

Help us make cervical cancer a disease of the past:

Volunteer

jostrust.org.uk/volunteer

Campaign

jostrust.org.uk/campaign

Donate

jostrust.org.uk/donate

Contact us:

 **Jo's Cervical Cancer Trust** CAN Mezzanine, 7-14 Great Dover Street, London SE1 4YR

T 020 3096 8100

W jostrust.org.uk

E info@jostrust.org.uk

 @JoTrust

 Jo's Cervical Cancer Trust

 [joscervicalcancertrust](https://www.instagram.com/joscervicalcancertrust)

Call our helpline:

0808 802 8000

Registered in England and Wales. Company Limited by Guarantee: 7111375.

Registered Charity No: 1133542 / SC041236

“We’re made to feel invisible”
Barriers to accessing cervical screening for
women with physical disabilities

Foreword

Contents

	Page
Foreword	1
Executive summary	2
Introduction	4
Our research	6
Fi's story	8
Jo's story	10
Kerry's story	12
Conclusion	15
Recommendations	16

“It shouldn't be this hard.”

Every eligible woman should be able to access cervical screening should they wish to. It can prevent the development of cervical cancer and saves around 5000 lives in the UK every year. Going for a test can be difficult for many reasons, and with cervical screening uptake in decline we should be working to overcome barriers not introducing them. Sadly, as this report highlights, the needs of women with a physical disability are being forgotten.

Ethically, legally and morally, it should not be the case that women with a physical disability are often faced with additional hurdles or even being denied access to this potentially lifesaving test.

The Equalities Act 2010 puts a duty on NHS providers to make reasonable adjustments for people with disabilities to ensure that they are not disadvantaged compared to people without disabilities.

Yet 63% of women who took part in this research said that they have been unable to attend cervical screening because of their disability.

Their voices in this report are strong, exasperated and frustrated by the inequality they are experiencing.

It is worrying to see the level of stigma that exists regarding sex and disability. Such assumptions are hurtful, outdated and completely untrue. As this report shows, in some cases assumptions or lack of awareness could even be putting lives at risk with women not being provided with the adjustments they need or even being actively discouraged from accessing screening.

This has to change

Every GP practice must have policies in place to ensure women living with a disability can access a test, with training and regulation ensuring this becomes a reality.

This report covers a range of measures and adjustments. In no way are we saying every area should implement all of them, we fully understand that funding and resources are in finite supply and some will not be feasible in certain areas. It is for local teams to assess their current provisions, identify where gaps exist and implement appropriate pathways or adjustments so as to ensure equal access to the screening programme for all who wish to take part.

I hope that this report encourages urgent action to end the unacceptable, yet hugely fixable, inequality we are faced with.

I'm grateful to everyone who has provided their expertise to help shape this report. Most importantly thank you to all the women who shared their experiences with us. Without them we would not be able to highlight such a wide range of experiences and needs.

To us, you are not invisible.



Robert Music
Chief Executive
Jo's Cervical
Cancer Trust

Executive summary

Cervical screening uptake in the UK is rapidly declining. It is currently at a 21-year low in England alone and among some age groups as few as one in two are taking up their invitation for this potentially life-saving test.

There are many factors contributing to low attendance, including psychological, cultural and literacy barriers. Access is a further barrier, with many finding it hard to get an appointment. Work, childcare and travel can all impact ability to get an appointment at a convenient time. Due to public health budget cuts, others find that sexual health services, where they used to attend screening, no longer offer that service.

Women with a physical disability are a group who can have even more barriers to overcome. In recent years, we at Jo's Cervical Cancer Trust have heard from an increasing number of women who have struggled to attend cervical screening or even been denied access. For some, simply getting their wheelchair through the door of the GP surgery has proved impossible, while others have been told equipment such as hoists or adjustable beds are not available to them. Many have faced stigma and misconceptions along the way.

"...It's as if my health, especially as a woman, is not important."

