

# We can end cervical cancer

The opportunities and challenges to  
eliminating cervical cancer in the UK

# This report is supported by:



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**“We can all leave behind a great legacy if we seize the opportunities that are within our reach now, so that girls who are born today will live to see a world free of this disease.”**

*Dr Tedros Adhanom Ghebreyesus, Dr Zsuzsanna Jakab (WHO)*

# Introduction

**At Jo's Cervical Cancer Trust, our vision is of a day where cervical cancer is a thing of the past. This goal is not beyond our reach. Countries, governments, and NGOs around the world are committing to – and taking actions towards – a day where this cancer is eliminated.**

In November 2020, the World Health Organization published the “Global strategy to accelerate the elimination of cervical cancer as a public health problem”<sup>1</sup>. This built on a call made by the Director-General in 2018 for all countries to take action to help “end the suffering caused by cervical cancer”. He called for political will and urged for stakeholders to unite behind this common goal. Since then, a growing number of countries have published commitments and strategies to eliminate cervical cancer. So far, UK governments have not yet demonstrated the ambition and commitment of other nations when it comes to cervical cancer elimination. We want to change this.

The UK has the tools to get there. We have a wide-reaching HPV vaccination programme, and highly effective cervical screening and colposcopy services. Innovations in these programmes mean we are preventing more cases than ever before. However, we also face inequity in access, falling uptake, and other barriers preventing progress. The potential to eliminate a cancer is something that should be celebrated and embraced. To get there we must tackle the issues of today, as well as looking to the programmes of the future. This requires political will, investment, and collaboration.

**This report is calling on UK governments to rise to the challenge and to commit to taking the necessary steps to achieve a future free from cervical cancer.**

We know that cervical cancer will not disappear overnight, and that not every case of cervical cancer can be prevented. We also recognise that the NHS is under extreme pressure, which has only been exacerbated by the impact of COVID-19. Workforce shortages, diagnostic backlogs, delays in treatment, crises in emergency care, and high demands are stretching the entire NHS.

However, we have an opportunity to effectively consign a cancer to the history books. This will reduce costs to the NHS and UK economy, as well as saving lives. We want to achieve this as fast as we can.

This report outlines the current state of cervical cancer prevention in the UK, and the challenges and opportunities we face. The workforce delivering, developing, and supporting these programmes are vital for the success of this ambition, and it is important their voices are heard. We surveyed those working within cervical cancer and prevention in the UK and include responses from 848 individuals in this report. These respondents include primary and secondary care professionals, cytologists, pathologists, oncologists, researchers, and others who work across and alongside the cervical cancer prevention and treatment pathway.

We have also included some quotes from those living with and beyond HPV, cell changes and cancer.

While we look to a future without cervical cancer, we must continue to increase the level of support and standard of care for those living with and beyond cervical cancer. Those diagnosed deserve to have their voices heard. Being forward-looking must not mean that they are overlooked, and we must continue to expand research, improve access to treatments, and banish the stigma and blame that too often comes with a cervical cancer diagnosis.

### Terminology used in this report

The World Health Organization (WHO) defines the elimination of cervical cancer as a public health problem as 4 or fewer cases detected per 100,000 women in any year<sup>2</sup>. This is different to the eradication of a disease, which refers to a permanent reduction to zero cases, with preventative measures no longer necessary. Elimination requires ongoing preventative actions.<sup>3</sup> Our focus at Jo's is to decrease

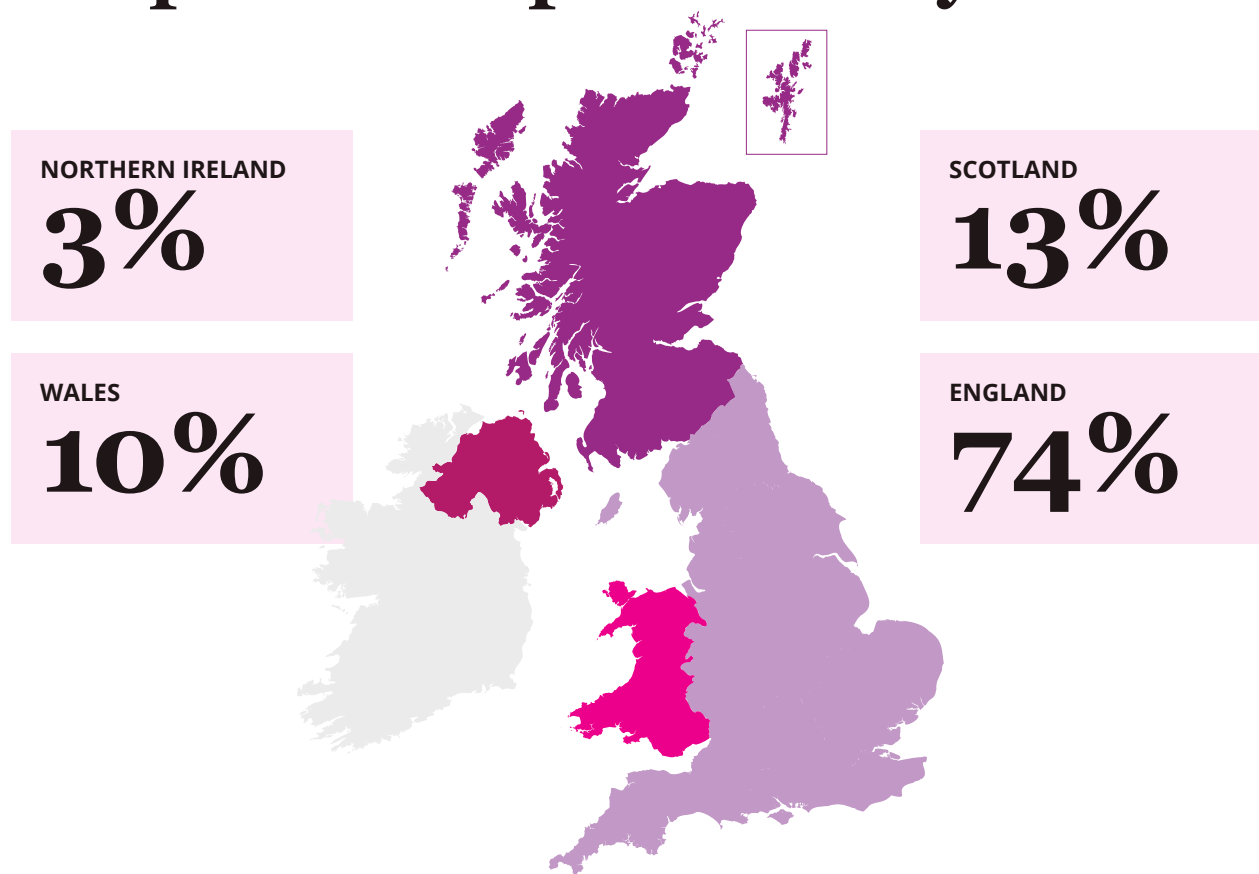
to as few cases as fast as possible. In this report we will be using the word 'elimination', in our campaigns and public-facing communications we will speak of 'ending cervical cancer'.

