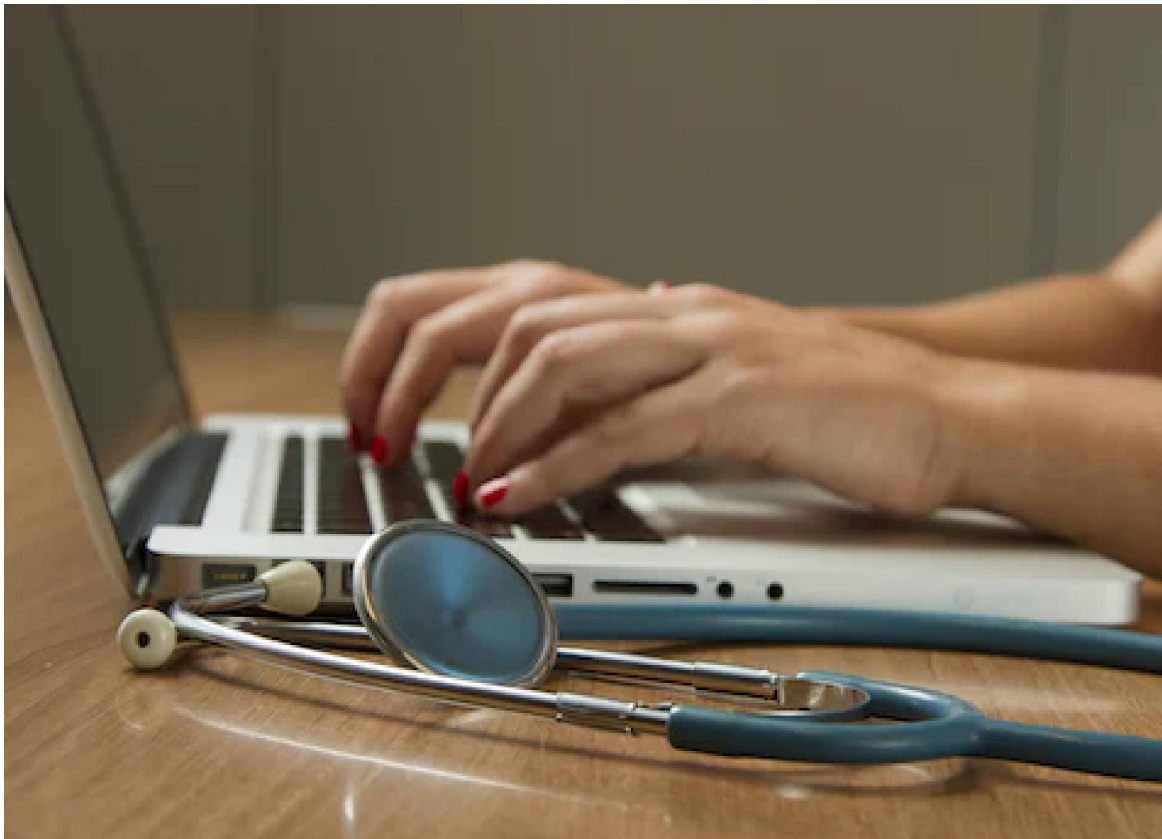


# Experiences of Cervical Screening in West Essex.



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## 1.0 Introduction

### 1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system. One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing health and social care services and choice in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthened as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are meeting daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share complex experiences such as the one's shared in this report.

### 1.2 Background

Healthwatch Essex were approached by Hertfordshire and West Essex ICB to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing. Two projects are selected per calendar quarter for in depth engagement, with the production of a report based on this engagement.

### 1.3 Acknowledgements

Healthwatch Essex would like to thank all the members of the public who took part in this project through the survey and interviews. Our thanks are also made to those individuals who took the time to meet with us and share their personal stories.

### 1.4 Terminology

CIN - Cervical intraepithelial neoplasia (CIN) is a term that describes abnormal changes of the cells that line the cervix.

HPV -Human papillomavirus.

ICB - Integrated care Board.

LLETZ procedure -large loop excision of the transformation zone (LLETZ).

NCT - National Childbirth Trust.

PCT -Primary Care Trust.

## **1.5 Disclaimer**

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the projects time frame. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

## 2.0 Purpose

The aim of this project is to gather people's lived experience of accessing and using the cervical screening programme across west Essex.

### 2.1 Engagement methods

We connected with a wide range of organisations and services in the execution of this project, including Essex County Council, Rainbow Services, Primary Care, community and voluntary services working with homelessness, addiction and mental health, our Ambassadors and carers support, in order to share details of our project and our Facebook page and website link requesting women and people with a cervix for their feedback and lived experience regarding the cervical screening process. We also shared this request to numerous local Facebook groups in the west Essex footprint. The Facebook posts reached over 80,000 residents across this area.

The survey link was also emailed to numerous groups and organisations across west Essex including:

Harlow Latton Ladies Group  
National Women's Register-Saffron Walden  
Essex Women's Institute  
Essex Ladies Golf Club  
West Essex Cricket Club  
Essex Bowling Association  
Tye Green Indoor Bowls Club  
Changing Pathways-DV support  
Essex Pole and Tone  
Stanstead Mountfitchet parish council  
NCT groups  
Epping forest Outdoor Group  
Epping Bowls Club  
Epping Art Society  
Life Church Epping  
Women 4 Women Essex  
New City College

Harlow College

Saffron Walden Council

Great Dunmow Council

Ongar Town Council

North Weald Bassett parish council

Epping Forest Child and Family Wellbeing Team

Home Start Essex

Support 4 Sight

Rainbow Services

Harlow Salvation Army

Streets 2 Homes





## 2.2 The Survey



We devised a survey asking women and people with a cervix to complete it, answering questions about their cervical screening experience. We were looking for positive and negative lived experiences.

