



Jo's Cervical Cancer Trust

written response to Scottish Government new cancer strategy consultation 2022

Introduction

Jo's Cervical Cancer Trust are the UK's leading cervical cancer charity. Cervical cancer can be devastating but we're here to reduce the impact. We provide trustworthy information, campaign for change and provide support at every step. We are pleased to have the opportunity to respond to this new cancer strategy consultation.

Background

In Scotland, 323 women are diagnosed with cervical cancer each year¹, with 95 women losing their lives as a result². Cervical cancer is the 14th most common cancer in females in the UK, accounting for 2% of all new cancer cases in females³. Cervical cancer mortality rates are significantly higher than the UK average in Scotland and Wales⁴.

Cervical cancer is one of the most preventable cancers. We are very fortunate to have two prevention programmes in the UK; the school-based HPV vaccination programme, and the cervical screening programme. Cervical screening protects against 7 in 10 incidences of cervical cancer¹, while the HPV immunisation programme has significantly reduced diagnoses in women born since Sept 1, 1995.

With regular, routine cervical screening, those at the highest risk of cervical cancer can be monitored closely, and cervical cell changes can be picked up before they become cancerous. Through the combination of a robust cervical screening programme, and widespread HPV vaccinations, our vision at Jo's Cervical Cancer Trust is of a day where cervical cancer is a thing of the past.

Prevention

The consultation highlights the importance in deciding “*what aspects of cancer prevention, management and care are the most important.*”

As mentioned, cervical cancer is one of the most preventable cancers, through a combination of HPV vaccines, cervical screening, and colposcopy services.

¹ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence#heading-Zero>

² <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/mortality#heading-Zero>

³ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence#heading-Zero>

⁴ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/mortality#heading-Zero>



Cervical Screening

Cervical screening is the best protection against cervical cancer, and we would like the strategy to emphasise that cervical screening is not a test to detect cancer, rather it is a test to determine who is at a higher risk, so that cancer can be prevented. There are a wide range of barriers to screening attendance and fear of cancer is one, so this messaging is important.

- Barriers include physical disability, anxiety, pain, experience of trauma, and gender dysphoria. We encourage the Scottish Government to work with the third sector to continue identifying and addressing barriers, and ensuring providers have the knowledge and resources to do so; this may include the use of text reminders, drop-in sessions, or community outreach.
- It is also important to consider the impact that employment and/or childcare arrangements can have. Only 1 in 5 who work full-time were able to get a convenient appointment last time they tried to book⁵. In addition to reviewing availability of appointments across the programme, we urge Public Health Scotland and the Scottish Government to lead from the top and ensure its own staff can attend appointments, if they are unable to find a convenient appointment outside of work hours, while encouraging employers to do the same.
- To support prevention and early diagnosis, we are eager to see faster progress in pilots and feasibility studies around HPV self-sampling and urine testing. The Scottish Government has committed to a pilot and we urge for speed to ensure the UK National Screening Committee can recommend HPV self-sampling.
- In order to reverse the long-term trend of declining cervical screening attendance we need to build the evidence base for other emerging interventions, particularly those that may encourage uptake in harder to reach groups of our society.
- We encourage investment to develop a more personalised approach to encouraging and supporting people to attend their cervical screening appointments.

HPV vaccines

When considering cancer prevention we would urge the strategy to make mention of the HPV vaccine. Recent evidence has shown the vaccine to be very effective. Data shows that the HPV immunisation programme in England “*has successfully almost eliminated cervical cancer in women born since Sept 1, 1995*”.⁶

⁵ <https://www.jostrust.org.uk/only-1-5-who-work-can-attend-smear-test-appointments-resulting-high-numbers-delaying-or-taking>

⁶ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)02178-4/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)02178-4/fulltext)



- We urge for action to tackle the inequalities and disparity in uptake of the vaccine, particularly for those from a more deprived background.
- We are hopeful that ongoing research and studies will support JCVI plans to move to a single-dose of the nonavalent HPV vaccine, and that this will be equally effective in preventing cervical cancer incidences across the population.
- We urge the government to carefully consider how changes to the HPV vaccine programme will be communicated to the public, to ensure the reasons for changes are understood and confidence in the programme is maintained.
- We encourage the government to reinvest any financial savings made as a result of this change into targeting groups that currently have below average uptake of the HPV vaccine – such as non-white Scottish ethnic groups, and those from a deprived socioeconomic background.

Colposcopy

Colposcopy services are a crucial aspect of cervical cancer prevention yet are rarely discussed as such, with no mention in the 2016 Beating Cancer: Ambition and Action plan, or the 2020 Recovery and redesign: cancer services - action plan.

