

Updated  
November 2019

# Women Engage!

## Living with HIV and Cervical Cancer

A guide to our involvement in its Prevention, Screening and Early Diagnosis, Treatment and Research





Beyond HIV and AIDS



ZIMBABWE



"Determined to END AIDS"



ATHENA INITIATIVE



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ICW Latina



Comunidad Internacional de Mujeres viviendo con VIH SIDA

ICWM



INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV MALAWI

ICWWA



INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV WEST AFRICA

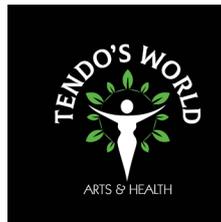


TANZANIA AIDS FORUM

JCW+



Jamaica Community of Positive Women



FPADHIV #PositiveAffirmationDay 2nd December #PAD2017



Salamander Trust ON THE RIGHT(S) TRACK



STOP AIDS.



## PREFACE TO 2nd EDITION, NOVEMBER 2019

Since publishing this paper, we highlight specific key milestones toward the World Health Assembly, where the [WHO 2020-2030 global strategy](#) will be ratified with clear goals and targets to control cervical cancer:

a) The regional consultations including the [AFRO consultation in Brazzaville](#) have been positive. The global response is now being fed into preparations for the WHO Executive Board in January 2020, where a draft resolution text will accompany the draft strategy.

b) Also new is the WHO guideline on [improving data for decision-making: a toolkit for cervical cancer prevention and control programmes](#).

This should soon be available in French and Spanish also.

c) In addition, new guidance on thermal ablation of pre-cancerous lesions identified through screening has now been published: <https://www.who.int/reproductivehealth/publications/thermal-ablation-for-cervical-pre-cancer-lesions/en/>

d) Keep a look out for:

- programme guidance for introducing HPV testing, which should be published soon.

As women engage at the national level, now is the time to ensure that National Strategic Plans (NSPs) that are being reviewed include responses to cervical cancer.

Let's continue to urge our governments to make public commitments to control cervical cancer; and for governments to sponsor the resolution to the WHO draft strategy.

The financial contribution of UNAIDS towards this policy brief is gratefully acknowledged. However, its content and ideas expressed therein do not necessarily reflect the views and opinions of UNAIDS or engage the responsibility of UNAIDS.

*The creation of this booklet was funded by UNAIDS. All perspectives in it, unless otherwise stated, belong to the women in all our diversity who contributed to it. Special thanks to key technical contributions from UNAIDS, WHO, UICC especially.*

*We acknowledge and thank all those who supported the development of this document and, in turn, support our voice. In addition to all the named logos we also thank those who signed this in their own capacity: Florence Riako Anam (Kenya / S Africa); Fungai Murau (Zimbabwe / UK); Jane Shepherd (UK); Joan Chamungu Msuya (Tanzania); Liz Tremlett (UK); Patricia Asero Ochieng (Kenya); and Sophie Strachan (UK).*

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The documents illustrated on the front cover are: a) HPV, HIV and Cervical Cancer - Leveraging synergies to save women's lives. UNAIDS. 2016; b) Consolidated guideline on sexual and reproductive health and rights of women living with HIV. Geneva: World Health Organization; 2017. c) HPV vaccine communication. Special considerations for a unique vaccine: 2016 update. Geneva: World Health Organization; 2017. d) Comprehensive cervical cancer prevention and control: a healthier future for girls and women. WHO Guidance Note. World Health Organization. 2013. e) Scaling-up HPV vaccine introduction. World Health Organization. 2016. and f) Comprehensive Cervical Cancer Control: A guide to essential practice, 2nd edition, WHO. 2014.

A blue silhouette of a woman with curly hair, wearing a tank top and pants, shouting into a megaphone. The background is a light blue gradient with abstract blue shapes at the top.