59 people completed the online survey and around half of them offered a one-to-one interview so that they could share more details about their experiences.

### Question 1:

Do you receive a letter inviting you to attend a cervical screening appointment?			
Answer Choices		Response Percent	Response Total
1	Yes		95.74% 45
2	No		4.26% 2

### Question 2:

Do you attend your cervical screening invitation?			
Answer Choices		Response Percent	Response Total
1	Yes		84.78% 39
2	No		15.22% 7

### Question 3:

We then asked, ‘If you do not attend your screening invitation then please tell us why, what are the barriers for you, being nervous, not being aware what happens during the screening, previous poor experience, worried about the results, cultural or religious values etc’:

Responses were as follows:

“I had a previous very unpleasant experience where the nurse did not appreciate that I was uncomfortable. I said it hurt and she said, ‘it does not!!’ I never got an invitation again so presume she thought I was difficult”.

“I could not make appointment at a suitable time as I'm a full-time carer with no support”.

“I had my last cervical screening two weeks after my 60th birthday. I was told that I would be over 65 (by two weeks!) before the next one was due, so I would not get my final smear. I contested this at GP level, PCT level and NHS England only to be told a big fat NO. I was told that even if I did get my test done at my GP surgery, it would be rejected for testing”.

“I don't feel that it's very important. I feel that the facts and figures lie. I feel there is too much pressure put on women to attend”.

“I had bad experiences during my first three screenings”.

“I am going to be 47 in a few weeks' time, and I have only ever had one smear test which is my choice. I know I am mad but the way I see it, it's my body and I don't want to have it done. When I did have a smear test, I found the whole thing uncomfortable and embarrassing which I know is silly as it can save my life. I would go for a smear test if I thought there was something wrong”.

“There's embarrassment, its invasive, too many false positives. Nurses running late, difficult to get an appointment or to get through to the surgery. If you do get through, then the receptionists are often rude and unhelpful”.

“I have had one smear test when I was very young and found it extremely painful and distressing. I have avoided going ever since, though not doing so does scare me because I know how important it is. I have experienced trauma throughout my life which makes this kind of procedure extremely difficult for me, and I just cannot go through with it as it triggers me so badly”.

“I attend them now, but I have missed them in the past. I had to rebook because I felt uncomfortable and triggered”.



Question 4:

If you do attend your invitation, how easy or difficult is it to book an appointment at the GP surgery?				
Answer Choices			Response Percent	Response Total
1	Very easy		36.36%	16
2	Easy		29.55%	13
3	Neither easy nor difficult		11.36%	5
4	Difficult		13.64%	6
5	Very difficult		9.09%	4

Question 5:

We then asked, ‘please tell us about your screening appointment experience, are you made to feel comfortable, is the process explained fully to you, do you feel able to ask questions or raise any concerns, do you feel supported during the appointment etc’:

Responses were as follows:

“The last time I went I was put completely at ease. All it takes is a friendly nurse/doctor to welcome you in with a smile and a happy tone. You don't really need to have yourself on show, you are covered for the most part. As a large woman, I am nervous going to the doctor for anything, for fear of being told whatever is wrong with me is because of my weight, but this is one appointment where I'm just a woman”.

“I was made to feel comfortable, and the nurse explained what she was doing throughout”.

“It's easy, quick, does feel a bit uncomfortable but better safe than sorry”.

“It's always very straight forward, explained clearly and help is made to make me feel relaxed - as much as you can!”

“I was able to have an appointment on a Saturday at my GP surgery. It was explained well not rushed”.

“It’s horrible, uncomfortable and to be endured. I hate them but such is life. Please ensure you don’t call us people with wombs, it’s soul destroying! I am only responding because you said ‘women’!”

“I really struggle with my screening test due to finding the use of the speculum painful. It has been this way since my first screening many years ago, but the lovely GP who first attempted the procedure suggested I come back another time and prescribed me some mild diazepam tablets to take prior to my next appointment. This made such a difference; I was less tense, and I was able to have the screening successfully at the second appointment. Now, years later, when I get my invitation letter, I still always request a few tablets from my GP once I have booked it - though still uncomfortable, I can tolerate the procedure with the medication taking the edge off my anxiety. I always tell the clinician that I find the procedure uncomfortable and ask them to use the smallest speculum they can, and no one has ever questioned that. They have always been kind and there seems to be a sense of camaraderie almost between patient and clinician as no one really likes having this done! The clinicians I have had for this procedure have always happened to be women, and to me that makes a difference because I know they are likely to have been through it too. I think it is important for all patients having this procedure to feel empowered to tell their clinician if they are nervous or find it painful etc. but not everyone knows that it is ok to speak up - if that kind GP had not supported me at the very beginning, I don’t know if I would have felt comfortable to speak up next time. I also would have had no idea that it was possible to have a very mild dose of diazepam to help get through it”.

“It was quick and easy, but the nurse ripped my vagina with the speculum, so I was in pain for a few days after. No lubricant was put or offered to go on the speculum which made it uncomfortable, but this wouldn’t put me off going again”.

“I was made to feel relaxed, comfortable - the process was explained to me although I've had many cervical screening appointments. I definitely felt I could ask questions and felt very supported. I have had horrendous cervical screening appointments in the past when I lived in a London Borough so to see the opposite approach is reassuring and is not a one off with my surgery - the nursing team are very supportive”.