The cervix is a part of the female reproductive system. It joins the top of the vagina to the lower part of the womb. Women are usually born with a cervix. Someone may also have a cervix if they are:

- a trans man and/or non-binary person who was assigned female at birth.
- a man who has a difference in sex development (DSD) or is intersex.

In rare cases women may be born without a cervix. A woman who has had surgery, such as a hysterectomy, may have had their cervix removed. For brevity and clarity, this report will primarily use the word 'women' to refer to all people that have a cervix.

## Respondents per country:



# Cervical cancer in the UK

**In the UK, around 3,200 women are diagnosed with cervical cancer every year, with over 800 losing their lives. That translates to 9 women a day diagnosed with cervical cancer, with 2 women a day losing their lives.**

Cervical cancer is largely preventable through the combination of HPV vaccination and cervical screening. While most types of human papillomavirus (HPV) do not cause cervical cancer, about 14 high-risk HPV types cause over 99% of cases<sup>4</sup>.

Incidence is highest amongst women aged 30-34. Deaths are more common in women living in the most deprived areas, with around 520 diagnoses in England linked with deprivation every year. 10-year survival stands at 51%<sup>5</sup> with tens of thousands currently living with and beyond diagnosis. A further 220,000 are diagnosed with cervical cell changes that have the potential to develop into cervical cancer if left untreated.

**“The after-effects of treatment have had a big financial impact. There’s all the hospital parking fees, transport, and then having to leave work because of my health.”**

***Cervical cancer patient***

Radiation Disease (PRD)<sup>6</sup>, early menopause, infertility, bowel problems, and lymphoedema. There is also a financial impact, with a combined individual financial loss of £14 million a year - £5,844, on average, for each woman diagnosed.

This financial burden is anticipated to worsen amongst the ongoing cost of living pressures<sup>7</sup>. In 2014 it was estimated the NHS spent around £21 million a year treating cervical cancer, while the UK economy lost £9 million in tax revenue because of women stopping work.<sup>8</sup>

IN THE UK:

**9 women  
a day**  
ARE DIAGNOSED WITH  
CERVICAL CANCER

Cervical cancer can have significant physical, emotional, and financial impacts which can last far beyond diagnosis and treatment. Treatment – including brachytherapy, radiotherapy, and surgery – can lead to long term side effects including Pelvic

# The World Health Organization global strategy to eliminate cervical cancer

In 2020, the World Health Organization published a global strategy to accelerate the elimination of cervical cancer as a public health problem. **Cervical cancer is the fourth most common cancer worldwide in women. In 2018, an estimated 570,000 women were diagnosed with cervical cancer and about 311,000 died from the disease<sup>9</sup>.**

The WHO defines the elimination of cervical cancer as a public health problem as 4 or fewer cases detected per 100,000 women in any year. They have set out three targets which they urge countries to meet by 2030, and maintain for several decades, to move towards elimination:

- **90% of girls fully vaccinated with HPV vaccine by age 15 years.**
- **70% of women are screened with a high-performance test by 35 years of age and again by 45 years of age.**
- **90% of women identified with cervical disease receive treatment (90% of women with pre-cancer treated, and 90% of women with invasive cancer managed).**

The WHO states that achieving the 90-70-90 targets by 2030 would result in over 62 million cervical cancer deaths averted globally by 2120<sup>10</sup>.

## Global ambitions

Australia, Canada, and Rwanda are just three of the countries that have already developed their own strategies and targets to accelerate cervical cancer elimination within their populations.

- In 2019 the Canadian Partnership Against Cancer developed an action plan to eliminate cervical cancer in Canada by 2040<sup>11</sup>. They have set 90/90/90 targets with the aim of "90% of eligible women being up to date with an HPV test".
- In 2021, Australia announced the development of a collaborative National Cervical Cancer Elimination Strategy, with the ambition of eliminating cervical cancer by 2035<sup>12</sup>. The Federal Government committed \$5.8 million towards becoming the first nation in the world to achieve elimination<sup>13</sup>.
- Cervical cancer is the most common cancer among women in Rwanda, with an incidence rate in 2020 of 28.2 per 100,000 women. Rwanda became the first African country to vaccinate against HPV and has been recognised by the WHO as a front-runner on the path to elimination<sup>14</sup>.
- The Commonwealth launched the International Taskforce on Cervical Cancer Elimination in the Commonwealth in 2021, with their own commitment that all girls aged between 9-13 years will have access to the HPV vaccine by 2025<sup>15</sup>.

The WHO targets fit a global elimination model, yet each country has its own resources and policies regarding cervical cancer prevention. As of June 2020, only 55% of the 194 WHO Member States were considered to have introduced HPV vaccination. In 2022 only 139 (69%) countries and territories had official recommendations for cervical screening, including just 33% of countries in Africa<sup>16</sup>.

**“Strategic actions must be customized by each country to take into consideration its unique structural deficiencies, level of readiness to implement, and other factors to care (such as sociocultural or gender, and myths and misconceptions about the disease and its prevention and treatment) that drive cervical cancer incidence, morbidity and mortality.”<sup>15</sup>**

*World Health Organization, Global strategy to accelerate the elimination of cervical cancer as a public health problem*

