Jo's cervical cancer trust

WOMEN'S HEALTH STRATEGY CONSULTATION RESPONSE

Introduction

Jo’s Cervical Cancer Trust is the UK’s leading cervical cancer charity. We provide information and support across all aspects of cervical cancer and prevention. Five million women and people with a cervix are invited to cervical screening (smear tests) every year, 220,000 are diagnosed with cervical cell changes, and around 3,200 are diagnosed with cervical cancer. 49,000 are currently living with or beyond a diagnosis of cervical cancer.

We want to see cervical cancer become a thing of the past, which we know is possible through our cervical screening and vaccination programmes. Until that day, we will help women at every step of their journeys, and we are pleased to have the opportunity to respond to this important consultation, to help shape the future of women’s healthcare in England, and to amplify the voices of the community we represent.

Across all aspects of cervical health there are gaps in research and data, inequalities, and a lack of information and support for those affected. Stigma and misinformation are sadly rife, and throughout women’s experiences of cervical health, we are seeing a system that is not built with women’s needs at its centre.

Please note that, because this is a direct response to the Women's Health Strategy Consultation, we primarily use 'women' and 'woman' throughout.' Many of the issues raised throughout this response relate to women as well as other people with a cervix, including trans men and/or non-binary people.

A life course approach

Cervical cancer prevention needs a life course approach. From HPV vaccinations offered in adolescence, to cervical screening from ages 25-64, motivations and challenges to accessing these prevention programmes change with age, and are affected by a myriad of socio-economic, emotional, and physical factors. For those affected by cervical cell changes or cervical cancer, the side effects - physical and psychological - can last a lifetime.

To live well and access the appropriate healthcare, it is vital that systems are designed around those who use them. This means asking questions and listening to women of all experiences and backgrounds. At Jo's Cervical Cancer Trust we hear from countless women who have had their symptoms or experiences overlooked. We aim to coproduce all our services and information with the women that they aim to serve, and this approach should be adopted more widely to see person-centred information and services.

HPV: Education, data, and stigma

HPV (human papillomavirus) is the cause of almost all cervical cancers (99.7%). The virus is extremely common and affects around 80% of people during their lifetime, regardless of sex or gender. The role of HPV is key for cervical cancer prevention, with children offered a HPV vaccine at around 11-12 years old, which prevents around 70% of cases. The Cervical Screening Programme has recently introduced HPV primary screening, a far more effective way of testing samples than the previous method of cytology.

The virus is shrouded in a lack of understanding and a high level of stigma. Lack of education around the virus affects women throughout their life, with a disproportionate emotional and psychological impact on women due to there being no HPV test for men, with men only finding out they have the virus if they develop an HPV-related cancer.

Through our research we know:

- A third of women have not heard of HPV (29%)
- 39% would be worried what people thought of them if they were told they had HPV.
- 41.7% would worry their partner had been unfaithful. *[1]*

Confusion, stigma, and shame around HPV diagnosis has led to the number of calls about HPV to our Helpline doubling in the last three years. *[2]* Misconceptions around the nature of the HPV virus, and its relation to sexually transmitted infections (STIs), can lead to concerns around infidelity and relationships breaking down, which we regularly hear through our services and from our colleagues within the NHS.

For those living with and beyond cervical cancer, the HPV diagnosis often prevails. Sadly some of our community face additional stigma following their cancer diagnosis as a result of HPV.

The age at which children are offered the HPV vaccine is the ideal opportunity to provide education on the nature of the HPV virus, yet this opportunity is not being made full use of. We want to see the inclusion of HPV in PSHE so children and parents have greater understanding of the HPV vaccine and the nature of the virus - to ensure fully informed consent, and to help tackle stigma from an early age. Furthermore, misunderstanding of the virus and the vaccine can lead to people believing they are fully protected from the virus and not at risk of cervical cancer, which is not the case.

We want to remove the perception of HPV as an STI. This brings stigmas of promiscuity and dirtiness, and can result in guilt and shame. It is also distinct from other sexually transmitted conditions, due to the fact it cannot always be identified, there is no treatment, and it cannot always be prevented.