“The whole experience is awkward and unpleasant, and being told to open up my legs while laying down only adds to my tension and makes the experience unpleasant. I had to be referred to the hospital last time and that was much more comfortable than the doctors, I could put my feet in stirrups and had a hospital sheet over the bottom part of me. I’m not a shy person but feeling completely naked down there and exposed is not nice when at the doctors”.

“It was flawless, all information was given in a kind manner, the procedure itself is extremely unpleasant but I always find the women are very understanding and very professional and considerate”.

“A lovely practitioner made me feel very relaxed and comfortable. She explained everything clearly and went through a few questions about my medical history. She discovered that my Mirena coil needed removing and did this at the same time. She was very calming and professional and chatted to me the whole way through which really helped. She took her cues from me and acted upon them”.

“The only issue I found was being a full-time worker and most places not doing late evening appointments. It isn't nice using annual leave for a smear and not nice having to take a day of leave. However, in my instance it was worth it as the result was abnormal”.

“Last time I had to make a complaint to the surgery. The nurse taking my smear was very rude and unprofessional. I have had Cin 1 and 2 cells and a Letz procedure, so I am very cautious having my smears now and I was made to feel a fool at 40 years old. This experience would put many people off”.

“Although trying to book an appointment through my GP is difficult, on the day the process is well explained although the nurses can appear robotic at times. They are also very prone to running very late which adds to the stress of attending”.

“A while back I had an abnormal result which was concerning. The process of 'watch and wait' was just worrying, so I was relieved with a second smear from a Marie Stopes clinic which came back normal, which was reassuring. I paid for this which I would rather not have done on principle, but it was actually worthwhile for the peace of mind given”.

“The nurses are always friendly and explain each step to make me feel at ease, any questions I ask, they are happy to answer”.

“I am always supported during the appointment and yes, the process is explained to me. Although I have been having them for many years”.

“All was OK. The nurse was lovely, very friendly. It was over before it started really!”

“The nurse was very friendly. She explained everything thoroughly”.

“I've never had a problem with my screening appointment. The nurses have always been very helpful, have explained everything and put me at my ease. I don't feel there is anything that needs to be improved”.

“It's easy, not too embarrassing, and the nurse is always very friendly and helpful”.

“I have always felt supported, and the staff are friendly and helpful”.

“The screening appointment is totally fine - no issues”.

“It's quick, painless and not embarrassing”.

“The process was not explained at all, it was rushed, and I was made to feel silly when I complained it was uncomfortable”.

“When I did have my one smear test all them years ago the nurse was nice and did her best to make me feel comfortable”.

“The appointment is fine, and explanations are clear, but it is unpleasant nonetheless”.

“The surgery's lines are always busy, often with half hour wait. Booking online would be a much better option. The appointment itself is always uncomfortable, I have never not experienced pain during and after. Surely something can be done to mitigate the pain”.

“I have always been made to feel comfortable and supported throughout my appointments”.

“I have to say I am almost 40, have had two children and still find my screening appointment absolutely horrific. I've had one good experience that didn't hurt. ONE! The last one was painful and so awkwardly uncomfortable (I'm upset before I even lay down) I'm seriously considering whether I will go to the next one when I'm called. I always wonder why it's such an awful experience (I'm never made to feel comfortable) and painful when I know it doesn't have to be because of that one time it didn't hurt”.

“I have great issue with the curtain being pulled around and sometimes the nurse leaving the room which obviously means the door isn't secure, also being given blue paper to cover your lower half and being told to relax and leave your legs wide open when you have both physical and emotional trauma. Your instinct is to tense up and cover up”.

“I was made to feel very comfortable, and the procedure explained”.

“The last time I attempted to have the procedure, I became distressed when on the bed. The nurse kept pushing the speculum in and it was really hurting, but she said she couldn't get it far up enough. I asked her to stop so that I could sit up and try to calm myself. She stood in front of me with folded arms and said, 'For goodness's sake, what's wrong with you, have you been raped or something?' I had to get off the bed and leave, I cried all the way home”.

“I am lucky that I have only had positive experiences with my cervical smears. The nurse has worked at my GP surgery for over 20 years and has always done mine kindly and gently”.

“Several years ago, when living in Harlow, I had a couple of bad experiences when attending my smear test. On one occasion, I was called for a colposcopy due to my sample showing some abnormalities and was advised by my doctor that this meant I had cancer, which of course was not the case. This was especially distressing as I was in my early 20s and had only just left home and moved away from my family so had no support. On another occasion, the person performing the test experienced some problems with the instruments and left me on the table, with them still incorrectly inserted, whilst she went to fetch a colleague. I ended up surrounded by three people whilst in this position, which I found extremely degrading and distressing”.




“I often ‘almost don't’ attend my smear appointments. There seems to be limited awareness of trauma-informed practice, particularly for women (how many - is it 1 in 4 now?) who have suffered sexual assault, rape, and/or domestic abuse. Laying in ‘smear position’ with your skirt pulled up, or trousers off for an intrusive procedure (although vital) is a triggering situation and can easily trigger panic, anxiety and fear. This is a hard thing for a person to ‘tell’ even a very nice female nurse. In addition, often people don't want their past trauma on their medical notes so there's an added conflict there. Afterwards, the same feelings as those from the original traumatising experience can re-surface. It's exactly the same with dentists. My feeling should be that there are ‘trauma-informed appointment slots’ where no questions are asked, but the medical professional has had trauma-informed training and is fully aware of the potential effects of the cervical screening procedure. I think many women would then feel safer and attend their smear. Also, to underline that they can bring a trusted friend along with them who will be



welcomed to sit ‘head end’ and soothe the patient and then be some support for them afterwards. I do attend, but every time, when I’m driving home, I’m crying and shaking”.

