TURNING THE TIDE

RECOMMENDATIONS TO INCREASE CERVICAL CANCER SCREENING AMONG WOMEN WHO ARE UNDER-SCREENED

An ACCESS Consensus Group paper for high-income countries with organised cervical cancer screening programmes

Endorsed by

FIGO
International Federation of Gynecology and Obstetrics

ACCESS
International Consensus Group on Cervical Cancer

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FOREWORD BY THE CO-CHAIRS OF THE ACCESS CONSENSUS GROUP

Cervical cancer is a largely preventable disease, yet far too many women still die from it. HPV vaccination is a highly effective prevention intervention but it will take decades for it to offer population-wide protection. In most high-income countries, organised cervical cancer screening programmes have been in place for decades and have helped significantly reduce the incidence and mortality rates of the disease. Despite this success story, participation rates in screening programmes remain suboptimal. In Europe, screening participation rates vary hugely between countries, at 80% in some but as low as 25% in others[1], and are stagnate or have declined in some countries in recent years.[2,3,4]

> "In Europe, screening participation rates vary hugely between countries."

Low participation rates in screening programmes have a very detrimental impact on women's health outcomes. This reality was exacerbated by the global COVID-19 pandemic which led to a further decrease in screening coverage. Women who do not receive regular screening are at higher risk of developing cervical cancer, and when diagnosed, they are more likely to have advanced disease and poorer outcomes.[5] It is recognised that there are groups of women who are consistently under-screened due to a wide range of factors including, among others, lack of awareness, lack of access or cultural beliefs. Empowering women in these groups to take up the offer of screening would deliver both individual health and societal benefits.

In light of these challenges, the ACCESS Consensus Group has come together as an international, multi-disciplinary expert group to accelerate cross-border collaboration, share best practices and propose solutions. This paper presents evidence-based recommendations on how to improve outcomes in high-income countries by increasing participation in cervical cancer screening among under-screened women. The goal is to turn the tide and reverse the declines in screening uptake by supporting the under-screened population and ensuring women have optimal access to this vital cancer prevention tool. We urge decision-makers to implement these recommendations and save lives. The time to act is now.

Samantha Dixon

CEO, Jo's Cervical Cancer Trust

Prof. Philippe Descamps

Vice President of FIGO

Head of Department - Gynaecology and Obstetrics, CHU Angers

President of International Relations Committee, CNGOF

EXECUTIVE SUMMARY

Endorsed by FIGO International Federation of Gynecology and Obstetrics

For the first time ever, we have the opportunity to eliminate a type of cancer. For high-income countries with organised screening and vaccination programmes, cervical cancer elimination is a realistic possibility in the coming years. We have the tools to prevent cervical cancer, but low uptake rates of preventative measures means that we risk going backwards rather than forwards. Screening is the most impactful intervention to reduce the burden of cervical cancer in the short term, but screening participation rates are sub-optimal in many high-income countries, and, in some cases, they have even been declining.

Some of the lowest-income women in the most disadvantaged communities are at the greatest risk from cervical cancer, partly as a result of lower rates of screening participation. Urgent action is needed to address low and declining screening participation rates and to stop women dying from this largely preventable disease. There is a particular need for initiatives targeted at under-screened groups to address this inequity.

The *Advancing Cervical CancEr ScreeningS (ACCESS) International Consensus Group on Cervical Cancer,* a multi-disciplinary group of leading experts in the field, calls on governments and healthcare authorities to:

- Develop national action plans for cervical cancer elimination within a defined timeframe, utilising the WHO's elimination framework.
  - Plans should be ambitious, going beyond WHO targets, both to increase rates of screening participation and to reduce inequities in participation.
  - Plans must align with broader healthcare and women's health strategies.
- Significantly increase efforts to raise awareness of cervical cancer screening among under-screened populations, using targeted and culturally relevant communication approaches created in partnership with healthcare professionals and communities.
- Improve the accessibility of cervical cancer screening for under-screened populations, including through the use of new technology such as self-sampling, electronic invitations and reminders and by offering more convenient screening locations and times.

> **"Urgent action is needed to address low and declining screening participation rates and to stop women dying from this largely preventable disease."**

In total, the ACCESS Consensus Group is making six key recommendations:

1. Develop cervical cancer national elimination plans with goals for elimination by a defined date, including ambitious national screening programme participation targets at the population level

2. Implement targeted and culturally-relevant education, information and awareness-raising initiatives, particularly focused on under-screened women

3. Improve the accessibility of cervical cancer screening

4. Support healthcare professionals to increase participation in cervical cancer screening

5. Encourage and support the creation of national cervical cancer patient advocacy groups and national cervical cancer prevention coalitions

6. Ensure that health insurance appropriately covers screening in all high-income countries

ABOUT THE CONSENSUS GROUP

The creation of the ACCESS Consensus Group is a timely and much-needed initiative. The burden of cervical cancer is an issue affecting women globally, and concerted efforts are needed to improve screening rates and reduce mortality worldwide. The establishment of this group of multi-disciplinary experts will facilitate international collaboration and sharing of best practices in cervical cancer screening. With the diverse expertise of the members of the group, this initiative has the potential to make significant contributions to improving cervical cancer screening programmes and ultimately to reducing the disease burden.

Studies show that cervical cancer screening participation has been on the decline in some countries. England, for example, has seen a decline over the last 20 years[6], with most recent data showing a decline of 2.3% between 2016 and 2022 in women aged 50-64 and a decline of 1.1% for the same period in women aged 25-49.[7] Additionally, a decrease in screening of 6.4% due to the COVID-19 pandemic was observed in 2020.[8] Up-to-date screening has similarly declined by 8.6% in the US (in 2019 as compared to 2005, particularly among underserved populations[9]), and also in the Netherlands where screening participation fell by 4% in 2016 after the introduction of a new cervical cancer screening programme, and unexpectedly by another 3% in 2017.[10,11] The COVID-19 pandemic has also exacerbated this decline in screening and in 2021, Dutch screening participation was still considerably below the 60% observed in 2016.[12]

Given this concerning international trend in screening uptake, which puts women at increased health risks, the ACCESS Consensus Group has been brought together to consider cervical cancer screening participation in high-income countries with established cervical cancer screening programmes. Group members are able to provide international expertise as well as pertinent insights from their local contexts. Findings and resulting recommendations of the Group are intended to serve the ongoing efforts of policymakers and those involved in planning and delivering cervical cancer screening programmes to increase participation rates.