"In the back of my mind I have always worried about HPV or some other form of cancer that could pop up somewhere else. I have never had the courage to ask any of my doctors this particular question, as I was too scared of the answer."

“I had the HPV vaccine when I was at school and I'm still unsure as to how I have actually contracted the virus. None of this has ever been explained to me in school or when I had my abnormal result.”

“It’s going to be frowned upon isn’t it? Because your automatic assumption is that somebody’s been... naughty. Oh my God, she has cervical cancer so she must have a numerous amount of partners somewhere.”

Symptoms being ignored

We hear from too many women who have not been offered the appropriate tests when presenting in primary care with common symptoms of cervical cancer - such as unusual bleeding and changes to vaginal discharge. Instead they are told these are probably side effects of contraception, water infections, or hormones. This is particularly the case in younger women, where only 30% of 18-24 year olds who reported unusual bleeding are given an examination, compared to 57% of those aged 55+. *[3]*

Through our research we know over half (52%) of women do not know bleeding during or after sex is a symptom of cervical cancer, and 63% are not aware that post-menopausal bleeding is a symptom of cervical cancer. *[4]* Awareness of symptoms is lowest amongst women aged 18-24, under the age of cervical screening, where almost half of whom believe vaginal bleeding to be normal or expected. *[5]*

While guidance is in place for the management of under 25s with abnormal vaginal bleeding this is not always followed, leading to delays in potential treatment. Worryingly, over 1 in 4 who reported bleeding were given a cervical screening test - which in fact slows down a diagnosis while waiting for appointments and results. There is a clear need for increased awareness amongst healthcare professionals of the correct pathway - a visual examination - if a patient has cervical cancer symptoms.

The Clinical Practice Guidance for the Assessment of Young Women aged 20-24 with Abnormal Vaginal Bleeding is also 11 years old now, and we are unaware of plans to review or update it.

Inequalities in awareness and access in cervical screening

Cervical screening is the best protection against cervical cancer, and prevents 7 in 10 incidences, yet uptake has been in slow decline with over 1 in 4 not taking up their invite, and even lower attendance in some groups.

Through our research we know there are multiple barriers to attendance; including fear, embarrassment, conditions which can cause pain, disability, and experience of trauma. It is important that women are supported through screening and know where to access support and tips. A life course approach is essential, as perceptions and challenges are different; for example, for younger women attending their first screening to those who are post-menopause.

- A worrying 40% of lesbian and bisexual women have been told that they don't need cervical screening. *[6]*

- There are some physical barriers faced by disabled women, e.g. GP surgeries lacking equipment such as hoists, and a lack of available home visits. As a result 63% said that they have been unable to attend cervical screening because of their disability and 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. *[7]*

- 72% of women who have experienced sexual violence have delayed cervical screening or not attended, because of their experience. *[8]* While some specialist clinics are available - such as **My Body Back Project** - these are few and far between.

- Following menopause, some women find cervical screening more uncomfortable and painful than before. *[9]* Healthcare professionals should be aware of all the options they can give a patient, in order to make their experience as comfortable as possible. Again, women need to be provided with the information and tools necessary to self-advocate and feel in control of the procedure.

- 56.1% of Black, Asian and minority ethnic women report delaying screening with 15.8% delaying by more than three years. *[10]*

To increase cervical screening attendance it is vital that those involved in promoting and delivering it are aware of the wide range of challenges that exist, and can provide the support, adjustments and information needed for each individual. A one-size fits all appraoch does not work. Everyone the patient encounters at their cervical screening - including reception and non-clinical staff - can impact the patient experience.

We want to see far greater progress on HPV self-sampling which allows women to - literally - take the test into their own hands. This would be particularly beneficial for those who experience pain or anxiety. There needs to be more urgency in running pilot studies, so the UK National Screening Committee can receive the evidence it needs for self-sampling to become part of the national screening programme. *[11]*

Diagnosis and treatment

Around 220,000 women will be told they have cell changes (abnormal cells) each year, and many will be treated to prevent the potential development of cervical cancer. Despite such a large number of women being affected, we believe that this group of women - and their experiences - are hugely overlooked.