“I had one where I was told after having it done it was early even though they had sent the letter. I was three days early and the system said it wouldn’t be checked because of being early and I would need to come back the following week. Even the nurse agreed it was ridiculous and phoned the technician, but they said the system would reject it. So, I rebooked”.

“I was made to feel very comfortable. The nurse explained what was happening and I felt very comfortable”.

Demographic questions:

Please tell us your age			
	Answer Choices		
		Response Percent	Response Total
1	18 - 24 years	0.00%	0
2	25 - 49 years		63.83% 30
3	50 - 64 years		34.04% 16
4	65 to 79 years		2.13% 1
5	80+ years	0.00%	0
6	Prefer not to say	0.00%	0

Please tell us your gender			
	Answer Choices		
		Response Percent	Response Total
1	Woman		97.87% 46
2	Man	0.00%	0
3	Non-binary	0.00%	0
4	Prefer not to say	0.00%	0
5	Prefer to self describe:		2.13% 1

### Is your gender identity the same as your sex recorded at birth?

Answer Choices		Response Percent	Response Total
1	Yes	100.00%	47
2	No	0.00%	0
3	Prefer not to say	0.00%	0

### Please tell us which sexual orientation you identify with

Answer Choices		Response Percent	Response Total
1	Asexual	0.00%	0
2	Bisexual	6.38%	3
3	Gay man	0.00%	0
4	Heterosexual/straight	87.23%	41
5	Lesbian/Gay woman	0.00%	0
6	Pansexual	0.00%	0
7	Prefer not to say	0.00%	0
8	Prefer to self describe:	6.38%	3

### Pregnancy and maternity


Answer Choices		Response Percent	Response Total
1	This question does not apply to me	91.11%	41
2	I am currently pregnant	2.22%	1
3	I am currently breast-feeding	4.44%	2
4	I have given birth in the last 26 weeks	0.00%	0
5	I prefer not to say	2.22%	1

Please select your ethnicity




Answer Choices		Response Percent	Response Total
1	Arab	0.00%	0
2	Asian/Asian British: Bangladeshi	0.00%	0
3	Asian/Asian British: Chinese	0.00%	0
4	Asian/Asian British: Indian	0.00%	0
5	Asian/Asian British: Pakistani	0.00%	0
6	Asian/Asian British: Any other Asian/Asian British background	0.00%	0
7	Black/Black British: African	2.13%	1
8	Black/Black British: Caribbean	0.00%	0
9	Black/Black British: Any other Black/Black British background	0.00%	0
10	Mixed/multiple ethnic groups: Asian and White	0.00%	0
11	Mixed/multiple ethnic groups: Black African and White	0.00%	0
12	Mixed/multiple ethnic groups: Black Caribbean and White	0.00%	0
13	Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background	0.00%	0
14	White: British/English/Northern Irish/Scottish/Welsh	76.60%	36
15	White: Irish	2.13%	1
16	White: Gypsy, Traveller or Irish Traveller	0.00%	0
17	White: Roma	0.00%	0
18	White: Any other White background	14.89%	7








**Please select your ethnicity**

19	Prefer not to say		4.26%	2
20	Other (please specify):		0.00%	0

**Do you consider yourself to be a carer?**

Answer Choices		Response Percent	Response Total
1	Yes		15.56% 7
2	No		80.00% 36
3	Prefer not to say		4.44% 2

**Please select any of the following that apply to you:**

Answer Choices		Response Percent	Response Total
1	I have a disability		4.26% 2
2	I have a long term health condition		17.02% 8
3	I am a carer		10.64% 5
4	None of the above		63.83% 30
5	I prefer not to say		4.26% 2

### 2.3 The Interviews

Individual interviews were conducted to collect personal stories. All participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.



**Maz:**

“I have only had one good experience of cervical screening. I always attend but I am very reluctant, and it is very painful. My cervix is in an awkward position-far back and this causes issues when I am having the smear test done”.

Her last test was done by a nurse, and she said it was the first time it had not hurt. Maz queries why all nurses cannot complete the test in a pain free way? And what did that particular nurse do which was different?

She recalled that there were good bedside manners from the nurse. Maz can get very worked up and anxious. In the past there has been no time taken to reassure her.

She puts her fists under her pelvis to lift it up, which she finds much easier.

Maz said she feels embarrassed about being upset as well as the situation itself.

**Meena:**

Meena talked about how difficult it can be to make the appointment in the first place:

“Getting an appointment is a nightmare by either trying to book online as they are very slow in responding or if you dial in, it takes forever to get through and I don't like making appointments like that face to face in a crowded reception area. The option of weekend appointments would be helpful. I have a health assessment every two years as part of my health insurance through my employer and this includes a smear test”.

I asked Meena what differences she felt there were between having a test done privately and at the GP surgery. “I think that having it done privately (although I can't get a Saturday appointment), feels a lot less rushed and you are treated more like a person rather than a number in a queue. The room also feels more relaxed, and they use stirrups which I find more comfortable than bending my legs right back”.

Meena then talked about the differences between her first smear tests and her stepdaughter who has recently had a letter for her first one. “My stepdaughter got her first letter a couple of months back and there was a leaflet in the envelope explaining how it was done and what they were doing. My first letter when I was 20 was just a rough piece

of computer-generated letter. I think its improved but there is still a long way to go in stating that this test is optional, I feel that as women we are pressurized into getting this done both by our GPs and these days on social media too. My first two smears that I had in 1994 when I was 20 and again in 1997 at 23 were both done by male doctors with a female nurse in the room, and that would never happen now. I think it's a very personal thing to have done and something I have never really felt comfortable with.”