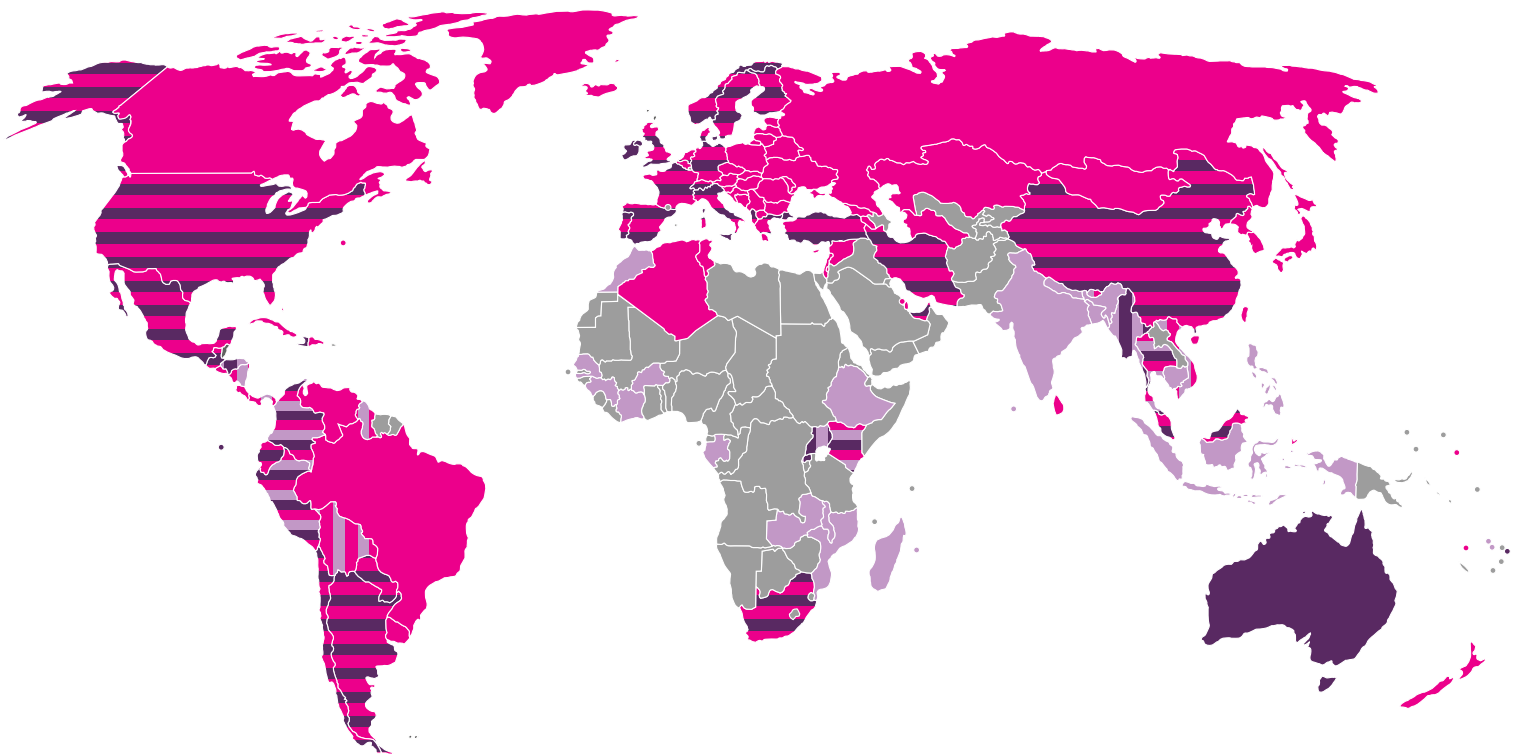


FIGURE 1: Official recommended tests for primary cervical cancer screening<sup>17</sup>

- HPV
- Cytology
- Visual Inspection with Acetic acid
- One main primary test
- More than one main primary test (either a co-test or for the same or different screening indications)
- No official recommendation



The UK has well-established and effective screening and vaccination programmes, and a National Health Service that is free at the point of use. A UK, or individual country-based strategy, should be based on the specific opportunities it has and the populations it serves.

**“The UK has more resources and is more affluent so, while the 70% screening target is good in a global sense, the UK should aim to exceed this target.”**

*Medical Laboratory Assistant – England*

**“We are a high-income country, these [targets] should be bare minimum, we should be striving to achieve better than this.”**

*Gynaecologist, Oncologist, and Colposcopist – England*

	Current incidences per 100,000	Screening coverage	Vaccination coverage
<b>WHO targets</b>	<b>4</b>	<b>70%</b>	<b>90%</b>
<b>England</b>	<b>9.7</b>	<b>69.9%*</b>	<b>60.6%**</b>
<b>Scotland</b>	<b>12.5</b>	<b>69.3%*</b>	<b>85.4%**</b>
<b>Wales</b>	<b>12</b>	<b>69.5%*</b>	<b>55.1%**</b>
<b>Northern Ireland</b>	<b>10</b>	<b>71.3%*</b>	<b>56.4%**</b>
<b>UK average</b>	<b>11.1</b>	<b>70%</b>	<b>64.4%</b>
<b>Australia</b>	<b>6.3</b>	<b>55.4%</b>	<b>78.2%</b>
<b>Canada</b>	<b>7.1</b>	<b>73%</b>	<b>87%</b>
<b>Rwanda</b>	<b>28.2</b>	<b>&lt;28.3%</b>	<b>93%</b>

\* Latest reported annual screening stats per country<sup>18</sup>

\*\* Latest reported HPV vaccination coverage for two doses (Female) per country by end of Year 10/S4<sup>19</sup>

# Challenges and opportunities in the UK

- **87% of the healthcare and associated professionals surveyed believed that cervical cancer elimination should be a priority for UK governments.**
- **87% were personally motivated by this ambition.**
- **Only 17% thought that enough was being done to eliminate cervical cancer in the UK.**
- **Only 20% think enough is being done to ensure high levels of HPV vaccine uptake, and just 16% believe that enough is being done to support cervical screening uptake.**

Different components of the cervical cancer prevention pathway in the UK sit with different teams. Vaccinations are largely delivered by local school-based immunisation programmes, and occasionally in primary care. Cervical screening, laboratory, and colposcopy services are overseen by national Cervical Screening Programmes. Screening is largely delivered in primary care, but may also be delivered in some sexual health services. As such, there is no one body or team responsible for cervical cancer prevention and a collaborative and concerted approach for elimination is needed.

## **When asked what the biggest opportunities are to eliminate cervical cancer in the UK, our survey respondents said:**

- **HPV self-sampling (70%)**
- **National public awareness campaigns about the role of vaccination and screening in eliminating cervical cancer (68%)**
- **Increasing cervical screening coverage (53%)**
- **Extending the vaccination programme (43%)**
- **Targeted/risk-based screening (35%)**

# 87%

**believe cervical cancer elimination should be a priority**

# HPV vaccination

The HPV vaccine has been routinely offered to girls aged 12-13 years since 2008 and to boys aged 12-13 since September 2019. Cases of cervical cancer have fallen by 87% amongst women in their 20s due to the vaccine<sup>20</sup>.

The UK is currently rolling out a 9-valent HPV vaccine which protects against even more cancer-causing strains of the virus<sup>21</sup>. Studies into the therapeutic uses of vaccines are looking at novel and more effective ways to treat HPV, cell changes, and cervical cancer.