Treatment for cell changes is highly effective, but it can have a lasting impact on those who receive it. There is very little formal research on the physical and psychological consequences of treatment for cell changes.

> **"I had LLETZ but at no point beforehand was I told what it was or what & why it was happening. I was young, on my own and absolutely terrified and I wish I'd refused to have it at that point and insisted on making another appointment for another time." [14]**

Our own research identified high numbers experience side effects such as pain during sex, infection, anxiety, and ongoing psychological distress from the accompanying HPV diagnosis. Worryingly, 20% said possible impacts weren't explained to them, and 60% were not told about the different available treatment types prior to their own treatment. *[13]* We hear reports from women who don't understand what is happening to them, and feel as though they are being rushed through the process with limited information and choice.

Greater research is desperately needed to fully understand the physical and emotional consequences of treatment for cell changes and a greater recognition of the impact it can have. There is a need for greater consistency and applied guidelines over the treatment and management of women with cell changes too.

Fertility

Treatment for cervical cancer and cell changes can sometimes result in loss of, or changes to, fertility. Women tell us this is often one of their first concerns when diagnosed.

Our research shows 45% of women who underwent treatment for cervical cell changes had fears around their fertility. *[15]* Many felt unsure how treatment could affect their fertility or future pregnancies, and some did not know about the effects that treatment could have until they were already pregnant. Pregnant women are not always asked about if they have previously had treatment for cell changes - nor are they always made aware that this is important information to disclose.

However some treatments, such as LLETZ, can increase the risk of a premature birth or miscarriage, so it is vital that this information is shared with the patient and healthcare professionals. *[16]*

Loss of fertility can bring a significant impact to emotional wellbeing, in addition to the physical impact. Women in our community have told us about insensitive ways they have been asked if their family is ‘completed yet’, or when it has been assumed that they ‘weren’t planning on having any more kids’. Some women tell us that they felt rushed into making decisions about having children. This can be very hurtful at a time a woman may have received life-changing news about their fertility.

We want all women to receive the appropriate support and advice to make these decisions and to receive emotional and practical support following them.

As is common through cervical cancer and cell changes treatment - there is no standardised pathway and there is a lack of guidance around fertility preservation, fertility options, and access to specialist consultants.

Living with and beyond cervical cancer

Menopause

Some treatments for cervical cancer can trigger the menopause; including hysterectomy, pelvic radiotherapy, or chemotherapy. Menopause after pelvic radiotherapy or chemotherapy may be temporary or permanent depending on age and the dose or type of treatment.

We are concerned that there is not enough physical and emotional support for women going through the menopause, particularly for those who have had it triggered by medical intervention, as they are likely to be younger and less likely to have peer to peer support. We support the aims of Menopause Support -and other menopause organisations - and their #MakeMenopauseMatter campaign; calling for more education, information, advice, and support for those affected by menopause. *[17]*

Pelvic radiation disease

Pelvic radiation disease describes a variety of long-term side effects that can result from radiotherapy treatment to the pelvic region. The Pelvic Radiation Disease Association (PRDA) estimates that at least 100,000 people in the UK experience ongoing problems following radiotherapy to the pelvic region - including include pain, fatigue, lymphoedema, bone fractures, hormonal changes, infertility, and psychological difficulties - with research showing that 80% of patients develop a chronic change in their bowel function. *[18]*

One of the largest barriers for women with PRD accessing support is limited knowledge of the condition. As the symptoms can be so varied, and can occur a considerable amount of time after treatment, they can be difficult to identify as PRD unless a healthcare professional has a pre-existing awareness of the condition. Our research has identified a common theme, where patients report feeling as though they have been left to 'deal' with these issues on their own, and have their symptoms dismissed. *[19]*

"In 2014, I went to a GP as I had heard there was medication that would help. After three visits, I was given two medications to try, neither of which really helped. I went back to the GP who brushed me off and said there were no other treatments available."

"I have had diarrhoea every day since Christmas Eve 2016 but despite this have managed to gain ten stone. My GP has been of little help suggesting that I get a gastric band or just stop eating."

