Jo's cervical cancer trust

Welsh Senedd consultation on gynaecological cancers

Jo's Cervical Cancer Trust written response.

Jo's Cervical Cancer Trust is the UK's leading cervical cancer charity. Our vision is a future without cervical cancer. Until that day, we will provide support and information to everyone affected by cervical cancer, and campaign for excellence in cervical cancer treatment and prevention.

There are around 160 cases of cervical cancer in Wales every year, with 52 women losing their lives to this disease annually[i]. Cervical cancer is largely preventable through a combination of cervical screening and HPV (Human papillomavirus) vaccination.

The Public Health Wales Screening Division Inequities report (2020-21) showed that just **69.5%** of eligible women attended their cervical screening[ii]. The 2022 COVER report showed coverage of the complete two doses of HPV vaccine in girls in the 2021/22 School Year 10 is worryingly low at **55.1%[iii].**

In addition to preventing cervical cancer, we want any cases that do occur to be identified as early as possible. Early diagnosis means less-invasive treatments and better health outcomes.

To support in the development of this consultation, we surveyed 55 women from Wales who had experience of cervical screening, possible symptoms of gynaecological cancer, or experience of cervical cancer. Some of their feedback is quoted throughout this response.

Information and awareness of risk factors for gynaecological cancers across the life course and the symptoms associated with gynaecological cancers.

Public awareness of cervical cancer symptoms is low, with over half (**52%**) of women in the UK unaware that bleeding during or after sex is a symptom of cervical cancer[iv]. Low awareness among health professionals, particularly in primary care, can further delay diagnosis. Awareness raising must include both individuals as well as the professionals who support them.

Vaccine hesitancy and low understanding around the HPV vaccine are widely recognised as barriers to uptake[v]. Certain groups are far less represented in uptake including those living in areas with prominent levels of social deprivation, some ethnicities, and those previously excluded or not in school[vi]. Among parents of soon-to-be eligible children in England and Wales, just **55%** were aware of HPV and the girls' HPV vaccination programme[vii].

Understanding and awareness of HPV, the virus responsible for 99.7% of cervical cancers is also low, with queries about HPV making up more than **40%** of the calls to the Jo's Cervical Cancer Trust Helpline, and over **30%** of the submissions to the Ask the Expert service.

Myths about who is at risk of contracting HPV, and the nature and longevity of the virus, can also lead some women to falsely believe that they would not benefit from attending a cervical screening. An improved understanding of HPV can facilitate understanding of HPV vaccinations and cervical screening in preventing cervical cancer, enable women to make

better informed decisions about their health, and emphasise the importance and relevance of the cervical cancer prevention pathway.

"There is some awareness but no education on cervical cancer and smear test [and] I believe there needs to be more."

"There is some [awareness] but not in the right areas. The only information I know I have researched myself after treatment. It needs to be more mainstream and normalised as a conversation from school right the way through teenage years and adulthood. The conversation around HPV risks needs to start when girls become sexually active."

Of the 41 survey respondents who shared their thoughts on symptom awareness, **51%** think that there is some awareness about risk factors and symptoms related to cervical cancer, but there could be more. **17%** think there is only a little awareness and education, while **17%** say there is hardly any awareness or education.

Barriers to securing a diagnosis.

While guidelines exist for managing young women with abnormal bleeding, these are not always followed. Worryingly, over **1 in 4** who report bleeding are given a cervical screening test - which in fact slows down diagnosis while waiting for appointments and results[viii]. 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.

"Referred me for bloods. Nothing since."

"Took me off my HRT."

Cervical screening using cytology prevented **7 in 10** incidences of cervical cancer, and HPV primary screening prevents even more[ix], yet uptake has been in slow decline. **1 in 3** women are not up to date with their cervical screening – with coverage at its lowest level for 20 years - and even lower attendance in some groups[x]. There are multiple barriers to attendance, including fear, embarrassment, pain, disability, and experience of trauma. **1 in 5** women in the UK mistakenly believe that cervical screening can detect ovarian cancer[xi]. It is important that women are informed about cervical screening, are supported through the test, and know where to access support, tips, and reliable information.

Whether women feel they are being listened to by healthcare professionals and their symptoms taken seriously.

Through Jo's services, we hear from women who feel like their concerns are not taken seriously by their GP and are told to wait to see if their symptoms abate, or they are told to wait for their cervical screening. This leaves women feeling concerned and annoyed.

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Of 10 women in Wales who spoke to their GP about possible gynaecological cancer symptoms, **12%** felt their concerns were not taken seriously, **6%** were told to wait for their cervical screening, and **6%** were told to come back later if their symptoms didn't change. **24%** were annoyed by their GP's response, and **18%** were worried.

