Jo's Cervical Cancer Trust response to the Disability Action Plan 2023-2024 consultation

Jo's Cervical Cancer Trust is the UK's leading cervical cancer charity, and our vision is of a future without cervical cancer. Cervical screening plays a key role in eliminating cervical cancer, but our research has highlighted a disproportionate lack of uptake amongst disabled women. With 88% of physically disabled women stating that it more difficult for them to access screening[i], we are calling for government action to improve access to these life-saving tests.

Response to question 13:

What do you think of the plans and suggested areas of action described in this consultation as a whole? Are these the right things for the government to be focusing on over the next year?

'Digital Flags'

Good patient experience is essential to ensure that patients continue to attend cervical screening. The plans for NHS England to implement a 'digital flag' for patient health records - to identify those with a learning disability and outline reasonable adjustments to support their care[ii] - could help ensure that women with learning disabilities are informed and empowered when they attend their screening appointment.

We believe that there could be a benefit in expanding this 'digital flag' system to include physically disabled women. For some disabled women, cervical screening remains inaccessible if their GP practice does not have the appropriate equipment such as wheelchair access, accessible parking, hoists, stirrups, or a height-adjustable couch. If these access requirements can be flagged in advance, this will allow staff the opportunity to ensure that they have all the necessary facilities, and to consider what additional adjustments could be made to improve patient experience – such as a longer appointment, or the prescription of painkillers.

If a GP practice does not have the facilities needed, this information may allow them to refer patients to a more accessible venue or consider the option of a home visit. Where GPs send second reminder letters to those who have not responded to their initial invitations, a 'digital flag' could ensure it is sent in the best possible format – for example braille, or large text. Being aware of patient needs before an appointment can help ensure that women receive the best care from their GP practice team and are not faced with an inaccessible service on the day of their screening.

Care Quality Commission statutory Code of Practice

The Department of Health and Social Care also plans to develop a statutory Code of Practice for Care Quality Commission-registered providers, to ensure that their staff receive appropriate training on learning disabilities and autism, which we believe could be valuable in improving patient care and tackling stigma and misconceptions.

Existing CQC guidance highlights some of the barriers that disabled women face when accessing cervical screening, including previous negative experiences. Our research shows that 49% of disabled women have chosen not to attend cervical screening because of a previous bad experience related to their disability[iii]. Some women report that healthcare professionals do not know how to perform the test on them because of their disability, while others have had their pain dismissed. 20% of the women we spoke to said it had been assumed they are not sexually active because they are physically disabled.

We would encourage the DHSC to consider similar training for Care Quality Commission-registered providers that addresses the stigmas and misconceptions that disabled people face and highlights the barriers that they may encounter when accessing healthcare.

Strengthening the evidence base

There is little standardised data from across the UK identifying regional or specific barriers to screening for disabled women. Without this data it is difficult to identify problem areas or patterns of inaccessibility. It is also difficult to recognise where these issues overlap with other barriers, such as rural regions or areas of high deprivation. Improved data collection in healthcare settings – and indicators to assess the effectiveness of services – could provide a clearer picture of the scale of this issue and help lead to more effective actions in addressing it.

Response to question 14:

What alternative actions might the government consider that would make a positive difference to the lives of disabled people?

Barriers to cervical screening for disabled women

2019 research from Jo's Cervical Cancer Trust found that disabled women can face significant barriers when attending cervical screening[iv]. The survey of 335 disabled women found:

- **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**.

Key barriers to accessing screening include:

- A lack of wheelchair access in GP practices.
- Poor provision of hoists, height adjustable couches, and stirrups.
- No home visits for those who are unable to leave their home or bed.
- No onwards referral to more accessible venues.

- Being told they are too complicated.
- Stigmas and misconceptions.
    - For example, assumptions that disabled women are not sexually active.

These barriers can be further compounded by other factors. For example, disabled women are more likely to live in more deprived areas and have lower income,[v] and studies consistently find that screening coverage is worse among individuals from more deprived socioeconomic backgrounds[vi]. Research also shows that disabled women are more likely to experience sexual violence than non-disabled women[vii]. Disabled women tend to have poorer mental wellbeing than non-disabled women[viii] and evidence shows that screening uptake in England is low amongst adults with severe mental illness[ix].

Sensory disabilities can also impact screening accessibility, with 14% of the deaf population missing a GP appointment due to not hearing their name being called out in the waiting room[x]. Cervical screening can be additionally daunting for those who face barriers in communicating with their nurse, for instance deaf women have highlighted feeling more anxious because they cannot hear the nurse talk through the steps and what they may feel during the screening[xi]. Women with visual impairments also recount discomfort during screening as a result of nurses not accounting for their disability, such as not explicitly stating where the examination bed was or what the speculum may feel like[xii]. Poor patient experience of cervical screening can dissuade women from attending again in the future.