## Key Messages

All women, irrespective of our HIV status, our age, race, ethnicity, where we live, livelihood, disability or economic status, our key population status as women who use drugs or as sex workers, our sexual orientation, and many other factors, have the right to access essential and life-saving healthcare. This is embedded in numerous human rights agreements including the right to the highest attainable standard of health, to life, privacy, to scientific progress, to be free from discrimination and gender inequality.

Women living with HIV are four to five times more likely to develop cervical cancer than women who are not living with HIV.<sup>1</sup> Many women are experiencing huge challenges and dying a painful and often lonely death. HIV and cervical cancer intersect and disproportionately affect women especially in lower- and middle-income countries (LMICs)<sup>2</sup> due to the fact that cervical cancer is detected too late and women lack access to screening and treatment. CERVICAL CANCER IS PREVENTABLE BUT IT WILL TAKE MORE THAN A BIOMEDICAL APPROACH.<sup>3</sup>

Screening, with a simple local treatment of any precancerous lesions, can support up to 80% of women in avoiding their HPV advancing to cervical cancer.<sup>4</sup> Early initiation of ART and maintaining adherence is also likely to reduce incidence and progression of precancerous abnormal cells and ultimately incidence of invasive cervical cancer.<sup>5</sup> Even though we do not have specific data for women living with HIV, it is thought that even a single smear after the age of 30 in a woman's lifetime can make a big difference. This is especially important for women living with HIV.<sup>6</sup>

Vaccines greatly reduce the risk of cervical cancer.<sup>7</sup> To be effective, the vaccines have to be administered before HPV enters the body and are therefore recommended at age 9-14, before most girls start having sex. Currently not enough vaccines are produced to meet the growing demand. The overall costs make financing vaccination of girls a challenge particularly in lower income countries. We believe that all girls and boys should be vaccinated when enough doses become available and affordable for all.

Dimensions of intersectionality are important in any response to cervical cancer and include, but are not limited to, our age, race, ethnicity, disability, poverty, where we live, our key population status as women who use drugs and female sex workers, sexual orientation and identity, livelihood, economic status, the way society and law regulate and criminalise our behaviour, and many other variables, including violence against us. All of these different aspects can also make women more vulnerable to cervical cancer.

We also know that investment must focus on prevention and early detection of precancers and cervical cancer at early stage of disease. We call for a holistic collaborative approach to the issue and to ensure that this is part of a package of care that all women living with HIV in all our diversity have access to.

**The recommendations in here are important – Please act on them! (Pg. 14-23)**

# Introduction

All women, irrespective of our HIV status, our age, race, ethnicity, where we live, livelihood, disability or economic status, our key population status as women who use drugs or as sex workers, our sexual orientation, and many other factors, have the right to access essential and life-saving healthcare. This is embedded in numerous human rights agreements including the right to the highest attainable standard of health, to life, privacy, to scientific progress, to be free from discrimination and gender inequality.

## **Cervical Cancer is preventable but it will take more than a biomedical approach.<sup>3</sup>**

Some of us have no access to healthcare because of our economic disparity, some of us are received and treated badly by service providers, and some of us are faced with society and law regulation that criminalise our behaviour. All of these structural barriers define our ability to access services.<sup>8</sup> Much is required to address these disparities in how we are able to attain health. This includes reducing poverty, elevating the status of women, and addressing social, cultural and legal barriers to our health access. Current realities cannot be overlooked or ignored when formulating effective and ethical healthcare responses to prevent and treat cervical cancer.

A critical component of the right to health as it relates to cervical cancer requires that governments ensure access to prevention (vaccines and screening services) and treatment. Practices which directly or indirectly affect our choices, including barriers to treatment and services, undermine human rights and have grave consequences, not only for mental and physical health but in all spheres of our lives. Addressing all of this, including cervical cancer, is part of the 2030 Agenda for Sustainable Development Goals.