### Mandy:

Mandy had a very poor first experience:

“When I was 16 back in 1989, I went to the local family planning clinic and started on the pill but was only given three months' supply. When I went back for a repeat prescription I was told there and then that all women on the pill had to have a cervical smear and that I would be having one there and then or I wouldn't be able have the pill. The procedure wasn't explained at all apart from being told to remove my lower underwear and place my feet in the stirrups and it was done by a male doctor with a female nurse in the room and I have never felt more embarrassed, and it really hurt. Forward to 1991 and I was away at university. I registered with a local GP and when I went to get the pill from them was told my smear was overdue and they wouldn't accept me until I had had a smear. This was done a couple of weeks later by a female doctor with a female nurse present and this time I had to lay on a couch with no stirrups and also my breasts checked for lumps. Thankfully I was given a gown to wear but I wasn't expecting the breast exam.

By 1994 I had left university and moved again. Registering with a GP was easy and after a 6-month pill check once again, I was told my smear was urgently overdue and to make an appointment to see the nurse urgently. This I did and this time there were stirrups, but I had to undress totally with no gown for a smear and breast check. This time I said I wasn't happy at being screened and I was told in no uncertain terms that ALL women HAVE to have these tests.

I then got married and had three children and after baby number three at the age of 36, at my six-week postpartum check I was once again told that I needed a smear urgently and they would do it there and then. I still hadn't properly recovered from giving birth a few weeks before and the pain was off the scale. Thankfully shortly after that my husband had a vasectomy, so I didn't need contraceptives and despite immense pressure from GPs, nurses, and even receptionists I refuse to have this test.

The thing I can't get over is why some surgeries insist on women laying on a bed with stirrups which I find humiliating while others don't. When I asked one of the nurses why they use this type of bed with stirrups I was told it's because it makes taking the smear easier! For whom??”

### Sue:

“I have only ever had the one cervical screening test and that was back in 2011, it wasn't a pleasant experience. This is the first time I have really talked about it. Like everyone else I got a letter inviting me to cervical screening six months before I was 25. I tried calling

my surgery to book an appointment and the phone rang and rang, no answer so I gave up. Eventually one of the staff called me to ask why I hadn't booked an appointment so I tried to book and there were no appointments later in the afternoon or early evening so I couldn't attend, cue a stropky receptionist who was making out to me that it was my fault that I was a non-attender.

I then got a job where I get private medical insurance, I needed some jabs for a trip abroad so I booked in to get them done by a travel clinic at my local private hospital and the lady on the phone said I also qualify for a private 30 minute well woman check which included a cervical smear, would I like to book. I thought great and I was able to go on a Saturday morning. The female nurse who called me in was quite grumpy and a lot older than me, I couldn't get a rapport going with her. She asked a lot about my medical history and made me undress down to my underwear and I was weighed, blood pressure take, BMI and height measured. She then asked me to go being the screen and remove my underwear as she was going to do a breast examination followed by the smear and then a pelvic exam. I wasn't expecting this, and I felt very uncomfortable about it, I was expecting to take my top off and back on again for boobs, and then bottoms off for the smear. It was pretty embarrassing laying on the couch with my feet in the stirrups totally naked. The smear itself was incredibly uncomfortable, I said it was hurting but she said if she didn't do it there and then I would have to come back another day and get it done and not to be silly and just relax, which was all well and good, but she wasn't the one laying down and having a foreign object inserted into her vagina.

I have never been back since even though my GP has mentioned it to me numerous times over the years. These days I buy an off the shelf HPV test that I do at home and if it ever comes back positive, I will then see my GP. Even the receptionists have given me grief over my nonattendance, a receptionist once told me it's nothing to be embarrassed about as 'her' nurses see women's vaginas every day and it's nothing to be embarrassed about. That's not the point".

### Yumi:

"Well, obviously they're necessary and that's the reason I go, but they have always been extremely uncomfortable and painful. I've regularly experienced bleeding afterwards, which has never been pleasant. So basically, that's my overall experience. Again, I'll regularly go whenever invited, but I understand that some people, if they had to experience that pain, they might not attend the following time. The staff are always friendly. They're always polite, professionals".

Yumi went on to talk about the process of making an appointment: "It is a nightmare. I guess that those surgeries at the moment are extremely busy, so it is really hard to actually speak to someone and once you have to speak to someone, I guess that they do have to ask you sort of why you're booking an appointment, but it seems rather intrusive if a receptionist is asking you those kinds of questions. I would much rather be able to book it online".

## Zena:

“I went in for a cervical screening and this is one of the worst experiences I have had. I requested the smallest speculum as previous experiences with the larger ones had left me traumatised. The nurse was argumentative and dismissive of my concerns. I had to really assert my case before she relented. No lubrication was used and to add to the discomfort she seemed inexperienced and had multiple attempts inserting the speculum until finally after some verbal directions from myself she managed to insert it and carryout the screening. It was another traumatic experience to add to my ever-growing list. I am very worried about my next cervical screening!”