"I haven't had a smear test since I became disabled. Keep being texted and called about it but I find the contact dries up instantly when I start asking about how they could make it possible. Last time the person said she'd phone back with a plan to make it accessible... that was last summer & I'm still waiting for that call back."

GP practices are obliged to make reasonable adjustments for people with a disability when accessing services and, in this report, we acknowledge examples of good care. However, the inequality we have found is stark, with many women reporting experiences that are simply not acceptable. This postcode lottery means that some women are missing out on a test that they have a right to access. A test that could potentially save their life.

This report aims to shine a light on the barriers that women with physical disabilities are facing across the UK in accessing cervical screening. Through our recommendations we hope to influence existing practice and raise the voice of women who have previously been invisible.

"Health professionals have sometimes assumed that I should be taken off the cervical screening patient list - it has not been clear what their reasoning is but they have seemed more concerned about getting me to sign-off on it than concerned about solving any issues."

"Disabled women are being denied access to cervical screenings due to a lack of equipment like hoists in GP surgeries. There is also the presumption that we don't need this screening."

Key findings

We surveyed **335** women with a physical disability or physically debilitating symptoms as a result of a long term health condition:

- 88%** said it is harder for women with physical disabilities to attend or access cervical screening
- 63%** said that they have been unable to attend cervical screening because of their disability
- 49%** said that they have chosen not to attend cervical screening in the past for reasons such as previous bad experiences related to their disability or worries about how people might react.

Recommendations

All women should have equality of access to cervical screening and we hope the following recommendations will get us closer to making this a reality for women with physical disabilities:

- 1** National support to address inequity in access
- 2** Each GP practice to review their policies and practice and ensure pathways or adjustments are in place to ensure every woman can access cervical screening
- 3** Care Quality Commission and health inspectorates to regulate access in general practice
- 4** Research looking at the most effective way of offering cervical screening to women with a physical disability, including feasibility of HPV self-sampling
- 5** Sample taker training, and refresher training, to include potential needs and adjustments that should be considered for women with a physical disability.

"It's extremely painful and I feel like the nurses don't believe how painful it is. I also really struggle with the beds and getting in a safe and comfortable position."

"I am bedbound and unable to attend an appointment and there was no home visit available."

"My original appointment was booked upstairs and there is no lift."

Introduction

Cervical screening is the best protection against cervical cancer. A disease that, every day, claims two lives and sees a further nine women receiving a life-changing diagnosis. However uptake across the UK has been falling annually with over one in four women currently not attending. Among some groups of women this figure is far higher.

Through our previous research¹ we know there are a wide range of reasons which can affect ability and intention to book and attend cervical screening. Fear, embarrassment, previous bad experiences, not understanding what the test is for and difficulty accessing a convenient appointment are just a few.

While these barriers may affect anyone, some groups face further, specific barriers.

In the UK, there are 13.9 million people² with a disability, of which 56% are women.³ Over half report having mobility impairment.⁴ For these women, specialised support or alternative routes may be required in order to have equity of access to cervical screening.

Examples include home visits for those unable to leave the house, additional equipment at the GP practice such as a hoist, height-adjustable couch and stirrups, or referrals to hospitals or practices equipped according to their needs.

Under the Equality Act 2010, there is a duty on all service providers in England, Scotland and Wales to make reasonable adjustments for people with disabilities to ensure that they are not disadvantaged compared to people without disabilities. The Equality Act 2010 means that if a person has been refused medical treatment due to their disability then it is direct discrimination. In Northern Ireland, this provision is covered in the Disability Discrimination Act 1995 and the Disability Discrimination Order 2006.⁵ These 'adjustments' cover all healthcare services and might include physical changes to a building, providing extra services, or changing policy and procedures.⁶

As part of their key lines of inquiry during any inspection of an NHS GP practice in England, Care Quality Commission inspectors consider 'are reasonable adjustments made so that people with a disability can access and use services on an equal basis to others?'. This relates to all areas of health at the practice.⁷

Access to cervical screening for women with a physical disability is a previously overlooked area. While many areas have excellent pathways and practice to ensure equitable access, others fall far short of this. These are the stories we hear at Jo's and the stories this research has uncovered.