"My health care team for my treatment were generally very good. My experience of the nurse who took my cervical screening was not, alongside the communication from admin staff who said, "well no news is good news," when I was waiting for results. Also, one nurse on the ward was not compassionate at all towards me and hurt me when giving me my injection for blood thinning. I don't blame her as an individual though, I guessed that she was overworked, under paid and probably hadn't stopped for food! Care needs to be at all levels of the system for others to be able to be compassionate in their jobs too."

HPV vaccination and access to timely screening services including inequalities and barriers.

In Wales, coverage of two doses of HPV vaccine in girls in the 2021/22 School Year 10 was just **55.1%.** This is an improvement from 2020/21, when just **37.7%** of girls received the full course of the vaccine but is still significantly below the pre-pandemic levels of **81.2%** coverage in 2018/19[xii].

The impact of the COVID-19 pandemic on the HPV immunisation programme has been significant, largely due to an interruption of the school-based vaccination programme. However, even prior to this, there were disparities and inequalities in vaccine uptake that need to be addressed.

Increased education in schools, national campaigns, and targeting the most under-represented communities are opportunities that should be seized. In addition to schools, greater parental awareness of HPV and the vaccine has been shown to have a positive impact on deciding to vaccinate children.

More opportunities to catch up on vaccinations are also needed to improve the performance of the immunisation programme. The move to a one dose schedule of the vaccine means it is more important than ever to know who has received the vaccine and ensure that there are ample catch-up opportunities so that nobody misses out on its protection.

There are significant inequalities in cervical screening coverage across different UK regions and demographics. Prompt restoration of services during COVID-19 has reportedly limited the impact on excess cervical cancer deaths, but many barriers to screening persist across the UK that were present prior to the pandemic. **Two-thirds** of physically disabled women have been unable to attend screening[xiii] and almost **half** of survivors of sexual violence have not attended[xiv]. Women living in poorer areas are less likely to attend[xv] while **80%** of women in full-time work struggle to get a convenient appointment[xvi].

Access to screening is also a significant barrier. Workforce pressures in primary care, and limited options of where and how to access screening, are significant challenges. Most tests are performed at GP practices, with some provision at sexual health clinics. For those who need to travel a distance to their GP, those with full-time work or childcare commitments,

and physically disabled women, the lack of choice in where to access screening can be prohibitive.

Out of 48 of our survey respondents who had accessed cervical screening in Wales, **13%** said they had to wait a long time for an appointment, **6%** were unable to make an appointment when they tried, and **2%** were unable to have a screening at their GP because the practices were not accessible.

Developing a more accessible test, providing more screening out of hours, and providing screening at more locations are possible steps for improving accessibility and uptake.

NHS recovery of screening and diagnostic services and the prioritisation of pathways for gynaecological cancers

Workforce pressures in colposcopy have been documented for several years. In 2019 the Wales Cancer Alliance said, "*the colposcopy workforce is aging with vacancies in many health boards*." In a workforce that is already under pressure, significant numbers entering retirement will have a tangible impact on patient care. Capacity and workforce pressures are felt by women attending the service too. A Jo's Cervical Cancer Trust report on patient experiences of cervical cell changes found that – of over 1000 respondents - **42%** felt they didn't have enough time to consider their options or make decisions and **29%** didn't think they had enough information and support to understand the benefits and risks of treatment[xvii]. A poor patient experience could lead to reduced inclination to attend again.

As of October 2021, cervical screening coverage across Wales is **69.5%.** This has declined from **73.2%** reported in 2019/20. We urge public awareness campaigns, and efforts to improve the accessibility of cervical screening, to improve this uptake.

Of 38 women in Wales who had recently accessed cervical screening, **13%** had to wait a long time for an available appointment, **8%** were unable to make an appointment when they tried, and **2%** were unable to have a screening because of an inaccessible GP practice.

Research into gynaecological cancers, their causes and treatments, and actions needed.

There are gaps in knowledge about many areas of cervical cancer. Addressing these will help prevent more cancers as well as provide answers and reassurance for women affected. This includes predictors or risk factors for persistent or recurrent HPV infections and cervical cell changes, and the cause of non-HPV cervical cancers. Research into therapeutic vaccines is also in its infancy. The existing HPV vaccination programme has been hugely successful, with cervical cancer cases falling **87%** in vaccinated cohorts[xviii], which should give us hope for what future advances could bring.

The development of new kinds of tests - that may be less invasive, more effective, or less frequent – could make screening more accessible to many. There may be a need to explore whether current screening intervals and eligibility parameters remain appropriate, as some modelling suggests cervical cancer incidences could increase in older women over the next two decades.