- 220,000 women and people with a cervix are diagnosed with cervical cell changes each year, and many experienced anxiety, confusion, shame, and unexpected side effects as a result of their diagnosis and treatment⁷. The same barriers that impact attendance of cervical screening are present – and often heightened – with colposcopy services.
- There is currently little formal research into patient experiences of colposcopy – diagnosis, treatment, and beyond - and we urge this forgotten area of cancer prevention to receive the resourcing and study it requires.
- We believe that the lack of standardisation and guidance surrounding colposcopy leads to unacceptable variations in patient experience, this includes disparities in practice around pain management and provision of information.
- The brevity of colposcopy appointments has been identified as an issue for many. Strengthened workforce capacity, increased appointment length, and the ability to offer a second appointment to provide more time to process next steps, should be considered as means of addressing this.

⁷ <https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/cell-changes-experiences>



Deprivation

We welcome the recognition of the relationship between deprivation and cancer incidences and outcomes, with particular notice being given to cervical cancer.

Cervical cancer incidence is highest within the most deprived communities, with rates 26% higher, and we keenly support initiatives to tackle this disparity. We see the impact of socio-economic background on HPV vaccine uptake, cervical screening attendance and, ultimately, cervical cancer incidences and deaths.

Awareness and diagnosis

The consultation notes, “*The earlier a person is diagnosed with cancer, the more likely they are to have a good outcome*”. Being able to recognise the symptoms of cervical cancer is crucial for early diagnosis, however awareness levels of cervical cancer symptoms are low, with recent research showing only 2 in 5 young women knowing any symptoms⁸.

- Health communications and awareness raising around cervical cancer prevention, symptoms, and the importance of cervical screening must be engaging and inclusive of all affected communities. We would encourage partnership between the government, care providers, and the third sector when developing communications
- As previously mentioned, a more personalised approach is needed to encourage hard-to-reach groups to attend cervical screening.
- Human papillomavirus (HPV) is a common virus that 8 in 10 people will have at some point in their lives. The body usually clears it within 2 years, but cervical screening in Scotland tests for this virus because it causes 99.7% of cervical cancers.
- The recent move to HPV primary screening across most of the UK is welcome, as this test is more effective and sensitive than previous tests. However, more women than ever before are finding out that they have HPV, and this is leading to feelings of anxiety and shame⁹.
- The information gap that persists around HPV causes a high level of anxiety and ongoing stigma, and we urge the government to consider ways in which HPV education can be improved – through public campaigns or greater levels of education in schools.
- Our modelling suggests we are set to see an increase in cases in those who have not benefitted from the HPV vaccination – those currently in their 40s and 50s. Among this group in particular, improving awareness of, and access to, screening and aiding early diagnosis is paramount.

⁸ <https://www.jostrust.org.uk/node/1081339>

⁹ <https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/cell-changes-experiences>



- We are concerned that ongoing pressures on the NHS across the UK are leading to delays and backlogs in services – particularly gynaecology – which may negatively impact rates of early diagnosis. We are also concerned that the pressure being faced by GPs may delay crucial urgent referrals. It is essential that workforce plans consider the impact that pressures on primary care can have on the cancer workforce and cancer outcomes.

Treatment

The 62-day standard states that 95% of eligible patients should wait a maximum of 62 days from urgent suspicion of cancer referral to first cancer treatment. People with cancer should receive timely treatment, however from 1st October to 31st December 2021 the 62-day standard was not met by any of the NHS Boards¹⁰. This standard has consistently not been met since 2013.

- In 2019 the Scottish Cross-Party Group on Cancer warned, “*Chronic staff shortages and inadequate funding are hindering efforts in Scotland to improve cancer survival rates.*”¹¹ The impact of the pandemic has only intensified this issue. Workforce planning must be central to the strategy to deliver timely care.
- There is no standardised pathway for cervical cancer treatment and care. This can lead to feelings of confusion and anxiety. In these circumstances the MDT – and in particular, Clinical Nurse Specialists (CNS) - are vital. We urge the government to invest wholeheartedly in the cancer workforce to ensure all cancer patients are supported holistically by the full team of specialists they need. The importance of a CNS cannot be understated and every patient should have access to a named CNS.
- The impact of the pandemic has been felt across the pathway. Some women reported feeling unwilling to present to primary care with symptoms for fear of wasting GP's time, and screening attendance was impacted as the programme was paused and reopened¹². When attending further tests and treatment, many regretted being unable to take a loved one with them¹³. The impact on the workforce cannot be understated, and we urge immediate remedial action to maintain and increase staffing levels across the NHS.
- There is currently only one targeted medication used to help treat advanced and late-stage cervical cancers in the UK. Investing in research, and embracing innovation in diagnostics and treatment, will be essential to improve survival rates and quality of life for those diagnosed with cervical cancer.

¹⁰ <https://publichealthscotland.scot/publications/cancer-waiting-times/cancer-waiting-times-1-october-to-31-december-2021/>

¹¹ <https://www.bmj.com/content/367/bmj.l6578.full>

¹² <https://www.jostrust.org.uk/about-us/news-and-blog/blog/impact-covid-19-cervical-screening>

¹³ <https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/cell-changes-experiences>



- A new medication pembrolizumab (Keytruda) is currently undergoing NICE appraisal, to be used in combination with platinum-based chemotherapy for treating recurrent, persistent or metastatic cervical cancer¹⁴. This drug has been shown to lengthen progression-free and overall survival of those with cervical cancer. We urge the Scottish Medicines Consortium to consider the merits of making this medication available to recurrent, persistent, and metastatic cervical cancer patients through NHS Scotland.