"It would make a great deal of a difference if staff were more aware of their attitude towards disabled young women and the smear test. A look of dread towards me is the difference between me becoming tense and awkward. The opposite would allow me to have open communication about my physical limitations and how we could work together to adapt to the situation."

"The GP doesn't have a mobile hoist. When I asked to be referred on to somewhere that does he fobbed me off saying that it wasn't worth it as I'd probably never get this type of cancer. I wasn't worth the extra effort I felt."

NHS Cervical Screening Programme Guidance for the training of cervical sample takers (Public Health England, 2016)

Public Health England's guidance to Primary Care on cervical screening states that they should consider the clinic facilities for women with physical disability. These include: access to the venue; the height of the couch; the woman's physical limitations; the possibility of a domiciliary visit; and the need for assistance and seeking specialist advice if necessary.

NHS England and Public Health England Section 7a service specification for cervical screening (NHS England, 2018)

The Section 7a Service Specification states that the cervical screening programme should, "optimise attendance rates and maximise accessibility of the service for all groups in that community." It also states that the provider should have procedures in place to identify and support groups that are considered hard to reach or vulnerable. These groups include homeless people and rough sleepers, gypsy travellers groups and sex workers, those in prison; those with mental health conditions; those with drug or alcohol harm issues; those with learning disabilities, physical disabilities or communications difficulties.

Your health, your rights: The Charter of Patient Rights and Responsibilities (NHS Scotland, 2012)

The Charter of Patient Rights and Responsibilities in Scotland makes clear that physical disability should not be a barrier to any NHS service:

You should never be refused access to NHS services in Scotland on the basis of unlawful discrimination against you, because of your age, disability, gender reassignment, marriage, civil partnership, pregnancy, maternity, race, religion or belief, sex, or sexual orientation.

Doing Well, Doing Better: Standards for Health Services in Wales (NHS Wales, 2010)

The Standards for Health Services in Wales clarify that premises should be designed to ensure accessibility for services:

Are your premises safely accessible for people with a disability or sensory loss? This standard is about the design and condition of all healthcare premises and the fixtures, fittings and services. Organisations and services need to consider issues relating to security, safe and sustainable design, clear signage, planning, privacy, fire safety, general health and safety and disability discrimination.

Our research

Our research reveals widely varying, and sometimes shocking, experiences and clearly highlights the urgent need for national and local action to ensure that everyone eligible for cervical screening can attend.

335 women took part in an online survey and five women took part in in-depth semi-structured interviews. Those who participated represented a wide range of conditions and disabilities, including spinal muscular atrophy, Ehlers-Danlos syndrome, paraplegia, myalgic encephalomyelitis and cerebral palsy.

It is important to note that the people who took part in this survey were self-selecting and therefore may have been more likely to take part if they have had problems accessing screening.

Findings

88% of those who took part in the research said that they felt it is harder for women with physical disabilities to attend or access screening.

63% of respondents said that they have previously been unable to attend cervical screening due to a lack of appropriate access or home visits.

49% of respondents said that they have chosen not to attend cervical screening in the past due to a previous bad experience related to their disability or worries about how people might react.

45% said that they felt their needs have been forgotten and **38%** said that they feel the doctors or nurses don't take their needs seriously.

"[I was] so embarrassed by previous experience and they fuss made by the nurse. I was told "Oh for goodness sake, it takes less than a minute, did you not take your paracetamol before coming!""

Wheelchair access in GP practices

Only **63%** of respondents said that their GP surgery provides wheelchair access.

