Future Cancer Inquiry 2023
Jo's Cervical Cancer Trust written response

Jo's Cervical Cancer Trust is the UK's leading cervical cancer charity. Our vision is of a day where cervical cancer is a thing of the past. Cervical cancer is a largely preventable disease, with HPV vaccinations and cervical screening. By improving the uptake of these prevention interventions, and continuing to refine the accuracy of diagnostic tools, cervical cancer can be eliminated.

Until then, Jo's will continue to provide information and support for anyone affected by cervical cancer. We will campaign for excellence and raise awareness of HPV vaccinations, cervical screening, colposcopy, cancer treatment, and living with and beyond cervical cancer.

There is a notable link between deprivation and incidences of cervical cancer and worse cancer outcomes. Cervical cancer incidence rates are 65% higher in the most deprived quintile compared with the least[i], and there are 148% more deaths in the most deprived groups, compared to the least deprived[ii].

Innovations supporting the prevention and treatment of cervical cancer could make a significant difference to the health inequalities faced by this group.

Cervical screening

Cervical screening is one of the best tools for preventing cervical cancer. Cytology-led screening prevents over 7 in 10 incidences of cervical cancer, and HPV primary screening is preventing even more. In the UK almost 1 in 3 women do not attend their screening when invited, and barriers can include experiences of pain, embarrassment, or not having the time to attend a GP appointment.

Two-thirds of physically disabled women have been unable to attend screening[iii] and almost half of survivors of sexual violence have not attended[iv]. Women living in poorer areas are less likely to attend[v], while 80% of women in full-time work struggle to get a convenient appointment[vi].

Improving access to cervical screening is vital for tackling health inequalities. By identifying who has high-risk HPV (Human Papillomavirus) we are better able to monitor who is at an increased risk of developing cervical cancer, as HPV is responsible for 99.7% of cervical cancer incidences. Colposcopy services can also help diagnose cervical cancer even when symptoms are not yet present.

Over 50% of cervical cancer incidences are in women who have never been screened or are under-screened[vii], and cervical screening coverage is at its lowest level in 20 years, after years of steadily declining participation[viii]. Research suggests that if cervical

screening coverage continues on its current trajectory, we can expect to see a 100% increase in cervical cancer deaths amongst 60–64-year-olds by 2040[ix]. Improving cervical screening uptake is essential to address this.

Implementation of HPV self-sampling

Countries including the Netherlands, Australia, and Denmark now offer HPV self-sampling using a vaginal swab to women who do not attend their cervical screening[x]. This has been shown to increase participation[xi], as well as being favoured by patients over clinician-led screening[xii]. The clinical accuracy of HPV self-sampling is high[xiii], though with a slightly reduced sensitivity for CIN2+[xiv].

Research into HPV urine testing kits is also promising, with high levels of specificity and positive predictive values[xv]. Like self-sampling using a vaginal swab, research suggests that urine sampling is considered more private and less painful than clinician-led screening[xvi]. With further development HPV urine testing kits offer the potential of women being able to test for HPV in their own home and find out their own results in a similar manner to pregnancy tests[xvii].

HPV self-sampling could provide a step change for many who find the existing test inaccessible, and healthcare professionals view self-sampling as one of the biggest opportunities the UK has to eliminate cervical cancer[xviii].

More development is needed to improve the sensitivity and accuracy of these tests, to enable them to be offered as part of UK national programmes and provide choice and alternatives to the eligible population. Research to understand how best to embed these tests in the national screening programmes is also required, to ensure screening is delivered in the most effective and accessible way.

Cytology

Cervical cytology is a test used to detect abnormal changes in cervical cells. In Northern Ireland, the screening programme consists of cytology followed by HPV triage, while in the rest of the UK HPV primary screening is followed by cytology.

Cervical cytology currently relies on trained cytologists using a microscope to look for cell changes. Potential developments and innovations could see this diagnostic tool becoming more sensitive and more standardised.

DNA Methylation

Research suggests that genetic alterations, resulting from a process called DNA methylation, can be used as biomarkers for HPV and high-grade cervical cell changes. By testing for high methylation levels of tumour-supressing (TS) genes, it can be

possible to distinguish non-progressive HPV infections from those that will progress to cancer, and more accurately predict those at greatest risk of developing cervical cancer[xix]. Studies to date show that methylation analysis displays a clinical sensitivity and specificity similar to cytology[xx].

There are several benefits to using DNA methylation analysis as a diagnostic tool, rather than cytology. There are ongoing workforce pressures and a dearth of trained cytologists across the UK, and implementing DNA methylation triage would reduce the need for as many trained cytologists in this area. Cytology can also be subjective, relying on the skill of the cytologist, while methylation analysis can be standardised. The equipment needed for DNA methylation analysis is also commonly available across laboratories, and can provide quick, high-throughput assessment of samples[xxi].