570,000 women diagnosed with cervical cancer in 2018 and approximately 90% of 311,000 cervical cancer related deaths occurred in low- and middle-income countries (WHO). If nothing is done, new cases of cervical cancer are expected to rise to 720,415 and deaths will rise to 394,905 per year by 2025 [HPV and Related Cancers in the Global Alliance for Vaccines and Immunization \(GAVI\) Countries. A WHO/ICO HPV Information Centre Report 2012.](#)

Many women are experiencing huge challenges and dying a painful and often lonely death. This is especially true in lower- and middle-income countries (LMICs) due to the fact that cervical cancer is detected too late and women lack access to screening and treatment. In high-income countries (such as Canada and the USA) age-standardised cervical cancer rates are relatively low (less than 7.3 per 100,000 women) due to common large-scale, cervical cancer screening.<sup>9</sup> By comparison, in sub-Saharan Africa (eg Malawi and Zimbabwe are over 60 per 100,000 women) and Central and South America (eg Guyana and Bolivia), regular screening is uncommon and incidence rates are especially high (exceeding 30 per 100,000 women).<sup>9</sup>

This advocacy booklet is about cervical cancer and why it is a huge concern for women living with HIV in all our diversity or anyone who is working with or supporting us. It is written by and designed primarily for women living with HIV and those who seek to support us.

## \*What do we mean by 'in all our diversity'?

When we refer to women living with HIV in all our diversity we acknowledge that we include: heterosexual women, women who are lesbian, bisexual, transgender men, women who use drugs; sex workers; adolescent girls and young women; women who are currently or have previously been incarcerated, detained or are homeless; women who are economic or political migrants; women who are Indigenous; and women living with disabilities. Nb we recognise that, since the cervix is the neck of the womb, girls and women who may have been born without a womb, women who have had a total hysterectomy (which means removal of the womb and cervix)<sup>10</sup>, and/or trans women may not find this brief directly relevant to themselves.

We know all too well that cervical cancer incidence overlaps with HIV. Women living with HIV are four to five times more likely to develop cervical cancer than women who are not living with HIV.<sup>11</sup> Once we have Human Papilloma Virus (HPV) (a key cause of cervical cancer) we are more likely to develop pre-invasive lesions that can quickly progress into invasive, life-threatening cervical cancer, if untreated.<sup>12</sup> As women living with HIV on treatment live longer, we are seeing more women living with HIV develop cervical cancer.<sup>5</sup>

*"I was screened in the public system the result takes a year to come. It comes back inconclusive 2 more test was positive. Poor treatment judgment leave me fighting for my life. I was given health care but not adequate care, because of my HIV status."* L Dunn, Community facilitator, contributing to [cervical cancer webinar](#).

Cervical cancer prevention, early diagnosis, treatment and palliative care are all recommended priority health interventions, based on cost-effectiveness in the WHO global action plan on noncommunicable diseases.<sup>13</sup>

This call to action explains key facts around cervical cancer to ensure that women living with HIV in all our diversity\* understand what is required to protect ourselves, what the global response has been and what opportunities exist to ensure our leadership and engagement.

This booklet also explores why this is important to us as individuals and community advocates and what we require from the UN; from other partners investing in cervical cancer prevention and treatment services; and from governments who respond at national levels.

"This situation can be addressed if existing prevention and control interventions were made universally available. Tackling cervical cancer will contribute to reaching the 2030 Agenda for Sustainable Development Goals to:

- End poverty in all its forms everywhere;
- Ensure healthy lives and promoting well-being for all at all ages;
- Ensure inclusive and equitable quality education and promotion of life long opportunities for all;
- Achieve gender equity and empowerment for all women and girls; and
- Reduce inequality within and among countries."

[Background paper or the Partners Meeting to Scale up Cervical Cancer Prevention and Control Through a New UN Global Joint Programme to end cervical cancer](#)

We recognise that, as women living with HIV, in all our diversity, we also have a responsibility to ensure we are aware of our own health. We also, where possible, need to collectively organise and call for services fit for purpose. And to raise the alarm where they are still not available or where we are not able to access essential services because of existing barriers.