Some of the recommendations and best practices in this document may also support ongoing work in low- and middle-income countries (LMICs) where cervical cancer incidence and mortality are the highest. It is envisaged that as a next stage, the Group will consider the particular challenges faced by these LMICs and identify solutions that address their specific needs.

The ACCESS Consensus Group currently consists of 10 members bringing diverse expertise from across the European Union (EU), United Kingdom (UK), United States (US) and Canada.

Co-chairs

- **Samantha Dixon**, CEO, Jo's Cervical Cancer Trust, UK
- **Prof. Philippe Descamps**, Professor and Chairman, Department of Obstetrics and Gynaecology, University Hospital Angers, Vice President of FIGO, and President of International Relations Committee, CNGOF (French College of Obstetricians and Gynaecologists), France

Members

- **Dr. Francesc Xavier Bosch Jose**, Clinical oncologist, epidemiologist, former Board member of Papillomavirus Society (IPVS), Co-director of HPV Information Center (ICO and IARC), Spain
- **Dr. Anne Connolly**, GPSI in gynaecology, Royal College of General Practitioners (RCGP) women's health clinical champion, Chair of Primary Care Women's Health Forum (PCWHF), UK
- **Prof. Maria Kyrgiou**, Consultant Surgeon in Gynaecology and Gynaecological Oncology, Imperial College London, UK
- **Dr. Joseph Monsonego**, Gynaecologist-oncologist, President of EUROGIN, President of 1000femmes1000vies patient association, France
- **Ody Neisingh**, independent consultant and public affairs advisor, with extensive working experience at WOMEN Inc. and UN Women, and member of the European Economic and Social Committee on behalf of gender equality civil society, The Netherlands
- **Dr. Lananh Nguyen**, Director of cytopathology and Assistant professor, Department of Laboratory Medicine, Unity Health Toronto, University of Toronto, Canada
- **Dr. Mairead O'Connor**, Research Officer, National Screening Service Ireland, behavioural scientist, Ireland
- **Dr. Jennifer Susan Smith**, Professor, Department of Epidemiology, Gillings School of Global Public Health, University of North Carolina, US

Background

BURDEN OF CERVICAL CANCER IN HIGH-INCOME COUNTRIES

In high-income countries, the burden of cervical cancer has been dramatically reduced due to the availability of comprehensive healthcare services, widespread availability of cervical cancer screening, innovation in screening technologies and vaccination coverage against human papillomavirus (HPV), the primary cause of cervical cancer. However, cervical cancer still poses a significant health burden in these countries and in 2020, many women still died from the disease, including 200 in Sweden, 1,452 in France and 5,706 in the US.[13,14,15]

These cases are often associated with women who are screened irregularly, or not at all, known as under-screened or non-responders. These women are often among those insufficiently informed about cervical cancer, with limited access to healthcare or who face barriers to timely diagnosis and treatment. Cervical cancer therefore represents a significant health inequality based on socioeconomic factors, geographic location, and access to healthcare. Marginalised populations, such as ethnic minorities, low-income individuals, immigrants, and rural communities, are typically at a higher risk of cervical cancer due to lower participation in screening.[16]

Whilst this paper is primarily focused on high-income countries, it is important to acknowledge that the greatest burden of cervical cancer is in LMICs. Despite ongoing efforts to improve screening and vaccination programmes in these countries, there is a need for further support to strengthen health systems and increase access to essential services.

The ACCESS Consensus Group will seek opportunities to translate relevant findings from this White Paper to LMICs, where appropriate and feasible. By adapting the present recommendations to the unique challenges and contexts of LMICs, policymakers, in collaboration with healthcare professionals and patient and women representatives, can identify strategies that are implementable and effective in improving cervical cancer prevention and treatment in these settings.

> “Marginalised populations are typically at a higher risk of cervical cancer due to lower participation in screening.”

ROLE & IMPACT OF CERVICAL CANCER SCREENING AS KEY TO RAPID REDUCTION OF MORTALITY

Cervical cancer screening programmes have been in place across the EU, the UK, the US and other middle- to high-income countries since the 1980s and have led to a reduction of cervical cancer rates by up to 80%.[17] In Europe, research has shown that women who attend regular screening reduced their chances of dying from cervical cancer by up to 92% as compared to those who did not attend screening.[18] Once detected, treatment of precancerous lesions is highly effective and most women treated will not develop cervical cancer.[19]

As we look at new approaches and solutions to screening such as self-sampling, a key priority is always considering the best interests of women, the need for the highest standards of test accuracy and effective follow-up and treatment. The full continuum of cervical cancer care is vital for optimising outcomes, improving survival rates, and reducing the burden of this disease.

CURRENT POLICY LANDSCAPE

In February 2021, the European Commission published its *Europe’s Beating Cancer Plan Communication* - a forward-looking initiative including a Cancer Screening Scheme to “help EU Member States ensure that 90% of the EU population who qualify for cancer screenings are offered screening by 2025.”[20] This was reinforced by the 2022 *Council Recommendation on strengthening prevention through early detection: A new EU approach on cancer screening.*[21]

Prior to that, in May 2018, the World Health Organization (WHO) announced a global call for action to specifically eliminate cervical cancer, underscoring a renewed political will to make elimination a reality and calling on all stakeholders to unite behind this common goal. In August 2020, the World Health Assembly adopted the *Global Strategy for cervical cancer elimination.*[22]

According to the WHO strategy, to eliminate cervical cancer, all countries must reach and maintain an incidence rate of below four per 100,000 women. Achieving that goal rests on three key pillars and their corresponding targets[23]:

- **Vaccination:** 90% of girls fully vaccinated with the HPV vaccine by the age of 15.
- **Screening:** 70% of women screened using a high-performance test by the age of 35, and again by the age of 45.
- **Treatment:** 90% of women with pre-cancer treated and 90% of women with invasive cancer managed.