## What are the biggest barriers to the performance of the HPV vaccination programme?

- Lack of understanding around HPV and the efficacy of vaccinations (72%)
- Antivaccine sentiment (56%)
- Inequalities in uptake/difficulties in reaching some communities (50%)
- Workforce shortages affecting delivery (38%)
- Competing priorities across the NHS (34%)

Cases of cervical cancer have fallen **87%** IN WOMEN IN THEIR 20S DUE TO THE VACCINE

“The HPV immunisation programme has successfully almost eliminated cervical cancer in women born since Sept 1, 1995.”

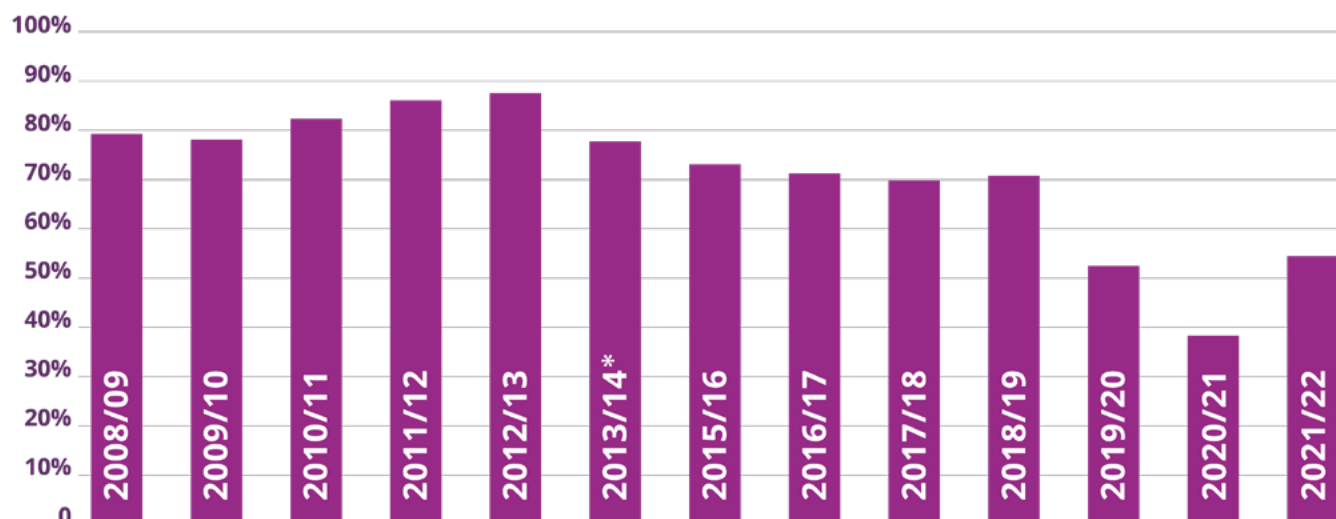
*Falcaro, Milena et al.*

“If the opportunity to have the HPV vaccine had been available to me, I might not have had cervical cancer. It really excites me that [my daughter's] generation are so much less likely to have the disease thanks to the vaccine, but it will only work if we continue to make noise about it and encourage people to take up the vaccine.”

*Sophie*

**FIGURE 2: Share of girls that received full course of HPV vaccination in Wales from 2008/09 to 2021/22 (aged approximately 12-14 years old)<sup>30</sup>**

**\*A completed dose was reduced from three to two doses in September 2014.**



**Vaccine hesitancy and low understanding around the HPV vaccine are widely recognised as barriers to uptake<sup>22</sup>. Certain groups are far less represented in uptake including those living in areas with high levels of social deprivation<sup>23</sup>, some ethnicities<sup>24</sup>, and those previously excluded or not in school<sup>25</sup>. Among parents of soon-to-be eligible children, just 55% were aware of HPV and the girls' HPV vaccination programme<sup>26</sup>. The impact of the COVID-19 pandemic on the HPV immunisation programme has also been significant.**

Data from England for the 2021/22 school year showed that HPV vaccine uptake in girls and boys who are eligible for their first dose of the HPV vaccine had fallen by 7% and 8.6% respectively from the previous year<sup>27</sup>. Coverage in England for girls receiving two doses by year 9 was just 67.3%. While this is 7.1 percentage points higher than the 60.2% achieved in 2020/21, it is still 20% lower than pre-pandemic levels.

In Wales, coverage of two doses of HPV vaccine in girls in the 2021/22 School Year 10 was just 55.1%<sup>28</sup>. This is an improvement from 2020/21, where 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<sup>29</sup>.

“ [One of the biggest challenges facing the HPV vaccination programme is] funding cuts in school nursing workforce and under recognition in communities about the benefits.”

*GPSI Gynaecology - England*

“ I think [there should be] a more focussed effort on delivery, between the school nursing and GP teams. There is a lag in the sharing of data on vaccination and people need more info/opportunity to access if they miss at school or do not have but wish to accept later.”

*Practice Nurse - England*

Limitations to IT systems and accessing data were also raised as barriers by a significant number of respondents. HPV vaccines are primarily given by school immunisation teams which are recorded to Child Health Information Services. There is often a manual process to transfer them to GP records and vaccinations administered elsewhere may not make it into the GP record. Meaning there is an incomplete picture of who has and hasn't benefited from vaccination<sup>31</sup>. Personalised communication or risk-based screening rely on accurate and accessible records of vaccination history.

**“Lack of a modern national screening call/recall database which holds integrated cytology, histology, colposcopy results/outcomes and HPV vaccine status.”**

*Consultant Biomedical Scientist – England*

## What should be the priorities to increase performance of the HPV vaccination programme?

- **More education about the HPV vaccine in schools (68.3%)**
- **National awareness campaigns about HPV and cervical cancer (58.1%)**
- **More catch-up opportunities (53.4%)**

To improve the performance of the HPV vaccination programme, survey respondents highlighted the need for more catch-up opportunities. 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. The significant decline in HPV vaccine coverage following the COVID-19 pandemic should be addressed and reversed as a priority.

Increased education in schools, national campaigns, and targeting the most under-represented communities are considered possible opportunities

to improve uptake. Greater parental awareness of HPV and the vaccine has been shown to have a positive impact on the decision to vaccinate children<sup>32</sup>, with low awareness or understanding among health care professionals also being found to be a barrier to uptake<sup>33</sup>

While there is no one solution for improving HPV vaccine uptake, it is important that outreach and communication efforts are accessible and tailored for the communities they seek to reach. Engaging with local communities can help uncover specific barriers, such as a need for more translated materials, or families being unlikely to respond to paper-based methods of gaining consent<sup>34</sup>, and opportunities for improvement can be co-developed. Improved awareness allows teenagers and young adults to make informed decisions about the vaccine and supports greater understanding of HPV and its role in causing cervical cancer.