There is very little public information about, or uniformity in, the provisions for disabled access at GP surgeries. CQC guidance states that 'reasonable adjustments' to ensure equity of care for people with a physical disability might include ramps and stairway lifts, wider doorways, automatic doors and disabled wide-door accessible toilets with low basins.⁶

"The last time I went for a cervical screening I was really nervous and clammed up so the nurse had problems doing the test on me... it was a really bad experience for me and I've never been back for a smear test since."

"I couldn't physically fit my wheelchair through the door of the surgery."

"When I am well enough to go to my GP practice the wheelchair access is difficult at the surgery due to no allocated disabled parking and no safe drop-off point."

"The wheelchair access is poor as the corridors are so narrow."

Simply getting through the door is evidently a barrier for some women. Where this is the case, the provider must make women aware of alternative practices or services where they can attend cervical screening.

Lack of disabled parking was also mentioned by some respondents.

Availability of equipment including hoists, height-adjustable couches and stirrups

There are currently no requirements for every GP surgery to have a hoist. Sufficient training, in addition to space, is needed for them to be used safely. Yet this piece of equipment can enable those with a disability to access a potentially life-saving test, in addition to a range of other examinations.

When asked what would make cervical screening easier, **23%** said that a hoist can get them on the bed and into a comfortable position.

Only **1%** of respondents said that their GP surgery provides a hoist.

A number of respondents said that they were unable to have a test because their surgery did not have a height-adjustable bed.

Provision of hoists must be considered and extended, while height-adjustable beds and other equipment should be made more readily available.

In the absence of adequate equipment provision, reasonable adjustments should be made in order to ensure that women with physical disabilities can access cervical screening, either at home or a nearby equipped service.

40% said that a longer or double appointment would make accessing cervical screening easier for them.

Double appointments can enable more time to understand the needs of the woman, discuss ways to make cervical screening easier, including answering questions and time to raise concerns. Women should be aware they can request a double appointment and where appropriate they can be offered one.

"I am bedbound and my GP service won't do the test at home, although they do home visits for other things."

"I don't need a hoist to get in the bed but rather assistance to get up. Narrow couches are just not suitable. When I attend my specialist consultant they have extra wide and height adjustable couches."

"I always wanted to attend. When disability made it impossible the GP offered no support with this."

"I require a hoist for all transfers and as my GP does not have a hoist I was unable to attend. I was told they could arrange a home visit but nobody ever followed up. That was a few years ago."

"As a wheelchair user I find it incredibly difficult to get onto the examination couch all of which are old and fixed height in the surgery."

"I went for my last smear but because there were no stirrups or assistance available to hold my legs where they needed to be, my smear could not be taken."

Fi's Story

I have muscular dystrophy and, at 30 years old, I've never had cervical screening. To access the test, I need a hoist to be available in order to transfer onto the examination table as self-transfer is not an option for me.

Unfortunately, despite the fact my GP knows that I have access issues, I was told that there was no hoist available and I was not able to have a home visit either because my GP practice doesn't cover insurance at patient's homes. I spoke to several different members of staff at my GP surgery about getting a hoist and asked if they could get hold of a mobile hoist from a hospital but I was told it would take too long and there would be too much paperwork.

I was even told that I could be taking a hoist away from patients in greater need. I felt like I was being guilt-tripped into dropping my pursuit of accessing routine screening that all other women have equal access to.

After protesting, my GP said that cervical cancer is a rare cancer and he could take me off the list for routine cervical screening. I was shocked. This has made me wonder if women without a disability would be told they could be taken off the register simply because it was too difficult to arrange screening for them.

I feel so angry and let down and it makes me wonder how many other women have been in a similar situation. It's as if women with disabilities in modern day Britain simply don't matter.

“I felt like I was being guilt-tripped into dropping my pursuit of accessing routine screening that all other women have equal access to.”



Home visits

For women who are unable to leave the house because of their disability, a home visit by a trained sample taker (such as the practice nurse) may be necessary. While some women do access screening through home visits, there is unequal access across the country.