High-income countries with advanced healthcare systems and prevention programmes could be expected to surpass these targets and achieve elimination much more quickly than LMICs, including by reaching a lower cervical cancer incidence than the recommended four per 100,000 women. Since 2020, in response to the *WHO Global Strategy to Accelerate the Elimination of Cervical Cancer*[24], countries including Australia and Canada[25,26] have committed to eliminating cervical cancer. Ireland is also set to define its elimination target in late 2023 and, in the context of a wider strategy on women's health, England has set an ambition to see a future where "almost no-one develops cervical cancer."[27] There are many high-income countries, however, which are yet to explicitly commit to the goal of elimination of cervical cancer.

Against the backdrop of countries striving to achieve these ambitious international goals, authorities across the EU, UK and US are currently evaluating their cervical cancer screening guidelines and exploring ways to intensify international collaboration:

- The EU is collaborating with the International Agency for Research on Cancer (IARC) on developing the next update of the *European Guidelines and Quality Assurance scheme for cervical cancer.*[28]
- The UK National Screening Committee cervical cancer screening recommendation is currently due for review.[29]
- The US Preventive Services Task Force (USPSTF) is undertaking research to inform its next iteration of national screening recommendations.[30]
- In May 2023, the EU initiated a partnership with the US via an EU-US Health Task Force, which includes advancing cooperation for cancer prevention between Europe's Beating Cancer Plan, the EU Cancer Mission and the US Cancer Moonshot and US National Cancer Plan.[31]

The ACCESS Consensus Group calls on authorities to use these screening guideline review processes and cross-country collaborations to carefully assess existing best practices and implement measures that will address the current challenges in optimising participation in cervical cancer screening, particularly among under-screened women. When considering emerging technologies, it is advised to adhere to thorough research and clinical validation, as often required by regulatory authorities, and to ensure feasibility and effectiveness prior to implementation.

CURRENT STATUS OF PARTICIPATION IN CERVICAL CANCER SCREENING

High-income countries vary in relation to their current screening participation rates.[32,33] The table below presents examples of screening participation rates and frequency of screening in a set of high-income countries for which data are available.

FIG. 1: EXAMPLES OF CERVICAL CANCER SCREENING RATES AND OTHER MODALITIES IN SOME HIGH-INCOME COUNTRIES

COUNTRY	% OF WOMEN SCREENED	SCREENING AGES AND PERIOD
Canada	**74.0**[34,35]	Ages 25-69: every 3 years[36]
France	**59.0**[37]	Ages 25-29: every 3 years Ages 30-65: every 5 years[38]
Ireland	**78.7**[39]	Ages 25-29: every 3 years Ages 30-65: every 5 years[40]
The Netherlands	**54.8**[41]	Ages 30-60: every 5 years[42]
Spain	**80.0**[43]	Ages 25-34: every 3 years Ages 35-65: every 5 years[44]
United Kingdom	**69.9**[45]	Ages 25-49: every 3 years Ages 50-64: every 5 years[46]
United States	**73.5**[47]	Ages 21-29: every 3 years Ages 30-65: every 3 or 5 years, depending on test method[48]

IMPACT OF VACCINATION AND CERVICAL CANCER SCREENING IN VACCINATED COHORTS

The introduction of HPV vaccination has the potential to significantly reduce the incidence of cervical cancer. Studies have shown that HPV vaccination is highly effective in preventing infection with the oncogenic types of HPV that are most commonly associated with invasive cervical cancer.[49] In vaccinated cohorts, therefore, a reduction in the incidence of these types of HPV is expected[50] and has been demonstrated in countries with high rates of vaccination such as the UK and Sweden.[51] Vaccination rates vary significantly among high-income countries, however, and in 2019, the average coverage rate of 43 WHO Member States for a first dose in girls was just 50%.[52]

The full impact of HPV vaccination on cervical cancer incidence will be seen over decades. When combined with regular cervical cancer screening, HPV vaccination has the potential to dramatically reduce the burden of cervical cancer in future generations. However, vaccination alone is not sufficient to prevent all cases of cervical cancer, and regular screening remains critical for prevention and early detection.[53,54]

> **“Vaccination alone is not sufficient to prevent all cases of cervical cancer, and regular screening remains critical for prevention and early detection.”**

IMPACT OF FOLLOW-UP AND TREATMENT ON CERVICAL CANCER

Follow-up after a positive oncogenic (high-risk) HPV test and/or detection of abnormal cervical cell changes is of paramount importance as it allows for appropriate treatment upon indication and ongoing monitoring. It ensures that women receive the necessary interventions to manage their condition effectively and minimise the potential progression of cervical cancer.

Treatment of precancerous cervical lesions is also critical in reducing the burden of cancer and improving outcomes for affected women. Treatment options depend on the stage and severity of the precancer or cancer and may include partial cervical excision or resection, hysterectomy surgery, radiation therapy, chemotherapy, or a combination of these approaches. Early-stage invasive cervical cancer is typically more treatable than advanced-stage cancer and, once detected, treatment of precancerous cervical lesions is highly effective.[55] In the US, the five-year relative survival rate for women with early-stage cervical cancer is 91%, while the five-year survival rate for women with advanced-stage cervical cancer, when the cancer has spread to other parts of the body, is 19%, highlighting the importance of regular screening and early detection.[56]

Main Barriers to Cervical Cancer Screening Participation & Review of Underserved Populations

Despite significant advances in screening programmes, the rate of participation in cervical cancer screening varies widely between countries and regions.[57,58] Even in countries with relatively high participation rates, women who do not receive screening regularly according to national recommendations are at a higher risk of unnecessary disease and death.[59,60] It is common across countries to see inequities in screening rates, with certain populations having lower rates of participation than others. There are many reasons for low participation rates. Some women may decide not to attend screening due to cultural or personal beliefs, concerns about the procedure or outcomes, or simply the lack of awareness of the importance of screening.[61,62] Others may want to attend screening, but face barriers to access such as language, lack of transportation, insurance coverage, chronic health conditions, lack of access to screening facilities, or have caring or work responsibilities.[63]

Addressing these different challenges requires tailored approaches that take into account the specific barriers that different populations may face. It is critical to address the root causes of low participation rates to improve screening uptake.