# Cervical screening

Cervical screening using cytology prevents 7 in 10 incidences of cervical cancer, and HPV primary screening prevents even more<sup>35</sup>. Women are eligible for cervical screening from the age of 24.5 years to 64 years of age. The call-and-recall programme ensures women are notified when they are eligible to book an appointment and are sent reminders.

HPV primary screening was implemented in Wales in 2018, in England in 2019, and in Scotland in 2020. Northern Ireland has not yet made this transition. This more sensitive and effective test helps identify who has high-risk HPV, which allows close monitoring and the detection of any cell changes at the earliest possible stage.

## What do you think are the biggest barriers to the performance of cervical screening programme?

- **Anxieties among the eligible population (66%)**
- **Workforce pressures in primary care (63%)**
- **Low levels of understanding among the public (62%)**
- **Inaccessibility for some of the eligible population (48%)**
- **Lack of digitalisation (32%)**

Almost 1 in 3 women across the UK are not up to date with their cervical screening, with screening coverage at its lowest level in 20 years<sup>36</sup>. Understanding of cervical screening is low, with a quarter of Scottish women not knowing what cervical screening is for<sup>37</sup>, and 1 in 5 women in the UK mistakenly believing that cervical screening can detect ovarian cancer<sup>38</sup>.

**“I now tell everyone to go for their screening, as mine literally saved my life. I had no symptoms and if I hadn't gone for my smear test when I did, it could have been a very different story.”**

**Liz**

OF THOSE SURVEYED, ONLY

**16%**

BELIEVED THAT ENOUGH WAS BEING DONE TO SUPPORT CERVICAL SCREENING UPTAKE IN THE UK

ALMOST

**1/3** of UK women

ARE NOT UP TO DATE WITH THEIR CERVICAL SCREENING

**There are significant inequalities in coverage across different UK regions and demographics.**

Data suggest that prompt restoration of services during COVID-19 limited the impact on excess cervical cancer deaths<sup>39</sup>, but many barriers to screening preceded the pandemic and persist across the UK. Two-thirds of physically disabled women have been unable to attend screening<sup>40</sup> and almost half of survivors of sexual violence have not attended<sup>41</sup>. Women living in poorer areas are less likely to attend<sup>42</sup>, while 80% of women in full-time work struggle to get a convenient appointment<sup>43</sup>.

In addition to low awareness of screening, access is identified as a significant barrier. Workforce pressures in primary care, and limited options of where and how to access screening, have been highlighted as 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 with childcare commitments, and physically disabled women, the lack of choice in where to access screening can be prohibitive<sup>44</sup>.

Developing a more accessible test, providing more screening out of hours, and providing screening at more locations, were all suggested as possible steps for improving accessibility and uptake. Cervical screening services could be made more accessible and acceptable to women if they were integrated with other routine sexual and reproductive health services<sup>45</sup>.

**“From personal experience I have found it difficult to get an appointment with a GP to have a cervical smear therefore I imagine access would be a problem for a lot of the population.”**

*Subspecialist Trainee in Gynaecology Oncology  
- England*

**“Availability of appointments with practice nurses in GP practices. No alternative to visiting your GP practice for a smear test – used to be able to go to Sexual Health. Invasive test– alternatives needed. Rural areas transport/ costs & may know your sample taker (no alternative sample taker).”**

*Screening Manager - Scotland*

**“Making screening more accessible, e.g., more appointments, appointments available at other services if women prefer to avoid their GP practice (i.e., sexual health clinics), longer appointments for first screens or women who have had negative experiences previously.”**

*Clinical Nurse Specialist in Contraception and Sexual Health - Scotland*

Survey respondents raised the 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 have long been called for by researchers and cancer charities<sup>46</sup>. Access to data relies in part on the systems in place. Robust IT systems across the pathway are an essential part of this and the lack of them was raised by several respondents, primarily in England.

At Jo's, we have been highlighting the issues within the IT systems for many years, particularly the system that supports the screening programme in England. In 2011, it was deemed "no longer fit for purpose" by a wide range of stakeholders, including the National Audit Office, and 12 years later little has changed. This is delaying changes and improvements which could help better target those at risk and improve communication such as text messages from GPs.

Digital methods for booking tests and communicating with women, and risk-based screening, rely on effective IT systems and data records. These developments could support NHS resources to be used more effectively, with targeted communications and different screening intervals for at-risk groups. Any consideration of risk-based screening would require data on vaccine status as well as other individual risk factors, which would require better information sharing between programmes.<sup>48</sup>

**“The IT systems which support cervical screening are no longer fit for purpose. Information is held on over 80 separate systems covering different parts of the country. There is no national database. As cervical screening starts at age 25 and ends at age 65 many women will move across boundaries, making it very hard to track their screening histories. Linkage of cervical screening information with hospital information (e.g., on colposcopy and histology) is difficult to achieve, hampering quality assurance of the service.”<sup>47</sup>**

***An Intelligence Framework for Cancer, 2011***

OF THOSE  
SURVEYED

**28%**

**identified out of date IT systems and technology as a barrier to the performance of the cervical screening programme**



**Over 50% of cervical cancer incidences are in women who have never been screened or are under-screened<sup>49</sup>. Our research has shown that if screening rates do not improve amongst unvaccinated women, we could see a 100% increase in cervical cancer deaths amongst 60–64-year-olds by 2040<sup>50</sup>.**

Public awareness campaigns, such as the Public Health England '*Cervical Screening Saves Lives*' campaign in 2022, can have a notable impact on uptake<sup>51</sup>. Jade Goody's very public diagnosis of cervical cancer, and death at the age of 27, encouraged almost half a million more women to attend<sup>52</sup>. However, these increases in attendance are usually short-term, which highlights the need for continuous education and awareness work, especially as this can help tackle fear and anxiety<sup>53</sup>.

**When asked what the top 5 priorities for the cervical screening programme should be, the five most popular responses were:**

- HPV self-sampling with swab as an option for all (51%)
- Flexibility in where screening is offered (47%)
- HPV self-sampling with swab for non-attenders (45%)
- Different communication methods (e.g., text reminders) (43%)
- National awareness campaigns (39%)

OVER  
**50%**  
of cervical cancer incidences are in women who have never been screened or are under-screened

# HPV self-sampling

Among the 48 countries with HPV-based cervical screening programmes, 35% have introduced self-sampling. In 8 countries, this is for under-screened populations and in 9 it is the primary screening option for all women<sup>54</sup>. This includes Sweden<sup>55</sup>, Australia<sup>56</sup>, and the Netherlands where self-sampling led to higher participation among non-attenders compared to other initiatives.<sup>57</sup>

Offering self-sampling to non-attendees has been shown to increase participation<sup>58</sup>, in addition to being favoured over clinician-led screening<sup>59</sup>.