# Understanding the Science

**What do we know:** Cervical cancer is almost always caused by the HPV and is preventable and treatable if detected early.<sup>14</sup> It is for this reason that HPV vaccination and screening for HPV are essential pillars to a comprehensive prevention approach. There are many strains or types of HPV, which are transmitted in different ways. HPV is common, especially among those who are sexually active and HPV carriage rates are highest amongst young women.<sup>15</sup> HPV type 16 and 18 are the dominant drivers of cervical cancer.

“Genital HPV is spread easily through skin-to-skin contact during vaginal or anal sex with someone who has the infection. HPV can be spread between sexual partners without a penis in a partner’s vagina, anus or throat. It can also be spread between women through skin-to-skin contact. Condoms and other latex barriers do not totally prevent transmission. Most people with HPV do not know they have it because they do not develop symptoms, yet they can still pass it on to someone else.”

“Certain types of HPV can cause warts on the hands, feet, mouth, or throat. About 30 to 40 types can cause infections in the genital area (the vulva, vagina, penis, buttocks, scrotum, and anus). The types of HPV that can cause genital warts are not the same as the types that can cause cancer. However, if you have warts, you may have also been exposed to the types of HPV that can cause cancer.” [The Well Project](#)

Many people’s bodies naturally recover from HPV. However, this is less common for women and men with compromised immune systems. Women living with HIV are more likely to develop pre-invasive lesions that can, if left untreated, more quickly progress to invasive, life-threatening cervical cancer.<sup>16</sup> Cervical cancer is often the final stage of untreated HPV.

## What does ‘screening’ mean?

The word ‘screen/screening’ in the context of cancer is often used to describe a process of checking to find if someone has precancerous changes of cells which, if untreated, can lead to cancer. If a screen finds abnormalities then follow-up appointments, and possibly treatment too, are essential, to prevent cancer or to treat it – preferably at an early stage.<sup>18, 19</sup>

Over time, HPV can affect the lining of the cervix (the neck of the womb) and the cells become precancerous. This can be a long process over several years and can also reverse itself. Once the lesion becomes cancerous, it can grow and spread around the body, which makes it more difficult and expensive to treat, so the emphasis has been on early diagnosis during precancerous stages. For this reason, it is essential for women living with HIV to be offered and encouraged to screen regularly. This screening, with a simple local treatment of any precancerous lesions, can support up to 80% of women in avoiding their HPV advancing to cervical cancer. Early initiation of ART and maintaining adherence is also likely to reduce incidence and progression of precancerous abnormal cells and ultimately incidence of invasive cervical cancer.<sup>17</sup>

**Important terms:** HPV can cause abnormal cells to form. This is called dysplasia and at this stage the cells are described as precancerous cells. Squamous Intraepithelial Lesion (SIL) refers to abnormal growth of squamous cells on the surface of the cervix. This is further characterised by cervical intraepithelial neoplasia (CIN) which has three precancerous grades depending on severity: CIN 1, CIN 2 and CIN 3 as shown in Figure 1.

**Vaccines:** There are effective preventative vaccines that protect against the types of HPV that cause cervical cancers. These vaccines greatly reduce the risk of cervical cancer.<sup>6</sup> To be most