Data also suggests that fewer women would be referred unnecessarily to colposcopy services if DNA methylation-based detection was the triage method instead of cervical cytology[xxii]. This could help reduce workforce pressures in colposcopy units and improve the patient experience of those who do attend[xxiii]. There is also the potential that being able to better identify non-progressive HPV infections could offer reassurance to those with persistent or recurrent HPV infections[xxiv].

DNA methylation-based detection is also effective on self-collected samples, while cytology relies on a clinician-taken sample[xxv]. If HPV self-sampling is implemented in the UK, using DNA methylation analysis at the triage stage could prevent women from having to receive an additional clinician-led screening. This could free up time and space in primary care, as well as making cervical screening more accessible and acceptable to many women.

AI and digital cytology

Digital cytology and artificial intelligence are also being considered as options for improving the consistency of triage after screening. In recent years, AI has been increasingly applied around the world to help diagnose various diseases, including "the classification of skin tumours, diagnosis and classification of retinal diseases, and imaging diagnosis of tumours[xxvi]".

Research has found that AI-assisted cytology is similarly – or more – accurate than manual reading[xxvii]. One study involving 700,000 women reported a 5.8% increase in sensitivity compared to manual reading[xxviii]. In 2022 a University Hospitals Monklands pilot - using digital cytology with AI - lead to an increased capacity of around 25% in the slide assessment as well as improving its analysis turnaround times[xxix].

Like DNA methylation, using AI with digital cytology could reduce workforce pressures in cytology and lessen subjectivity in the diagnostic process. It could also help to reduce the number of women who receive unnecessary treatment and tests.

For AI-assisted cytology to be widely used across the UK, digital cytology needs to be implemented first. For a digital service to be sustainable and dependable, a robust IT support system is an absolute necessity, and pathology laboratories are currently experiencing difficulty in this area[xxx].

Radiotherapy

Radiotherapy is a common and highly effective treatment for cervical cancer, and more people are surviving cervical cancer than ever before. However, while short-term side effects are common, radiotherapy treatment can cause a collection of symptoms known as Pelvic Radiation Disease. Symptoms of PRD can include incontinence, pain, infertility, lymphoedema, and nerve damage, and can be chronic and debilitating for those affected[xxxi].

Developments to improve the precision of radiotherapy treatment could help reduce the number of women affected by Pelvic Radiation Disease in the future. Better imaging solutions – such as the MRI-linac – can help limit the damage to health tissues near tumour sites[xxxii]. Currently there are only 5 sites in the UK with an MRI-linac.

The Royal College of Radiologists have highlighted that nearly a third of MRI scanners in UK hospitals are technically obsolete as they are ten or more years old, and there is a severe shortfall of radiologists[xxxiii]. Exploration of innovative diagnostic and treatment solutions must be accompanied with an investment in equipment and in retaining and growing the accompanying workforce.

More research is also needed, in order to better understand who is at most risk of developing PRD and acute side effects of cancer treatment. This could support with prehabilitation before treatment and better tailored follow-up support. Some research suggests that age[xxxiv] and gut microbiome diversity[xxxv] can help identify those at the greatest risk of long-term side effects. More research into this less well-known collection of symptoms could make a real difference to the quality-of-life of women following cervical cancer treatment.

More research could also lead to better levels of awareness about long-term side effects following radiotherapy, an improved ability to recognise the condition, and a greater likelihood of following best practice around symptom management and ongoing support[xxxvi].

Workforce and technology

There are great frustrations with technology, particularly in England, and calls for modernisation and standardisation in processes and systems[xxxvii]. In 2011 the IT systems which support cervical screening were deemed outdates "no longer fit for purpose" by a wide range of stakeholders, including the National Audit Office, and little has changed since then[xxxviii].

Outdated systems are holding back innovations. A modern screening database with screening, vaccination, colposcopy, and cytology records could improve and streamline communication between teams and with patients. Opportunities such as risk-based screening or opportunistic vaccinations are also being missed, as data is not tracked consistently and there is no clear record of an individual's HPV vaccine history[xxxix].

Without investment to the fundamental infrastructure that supports much of the cervical cancer prevention and diagnostic pathway, it is difficult to consider the implementation of new innovative and digital solutions.

Workforce pressures are felt in immunisation teams, primary care, cytology and laboratory services, colposcopy teams, and radiotherapy teams[xl]. With 30% of the specialist cancer nurse workforce estimated to retire in the next 10 years, there is a real need to invest in retention and recruitment across cancer care and prevention[xli].

To eliminate cervical cancer in the UK, we need strategies that recognise the importance of the entire cervical cancer prevention and diagnostics pathway and commit to improvements and resourcing throughout. This will allow the workforce to make the best use of the innovations and opportunities that are developing, and ultimately save and improve lives.

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