70.3% of our survey respondents named HPV self-sampling as one of the biggest opportunities to eliminate cervical cancer in the UK.

## When asked about priorities for the cervical screening programme, top responses included:

- **HPV self-sampling with swab as an option for all (51%)**
- **HPV self-sampling with swab for non-attenders: (45%)**
- **HPV self-testing with urine: (31%)**

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. The clinical accuracy of HPV self-sampling is high<sup>60</sup>. However, it has been found to have slightly reduced sensitivity for CIN2+ and there is a concern that women who are currently attending cervical screening may opt out of clinician sampling and therefore receive a less sensitive test than before<sup>61</sup>.

HPV self-sampling could provide a step change for many who find the existing test inaccessible. Policy decisions must balance risks against benefits, while research must continue to remove these risks, continue to identify further ways to tackle barriers to screening, and make all screening tests as accessible as possible for everyone.

OF THOSE  
SURVEYED

70%

named HPV self-sampling as one of the biggest opportunities to eliminate cervical cancer in the UK

“Going forward, focus should be placed on scenarios that offer less intensive screening for vaccinated women and more on increasing coverage and incorporation of new technologies to enhance current cervical screening among unvaccinated women.”<sup>62</sup>

*Alejandra Castanon et al.*

# HPV awareness

Queries and concerns about HPV make up more than 40% of the calls to the Jo's Cervical Cancer Trust Helpline, and over 30% of the submissions to our Ask the Expert service. With the introduction of HPV primary screening, more women are finding out they have HPV than ever before. Women receiving an HPV diagnosis report feelings of confusion, anxiety, and shame<sup>63</sup>. Where this news is received alongside a diagnosis of cell changes or cervical cancer, these negative emotions can be compounded<sup>64</sup>.

**“When I told my partner of my HPV diagnosis, needing his support and love, I instead heard back: “that’s an STD. I’ve not given you that. Who gave you that?””**

*Kristen*

## The need for greater awareness and education on HPV was highlighted throughout the survey:

- **‘More education about the HPV vaccine in schools’ (68%) and ‘national awareness campaigns about HPV and cervical cancer’ (58%) were recognised as priorities to increase performance of the HPV vaccination programme.**
- **‘Lack of understanding around HPV and the efficacy of vaccinations’ (72%) was seen as the biggest barrier to the HPV vaccination programme.**
- **‘Low levels of understanding among the public’ (62%) was identified as one of the biggest barriers to the performance of the cervical screening programme.**
- **Survey respondents chose ‘national public awareness campaigns about the role of vaccination and screening in eliminating cervical cancer’ (68%) as the second biggest opportunity to eliminate cervical cancer in the UK.**

The shame and stigma associated with HPV is overwhelmingly carried by women, as there is no HPV screening programme for men. This stigma can

negatively influence willingness to undergo an HPV test and the interpretation of screening results<sup>65</sup>. 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<sup>66</sup>.

Greater education about HPV can facilitate understanding of the role of HPV vaccinations and cervical screening in preventing cervical cancer, enable women to make better informed decisions about their health, and emphasise the relevance of the cervical cancer prevention pathway.

**“Because my [cervical cell] changes were from my HPV, I felt disgusting and dirty. You feel as though you’re to blame for having sex. Not enough education is given. Because it’s from HPV and that’s due to having sex/sexual contact, I felt ashamed and like I would be judged.”**

*Anon*

# Cytology, histopathology, and laboratory services

HPV primary screening tests samples for the presence of high-risk HPV. Cervical cytology is the process of screening samples of cervical cells for abnormalities. Cytology is undertaken when a sample has tested positive for high-risk HPV. Although, in Northern Ireland, the service still uses cytology as the first test on screening samples. When cytology suggests an abnormality, the person is seen at colposcopy. Biopsies can be taken to confirm or remove cell changes, and the tissue is analysed by pathologists in a histology laboratory.

Workforce pressures and staff shortages were raised as significant challenges within cytology and laboratory services. The consolidation of laboratories following the transition to HPV primary screening caused many to leave the workforce, in anticipation of the change leading to both a reduced workforce, and to challenges in recruiting new staff<sup>67</sup>.

*"Centralisation of services has reduced staffing and lost qualified staff unnecessarily."*

**Consultant Biomedical Scientist & CSPL – England**

*"The consolidation when introducing primary HPV testing was very poorly handled. Led by people who had no understanding of the subject, and who did not listen to feedback they were given. Far too many excellent staff left the service with the result that those left could not cope with the workload. There should be a review of what went wrong so that the same mistakes are not made again."*

**Retired Consultant Biomedical Scientist – England**

*"Recruitment and retention are the biggest issues in a service that is seen as unstable in terms of employment."*

**Consultant Biomedical Scientist – England**

*"Specialist laboratory staff are depleting and there is no long-term plan to replace them. We are very close to being in a situation where there are not enough specialist biomedical scientists and pathologists able to diagnose patients."*

**Business Manager (Medical Device Company) – England**

Frustrations with technology were keenly felt, particularly in England, with calls for modernisation and more standardisation in processes and systems:

*"Most labs are suffering with lack of IT funding and expertise. e.g., Open Exeter data base prolonged improvement project."*

**Senior Biomedical Scientist – England**

*"Lack of a modern national screening call/recall database which holds integrated cytology, histology, colposcopy results/outcomes and HPV vaccine status."*

**Consultant Biomedical Scientist – England**

*"Standardised IT systems and processes across cytology laboratories and a centralised database for NHSCSP."*

**Medical Laboratory Assistant – England**

*"IT is the biggest barrier we face. We need better access to patient histories, easier sample requesting and paperless options for faster laboratory processing."*

**Biomedical Scientist – England**

*"IT is very poor and out of date in the cervical screening programme nationally. Decisions are slow to be made – especially with things like AI screening as the staff numbers are fragile."*

**Lead Biomedical Scientist – England**

**“What is the one change you would like to see over the next 5-10 years to support the elimination of cervical cancer?”**

*“More funding to the labs to improve effective systems and increase the staff of cytology labs, which are becoming less manned and more irrelevant to new careers of individuals.”*

**Cytology Primary Screener – England**

*“The introduction of Digital Cytology Screening to reduce backlogs, improve programme efficiency and ensure that more women get diagnosed and treated in a timely manner.”*

**Cervical Screening Equipment Supplier – England**

*“Rapid adoption of digital pathology in cervical cytology.”*

**Consultant Pathologist – Northern Ireland**

*“We may have to re-think cytology, we are currently relying on a rapidly aging workforce. Many in my lab are aged 60-70 and who could retire at any time. The service could collapse, and I do not see ‘people in charge’ looking at this.”*

**Clinical Lead and CBMS – England**

Digital cytology and the potential for AI technology are anticipated to ease workload pressures and provide more accurate results<sup>68</sup>. While not routinely in use, some hospitals are moving towards digital pathology, with AI technology recently piloted in Scotland<sup>69</sup>. Other suggestions of digital innovations include the ability to add test results directly to patient GP records to speed up reporting, and risk-based screening intervals to alleviate pressure on services.