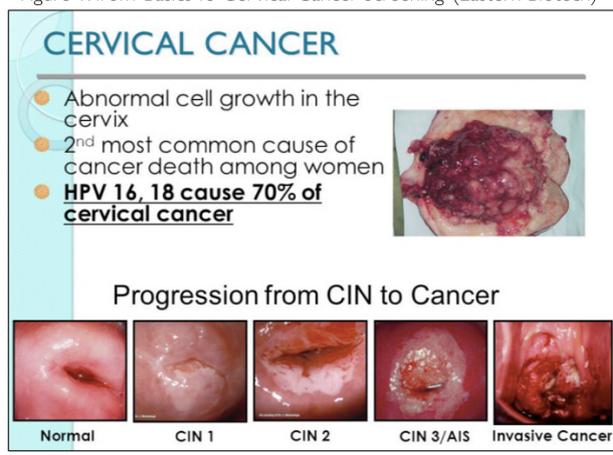
effective, the vaccines are best administered before HPV enters the body and are therefore recommended at age 9-14, when most girls have not yet started having sex. The HPV vaccines protect especially against HPV 16 and 18, which together cause 70% of the cervical cancers. Vaccines can prevent 70-90% of all cervical cancers. The impact and benefit from vaccination will only be demonstrated in a reduction of cervical cancer deaths decades from now, when girls currently being vaccinated have grown older. However, the affordability of vaccine for all girls globally is a challenge and now that the demand for vaccination has increased, there are simply not enough vaccines being produced globally to fill the need.

**‘What about boys?’** Many people ask whether it would not be fairer for all boys to be vaccinated as well as all girls, to protect them too, and to make it clear that sexual health is the responsibility of everyone in society, not just girls and women. If vaccinated, boys (and girls) can be protected from several HPV-related genital and oral cancers<sup>i</sup>. (Some countries have started HPV vaccine programmes for men who have sex with men because of this). However, on a Salamander Trust webinar (with support from UNAIDS), UNAIDS and WHO highlighted that globally 85% of all HPV-related cancers are cervical cancers, justifying this as the health priority especially for lower income settings. It was further explained that high coverage of the vaccine in girls (>80%) will induce a strong herd<sup>ii</sup> immunity that also protects boys and unvaccinated girls. Currently not enough vaccine doses are being produced annually for all girls to have access and the overall costs makes vaccination of girls, and boys an economic challenge in all but the most affluent countries. We believe that all girls and boys should be vaccinated when enough doses become available and affordable for all.

i To learn more about HPV-related oral cancer, which is beyond the scope of this booklet, click [here](#).

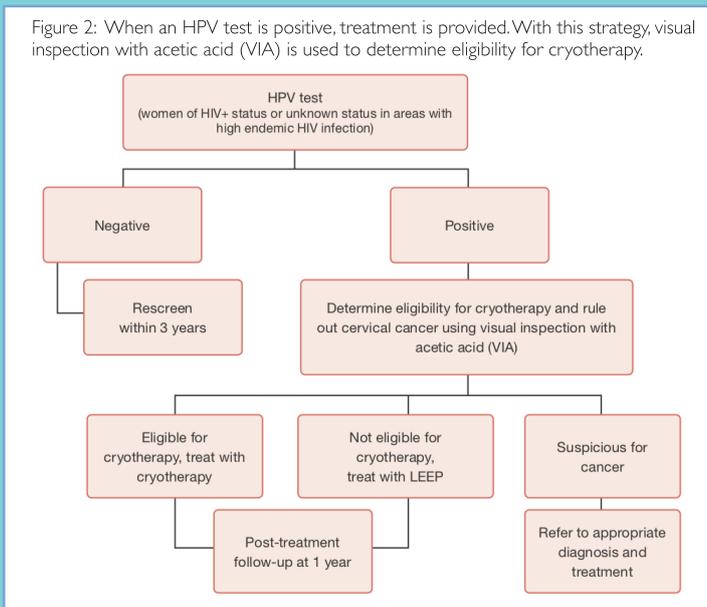
ii To know more about herd immunity, visit this site <http://vk.ovg.ox.ac.uk/herd-immunity>

Figure 1: from ‘Basics To Cervical Cancer Screening’ (Eastern Biotech)



**Methods of screening:** Each country implements its own national guidelines based on Guidelines developed by WHO. In this case WHO has three key documents. These are the 2017 WHO Consolidated guideline on the SRHR of women living with HIV; the [WHO Guidelines for screening and treatment of precancerous lesions for cervical cancer prevention](#) (2013) and the [2014 WHO publication Comprehensive cervical cancer control: a guide to essential practice](#).