> **“Women who do not receive screening regularly according to national recommendations are at a higher risk of unnecessary disease and death.”**

MAIN BARRIERS TO PARTICIPATION

There are many reasons why women may not get screened for cervical cancer. Some of the most commonly cited reasons include:

- Lack of awareness: Some women may not know the importance of cervical cancer screening.[64,65]
- Lack of appropriate provision of education: Some women may not understand the purpose of cervical cancer screening, recommended intervals between testing[66], or that they require cervical cancer screening after they have completed childbearing.[67,68]
- Cost due to lack of or insufficient health insurance coverage.[69]
- Cultural or religious beliefs such as modesty concerns, misconceptions, or misinformation within certain cultural or religious communities may discourage women from participating.[70]
- Lack of healthcare professional recommendation during a patient visit for another health issue.[71]
- Fear or anxiety related to actual or perceived discomfort associated with the test, or embarrassment or concerns about exposing intimate areas of the body to a healthcare professional.[72,73]
- Personal circumstances: Women may face practical barriers to attending screening due to distance, lack of transport, inconvenient clinic hours, difficulty finding a healthcare professional, or conflicting work or family commitments.[74]
- Trust or communication issues: Some women may have concerns about the trustworthiness, gender, or competence of healthcare professionals. Communication barriers, language differences, or perceived dismissiveness by healthcare professionals may also affect a woman’s decision to attend screening. There is also misunderstanding from some healthcare professionals, particularly around women with learning disabilities assuming that they do not need to be screened.[75,76,77]

- False sense of security: Women may feel healthy and therefore not believe in the need for screening. Further, women who have received HPV vaccination, which helps prevent certain types of cervical cancer, may incorrectly assume that they are fully protected and that they no longer need regular screening.[78]
- Physical disability can make it more difficult to access or attend screening. Barriers can include a lack of wheelchair access, problems getting onto the examination couch for the test and previous misunderstandings, dismissal and negative experiences of cervical cancer screening.[79,80]
- Not understanding current cervical cancer screening guidelines.[81]

UNDERSERVED POPULATIONS

There are also several underserved and/or marginalised populations that are typically under-screened for cervical cancer, and each faces unique challenges in accessing screening. For example, a review of factors [such as sociodemographic, healthcare-system, psychological, migration, knowledge, language and cultural, associated with cervical cancer screening participation among some under-screened migrant women in Europe] found that multiple barriers exist and are leading to screening participation lower than that of nationals. It demonstrates the need for healthcare services to adapt and strengthen their resources to meet the needs of all under-screened populations.[82]

The following figure presents an overview of some of the underserved groups and the specific issues they are exposed to.

FIG. 2: A SELECTION OF SPECIFIC UNDERSERVED POPULATIONS AND SOME OF THE CHALLENGES THEY FACE REGARDING PARTICIPATION IN CERVICAL CANCER SCREENING

UNDERSERVED POPULATION	CHALLENGES
Women who live in rural or remote areas	Geographical barriers to accessing screening facilities such as long distances to travel, lack of healthcare professionals conducting pelvic exams for clinician-collected screening and facilities, long clinic waits or lack of transportation. It may also be more likely that a woman personally knows their sample taker which increases embarrassment[83,84]
Women from ethnic minority or immigrant populations	Language or cultural barriers that prevent women from seeking out or accessing screening services[85]
Women from lower socioeconomic backgrounds and women without insurance or with other cost barriers	Barriers to accessing healthcare generally, e.g., financial barriers such as screening not covered by a national screening programme or lack of automatically available free healthcare, or caring and work responsibilities[86,87]
Homeless or transient women	Among others, physical and financial barriers to accessing healthcare[88,89]
Women with learning disabilities	Barriers to understanding the importance of screening and giving consent[90]
Women with mental illness	Women with a specialist diagnosis of mental illness are less likely to attend screening than women without such a disorder[91]

UNDERSERVED POPULATION	CHALLENGES
Women with physical disabilities	Healthcare setting is not wheelchair accessible, lack of equipment such as stirrups, height adjustable beds, or a hoist, lack of home visits, reported assumptions being made about sex and intimacy because of disability, with some women even being told they are not at risk of cervical cancer and that cervical cancer screening is not necessary for them[92]
Women from certain faith groups	Language, cultural or personal belief barriers that prevent women from seeking out or accessing screening services[93]
Women who have experienced sexual violence	Fear or anxiety due to experienced trauma[94,95]
Working mothers with small children, and single mothers	Practical barriers such as childcare and travel cost[96]
Obese women or women with body discomfort	Obesity/body discomfort is most likely a barrier to cervical cancer screening[97]
Menopausal or post-menopausal women	Perception that screening is not relevant anymore, fear of discomfort or pain[98]
Immigrant women fleeing a conflict	Inaccessibility of the screening service because of conflict[99]
Commercial sex workers	Prior experience of barriers to healthcare access such as poor treatment by healthcare staff, language barriers, and limited hours of operation[100]
Women living with HIV	Exposure to stigma and discrimination associated with HIV status[101,102]
LGBTQ community, transgender men and non-binary people who still have a cervix	Lack of cancer screening data and knowledge about screening guidelines by LGBTQ populations and providers, people 'forgotten' by the system as not registered as women, feelings of no need for screening, marginalisation and psychological distress, fear of homophobic reactions[103,104,105,106]

Recommendations to Increase Participation in Cervical Cancer Screening Among Under-Screened Women

There is a growing body of evidence on effective strategies to improve cervical cancer screening uptake that should be tailored to local contexts and populations and implemented through collaboration between healthcare professionals, patient and women advocates, policymakers and community organisations. The ACCESS Consensus Group has developed the following key recommendations to assist countries in increasing screening participation among under-screened women:

1 Develop cervical cancer national elimination plans with goals for elimination by a defined date, including ambitious national screening programme participation targets at the population level

Members of the Consensus Group debated the merits of setting universal targets for high-income countries with established cervical cancer screening programmes. However, given the variation between countries, including, but not limited to, differential current cervical cancer screening rates, screening modalities, set-up of national screening programmes and available resources and approaches to resource allocation, the Consensus Group does not believe a one-size-fits-all target is appropriate.