**83%** OF NORTHERN IRELAND RESPONDENTS

**believe implementing HPV primary screening would improve delivery of laboratory and pathology services**

Amongst Northern Ireland respondents, 83% believed that the implementation of HPV primary screening would improve the delivery of laboratory and pathology services. Northern Ireland remains the only UK country not to have made the switch to this more effective and sensitive test.

The impact of programme changes – including transitions to HPV primary screening, and changes in interval length – have been keenly felt by cytology services and the cytology workforce. This exemplifies the importance of looking at the cervical cancer prevention programme holistically, and ensuring long-term planning considers every service working to prevent cervical cancer.

# Colposcopy

**Colposcopy services provide further tests, monitoring and treatments after the identification of cervical cell changes. Following treatment for cell changes, around 90% will not have cell changes again. Colposcopy services in the UK balance treating those who need it, with minimising overtreatment<sup>70</sup>.**

When asked what would improve the delivery of colposcopy services, *"increased workforce capacity" (59%)*, *"improved availability of appointments" (35%)*, and *"long-term workforce planning" (34%)* were three of the top four responses.

*"Supporting and increasing the colposcopy workforce given the huge capacity pressure."*

**Consultant in Public Health – Scotland**

*"Due to COVID there is a huge waiting list for people waiting for colposcopy and many women are waiting for over a year in some instances for their appointment. Services are reduced across NHS boards. This needs to improve."*

**Specialist Sexual Health Nurse – Scotland**

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."*<sup>71</sup> In a workforce that is already under pressure, significant numbers entering retirement will have a tangible impact on patient care. Many respondents said they had observed an increase in referrals from primary care, in addition to experiencing an increased workload, following the move to HPV primary screening<sup>72</sup>.

**"I feel that everything is a rush job. I would now think twice before having treatment (at colposcopy) again in the future. This whole procedure has put me off."**

**Anon**

**"Biggest challenges locally in my area are not enough clinics, not enough staff, and not enough clinic space within secondary care facilities. Long waiting lists currently of 40+ weeks mean lots of anxious women. Move to HPV testing has increased number of referrals to colposcopy, without the corresponding increase in facilities."**

**Senior General Practice Nurse – Scotland**

Health Improvement Scotland standards state that individuals referred to colposcopy following an abnormal screening result should be seen “no later than 8 weeks for low grade referrals that do not require urgent assessment.”<sup>73</sup> Despite this, we have heard from women waiting up to 52 weeks for a colposcopy appointment in parts of Scotland. This is causing significant anxiety.

Capacity and workforce pressures are also felt by women attending the service, with **42% feeling 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**<sup>74</sup>. A poor patient experience can lead to reduced inclination to attend subsequent appointments.

Survey respondents highlighted the need for greater public awareness of cervical screening results and colposcopy, particularly as anxiety and lack of understanding can lead to women defaulting on their appointments. Research suggests that uptake of colposcopy appointments may be improved by improving women's understanding of treatment and encouraging health professionals to develop a service more sensitive to the various needs of women<sup>75</sup>. Developments in colposcopy technology also have the potential to more accurately determine risk, reduce the emotional burden of multiple follow-up appointments, and relieve pressure on the colposcopy workforce.

**“Many patients [do not attend] colposcopy due to fear. We need wider understanding of the process and better emotional and pain management for patients. This also goes for attending for screening at primary care.”**

*Biomedical Scientist – England*

OF SERVICE  
USERS  
SURVEYED

**42%**

feel they weren't given  
enough time to make  
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**29%**

didn't have enough information  
to understand the risks and  
benefits of treatment



# Research to facilitate progress

The need for research across the full pathway came through strongly in our survey responses. 28% said investment in research was one of the biggest opportunities to eliminate cervical cancer in the UK, with many others citing improvements, innovation, and extension of existing programmes:

- **Extending the vaccination programme: 43%**
- **Targeted/risk-based screening: 35%**
- **Urine self-sampling: 32%**
- **Improvements in vaccine efficacy: 32%**
- **Development of colposcopy technology to better aid diagnosis and treatment: 24%**
- **More digital innovation across the screening programme: 22%**
- **Extension of the eligible screening age: 21%**
- **Development of AI & other computerised systems to aid diagnosis & screening in laboratories: 15%**

Research and development span every area of preventing and, ultimately, eliminating cervical cancer. There is a role for organisations including research advisory committees and the UK National Screening Committee to help identify gaps, support with access to data, and ensure appropriate processes are in place to facilitate research. Funding bodies including UKRI, NIHR and Cancer Research UK play a critical part here. Adoption of new technology and policies requires political will, as well as investment and a skilled workforce.

There are still gaps in knowledge about many areas of cervical cancer. These include predictors or risk factors for persistent or recurrent HPV infections and cervical cell changes, and the cause of non-HPV cervical cancers. Addressing these areas 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<sup>76</sup> is also in its infancy, but the successes of the existing HPV vaccination programme should give us hope for what future advances could bring.

The development of new kind of tests, that may be less invasive, more effective, or less frequent, could make screening more accessible to many. There may also 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<sup>77</sup>.

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.

As cervical cancer becomes rarer, developments in treating the cancer must continue. This includes for women living with advanced cervical cancer, where very few treatment options currently exist.

**“In order to achieve its targets, the strategy must embrace innovative models of service delivery and computerized data and information systems, together with new and expanded training methods (for example, using virtual reality simulations) and interventions scaled up to population level.”**

***World Health Organization, Global strategy to accelerate the elimination of cervical cancer as a public health problem***



# Symptom awareness

**“We need to target those with a cervix from 24.5 years and educate them and health professionals about symptoms of cervical cancer.”**

*Nurse Colposcopist CNS – England*

The need to improve awareness of cervical cancer symptoms was mentioned throughout the survey. While acting on symptoms will not prevent cancer from occurring, early diagnosis means less invasive treatments and better health outcomes. Unfortunately, public awareness is low, with over half (**52%**) of women unaware that bleeding during or after sex is a symptom of cervical cancer<sup>78</sup>, and **over 1 in 3** not seeking help for potential cervical cancer symptoms. Low awareness among health professionals, particularly in primary care, can also delay diagnosis. While guidelines exist for managing young women with abnormal bleeding, these are not always followed<sup>79</sup>.

