When asked what the test was for, they gave varied responses including:

- detecting cancer,
- to see if their reproductive system was ok,
- checking for infection and sexually transmitted diseases with a couple of women specifically mentioning HPV.

When asked what age group the test applied to a number of women spoke about the need to be sexually active: *“30+ because that is when you are having frequent sex.”* Women, who were recent migrants, used “marriage” as a proxy for being sexually active. *“Only people who are married”*

## Knowledge about the procedure

When asked if they were aware what the cervical test entailed, many women said they were not sure. In particular, how long it might take, what preparation was needed, the instruments used, what pain relief was available, how long they would need to wait for results, or what choices they might have. *“I really don’t know what happens. I know they put something inside you. But beyond that I do not know...”*

Another woman said: *“Doctor/nurse will explain, take consent, lie down, bring all these things and put it in me. Don’t know how long, if there is any injection...Is it going to be an operation? How many minutes is it going to take? Do I need to prepare for it?”*

Most women said they had never seen a speculum before, and imagined it would be unpleasant: *“Inserting the speculum would be uncomfortable...”*

*It's going to touch us internally. It is going inside. The size makes me anxious"*

Echoing this point – another woman said: *"Haven't seen a speculum, but just the thought of something being inserted arouses feeling of discomfort and pain"*

*"I am worried about the size too-it's something that is going inside you so makes me anxious not knowing what size it would be"*

A younger woman spoke about her cultural norms of virginity and the importance of retaining virginity before marriage: *"My cousin lives abroad and has PCOS. The doctor wanted an examination and to use a speculum, but her mother said no. In the end they did an ultrasound. I was talking to my cousin about it, and she said she doesn't want the doctor to be her first [penetration]"*

Another said: *"If you are a virgin will it break your virginity?"*

## Barriers

When asked if there were any practical challenges that made it difficult for them to have a cervical test, we heard that it could be hard to take time off work or studies: *"I move around a lot because of work-it's mostly in Central London. In my last job there was no option to work from home. To go for the test, I would need to take leave from work which is off-putting."*

And it wasn't always easy to contact GP practices to arrange an appointment or get more information. *"I get texts asking me to book a [cervical] test with my GP surgery. I find contacting my GP surgery hard anyway. The GP website is really horrible. It's really busy, and it is hard to find where anything is. I would prefer if I could book on the website rather than wait endlessly on the phone. They wouldn't do it on a weekend. It would be helpful for me if they did so I can work it around my studies"*



Some were unsure when in their monthly cycle the test could or could not be done. *"I heard someone say it has to be two weeks after my period- that makes it difficult to plan things"*

One woman told us about her experience: *"I always wanted to do it... I had booked an appointment and was working on the outskirts [of London] and called in to [GP practice] say I was going to be late. The receptionist said up to 15 minutes is fine. I was on my break and rushed there in an uber. I was late but it was 17 minutes and the receptionist refused me the appointment."*

Women wanted more information not only about the procedure, but how long they'd have to wait for the results: *"They don't say how long it would take for the results, so you just wait. Your brain is restless."*

Another woman said: *"At this time I have built it up in my head because I don't have enough information. Maybe it's not that big a deal. It doesn't help that you hear little snippets of information from people. No one tells you it's mostly ok. They only tell you how uncomfortable it is. So, there is a lot of myth. You are expected to go and search for information yourself"*

Quite a few women said they'd prefer a call rather than a letter: *"The fact that we are not responding to the letters should imply we have some issues. If they could call and say it's not an operation, explain things, say it's going to take 10 minutes, then I'd go because then I'd think it's like getting my bloods drawn"*

The gender of the caller was important: *"A woman has been in your shoes. She would have had the procedure done herself and will understand and be able to tell from her experience. I can talk to her, confide in her, ask questions. With a guy it would be awkward."*

## How to encourage more women to attend for cervical screening

Based on our discussions in two focus groups, the following may encourage more women to get tested:

**Communication:** Receiving a phone call (rather than a letter or text) from a female member of staff telling them about their appointment, answering questions and encouraging them to attend.

**Information about pain/discomfort:** Women want open and frank disclosure about any pain or discomfort the procedure may cause and what they can be offered – or do themselves – do to minimise it.

**Information about the procedure:** Women want information on when and how the procedure is conducted, for example – when in the menstrual cycle it can and can't it be done, who does it, the tools used, when they should expect results, and what choices they have – for example to have a chaperone with them, or to request a smaller speculum, and if it would affect virginity.

**A female nurse or doctor conducting the procedure:** There was an overwhelming consensus for having a female healthcare professional carry out the test and confirming with the patient that this would be the case. *“A woman knows a woman's body.”*

**Weekend and out of hours appointments:** For some women, their place of work or education were outside the borough, making it difficult to accommodate the medical appointments during office hours in the week.