## Jennifer:

“My first one was around 14 years ago. I went to the surgery and the first one I had was not a great experience at all. No effort was made to explain what was going to happen and this was my first experience of cervical screening. It was just like, well, you must know what's going on, we'll just carry on kind of thing. And it was really, really uncomfortable. They made no effort to make me feel more comfortable. I think it got to the stage where she couldn't find my cervix and just kept going, ‘well, you must have one’, she said, and I was like, ‘yeah, I must have’. She spent ages trying to find it then she said ‘No, no, I can't find it.’ I think she even had to go out and get somebody else to come in. Which increased my stress levels even more because it was like, oh my God, what's wrong with me? What's going on? Why have I got somebody else in the room now? This is really, really not great for me. Anyway, they eventually found it and said it faces the wrong way, which makes it more difficult to find, but not impossible. Oh brilliant. Anyway, then they did the actual smear, and it was like oh my God, this is really uncomfortable. And I got home and was like if I have to go through those every three years, I really don't want to.

Three years passed and my next letter came, and I was like, no, I'm just gonna ignore that. Just ignore it. For a while. And then they sent another one. I ignored that as well. The story picks up again when I was in mental health hospital, I was there for seven months and there was a physical health nurse who was particularly into Women's Health at the time. And she was asking patients, ‘have you checked your breasts? Have you had your cervical smear?’ Have you done all that kind of stuff and it came to this little smear thing and I was like, no, I've kind of just avoided it and. She said you can have it done here. I can do it for you, and you don't have to go anywhere, so I was like oh God, ok, I will have it done because I know I have to have it done and it's a sensible thing to do. But she also had the same problem, that she couldn't find my cervix. And I went through the process again. She was a lot more trauma informed and explained everything, showed me the stuff beforehand and kind of said, you know, ‘we can use the smaller speculum’. You know, you just need to chill out and it will just be you tell me to stop at any point, you know, all that kind of stuff.

So, it's a much more pleasant experience in terms of being comfortable around the situation, but the actual trying to get it done again was really painful and just not good at all. In the end, she said ‘I don't want to put you through any more stress’. She referred me to a hospital consultant who specialised in doing smear tests on people with difficult

cervixes. She was so lovely and explained everything to me, showed me the stuff they were going to use, gave me time to ask questions etc. I don't know what happened, but I froze after the test and was not able to communicate as I had totally dissociated but all the staff were so lovely and just gave me time to come round. I have all my smear tests done at the hospital; I don't go through the GP. Seeing the same consultant who knows me and gives me time makes such a difference, she always puts me at the end of her clinic so if I need more time then I am not stressed out by thinking I am taking too much time and making others late for their appointments. Without the help from the nurse in the mental health hospital, I wouldn't have attended any screening appointments”.

### Lea:

“So, my story is that I had a cervical smear test two weeks after my 60th birthday. That was at the beginning of June 2017. Shortly after, on the 3rd of July, the same year I received a letter telling me that I had just had my last cervical cancer smear because women are not called after their 65th birthday, meaning that my next smear would've been in June 2022, two weeks after my 65th birthday. So effectively I missed it by two weeks.

I phoned my GP, and he said ‘no, you won't be eligible’, but I did wish to challenge it. And he said I was quite within my rights to do that as I was only two weeks over. I was trying to be proactive about my health. And I had had recalls on previous smear tests, so that was something I'd always kept up to date with the smear test. There's a family history. My mother, I don't know whether cervical cancer and ovarian cancer are linked, but five years before that date she died of ovarian cancer. And my daughter also had had pre-cancerous cells couple of years before that. So, I thought this is something I need to be on top of. Normally, I just kind of accept, ‘oh, well I'm not going to get anymore and that's it.’ But it was something I decided to try and sort out.

I was told to refer my query to my primary care trust which I did by email. And I was told, ‘No flexibility on dates. That's it. You're going to be over 65, go away.’ I was told by the PCT to refer my query to NHS England, which I did, and I've tried to find the email on my system, but I cannot find it. It's so annoying. And I was even given the necessary contact information to contact the NHS. So, I had the name and everything and I did get a reply to that, probably exactly the same information now. So, I went back to GP for this information who told me, interestingly that she could do a smear test, but it would be rejected for testing because I was over 65. That was their thing.

I mean, there is a sort of a happy ending to this story, fortunately for me, or unfortunately depending on the way you view it, because I'd had a pessary ring fitted for a prolapsed bladder and I kept getting infections from the pessary ring, culminating in a visit to the doctor. And as a result of that, she actually did a smear test, and I was referred to Gynaecology and I had a lot of tests. And it was put down to the fact that it was a severe infection from the ring. My body was rejecting it. So, I did get the smear test, but not in the way I'd intended.

So, my point, I suppose it seems petty to me to have been refused my request because of such a short margin of being on the wrong side of 65, I also had a family history of problems in that area.

I was trying to be proactive, and I felt like I was kind of banging my head against a brick wall. That's my story”.

## 2.4 Examples of screening projects/alternative methods:

As part of this project I spoke to Lucy Ainsley, Project Manager at the Very Important Invitation Project based in Suffolk. They work to address the barriers to cervical screening and support patients. The project is a co-production between Suffolk GP+, Public Health bodies, local charities, women and people in the community to promote accessible cervical screening <https://suffolkfed.org.uk/healthcare-services/cervical-screening/>

The project is currently in its third year and is funded by the ICB. They work with GP surgeries to help improve the environment within the clinical space to make it more comfortable for patients, they also look at language used by staff and deliver training to raise awareness and improve people's experiences. Elements of the project are:

- Working to raise attendance/develop relationships with various seldom heard groups - severe mental illness, learning disabilities, travellers, non-binary, transgender etc.
- Looked at use of language. Women and people with a cervix, not just using the word 'woman'.
- Colours on promotional material; yellow and black is easier for people with sight issues to see. No pink!
- They worked with The Portland Hospital-surgeries can have a small card at reception which shows they are trans friendly.
- Being mindful of people's different situations and experiences.
- Changing mindset in frontline staff- such as 'it's always been done this way' etc. Educate older members of the staff team.
- NHS template form - this is completed before the appointment so any issues/triggers/previous experiences etc can be identified and acknowledged. It covers trauma etc - they have changed some of the wording.
- Minimum of a 15-minute appointment, so time taken to ask a range of questions, and give a more holistic approach. Questions regarding sex life, periods etc, gives patients time to talk.
- Appropriate room set up, couches in the right positions for the patient and staff member. Working with practice manager to achieve a better environment. Not having the bed facing the door, makes patients feel more secure and comfortable. A three-month review is carried out with the surgery to monitor progress and evaluate.
- Using the correct lube - reducing the number of rejected samples.
- Translated material - working with local charities and organisations to see what languages are needed.
- Social media campaigns.
- Build relationships with the travelling community - monthly visits to sites to see what the women need and how they want it done.
- They are able to carry out stand-alone clinics - extended access service.

- Worked with Suffolk Rape Crisis and will deliver two clinics for people who have suffered rape/sexual assault.

### Self-testing

One interviewee talked about choosing to do her cervical test at home, and this was not something I had heard about before, so I wanted to find out more information. I found that patients can buy an HPV test from a pharmacy for around £50, complete at home and then send off for the results.

[Buy Home HPV Test Kits Online | Superdrug Online Doctor](#)

[What Is A Home HPV Test? | LloydsPharmacy Online Doctor UK](#)

It is understandable that some people may find this a much easier process to cope with than attending a surgery, it takes away the stress of having to make an appointment and gives them total control over how and when they carry out the test. I talked to some health professionals about this option and they had concerns around how reliable the test was and they would want to see more research before considering it as an option. It is an option which should be explored in more detail, it is important for people to have a choice around how these screening tests are carried out and that they feel more in control in this situation.

There was a YouScreen (Kings College London) trial in some London boroughs in 2021 where women were offered home testing kits:

[Cancer: Women to trial 'do-it-at-home' kits for NHS - BBC News](#)

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

I was unable to find the outcome of that trial but there are other findings from Kings College London regarding cervical self-screening:

<https://kclpure.kcl.ac.uk/portal/en/publications/offering-self-sampling-to-cervical-screening-non-attenders-in-pri>

**‘Offering non-speculum clinician-sampling and self-sampling substantially increases uptake in older women with lapsed screening attendance. Non-speculum clinician sampling appeals to women who dislike the speculum but prefer a clinician to take their sample and who lack confidence in self-sampling. Providing a choice of screening modality may be important for optimising cervical screening uptake.’** [Non-speculum sampling approaches for cervical screening in older women: randomised controlled trial – King's College London \(kcl.ac.uk\)](#)

Denmark and Australia are two countries which offer self-sampling tests. These tests are still carried out in a clinical setting but with the patient doing the actual test themselves. This is the video explaining the procedure from Australia:



<https://www.health.gov.au/self-collection-for-the-cervical-screening-test>

[National Cervical Screening Program monitoring report 2022, Summary - Australian Institute of Health and Welfare \(aihw.gov.au\)](#)

### Self-collection

Participants who self-collect their cervical screening sample and whose primary screening HPV test detects oncogenic HPV types need to return to a practitioner for an LBC (liquid-based cytology test) or attend for a colposcopy, depending on the oncogenic HPV types detected.

In 2021, of the 327 participants aged 30-74 whose self-collected primary screening HPV test detected an oncogenic HPV type other than 16 or 18, 60% had an LBC within 6 months.

In 2021, of the 130 participants aged 30-74 whose self-collected primary screening HPV test detected oncogenic HPV type 16 or 18, 69% had a colposcopy within 6 months.

[Cervical Screening and HPV Self-Sampling in Denmark - Cancer Prevention Group Blog \(kcl.ac.uk\)](#)

### HPV self-sampling instead of clinician-collected screening samples?

‘There is no doubt that HPV self-sampling can and should be an option for cervical screening. The benefits are too plentiful to ignore. In addition to the autonomy it brings for women, self-sampling offers equity and a means to address clinician-patient working pressures in primary healthcare. Imagine if, say, a third of all women screened by clinician-collected samples instead took a sample by themselves. The number of clinical consultations freed up for other purposes would be substantial. If this can be achieved without compromising screening quality, everyone stands to benefit: women, overworked healthcare professionals, the health system, and society itself. On the other hand, do we want self-sampling to fully replace clinician-collected samples? At present, I personally think not. It is about choice and providing options.’ [Jesper Bonde 2023](#)

It is important to look at other possible options to enable people to access the screening process. The current method has been used for a long time now and it doesn't work for all patients, having the option to do the test yourself in a clinical setting or at home could help to improve the uptake.

## 3.0 Key Findings and Recommendations

Almost 85% of the survey respondents attended their cervical screening appointment. This is very positive considering the general feeling is that the process is necessary but still an

unpleasant and difficult experience for many. 'It's horrible, uncomfortable and to be endured. Hate them but such is life.'

### [Cervical Screening Programme, England - 2021-2022 \[NS\] - NHS Digital](#)

**69.9% of eligible individuals aged 25 to 64 adequately screened.**

A 0.3 percentage point decrease on the previous year, when coverage was 70.2%.  
(Coverage assessed at 31 March 2022)

There was a wide range of feedback from the participants. The first step of making an appointment was difficult for many, as the time taken just to get through to the surgery was an issue and then trying to get an appointment which suited them was also a challenge. People who work full time or had caring responsibilities found it difficult or impossible to make an appointment that they could attend. 'I could not make appointment at a suitable time as I'm a full-time carer with no support.' Many people stated that being able to book this type of appointment online would make the process much easier. Pressure to attend appointments was also a factor in making respondents reluctant to attend, 'Even the receptionists have given me grief over my non-attendance, a receptionist once told me it's nothing to be embarrassed about as "her" nurses see women's vaginas every day. That's not the point.'