55% of respondents said that a home visit from a GP or nurse would make accessing cervical screening easier for them

22% of respondents said that they are unable to leave the house but their GP practice doesn't offer home visits.

If a patient is unable to leave the house or is too ill to visit the GP practice then they can request a home visit. A GP will only visit a patient at home if they think that the medical condition requires it.⁸

This appears to be an area where there is significant confusion and inequity. Women reported extremely varying experiences including being told home visits are not possible, that they are too complicated to provide or simply that having a test wasn't that important.

“I have been told by other members of staff at another GP practice (as well as my current) that I can't have one as they have no way of safely getting me onto the examination table and both surgeries aren't covered by insurance to do it in patients home where the right equipment is.”

This is clearly creating an inequality in the opportunities offered to women who are unable to leave the house, or for whom leaving the house can be highly distressing or debilitating.

Home visits, from a trained GP or nurse, should be considered if women are not able to get to the practice. Where they are not possible, arrangements for screening at a more accessible venue must be arranged to ensure women living with debilitating conditions are not put at increased risk of cervical cancer.

“I'm 99% housebound and a trip out of the house means weeks of illness afterwards.”

“I haven't had a smear test since I became disabled. Keep being texted and called about it but I find the contact dries up instantly when I start asking about how they could make it possible. Last time the person said she'd phone back with a plan to make it accessible... that was last summer & I'm still waiting for that call back!”

“Not had one in twenty years as I'm unable to get to the doctors for it and home visits not offered.”

“Before I was ill I used to attend whenever I was called for cervical screening, but since becoming ill I am unable to attend appointments. I have asked GP about having cervical screening at home but was told they are unable to carry out this service at home.”

Jo's Story

I have ME/CFS and fibromyalgia and have been trying to access cervical screening for eight years. My condition means that I cannot sit or stand for more than five minutes without pain or dizziness and I am therefore unable to leave my bed. I assumed that because I was able to get home appointments for injections or dental care that it would be just as easy to organise a home visit for screening. I was wrong.

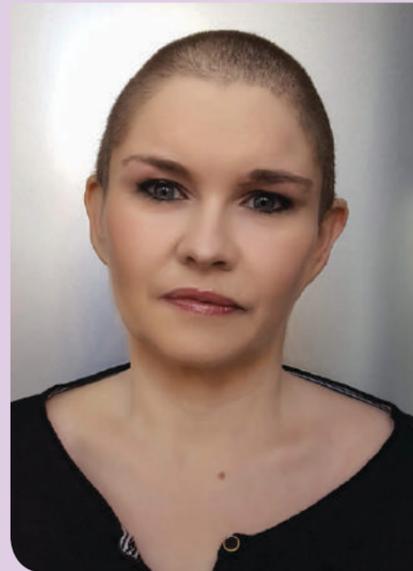
I have written to my GP about the possibility of having screening in my home but was told that it was not possible and no other arrangements were made for me.

However, after years of fighting and numerous letters to my GP, I have finally had my cervical screening. The nurse was lovely and it was very straightforward: she wore a head torch and we adjusted the height of my bed. I asked the nurse if, now they were aware they could carry out cervical screening in the home, they would make this an option to other women who are unable to leave house.

Sadly, the answer was basically "no". Apparently I'm an exceptional case due to the length of time since my last screening, and the long term nature of my ill-health. She said, in most cases the smear test would just be delayed until the patient was well enough to visit the practice, but each person would be dealt with on "a case by case basis".

It shouldn't have taken me eight years to finally have the test nor should it be the case that you can't access screening because of your condition or disability. It's so important that we make this test accessible to everyone and raise awareness of the barriers that are preventing us from accessing it.

“It shouldn't have taken me eight years to finally have the test nor should it be the case that you can't access screening because of your condition or disability.”



Arrangements for screening at another venue

Referrals to alternative GP practices or settings such as gynaecology can also help women attend cervical screening if their current practice cannot meet their requirements.