The Group recommends that each country develops a cervical cancer national elimination plan targeting elimination by a defined date. In this context, each country should model the impact of increasing screening participation, alongside other prevention interventions, and should set its own locally appropriate targets that represent ambitious yet achievable goals, enabling a significant number of lives to be saved over the coming years. Countries should furthermore conduct a scientific audit of their screening programmes to understand potential gaps that need to be addressed.

Screening targets should go beyond the headline participation rate and address other key indicators such as equity, testing approaches, screening frequency and ensuring follow-up treatment and management. Canada represents a best practice example, having set an ambition to eliminate cervical cancer by 2040.[107] Its action plan targets a headline screening participation rate of 90% of eligible individuals and an equity target of no less than 80% of eligible individuals in any identifiable group to be up to date with cervical cancer screening.

The Consensus Group expressed particular concern about the inequities in screening participation including low rates of participation among lower socio-economic groups and among certain underserved populations.[108] The ACCESS Consensus Group recommends specific targets aimed at improving cervical cancer screening participation among the most under-screened populations.

Members of the Consensus Group noted also that the prioritisation of cervical cancer in some countries followed from a prioritisation of women's health and dedicated women's health strategies, highlighting it as a best practice that countries should seek to emulate.

> **"Screening targets should go beyond the headline participation rate and address other key indicators such as equity."**

2 Implement targeted and culturally relevant education, information and awareness-raising initiatives, particularly focused on under-screened women

It is common to see lower rates of participation in cervical cancer screening among different demographic groups. Lower socio-economic groups or those with lower levels of education tend to be under-screened, as do some ethnic minorities. In the UK, for example, evidence shows that women from Black, Asian and Minority Ethnic backgrounds are less likely to attend screening than White British women. This was found to be due to a range of factors including language barriers and, for older age groups, a belief that their risk of cervical cancer was lower due to sexual inactivity.[109]

In order to address the challenge of low rates of cervical cancer screening participation among different social groups, it is essential that policymakers understand the reasons for non-attendance in their communities. If not currently available, research, including a review of existing literature, should be conducted to provide a foundation on which to build effective policy responses.

The Consensus Group stressed the role of education, information and awareness-raising initiatives in improving participation in cervical cancer screening by specifically focusing on the under-screened population. The group drew attention to a range of different approaches that have proved successful, and that decision-makers and non-governmental organisations (NGOs) should prioritise, including:

- Organising outreach programmes to under-screened populations
- Developing social media campaigns utilising social media influencers
- Supporting peer education
- Developing culturally appropriate media campaigns
- Using HPV vaccination as an opportunity to educate young women about comprehensive cervical cancer prevention, including the need for regular screening

From the results of a mass media education campaign, an Australian study reported a 27% increase in the uptake of cervical cancer screening across all socio-economic groups.[110] A 60-day quality improvement project was carried out in a clinic in the US where the majority of women attending the clinic were not properly screened for cervical cancer in 2016. Following the project, a total of 87% of women were starting to receive effective care, which consisted of same-day Well Woman Health Care Programme enrollment and a same-day Pap test or an appointment to return for a well-woman visit.[111]

For under-screened women, the Consensus Group placed a particular emphasis on targeted education and information initiatives, co-designed with the under-screened population in question. Initiatives should be adapted according to age, language, ethnicity, gender identity, and culture, and should address barriers or drivers to participation specific to each under-screened group. Additionally, women should be empowered to take control of their own health by providing them with comprehensive information about the importance of cervical cancer screening so they can make informed choices and actively participate in their own healthcare decisions.

The Consensus Group also stressed the importance of empathetic communication with women and ensuring information is simple to understand. For some populations, it is particularly important to address taboos about the female body. For example, some women report being uncomfortable talking to a male general practitioner (GP) and female sexuality may be a topic not to be discussed in some cultures, so discussion around female anatomy is often non-existent.[112] Women's reactions to abnormal Pap tests have also been studied and the results suggest there is a need for more, geographically-tailored and accurate information about cervical cancer and other HPV-related diseases, with physicians playing a major role in its provision.[113]

Case Studies

The Dutch National Institute for Public Health and the Environment (RIVM) researched non-participation rates among Turkish and Moroccan Dutch migrants, which has led to better-tailored information for this group of women such as simple infographics and video animations in different languages.[114] In spring 2023, the Dutch Cancer Society (KWF) and the Dutch Research Council (NWO) financed research that builds upon this prior study, focusing on exploring preferences for self-sampling, urine test or the original Pap test among this target group.

The "See, Test & Treat" programme of the College of American Pathologists (CAP) Foundation aims to provide comprehensive healthcare services to underserved women in the US.[115] The programme is funded by the CAP Foundation based on grant applications from pathologist-led sites. It focuses on offering free cervical and breast cancer screenings, along with immediate diagnostic results and access to follow-up care. The programme is designed to remove barriers that prevent women from receiving timely and essential healthcare services. It targets low-income, uninsured, or underinsured women who may face challenges in accessing healthcare due to financial constraints, lack of awareness, or other systemic factors. Events are held at local community health centres, hospitals, or clinics, where women receive Pap and HPV testing for cervical cancer screening, clinical breast exams, mammograms, and other necessary tests. The initiative started in 2001 and has completed 107 programmes in the period 2011-2021.

3 Improve accessibility of cervical cancer screening

Lack of accessible screening is one of the main barriers that stops women from getting screened. For instance, due to difficulties in fitting appointments around work and caring commitments. In some cases, problems can be exacerbated by over-stretched primary healthcare services including limited availability of appointments. The COVID-19 pandemic also significantly impacted access to screening services. The Consensus Group proposes several different options for improving the accessibility of cervical cancer screening:

SELF-SAMPLING

To specifically increase screening coverage among under-screened individuals, HPV self-sampling has been introduced into some high-income country screening programmes.[116]

In some countries, HPV self-sampling has been introduced not only for under-screened women, but also for the entire screening population, including individuals who have been regularly screened according to schedule, per national screening guidelines.[117,118] Performance of self-sampling for detecting CIN2+ in high-risk referral populations, and in research settings, has shown similar relative sensitivity compared to cervical cancer screening conducted by a healthcare professional (also known as clinician-collected).[119] In contrast, according to the largest, population-based, real-world study to date[120], relative detection of self-sampling for CIN2+ has been estimated as low as 76% compared to clinician-collected samples.[121,122] Given current unknowns concerning the risks to women who have previously regularly attended screening appointments who switch to self-sampling[123], such as potential lower follow-up for individuals who received positive HPV self-test results,[124,125,126] sampling by a healthcare professional should remain the preferred option for the majority of women, especially those who regularly attend clinician screening. However, for those women who do not attend cervical cancer screening appointments (e.g., habitual non-attenders), it is considered that self-sampling is undoubtedly better than no screening at all.

