Jo's Cervical Cancer Trust Manifesto

March 2021

Our vision is a day where cervical cancer is a thing of the past.

Will you help us get there?

Cervical cancer can be prevente We're doing something about it.

jostrust.org.ul



About Jo's Cervical Cancer Trust

Jo's Cervical Cancer Trust is the UK's leading cervical cancer charity. We provide trustworthy information, campaign for change, and offer support at every step.

From the first cervical screening invitation, to living with and beyond cancer, we are here for everyone who needs us, for as long as they need us.

Cervical cancer can be devastating but we're here to reduce the impact, and we won't stop until the day when cervical cancer is no more.

Our manifesto

Ahead of the elections to the Welsh Parliament in 2021, we are calling on political parties and candidates to commit to the following key priorities, to help us reduce the impact of cervical cancer in Wales.



Elimination of cervical cancer

There are around 160 cases of cervical cancer every year in Wales - the highest crude rate in the UK. At Jo's Cervical Cancer Trust, our vision has long been a day when cervical cancer is a disease of the past.

Cervical cancer is largely preventable, through the HPV vaccination and cervical screening. In August 2020, the World Health Organisation adopted a global strategy to accelerate cervical cancer elimination, and called for countries to publicly support this goal.

We are calling parties to commit to the ambitions set out in the World Health Organisation's strategy. Specifically, to address inequalities in uptake of HPV vaccination and cervical screening.

Will you support the World Health Organisation's Global Strategy to Accelerate the Elimination of Cervical Cancer?



HPV vaccinations

Vaccine catch-up plans and beyond



Human Papillomavirus (HPV) is a common virus that 80% of people will have in their lives. There are 13 'high-risk' types that are linked to cancer, and while the immune system usually clears HPV itself, this is not always the case. High-risk HPV causes 99.7% of cervical cancers.

The HPV vaccine provided by the NHS offers protection against 70% of cervical cancer cases. In Wales, girls and boys are routinely offered the 1st HPV vaccine when they're in school Year 8, and the 2nd dose 6-12 months later.

Due to Covid-19, educational settings have been closed intermittently since March 2020, which has had a significant impact on the uptake of the HPV vaccination programme in the 2019/20 and 2020/21 academic years.





HPV vaccinations Vaccine catch-up plans and beyond

The priority for the programme is now to ensure that all eligible children receive at least the first dose of the HPV vaccine, but we want to ensure that all children and eligible adults are able to receive both - or all three - doses as required, to ensure maximum protection.

We are calling on governments to ensure that HPV vaccination catch-up is a priority in cancer recovery plans, and that tackling misinformation around vaccines is a part of cancer roadmaps moving forward. Vaccination is a crucial element of cancer prevention that we cannot afford to overlook.

Will you ensure that school children don't miss out on the potentially lifesaving HPV vaccine?



"I'm sharing my story not with the intention of scaring people, but with the intention of highlighting the importance of smears, as it saved me from a lot more treatment and potentially even saved my life."

Claire-Marie, diagnosed with stage 1b1 cervical cancer in 2018.



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HPV self-sampling



Cervical screening is one of the best ways to prevent cervical cancer and prevents over 7 in 10 incidences.

Unfortunately, cervical screening attendance has been largely falling for the last two decades. Before the pandemic, 1 in 4 did not attend when invited, and we anticipate attendance to be significantly lower as a result of Covid-19.

We know that many women and people with a cervix find attending a cervical screening difficult for a number of practical, physical, and emotional reasons. Our research shows that 88% of women with a physical difficulty find it harder to have a cervical screening, and only half of sexual violence survivors attend when invited.



HPV self-sampling

HPV self-sampling is a popular and effective option that allows women the opportunity to take the test into their own hands and in the privacy of their home.



Jo, "We're made to feel invisible" report

The UK National Screening Committee requires evidence from further studies, pilots, and projects, before they can recommend HPV self-sampling as part of national screening programmes.

Some pilots are underway, but we need greater urgency, more resources, and political support, to ensure the research progresses at the pace needed.

Will you support the acceleration of HPV selfsampling research, so it can be offered as part of national programmes as soon as possible?

Jo's cervical cancer **trust**

Living with and beyond cervical cancer

88% of women have experienced at least 1 physical, longterm side-effect of their cervical cancer treatment, and 24% are living with at least 6 long-term effects.

Only half of those experiencing bowel and urinary problems have received treatment, and for women with negative changes to their sex lives, just 10% have received treatment.

Appropriate follow up pathways and referrals are desperately needed, and we are concerned about the impact of Covid-19 on the services supporting those living with and beyond cancer.

Will you commit to ensuring greater physical and psychological support for cancer patients, and faster referrals for those presenting with symptoms of long-term effects, such as Pelvic Radiation Disease?



"I find leaving the house really difficult and I have to make sure I don't eat for two hours before I leave because I'm terrified that I'll need the toilet. I've pulled away from friends and family as I struggle with panic attacks. My relationship with my husband - who is very supportive - is strained because I'm so tired all the time and the continence issues make it really hard for me to feel attractive. "

Jess, "I want my life back" report

The long-term side-effects of radiotherapy: Gaps in recognition and resourcing leaving patients suffering without treatment.



Welsh Cancer Strategy

We are concerned that Wales will soon be the only UK nation without a Cancer Strategy, and fear that the upcoming Cancer Quality Statement lacks the detail necessary to respond to the current crisis in cancer care in Wales.

Alongside 19 other charities in the *Welsh Cancer Alliance* coalition, we are calling for a more comprehensive and ambitious strategy, to ensure Wales can deliver high-quality and consistent services for cancer patients.

We are highlighting the particular need for the Cancer Strategy to include prevention, diagnosis, treatment, long-term care, and End of Life care.

Will you support our call for a comprehensive and ambitious Cancer Strategy in Wales?



Thank you



Show your support on social media: "I'm supporting @JoTrust's manifesto on #CervicalCancer, and their vision of a day where cervical cancer is a thing of the past. #JosManifesto"

If you're a Member of the Senedd/Aelod y Senedd, please contact us at <u>hannah.wright@jostrust.org.uk</u>, for individual briefings or information on issues related to cervical cancer and prevention.



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