There is a desperate need for the development of NICE guidelines on the diagnosis and management of the late effects of pelvic radiotherapy, and on the management of cervical cancer, to provide standardised pathways for identification and treatment of symptoms following radiotherapy.

Women's health in the workplace

It is crucial that women's health becomes a better understood topic in the workplace; particularly in regards to the importance of attending screening appointments, in showing understanding and compassion to those undergoing invasive treatment, and living with the long-term effects of cancer.

Access to cervical screening

Our research shows that busy lifestyles and the inconvenience of accessing cervical screening is one of the most common reasons given for delaying or missing an appointment. [20] Additionally, inflexible workplaces, zero hour's contracts, holding down multiple jobs, and childcare, can impact ability to access healthcare.

Women should be encouraged to attend their routine health checks, and should feel comfortable and supported by their employer to take time away from work to attend a cervical screening. Furthermore, they should not be financially disadvantaged for doing so. Our Time to Test campaign calls on employers to publicly show their commitment to raising awareness of cervical cancer prevention, and to ensure their employees can find the time to attend potentially life-saving cervical screening appointments. [21]

Returning to work following treatment

Cell changes

Through our support services and media volunteers we hear of a significant number of women returning to work the same day as receiving treatment for cervical cell changes. Common side effects of these treatments can include pain and bleeding for several weeks, as well as emotional distress, anxiety, and depression. It is concerning that women feel an obligation to return to work immediately after receiving such an invasive treatment. *[22]*

> **“My friend tried to get some time off work after having treatment [for cell changes]. And it was the men who didn't understand why and were like, ‘But you can still do work’. And she's trying to say, ‘No, I can't, I don't feel good.’”**

While there is limited formal evidence on the physical and psychological side effects of treatment for cervical cell changes, we want to ensure that all women have the information, preparation, and support they need, prior to, during, and following their treatment.

Cervical cancer

A recurring theme among those living with and beyond cervical cancer is feeling like they do not know anybody else affected. Cervical cancer remains a rarer cancer and unlike some other cancers, the chemotherapy drugs used to treat cervical cancer do not often lead to hair loss, and can lead to the assumption patients are “fine”.

Our research shows there is both an additional financial cost and a negative impact on women’s employment status following cervical cancer diagnosis. *[23]* Cancer-related expenses can include hospital car parking fees, wigs, specialist dietary food, replacing mattresses where there has been heavy bleeding, and childcare. Although childcare expenses are not specific to cervical cancer, as a women’s cancer that affects younger women, childcare costs can be high. r.

There is also a long-term financial impact of cervical cancer; considering 87% of women receiving treatment for cervical cancer had to take time off work, and 22% had to stop working altogether. In 37% of cases, women told us that they found it ‘quite difficult’ or ‘very difficult’ to make these changes to their working hours. The fact that this additional financial burden comes at a time when people already have enough to worry about makes its impact on wellbeing all the more concerning. *[24]*

There is no ‘one-size-fits-all’ policy for support in the workplace, and employers must be encouraged to apply a person-centred approach to support any employee during a period of ill health. More research is needed to fully understand the issues faced by women regarding employment and returning to work following treatment for cervical cancer, to ensure they can retain a good quality of life.

Guidelines and pathways

A major obstacle is the lack of a standardised pathway for the treatment of cell changes or cervical cancer. Unlike other cancers, there are no NICE guidelines for the treatment of cervical cancer and guidance and as a result there can be wide variation in the opportunities afforded to patients.

Research, evidence, and data

An ongoing theme surrounding HPV, cervical health, cell changes, and cervical cancer is a lack of data and formal research. Without such data we are unable to target health interventions where they are needed the most, and some conditions or experiences remain overlooked.

Many charities collect and collate their own data and research; evidence that is hugely beneficial to help build and inform strategies such as the Women's Health Strategy. At Jo's Cervical Cancer Trust we undertake our own social research, speak with experts in relevant fields, and rely on the information we receive through our Services. The research itself is useful and valuable, and in conjunction with other charities it forms a massive knowledge base, but it rarely features in academic literature and is therefore not always perceived as being as robust or reliable enough. Organisations such as ours need appropriate funding in order to formalise this research and support publication in peer-reviewed journals.