In the Netherlands, data from the Ministry of Health suggests that self-sampling has so far not led to a significant overall increase in screening participation. In fact, since 2013, participation rates have been on the decline.[127,128,129] While some research studies in high-risk populations point to the potential of self-sampling to improve screening participation among under-screened women[130,131], there is a recognition that further research is needed around the implementation of self-sampling in real-world settings to optimise its use as a screening option for under-screened populations.[132] Research needs include enhancing sample and workflow parameters to improve the accuracy of self-test results and identifying how to ensure successful follow-up testing after an initial positive HPV self-test.[133,134,135,136] Reducing the screening interval should also be considered as a potential mitigation for lower test accuracy.

Based on currently available evidence, the Consensus Group recommends that self-sampling should be reserved as an option for under-screened women who are habitual non-attenders whilst further research is being carried out for population-based screening and whilst implementation challenges are addressed in terms of potential disadvantages for frequently screened women switching from clinician- to self-collection approaches. This research is currently underway in the UK and Ireland.[137,138] As a pre-requisite, self-sampling products should also first be approved by regulatory authorities.

When offered, self-sampling should be given with information about its advantages and disadvantages and in combination with education about the importance of cervical cancer screening and follow-up care for women.

> **“Lack of accessible screening is one of the main barriers that stops women from getting screened, for instance, due to difficulties in fitting appointments around work and caring commitments.”**

Case Studies

In 2021, UK's NHS Cervical Screening Programme set up the study HPValidate whose results are expected in December 2023. The study involves people undertaking a self-sample as well as the usual clinician-taken sample when they attend their GP practice for cervical cancer screening. The laboratories test both the self-sample and clinician-taken sample for sensitivity and specificity. The aim of the study is to gather real-world evidence, evaluate the effectiveness of vaginal self-sampling and determine if it could be offered as an alternative option alongside the traditional clinician-taken cervical screening test.[139]

Good practice projects in assessing self-sampling implementation are observed in Canada where CervixCheck, the province of Manitoba's cervical cancer screening programme, conducted a pilot study to assess whether screening participation could be improved in unscreened women by offering a mailed HPV self-sampling kit.[140]

OPTIMISE INVITATION SYSTEM

Establishing an intentional and fit-for-purpose invitation and reminder system can prove effective in reaching women and increasing participation in cervical cancer screening for under-screened women who are engaged in the healthcare system.

Adopting technological solutions can support better accessibility and information around appointments, for example, moving towards email and text invitations and reminders.

Given that different communication preferences will exist, particularly between different age and socioeconomic groups, approaches should be tailored to the population being targeted. Looking back at the rapid uptake of digital solutions during the COVID-19 pandemic can help in adopting a mindset of urgency to invest in well-functioning technological means to deliver for women related to cervical cancer.

Case Studies

A randomised control trial run in the London borough of Hillingdon found that text message invitation reminders can help increase the number of women taking up the offer of cervical cancer screening. Text message reminders were implemented across all London boroughs between September 2018 and March 2019 and attendance increased by 4.8% over those 6 months, the equivalent of 13,400 more women being screened.[141]

In the Netherlands, a few weeks before a woman's 30th birthday, the Dutch RIVM mails a pre-invitation postal letter to announce the invitation to screening.

The Ontario Cervical Screening Program in Canada sends letters to eligible people inviting them to participate in screening by talking to their primary care physician and reminding participants when it is time for their next screening test (recall letter).[142]

TAKE SCREENING AND INFORMATION TO WOMEN

Providing non-general practitioner locations for screening (including integrating cervical cancer screening with vaccination services) with other women's health services or with sexual health services or non-traditional healthcare settings such as pop-up surgeries in community centres or workplaces should be envisaged. Providers should also consider offering cervical cancer screening appointments at varied times, including weekday evenings or weekends, as a potentially simple fix to avoid clashes with work and other commitments.

Promoting the use of targeted community outreach programmes in collaboration with charities or NGOs can help reach under-screened populations, provide education, build trust, and encourage screening participation. Co-producing outreach programmes with women the campaign is intended for, e.g. women with learning disabilities, can lead to an increase in understanding and intention to attend.[143]

Case Study

In Ireland, the health promotion team in the National Screening Service has worked in partnership with Pavee Point Traveller & Roma Centre to promote cervical screening.[144] Pavee Point is a national NGO addressing Traveller and Roma issues and promoting Traveller and Roma human rights. The partnership project engaged directly with the Traveller community to develop initiatives that are culturally sensitive, community-centred and community-led to address primary cancer prevention, early detection, and screening, as well as liaising closely with the health workers within the community. The project is enhanced by the collection of data intelligence to help understand the health needs and barriers of this community.

WORKFORCE

Workforce pressures in primary care, widely seen across countries, are making it harder for women to access appointments. In the UK, for instance, a significant reduction of screening provision at sexual health services due to staff shortages has meant fewer choices in when and where women can access screening.[145] Adequate funding and staffing of primary or obstetrics and gynaecology care is essential for improving screening uptake.

4 Support healthcare professionals to increase participation in cervical cancer screening

The Consensus Group stressed the important role that healthcare professionals have to play in encouraging and delivering a strong recommendation to their patients regarding cervical cancer screening participation. Professionals very often lack the communication skills that are required to do this and to address some of the identified barriers to screening. The Consensus Group recommends providing the following support to healthcare professionals:

I. Provide updated training and education to enable healthcare professionals to raise awareness of screening by counselling women on HPV infection and the importance of cervical cancer screening and to encourage a partnership approach between healthcare professionals and patients in cervical cancer care.

II. Provide training for sample-taker and non-sample-taker staff, including midwives in primary care practices, to improve empathy and understanding of barriers to screening, e.g. delivering trauma-informed care.[146]

III. Provide guidance to healthcare professionals on the role of innovative technologies and Artificial Intelligence (AI) to support the uptake and delivery of screening programmes.