The former Minister for Public Health and Primary Care stated:

“Primary care staff should therefore ensure that a patient can access effective, timely treatments (including health screening) in an environment that provides the patient (with) a safe, effective and comfortable environment. Some procedures may be able to be offered in a patient's home and, for others, a patient may require referral to a community or hospital setting.”⁹

However, it is evident from our research that there are a significant number of cases of women with physical disabilities not being offered alternative arrangements for cervical screening.

17% of respondents said that they were offered the test at a different venue such as a hospital or sexual health clinic.

“My surgery looked into other options for me, but there were apparently none in my area.”

“Sometimes you have to beg for a medical professional to come out to your house.”

“I dislocate joints easily due to my disability, so lying with my feet together and knees out is very painful. Ideally I'd prefer to have it done somewhere with stirrups so I'm not holding my legs in a position where I could dislocate my hips. I spoke to my GP about this and she thinks a gynaecologist would have a bed with stirrups but wouldn't take a referral for a smear.”

Kerry's Story

I have muscular dystrophy and use a wheelchair. For many years, I was able to access cervical screening through home visits organised by my local GP surgery, and at my last routine screening appointment I was told that I had cell changes and would need to be monitored through regular cervical screening. However, shortly afterwards I moved to a house in a different GP catchment area. I was told by my new GP surgery that home visits for cervical screening were not possible, the rooms were too small for my wheelchair to fit in and there was a lack of suitable provisions such as a wide bed or hoist. I wasn't offered an alternative arrangement so I wasn't able to get my next screening appointment. This was ten years ago.

For a decade, I regularly rang up my GP surgery to try and get this important appointment but I was told that it wasn't possible to arrange screening for me and was effectively denied my follow-up appointment. I lived with the worry that those abnormalities that I was diagnosed with ten years ago hadn't gone away, and potentially developed into something more serious.

I recently managed to get a hospital appointment to check if the cell changes had developed. However, because it had been so long since my last screening and they were concerned the cells might have progressed into something more severe, I needed to go under general anaesthetic and have an array of tests done, including a biopsy. I was placed in a high-dependency ward as the general anaesthetic could have negative effects on me due to my muscular dystrophy. Thankfully, my results came back clear and I'm now recovering from this operation. Although I'm relieved that I've finally managed to access this test, I'm frustrated that I wasn't given the option to have this done ten years ago and that the urgency of my situation was overlooked because they refused to offer me a home visit or make alternative arrangements for me. I felt like my needs had been forgotten and that I simply fell under the radar.

“I felt like my needs had been forgotten and that I simply fell under the radar.”



Waivers

In some cases, women reported being told screening is too complex to arrange and have been told it is not possible or even asked to sign a waiver stating that they do not wish to receive screening.

Cervical screening is a choice and all women are able to opt out if they choose, having weighed up the risks and benefits. However, this should be a choice only they can make and it is unacceptable that some women are being asked to opt out because of their disability.

“The nurse seemed to feel awkward and didn't really know what to do or suggest a solution. It seemed as though I was the first person with a physical disability she had ever had attend a smear test. Even if this was the case, there was a lack of warmth or reassurance as I was clearly nervous, struggling and conscious of the time.”

“(The) nurse was very kind, but she didn't seem aware of my illnesses or what issues they might create.”

Stigma and misconceptions

Our research has shown that a high level of stigma and misunderstanding still exists regarding disability.

38% of respondents said that GPs or nurses don't understand their needs or take them seriously.

76% of respondents said that having a doctor or nurse who understands their disability would make cervical screening easier for them.

Disability is diverse and complex. Furthermore, not all disabilities or physically debilitating symptoms resulting from long-term health conditions are visible. Sometimes known as “invisible disabilities”, there are a wide range of chronic and long-term health conditions that do not require the use of wheelchairs or crutches, such as myalgic encephalomyelitis or fibromyalgia. These can severely affect quality of life and necessitate adjustments and additional support in order for people affected to access screening. Having conversations with women about how their disability could impact ability to access screening is essential, especially with complex, rare or multiple conditions.