Significant gaps in data include:

- No data about ethnicity or socio-economic groupings collected with cervical screening or cervical cancer data, meaning interventions cannot be targeted where need is greatest.

- Limited research into the experiences of the 220,000 diagnosed with cell changes.

- Wide knowledge gaps on HPV, including why dormant HPV becomes active again, why some people clear the virus when others do not, whether couples with HPV can re-infect one another, and the merits of therapeutic HPV vaccination for those experiencing recurrent reinfection.

- Evidence shows that 99.7% of cervical cancers are caused by HPV, but we still do not understand the causes of the remaining 0.3%.

Such knowledge gaps mean reassuring patients and designing appropriate interventions and pathways is not possible. As a result some fall through the gaps.

Impact of COVID-19 on women's health

The impact of COVID on cancer services has been widely reported. Our own research and data from our support services over the past year has identified hesitancy in accessing primary care with symptoms of potential cancer, delaying cervical screening as a result of COVID-19, anxiety over missed appointments, treatments and tests, and isolation experienced by those undergoing cancer treatment.

We share the concern voiced by many that we will sadly see more later-stage diagnoses, more invasive treatment, and a greater loss of life as a result.

There are further, less-reported impacts, such as the closure of public toilets which meant those who have had bowel or bladder damage following cervical cancer treatment were often unable to travel or leave the house for an extended period.

Cervical screening attendance

Many cervical screening providers either paused or reduced provision of screening at points during the pandemic, leading to backlogs in those waiting for appointments. Our research identified high levels of anxiety about attending, confusion about whether cervical screening was still taking place, and concerns about putting additional strain on the NHS. *[25]* We also found many women unable to make appointments when they tried and even being told to call back in a few months. *[26]*

These challenges add to the wide range of pre-pandemic barriers to attendance; such as fear, embarrassment, pain or discomfort, and inconvenience. Certain groups, including South Asian women had far greater concerns about attending and were far more likely to say it was safer not to during the pandemic. The lack of face-to-face outreach in community settings is a concern, a priority going forward must be to identify which groups have not come forward for screening during the pandemic and develop interventions to reach them. *[27]*

In addition to rebuilding confidence in attending and clearing backlogs, COVID-19 does re-emphasise the need for HPV self-sampling to be offered as part of the national screening programme. We have seen how well the NHS and Public Health England can innovate in times of crisis, and we believe this urgency should be applied to integrating HPV self-sampling as part of the national screening programme.

HPV vaccine programme

Prior to the pandemic, there were substantial variations in uptake of the HPV vaccine across local authorities – ranging between 70% and 96% across the country. There are also significant disparities in uptake across different socio-economic groups and ethnicities. The pandemic has created additional challenges to delivering the HPV vaccination programme and we now have multiple school years who were due at least one dose of the vaccine during the course of the pandemic.

It has been announced that all school-aged vaccinations in England should be caught up by August 2021, but there are still some remaining concerns:

- Providers have been asked to produce restoration plans, but the details have not been published. Different postcodes will also be able to recover faster than others and this could widen inequalities that existed before the pandemic.

- Inconsistent school attendance and an increase in home-schooling will make it more difficult to monitor who has received their vaccine. Vaccination and GP IT systems are not linked, so those who don't receive the vaccine in school won't always be flagged by their GP and the opportunity to offer it may be missed.

- Some pupils may end up being vaccinated after the age of 15, at which point additional doses are required.

- Over the last few months we have also seen a worrying increase in anti-vaccine sentiments and misinformation campaigns. It is essential to ensure that confidence in vaccines remains high, with accurate information provided to both children and parents in advance of their invitation.

Ultimately, all women deserve the information, knowledge, confidence, and support to make informed decisions about their health, and to receive the best possible treatment and care.

We need women's voices and experiences to be centred and amplified, to ensure that future policy and healthcare plans are truly meeting and fulfilling their needs.

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