Applied health research will be crucial for developing better communication methods, reducing barriers, and developing more user-centric and streamlined programmes. Work to improve the uptake of screening and vaccination programmes – particularly amongst higher-risk groups – is essential if we want to continue to reduce cervical cancer incidences.

Priority given to planning for new innovations.

In June 2022, Bevacizumab (Avastin) was approved for use in Wales. This was a huge win for campaigners and patients, as Wales had previously been the only UK country not offering the potentially life-prolonging drug[xix]. Avastin was added to the Cancer Drugs Fund in England in 2014 for recurrent or metastatic cervical cancer and has been available in Scotland and Northern Ireland for several years.

Avastin is currently the only targeted drug treatment for advanced cervical cancer. Only a small proportion of patients with advanced cervical cancer are eligible to receive it because common side effects of the disease – such as vaginal bleeding – means the drug is not always safe for them.

We urge the All-Wales Medicine Strategy Group to accelerate approval for advanced cervical cancer drugs. It is unfair that women in Wales had to wait so much longer for Avastin to be made available. A new drug, Pembrolizumab (Keytruda), is currently in the NICE and Scottish Medicines Consortium approval process and we urge the AWMSG to begin this process and make Pembrolizumab available routinely for women receiving treatment for advanced cervical cancer[xx].

HPV-self sampling is recognised as an opportunity to make cervical screening more accessible and increase uptake of the test. Work in the UK around HPV self-sampling has been ongoing for many years with studies and pilots including PaVDaG in Scotland, and YouScreen and HPValidate in England. HPV self-sampling has been shown to increase participation with the screening programme amongst non-attendees, and the clinical accuracy of these tests is high[xxi]. The Welsh Health & Social Care Committee should consider how they might embed self-sampling into the national screening programme, if recommended by the UK National Screening Committee.

“I have had the most amazing support during my treatment & now from Maggie’s Swansea.”

“I cannot speak highly enough of my care whilst receiving care for cervical cancer.”

Gynaecological cancers grouped together by other characteristics such as ethnicity.

It is frustrating when gynaecological cancers are reported on together or referred to under the same umbrella. Each cancer has different symptoms, treatment pathways, and affects different demographics.

There needs to be improved reporting and access to data across the whole cervical cancer prevention pathway. HPV vaccines are primarily given by school immunisation teams, and it can be a manual process to transfer records to GPs. Vaccinations given elsewhere may not

make it into GP records, meaning there is an incomplete picture of who has and hasn't benefited from vaccination.

There is a need for improved data to support targeted interventions. This includes data about who is attending cervical screening - to facilitate community outreach and campaigns - and more data about which groups are at an increased risk of cervical cancer. For example, complete data of cancer incidence by ethnic group has long been called for by researchers and cancer charities. Access to data relies in part on the systems in place. Robust IT systems across the full pathway from vaccination through to results and follow up are an essential part of this.

Priority given to gynaecological cancers and who is responsible for the leadership and innovation.

Different components of the cervical cancer prevention pathway across Wales sit with different teams. Prevention generally starts in school, with local school-based immunisation teams, but sometimes HPV vaccines are given in primary care[xxii]. Cervical screening, laboratory, and colposcopy services are overseen by Cervical Screening Wales. Screening is largely delivered in primary care but may also be delivered by sexual health services. Gynaecology and oncology teams also play a crucial role in the diagnosis and treatment of cervical cancer. As such, there is no one single body or team responsible for cervical cancer prevention and treatment. It is vital that the needs of these teams are reflected in forthcoming action plans, and a collaborative and concerted approach is developed.

Disparities and inequalities in gynaecological cancer backlogs

There is great variation in cervical screening coverage at Local Authority level, with a difference of almost **10%** between coverage in Merthyr Tydfil **(65.7%)** and Monmouthshire **(74.7%)**[xxiii]. Women living in high areas of deprivation are less likely to have received the HPV vaccine and are less likely to attend cervical screening[xxiv]. The inequity gap - the difference between uptake/coverage in the least deprived communities compared to the most deprived communities - is **12.1%** for Cervical Screening Wales, a gap which has worsened in recent years[xxv].

We know that a future where cervical cancer is eliminated in Wales is possible, but until that day we want to see the absolute best treatment and care for those affected. To better prevent and treat cervical cancer we need greater levels of education about HPV, cervical screening, and vaccinations for school-aged children, adults, and healthcare professionals. There needs to be a concerted effort to improve symptom awareness for women and healthcare professionals, and there must be action to tackle the inequalities in cancer prevention and cancer outcomes. Research, investment, and implementation of new tests, treatments, and drugs provide exciting chances to improve and save lives.

Wales must seize these opportunities to reach a day where cervical cancer is no more.

For more information on this response, please contact hannah.wright@jostrust.org.uk.

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