“I am unable to leave my bed. I have been denied cervical screening since 1994. I have been repeatedly asked to sign a waiver saying that I do not wish to receive cervical screening. I have not signed a waiver because I would like to receive cervical screening.”

“I have lymphedema and during one visit to the GP, he told me that my condition didn't exist and that I was simply fat and lazy.”

“My disabilities are all invisible. My GP and the nurses are brilliant but as they can't see what's wrong with me, they struggle to understand how much pain I experience. I suffer from allodynia, so even a gentle touch can feel disproportionately painful.”

“As a wheelchair user I can't attend and was told as I'm not sexually active it's not something I should worry about.”

Sex and disability

In **99.7%** of cases, cervical cancer is caused by persistent infection with human papillomavirus (HPV). It is a very common virus that **4 out of 5** (80%) people will have in their lives. Genital HPV is usually passed on through sexual contact, including touching in the genital area and sharing sex toys, in addition to vaginal and anal sex. It can stay undetected in the body for many years and be contracted from first sexual contact.

Sadly, many women reported assumptions being made about sex and intimacy as a result of their disability, with some even being told they are not at risk of cervical cancer and that cervical screening is not necessary for them.

20% of respondents said that it has been assumed that they are not sexually active because of their physical disability.

While many health professionals fully understand HPV transmission and do not hold misconceptions regarding sex and disability, it is shocking to see that there are those who hold such beliefs. This is quite simply not acceptable.

“The last time that I was trying to arrange screening with a district nurse, she informed me that it was not necessary, saying that I would not get cervical cancer anyway.”

“Sexual health care for disabled women, preventative and treatment, needs to be discussed openly without assumptions.”

“I’ve always had understanding nurses, and so I feel very lucky. Not everyone has this sadly.”

Positive experiences

We know that there is a lot of great care in the UK for people with disabilities and many health care professionals go out of their way to ensure that services are accessible to their patients.

Some people highlighted positive experiences, including being offered screening in their homes, being able to access screening because of adequate equipment at their practice and being supported by understanding nurses who were knowledgeable about the impact of their condition on screenings.

“There is also the presumption that we don’t need this screening like every other woman as many people think disabled women are asexual, which is simply not true.”

“Doctor said it was obvious in your condition you are not sexually active.”

“In addition to my physical disability, I find the smear tests extremely painful and incredibly distressing... However, when I finally did make myself go the nurse was amazing.”

“My own experience has been positive as my GP surgery are very good and very patient, I have not had a bad experience.”

“My GP surgery... are very understanding of my disability and always make me a double appointment when I have to attend my screening.”

Conclusion

Cervical screening saves lives and every eligible woman who would like to take part in the screening programme should be able to.

While many GP practices have policies, equipment or adjustments in place to ensure this happens, this report uncovers a serious health inequity. It is a scandal that some women are unable to access screening because they have a physical disability. It is a basic healthcare provision and it is highly unacceptable that some women are having to fight for their right to attend or, as some of the stories in this report show, being flatly denied it.

We fully understand that general practice in many parts of the country is under immense pressure yet the cost of cancer, both to the person and that to the NHS, is highly significant. We must be doing everything we can to reduce the chance of a woman ever having to deal with a diagnosis and cervical screening provides just that.

While national guidance addresses the need for services to be accessible with disability not creating a barrier, it is clear that greater enforcement and regulation is needed. In addition, this report highlights the need for changes in perception, attitudes and approaches by many health care professionals involved in screening, so that everyone who is eligible for screening and wishes to attend can be confident that they will be treated with respect and their needs will be met.

“Just because we have a disability shouldn’t mean we can’t access screening. Our lives are just as important.”