IV. Develop clear pathways and best practice guidance for working with a patient who has additional requirements or needs onward referral (e.g. cannot be screened by a GP because of a physical disability).

V. Ensure there are financial incentives in place for healthcare professionals, such as performance measures like screening coverage targets, and at the very least ensure that financial disincentives are removed.

VI. Provide sufficient resources for the training of healthcare professionals, considering advances in digital technology such as by offering continued professional development webinars.

Case Studies

Ontario Health (Cancer Care Ontario) provided guidance in the form of tip sheets to primary care providers and colposcopists to support the screening participation in eligible populations during the COVID-19 pandemic.[147,148] Ontario Health works with Regional Cancer Programs to educate primary care and colposcopy providers on cervical cancer screening recommendations (e.g. screening summary tool, stock decks). Regional Cervical Screening and Colposcopy Leads and Regional Primary Care Leads provide expertise and education to healthcare providers in each region to support screening participation.[149]

In Spain, extensive use has been made of e-learning courses that provide up-to-date information on cervical cancer screening and vaccination. Targeted editions of the courses have addressed different groups of healthcare professionals with involvement in preventive practices such as screening programmes, gynaecology, paediatrics, GP and public health practices. There is also high circulation of a weekly e-newsletter (HPV World[150]) with concise results and recommendations from the research and public health fields.

As part of sample taker training and education in Ireland, the Screening Training Unit has developed a series of training events aimed at addressing learning and training needs of sample takers in increasing participation in cervical cancer screening. Topics covered have included increasing participation in cervical cancer screening from a primary care perspective, working with women with intellectual disabilities, assessing barriers and best practice in providing cervical cancer screening to autistic people, supporting the Trans community to participate in cervical cancer screening, LGBT+ awareness for cervical cancer screening, consent, menopause, HPV vaccination and others. These learning opportunities have provided the space for sample takers to reflect on how they can implement good practice to support different communities in accessing cervical cancer screening.[151]

In the UK, Pay for Performance (P4P) schemes such as the Quality and Outcomes Framework (QOF) support GPs who are granted payments representing up to 20% of their income for compliance with target indicators set across the spectrum of clinical activity.[152]

5 Encourage and support the creation of national cervical cancer patient advocacy groups and national cervical cancer prevention coalitions

The group noted that there are very few regional or national patient advocacy groups and disease prevention coalitions that are dedicated to, or prioritise, female cancers such as cervical cancer and cervical cancer prevention. Where they do exist, they play a valuable role in education and awareness-raising around cancer prevention as well as supporting patients with cervical cancer. Policymakers should look to support the development of cervical cancer patient advocacy organisations, cervical cancer prevention coalitions and educational initiatives as well as allocating increased funding to charitable organisations specifically supporting women and girls.[153] See Fig. 3 in the Annex below for an overview of some of the patient advocacy groups supporting women undergoing cervical cancer screening.

6 Ensure that health insurance appropriately covers screening in all high-income countries

In contrast to most other high-income countries, the US does not have a national cervical cancer screening programme in place that covers the costs of screening. The Consensus Group highlighted that health insurance policies in all countries should cover all available screening options and programmes that provide access to cervical cancer screening to those who do not have health insurance should be available.

Examples of Country Best Practices

SPAIN - FOSTERING MODERN COMMUNICATION STRATEGIES

The Catalan Institute of Oncology (ICO) has invested significant efforts to create modern communication strategies to update healthcare professionals on the novel options for cervical cancer prevention such as via the Cervical Cancer and HPV Programme of e-oncologia.[154] These materials are being translated into other languages and the platforms are open to collaborate with any interested preventive programme.

FRANCE - EDUCATIONAL EFFORTS OF PATIENT ORGANISATIONS REACHING WOMEN

The French patient association "1000femmes1000vies" developed an information leaflet entitled "Cervical cancer, Pre-cancer and Papillomavirus infections: why, how and for whom?" to educate women about key facts and figures surrounding cervical cancer and what one can do to prevent it, including highlighting the importance of screening.[155]

IRELAND - NATIONAL ROADMAP TO ELIMINATE CERVICAL CANCER AND NATIONAL STRATEGIC FRAMEWORK TO ADDRESS EQUITY IN SCREENING

Ireland's roadmap to eliminate cervical cancer was published in January 2023.[156] In early 2022, different national authorities established a working group with academics in Australia to develop a model to work towards cervical cancer elimination in Ireland and set Ireland's specific target date to reach this goal. This involves using Irish data, for example, on screening and HPV vaccine uptake, to tailor the model for the Irish population and allow Ireland to set a target date for the elimination of cervical cancer. The outcome will be made public later in 2023.[157]

The National Screening Service in Ireland is also currently developing a Strategic Framework to improve equity in screening for cervical, bowel and breast cancer.[158] The framework, which aims at the population understanding what screening is and being able to participate in screening if they want to, is currently in consultation phase and will be published in 2023. It envisages helping those with the highest risk of poor health, who would benefit most from screening but are often the least likely to participate for various reasons. Addressing the many unfair barriers that can prevent people from engaging with the available screening services is of primary concern.

GLOBAL/IRELAND - COLLABORATING INTERNATIONALLY TO DEVELOP BEST PRACTICES IN CERVICAL CANCER SCREENING

The International Agency for Research on Cancer (IARC), in collaboration with the Department of Health and the Health Service Executive of Ireland, developed a recommendations report on best practices in cervical cancer screening programmes to address global issues relating to the quality and coverage of cervical cancer screening programmes.[159] Best practices were identified in the areas of:

- Conducting cancer audits in cervical cancer screening programmes.
- Establishing legal and ethical frameworks to safeguard the interests of screening participants, health professionals, and programme managers associated with cervical cancer screening.
- Developing a strategy for effective and transparent communication with target populations and other stakeholders about the benefits, risks, and limitations of cervical cancer screening.
- Establishing a framework for developing workforce competencies in communication.