Side effects and late effects of treatment

The New Cancer Strategy Consultation Document notes, “*despite the increase in cancer, we are seeing reduced death rates, with an 11% reduction over the last 10 years*”, and that “*more people in Scotland are surviving cancer than ever before*.”¹⁵ This is welcome news. There are however important considerations that need to be taken as a result of this progress.

- Radiotherapy is a common and highly effective treatment for cervical cancer, and more people are surviving cervical cancer than ever before. While short-term side effects are common – the therapy can sometimes cause long-term side effects.
- Side effects of cervical cancer treatment can include early menopause, fertility issues, psychosexual issues, lymphoedema, and Pelvic Radiation Disease.
- Pelvic Radiation Disease (PRD) is a collection of symptoms affecting the pelvic organs – such as bladder and bowels – following toxicity exposure during treatment. These symptoms are often manageable and treatable, but clinical and patient awareness of PRD is low, and specialist late-effects clinics are few and far between¹⁶.
- We encourage greater research and investment into radiotherapy treatment, to support innovation and the development of methods with lower risk of contributing towards PRD.
- Access to HRT is a current concern, it is vital that access is retained.
- We urge the government to invest in post-cancer care, to ensure that people are living well – not simply surviving. We encourage the production of a standardised care pathway following cervical cancer – including Holistic Needs Assessments - to ensure that side effects and symptoms can be identified and treated promptly. Fully staffed specialist teams will be needed to deliver these services.

¹⁴ <https://www.nice.org.uk/guidance/indevelopment/gid-ta10669>

¹⁵ https://consult.gov.scot/health-and-social-care/cancer-strategy/supporting_documents/newcancerstrategyconsultationdocument%201.pdf

¹⁶ <https://www.jostrust.org.uk/our-research-and-policy-work/our-research/prd>

Data and innovation

We are pleased to hear that “*New developments in the Scottish Cancer Registration and Intelligence Service will make cancer data more readily available and will make data on waiting times, screening, diagnosis and treatment more easily linked to the Registry.*”

- Evidence on cancer incidence by ethnic group in the UK is something that has long been needed¹⁷. We urge for data to be collected and reported regarding the ethnicity of those who attend cervical screening, or develop cervical cell changes or cervical cancer.
- It is crucial that Public Health Scotland ensure their IT system remain up-to-date, and able to take advantage of emerging innovations – including the potential to on-board HPV self-sampling into the national screening programme.
- A vaccination registry would enable far greater monitoring of the impact of the current and future vaccination programmes, and open up the opportunity for a more risk-based screening programme.
- With Gardasil 9 (a nonavalent HPV vaccine) being rolled out across the UK in 2022, we are eager to see updated modelling that shows how we can expect this new vaccine to impact HPV infections and incidences of cervical cell changes and cervical cancer. It will be important to identify which groups remain at the highest risk of developing cervical cancer, so that communications and engagement strategies can be developed accordingly.
- We welcome mention of the Scottish Cancer Patient Experience Survey and Care Opinion, survey and hope to see them continue to include rarer cancers in addition to being representative of a wide range of communities, backgrounds, and ages. We believe this will support in the aim of ensuring patients are centred throughout the development and delivery of care.

¹⁷ <https://www.nature.com/articles/s41416-022-01718-5>



Cervical cancer elimination

The World Health Organisation's global strategy to accelerate the elimination of cervical cancer as a public health problem launched in 2020¹⁸. It is made up of three key targets to be met by 2030 focused on vaccination, screening and treatment

As yet there is no concrete commitment in Scotland to eliminate cervical cancer, aside from a single tweet from the Scottish Government Health Department in 2020¹⁹. Many other countries have strategies in place and we hope a new cancer strategy will set out that ambition and the need for targets to motivate and challenge us to get there as soon as possible.

Strategy

While our ultimate ambition is that of cervical cancer elimination, there are a number of shorter-term issues that desperately need addressing; namely, shortages in the cancer workforce and decreasing levels of screening attendance.

For this reason, we support the development of a strategy in the form of “*A longer-term strategy with short-term action plans which will evolve with changing landscape but remain consistent with the overarching ambitions.*”

We are grateful to have had the opportunity to respond to this consultation, and we look forward to working with Public Health Scotland throughout the implementation of a cancer plan.

For further information please contact Hannah Wright, Policy & Public Affairs Assistant at hannah.wright@jostrust.org.uk.

¹⁸ <https://www.who.int/publications/i/item/9789240014107>

¹⁹ https://twitter.com/scotgovhealth/status/1328749469085687809?s=20&t=_ntnpRRvtfgX8NyyKWpphQ