Messaging around symptoms should go hand in hand with prevention messaging, especially for those outside of screening age. Along with greater understanding amongst health professionals, symptom awareness should be a key component of any elimination strategy.

# 52%

of women are unaware bleeding during or after sex is a symptom of cervical cancer

**“Better education for those with a cervix as well as professionals regarding symptoms of cervical cancer is also paramount: bleeding being put down to hormones!”**

*Doctor – England*

# What is the one change you would like to see over the next 5–10 years to support the elimination of cervical cancer?

*"Improved IT systems in which information regarding each patient's HPV vaccination and screening history, as well as colposcopy and histology outcomes, are all available in one place. Currently, tracking a patient and their history can be very difficult and, if vaccination history is going to affect recall periods in the future, all this information will be better served in one system. This should be national rather than regional as the current Open Exeter system (update delayed by years...) makes it incredibly inconvenient to ascertain details for patients who have moved from another region. Ideally, request forms for screening samples should be submitted on/printed from this system to improve uniformity of requesting standards."*

**Biomedical Scientist/Cytoscreener – England**

*"Recording the ethnicity from vaccination to screening and treatment to get a clear picture of where (which communities) to target our efforts for the elimination of this cancer."*

**Professor of Cytology – England**

*"A more joined up approach to changes and implementation between countries. The current piecemeal approach undermines confidence and reduced understanding with the public."*

**Charity CEO – England**

*"HPV primary screening introduction in Northern Ireland."*

**Biomedical Scientist – Northern Ireland**

*"Increased awareness and uptake of HPV vaccination programme; improved awareness of the general public of why cervical screening is important."*

**Practice Nurse – England**

*"Media coverage on TV to let people know why it is so important for vaccinations and smears."*

**Charge Nurse – Scotland**

*"The NHS should switch the national screening strategy towards HPV self-sampling (sample kits sent by post) and a national screening campaign educating women on self-sampling."*

**Clinical Oncologist – England**

*"More acknowledgment given by the government to the service providers. From a pathology point of view the service has been treated as the poor relation of laboratory services. There has been no future proofing of the service. Due to uncertainty caused by consolidation of laboratories, recruitment and retention has been almost impossible, skill sets have been lost through retirement and soon there will be insufficient staff with the skills to provide the service. More certainty is required in order to stabilise the service and train the screeners of tomorrow."*

**Consultant Biomedical Scientist – England**

*"Increasing screening coverage, especially within the vaccinated population, including wide public health awareness of the importance of screening even when vaccinated."*

**Advanced Biomedical Scientist Practitioner – Wales**

*"For the government to class this as a priority."*

**Gynaecology Clinical Nurse Specialist – England**

*"Development of a therapeutic vaccine for persistent HPV, or trials to see if the HPV vaccine is useful for treatment of HPV. National roll out of self-sampling, national drive for cervical screening, extra facilities to enable women to get an appointment for cervical screening. Many women who I speak to struggle to get a GP appointment delaying their smear test."*

**Colposcopy Lead – England**

*"Increase in public information about HPV. Increase in research into HPV and whether vaccination at other times can improve cervical changes. Continued work on vaccines."*

**Nurse Colposcopist – Scotland**

*"The development of a nation-wide taskforce: think the other changes – publicity, campaign etc would follow on from this."*

**Senior General Practice Nurse – Scotland**

*"Increased funding for research and development."*

**Senior Biomedical Scientist – England**

*"Faster implementation of IT changes needed to progress with programme changes like HPV self-sampling and longer screening intervals."*

**Screening and Immunisation Manager – England**

# Call to action

The UK is taking steps towards reducing the impact of cervical cancer, but we're calling for that to happen faster. Crucially, we're urging that **no-one is left behind**. To eliminate cervical cancer in the UK, we need strategies that recognise the importance of the entire cervical cancer prevention pathway, and commit to improvements and innovation throughout.

## We are calling for:

### **1 UK governments to commit to eliminating cervical cancer and develop strategies that are ambitious, forward-looking, and evidenced.**

Cervical cancer could be the first cancer in the world to be eliminated, but we should not be complacent, or assume this is inevitable. Data modelling must be at the heart of any strategy setting out realistic but ambitious targets. UK targets should reflect the current state of programmes in the UK and be more ambitious than those set by the WHO.

### **2 Inclusion of workforce planning as part of cancer and cancer workforce strategies, which recognise the needs of the different workforces across cervical cancer prevention, which recognises the needs of the different workforces across cervical cancer prevention.**

Workforce planning must look to the needs of the programmes of the future and include the training and retention of staff. Changes to one part of the pathway should be made in conjunction with other areas where a knock-on effect may be felt.

### **3 Everyone to have have equal opportunity to reduce their risk of cervical cancer.**

Identifying opportunities to increase access and reduce inequalities to the prevention programmes should be prioritised. We need research to better understand barriers, outreach to communities less likely to engage in screening and vaccination programmes, support to help attendance, and speed in developing an HPV self-sampling programme that

could provide an opportunity to attend for those currently unable to access screening.

### **4 Research to close the gaps in understanding across the programmes.**

We need more research and greater speed in adopting innovations. There are opportunities to improve programmes, such as moving to HPV primary screening in Northern Ireland, and developing AI and digital cytology technology, that the UK should take advantage of. Work is needed to reduce inequalities, with opportunities including HPV self-sampling. Research into non-HPV cervical cancers is crucial if we are ever to truly make this a disease of the past.

### **5 Investment in technology.**

The workforce should be operating on systems which are fit for purpose, provide a complete picture of patient history, facilitate greater targeting of interventions, and do not hold up progress. We need data to measure progress and inform action, and these data must be clearly and consistently recorded on up to date and accessible systems.

### **6 Increased public awareness.**

Using a life course approach to information and education across the cervical cancer prevention programme, from vaccination to exiting screening. With accessible, patient-centred information at every step, everyone should be aware of their risk and understands what it means to take part.

## **7 Those with cancer to be included.**

The development of any strategies and actions to eliminate cervical cancer must not side-line those living with and beyond diagnosis. There will always be cases that cannot, and have not, been prevented. When looking to eliminate cervical cancer, we should also be looking to reduce the impact for those affected. This means investment in better and less invasive treatments, greater provision of care for those affected by the side effects of cervical cancer, and more treatment options for those with advanced cervical cancer.

The closer we get to elimination, the more important it is that the needs of this group are not overlooked.

# Dedication

**This paper is dedicated to all the women and people with a cervix who have lost their lives to cervical cancer, and to those in our community who are living with and beyond cervical cancer. You, your friends, and your family are always in our thoughts.**

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