Data from the UK and around the world highlights that not only is screening attendance significantly lower for disabled women than for women without disabilities, but that they are more likely to develop cervical cancer[xiii] and their overall cervical cancer outcomes are worse too[xiv].

Reasonable adjustments

GPs have a duty to make reasonable adjustments for disabled people to ensure that they are not disadvantaged compared with non-disabled people[xv]. Unfortunately, we know that many GP practices are situated in inaccessible buildings, and they often do not have the right equipment, training, or staff to provide the care that disabled patients deserve.

Hoists

For example, 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.

Only 1% of women reported their GP proving a hoist, whereas 23% of disabled women stated that hoists would make screening a more comfortable experience for them[xvi].

Home visits
55% of our respondents said that a home visit from a GP or nurse would make accessing cervical screening easier for them, while 22% said that they are unable to leave the house, but their GP practice doesn't offer home visits[xvii].

Guidance on the provision of home visits for cervical screening is varied, and provision is inconsistent across the UK. This means that some disabled women are being offered home visits upon request while others are told it is not an option. These inconsistencies shift the responsibility of screening accessibility to the patient and can lead to confusion and anxiety.

Along with confusion around guidance and insurance, conversations with primary care staff suggest that workforce pressures are making home visits more difficult.

Onward referrals
Guidance from the Care Quality Commission, NHS England, and the Royal College of Nursing recommends that patients are referred to a different practice or to hospital colposcopy or gynaecology services if they cannot be screened at their practice. However, our research shows that disabled women are rarely referred onwards – with just 17% saying they were offered the test at a different venue. There are also significant waiting lists for many colposcopy clinics across the UK, meaning that an onwards referral is not always the best option for the patient or for colposcopists, if reasonable adjustments can be made at the GP practice.

Recommendations
There are significant barriers to accessing cervical screening for disabled women, and notable disparities in care and patient experience across the UK.

We encourage the Government to review access to cervical screening across the UK, to gather a clear picture on where women are unable to access cervical screening. Where access issues are caused by a lack of equipment, we urge the government to ensure that every practice receives the resourcing they need.

We urge the Government to work with the Care Quality Commission and Healthcare Inspectorates to ensure that accessibility is a key measure of GP performance. Where practices are unable to perform screenings themselves, they should have a clear pathway for referring patients to accessible services, and these pathways should be consistent and understood by all relevant staff.

There is a significant need for clarity around home visits for cervical screening. If practices do not have the resourcing or training to carry out home visits, there must be a process to ensure these women are not left without the healthcare they are entitled to. It should not be left to patients to fight for access to screening, and disparities in practice across the country are leading to confusion and anxiety. The provision of access to cervical screening for women who are unable to leave their homes should be assessed by the Care Quality

Commission and Healthcare Inspectorates, and action should be taken immediately when there is no clear policy or practice.

HPV self-sampling may provide an opportunity for women to take an accurate HPV test in their own home – either using a vaginal swab or a urine sample – which could be beneficial to many disabled women who currently find cervical screening difficult to access. To ensure that self-sampling is as accessible as it can be, more research is needed to identify the most effective way that self-sampling may be offered to disabled women. If HPV self-sampling is embedded in national screening programmes, it is essential not to overlook those for whom this still won't be a viable option. Improving the accessibility of GP practices and the screening programme will still be necessary, to ensure that disabled women have equitable access to cancer prevention programmes.

Pre-existing disability is not reported in national cancer statistics, which makes it difficult to assess how significant the impact of inaccessible screening programmes is. As well as being less likely to engage with cancer screening programmes, research suggests that disabled people experience worse levels of cancer survival, higher overall and cancer-specific mortality, less access to state-of-the art therapies, treatment delays, undertreatment or excessively invasive treatment, worse access to in-hospital services, less specialist healthcare utilisation, more difficulty accessing pain medications, and inadequate end-of-life quality of care[xviii]. We would encourage the Government to consider the benefits of including data on pre-existing disability in national reporting of cancer incidences and mortality, to give us a clearer picture of the impact that disability has on cancer outcomes.

Crucially, we encourage the Government to continue working with disabled people to ensure that their voices and needs are centred in any ongoing discussions, actions, and initiatives to address inaccessibility and to improve disabled people's lives.

For more information, please contact media@jostrust.org.uk.

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