Many talked about historical experiences which were at times very traumatic and had an impact on their screening experiences and for some of them it led to delaying or not attending future invitations. Examples included, male doctors carrying out the procedure, not explaining the procedure/process, health professionals not listening to their patient- especially when stating they were in pain, being left on an examination couch while in a vulnerable position etc. These were all examples of poor practise/experiences which had an impact on the patient. 'On another occasion, the person performing the test experienced some problems with the instruments and left me on the table, with them still incorrectly inserted, whilst she went to fetch a colleague. I ended up surrounded by three people whilst in this position, which I found extremely degrading and distressing.'

Trauma awareness must be recognised and be part of the cervical screening process to enable women who are survivors to access the same service as others. 'I often 'almost don't' attend my smear appointments. There seems to be limited awareness of trauma-informed practice, particularly for women (how many - is it 1 in 4 now?) who have suffered sexual assault, rape, and/or domestic abuse. Laying in 'smear position' with skirt pulled up, or trousers off for an intrusive procedure (although vital) is a triggering situation and can easily trigger panic, anxiety and fear. This is a hard thing for a person to 'tell' even a very nice female nurse. In addition, often people don't want their past trauma on their medical notes so there's an added conflict there. Afterwards, the same feelings as those from the original traumatising experience can re-surface.'

Language used by the health professional has to be appropriate in all situations, but especially around trauma, 'The last time I attempted to have the procedure, I became distressed when on the bed. The nurse kept pushing the speculum in and it was really hurting, but she said she couldn't get it far up enough. I asked her to stop so that I could

sit up and try to calm myself. She stood in front of me with folded arms and said, 'For goodness's sake, what's wrong with you, have you been raped or something?' I had to get off the bed and leave, I cried all the way home.' A number of respondents stated that when they told the health professional that what they were doing was hurting, they were told it wasn't or to stop being silly and just relax. This is shocking behaviour and completely unacceptable. One respondent felt that the whole procedure was aimed at suiting the health professional and not her, 'The thing I can't get over is why some surgeries insist on women laying on a bed with stirrups which I find humiliating while others don't. When I asked one of the nurses why they use this type of bed with stirrups I was told it's because it makes taking the smear easier! For whom??'

Many respondents however did have positive experiences and recognised the kindness, respect and professionalism shown to them by health professionals, 'Flawless, all information given in a kind manner, the procedure itself is extremely unpleasant but I always find the women are very understanding and very professional and considerate.'

#### **Recommendations:**

- Making the appointment made easier - having the option to pre book appointments would be of benefit, as having to phone at 8am to attempt to make an appointment for a matter that doesn't necessarily have to be carried out that day is not an effective use of patient's/surgeries time. Having the option to book online should be explored.
- Trauma awareness - Training to raise awareness for all staff involved including receptionists as well as health professionals. 'My feeling is that there should be 'trauma-informed appointment slots' where no questions are asked, but the medical professional has had trauma-informed training and is fully aware of the potential effects of the cervical screening procedure. I think many women would then feel safer and attend their smear. Also, to underline that they can bring a trusted friend along with them who will be welcomed to sit 'head end' and soothe the patient and then be some support for them afterwards. I do attend, but every time, when I'm driving home, I'm crying and shaking'.
- Environment - making sure the clinical setting is as welcoming as it can be; where possible not having the bed facing the door, allowing women to be in a position that they find as comfortable as possible, having the option to use stirrups if required for them. But also factoring in that the health professional needs to be comfortable whilst they are carrying out the procedure. Using the correct lube so the patient is comfortable, and an adequate sample is taken.

- Taking the time - making the appointments slightly longer so a more holistic approach could be adopted, having the option to ask questions around general sexual and menstrual health. Checking to see if there is any previous trauma or negative past experiences that could impact the appointment. Giving the patient an opportunity to ask questions so they don't feel rushed or like a number instead of a person.
- Explanation and communication - explaining what is going to happen, allowing patients to see/feel the instruments being used if they want to, checking in with the patient during the procedure that they are as comfortable as they can be. Stopping if the patient is in pain or distress and allowing them time to calm down and continue or leave, it's their choice. Listen.

## 4.0 Conclusion

85% of people attending their cervical screening appointment following an invitation letter is a very positive number and above the national average. Many stated positive experiences and were happy with the process. This is a good outcome and a solid base to build upon.

There needs to be more work done regarding trauma awareness/training and the impact this has on an individual and their experience, not just for regular screening but across the healthcare system. Women must feel that they have a choice in where, how and when they decide to have a screening appointment. The one size fits all approach does not work in the current system, it requires a review and a rethink.

Looking at examples of good practice and how cervical screening is carried out in other ICB areas and countries can give suggestions/ideas on how to develop the programme.

Co production is vital part of the process of developing a programme that benefits as many people as possible. Building links and relationships with seldom heard communities will not just improve the uptake of cervical screening but also help to improve other health outcomes. Asking for lived experience can, at times, be a difficult process for both parties. It can be difficult to share one's own personal and sometimes traumatic stories and they can also be difficult to hear/read and process, but it is so important to hear those stories and for them to influence positive change.