CANADA - NATIONAL TARGET-BASED ACTION PLAN TO ELIMINATE CERVICAL CANCER

The Canadian Partnership Against Cancer coordinated efforts with a broad group of partners, experts and stakeholders, including the Public Health Agency of Canada, as well as First Nations, Inuit and Métis organisations and patients to create the Action Plan to Eliminate Cervical Cancer in Canada, 2020-2030. The Plan includes concrete priorities, targets and actions, engaging partners across the country in work to eliminate cervical cancer in Canada by 2040.[160]

UK - YOUSCREEN

In 2021, NHS England launched the YouScreen study, trialling HPV self-sampling in more than 31,000 women in London who were 15 months overdue for their cervical cancer screening.[161] As part of the trial, women were able to access a video explaining how to carry out the test at home. General practitioners, practice nurses and healthcare assistants were also able to offer YouScreen kits opportunistically to women overdue for their tests. The study aims to find out the best way to offer HPV self-sampling to women who have not responded to their invitation and is the first study of self-sampling in the UK. Study results are yet to be published. Being led by both GPs and gynaecologist-oncologists, the study also serves as a good practice example for interdisciplinary collaboration.

Conclusion

CONCLUSION

This White Paper has highlighted many actions that can be undertaken to increase participation in cervical cancer screening and reduce the impact of cervical cancer on women. International collaboration between experts should be intensified to allow for more frequent and much-needed knowledge exchange and best-practice sharing. Policymakers and health authorities should urgently consider the highest-impact interventions for their local context to address the devastating impact of cervical cancer and reduce the health inequalities that it creates. The ACCESS Consensus Group looks forward to partnering with stakeholders who share this critical mission.

METHODOLOGY AND DATA COLLECTION

Members of the Consensus Group were initially asked to provide their views on the content of the White Paper via an online survey. The secretariat of the Consensus Group then produced the first draft of the White Paper based on members' feedback and additional desk research. Members of the Consensus Group contributed further to the content by providing written comments to the secretariat. Virtual meetings were also held to inform the content of the paper and discuss and debate the Group's recommendations. An interview was held with one external expert to gather additional insights on cervical cancer elimination modelling and screening targets. Where there were differences of opinion within the Group, the Co-Chairs guided the recommendations based on the majority view and their own expert judgement. All members of the group reviewed and approved the content of this White Paper.

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Annexe

FIG. 3: EXAMPLES OF PATIENT ADVOCACY GROUPS AND OTHER ORGANISATIONS SUPPORTING WOMEN UNDERGOING CERVICAL CANCER SCREENING

ORGANISATION	COUNTRY	NUMBER OF EMPLOYEES/ ADVOCATES	DESCRIPTION/ SPECIAL FEATURE
Jo's Cervical Cancer Trust	UK	30-40	UK's only charity dedicated to those affected by cervical cancer and cervical abnormalities.
UK Cervical Cancer	UK	<10	Dedicated to raising awareness for cervical cancer detection and prevention in both the UK and developing countries.
The Eve Appeal	UK	20-30	Funds research and raises awareness for five gynaecological cancers - womb, ovarian, cervical, vulval and vaginal.
Stichting Olijf	Netherlands	<10	Buddy system where women who have experience with cancer guide women through the process of the disease.
Women INC.	Netherlands	20-30	NGO working on gender equality - advocates for equality of opportunity/women's workplace rights.
KWF Kankerbestrijding	Netherlands	~200	Supports cancer research, and the rapid introduction of new treatments into the market.
1000 femmes 1000 vies	France	40-50	Organisation dedicated to the eradication of cervical cancer, with a focus on prevention and early detection, including screening.
Imagyn	France	20-30	Committed to raising awareness, advancing research, and providing support to gynaecological cancer patients.
La Ligue Contre le Cancer	France	<10	A one-stop-shop non-profit organisation for cancer patients in France, offering information, support, and links to valuable resources.
Demain Sans HPV	France	10 associations	An initiative bringing together all patient and prevention associations involved in the prevention of diseases related to HPV. It provides information on screening and genetic risks, engages in fundraising for research and organises solidarity projects aimed at bringing together individuals affected by the disease.
GynCancer Förbundet	Sweden	<10	Support/lobby group for women fighting gynaecological cancers.
Nätverket mot Gynekologisk Cancer	Sweden	10	Patient group for women suffering from gynaecological cancers.
Nätverket mot Cancer	Sweden	<10	Network of 11 cancer-specific patient organisations, dedicated to advancing research and treatment.

ORGANISATION	COUNTRY	NUMBER OF EMPLOYEES/ ADVOCATES	DESCRIPTION/ SPECIAL FEATURE
ASACO: Asociación de Afectados por Cáncer de Ovario	Spain	<10	Non-profit organisation of women affected by ovarian and gynaecological cancer, their family members or carers and health professionals. The first association in Spain that includes patients of these oncological diseases and their relatives.
Asociación Española Contra el Cáncer	Spain	500+	Interest group for cancer patients promoting research, prevention and improved quality of care.
Marie Keating Foundation	Ireland	10-20	Mobile information units visiting schools, workplaces, colleges and community centres and giving presentations/information on cervical cancer and cervical cancer screening. School Cancer Awareness Program (CAP) covering cervical cancer and HPV vaccination.
Irish Cancer Society	Ireland	~200	A community of patients, survivors, volunteers, supporters, health and social care professionals and researchers working to save lives and improve the lives of people affected by all cancers in Ireland.
KIU - Kræft i Underlivet	Denmark	15	An association of volunteers with current or prior experience of a women's cancer supporting women's cancer patients and survivors.
ENGAGe: European Network of Gynaecological Cancer Advocacy Groups	Europe	75+ networks	Network of European patient advocacy groups representing all gynaecological cancers.
TogetHER for Health	US	<10	Promoting advances in HPV vaccination and screening.
Cervivor	US	<10	Global community of patient advocates who inspire and empower those affected by cervical cancer by educating and motivating them to use their voices for creating awareness to end stigma, influence decision and change, and end cervical cancer.
National Cervical Cancer Coalition	US	100+	An organisation associated with the American Sexual Health Association advocating for cervical health in all women by promoting prevention through education about early vaccination and regular screening.
HPV Global Action	Canada	30-40	Charity foundation dedicated to sexual and reproductive health education, and prevention of HPV transmission.

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CONTACT
secretariat@accesscg.org

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