Recommendations

1

National support to address inequity in access for women with a physical disability

With cervical screening attendance falling we must be focused on reducing the barriers that exist, including for those living with a physical disability where there should not be additional hurdles to overcome. The cervical screening programmes across the UK must take the lead in helping tackle this unacceptable situation and encouraging providers to take action through provider service specifications, communications channels, and training.

2

Each GP practice to review their policies and practice and ensure pathways or adjustments are in place to ensure every woman can access cervical screening

Every woman between the age of 25 and 64 has a right to have cervical screening. It is the responsibility of providers, namely GP practices, to ensure this can happen and each should review existing policies and practice. This will further provide an opportunity to educate staff in the needs of women and reinforce the wide range of disabilities and conditions that may affect ability to attend cervical screening. Where new policies are created, these must be communicated to those who will benefit. Local NHS, including Health Boards and Clinical Commissioning Groups, should encourage and support practices to do so.

3

Care Quality Commission and health inspectorates to regulate access in general practice

The Care Quality Commission and GP inspectorates across the UK should assess arrangements that practices have in place for providing cervical screening to women with a physical disability, including pathways for those who are unable to leave the house. Action should be taken if inspections conclude that service providers do not have adequate measures in place with timescales to rectify practice set.

4

Research looking at the most effective way of offering cervical screening to women with a physical disability, including feasibility of HPV self-sampling

There is limited research which has explored the needs and wants of women with a disability when it comes to having cervical screening. Further understanding regarding the most acceptable and effective pathways and adjustments should be established through targeted research among women with a range of physical disabilities.

HPV self-sampling provides an opportunity for many women to take their own test in their own home or at their own convenience. While not every woman with a disability will be able to use a self-sampling kit, there are many who may find it far easier than the existing sampling method. Research looking at attitudes to self-sampling is needed to identify the feasibility and most effective way of offering it to this group of women

5

Sample taker training, and refresher training, to include potential needs and adjustments that should be considered for women with a physical disability

While many women receive high quality care, others are not getting the support or service that they need. Furthermore stigma and assumptions held by health care professionals around sexual activity can be hurtful and even harmful, especially when some women are being discouraged from having cervical screening.

Covering potential barriers and adjustments for women with a physical disability in training will ensure sample takers are able to champion the issue in their practice, educate others including reception staff and practice managers and identify where adjustments may be necessary. Increasing understanding about sex and intimacy among disabled people, including HPV transmission, is also crucial. This report will hopefully pave the way in highlighting these issues.

References

1. Jo's Cervical Cancer Trust: <https://www.jostrust.org.uk/research>
2. Scope, Disability facts and figures, Available at: <https://www.scope.org.uk/media/disability-facts-figures/> Accessed 30th March 2019
3. Sport England, Mapping Disability the facts, 2016, Available at: <https://www.sportengland.org/media/3988/mapping-disability-the-facts.pdf>
4. Full Fact, How many people have a disability? 2018, Available at: <https://fullfact.org/health/how-many-people-have-disability/> Accessed 2nd April 2019
5. Equality Act 2010, 2010 c.15, Part 2, Chapter 2, Adjustments for disabled persons, Section 20 Available at: <https://www.legislation.gov.uk/ukpga/2010/15/section/20> Legislation.gov.uk>
6. Nigel's Surgery, Nigel's surgery 67: Reasonable adjustments for disabled people, Care Quality Commission, 2017, Available at: <https://www.cqc.org.uk/guidance-providers/gps/nigels-surgery-67-reasonable-adjustments-disabled-people>
7. Care Quality Commission, Key lines of enquiry, prompts and ratings characteristics for healthcare services, 2017, Available at: <https://www.cqc.org.uk/sites/default/files/20180628%20Healthcare%20services%20KLOEs%20prompts%20and%20characteristics%20showing%20changes%20FINAL.pdf>
8. Citizens Advice, NHS patients' rights, 2019 <https://www.citizensadvice.org.uk/health/nhs-healthcare/nhs-patients-rights/>
9. Letter from Steve Brine MP to Trailblazers on 28th February 2019