For women living with HIV or women whose HIV status is unknown and living in areas with high endemic HIV, the following should be noted. The evidence about screening and treatment to prevent cervical cancer is of lower quality for women living with HIV than for women who are HIV-negative or of unknown HIV status. However sexually active girls and women should have cervical cancer screening as soon as they are diagnosed with HIV. In other instances, WHO recommends that screening should ideally be offered to women of 30 years of age or older. The image in Figure two is just one taken from the WHO Guidelines for screening and treatment of precancerous lesions for cervical cancer prevention (2013). It recommends that women living with HIV who test HPV negative only have to repeat the HPV test every three years. There are a number of different algorithms presented in the guidance – e.g. there are others with VIA triage, and starting with VIA rather than the HPV test. Please refer to this document for more options. It further states the following:



“The recommendations in this guideline apply to women 30 years of age (recommended age to start screening) and older because of their higher risk of cervical cancer. However, the magnitude of the net benefit will differ among age groups and may extend to younger and older women depending on their baseline risk of CIN2+. Priority should be given to screening women aged 30–49 years, rather than maximizing the number of screening tests in a woman’s lifetime. Screening even once in a lifetime would be beneficial. Screening intervals may depend on financial, infrastructural, and other resources. For women of HIV-positive status, or of unknown HIV status in areas with high endemic HIV infection, the following should be noted. **Although the evidence about screening and treatment to prevent cervical cancer is of lower quality for women who are HIV-positive than for women who are HIV-negative or of unknown HIV status, cervical cancer screening should be done in sexually active girls and women, as soon as a woman or a girl has tested positive for HIV.**”

The 2013 WHO guidelines state that general screening every three years is important. It also states that women who have any kind of treatment should receive post-treatment follow-up screening at one year to ensure effectiveness of treatment. As noted above, for women living with HIV or those whose status is unknown, in areas with high endemic HIV, if the screening test is negative, the screening interval for repeat screening should be within three years.

Different methods of screening for changes of the cervix exist and include:

- **Pap smears** are the most well-established method in high income settings. Due to the high reliance on expert readings in the laboratory and repeated reminders to the public, this is not a feasible approach, in many parts of the world. A speculum is inserted into the vagina; a smear is taken and transferred to a slide. This is then sent to a laboratory and reviewed and interpreted by a qualified technician, looking specifically for cervical changes or cancerous cells. This method works well but the service is expensive and not widely available, or of poor quality or not accessible in many LMICs.

- **Visual Inspection with Acetic Acid (VIA)** is a simple method using a clear acid to enhance a visual check for the small changes in the cervix. This requires an internal examination by trained personnel, who can provide a private space. A speculum is inserted into the vagina; the healthcare provider swabs vinegar (acetic acid), on the cervix and looks for areas that change colour. VIA with immediate treatment is a proven screening method especially in low-resource settings. It works well in situations where Pap smears and HPV tests are not available, due to a lack of a skilled health workforce or high per-test cost. Screening and treatment of pre-cancers can all be taught easily and can be done in one visit but, as with the PAP smears, quality control is important. Currently, this is the mostly widely used way to screen for precancers.
- **HPV nucleic acid detection** (to detect DNA and RNA tests in HPV). This test is more accurate as it detects the actual virus itself rather than changes in cells on the cervix. A pelvic examination can be avoided as the woman herself can take the sample of cells from the cervix, using a self-administered vaginal swab that has to be returned and processed in a laboratory. Although these 'self-sample' test kits are not yet widely available, they are becoming more available and cheaper. If the HPV test is positive, then the woman should be encouraged to return to the clinic for a speculum exam which will determine treatment and/or referral. If the test shows no HPV then the woman does not need to repeat the test for another three years.

#### **Cervical Cancer Screening in Malaysia, program ROSE - Removing Obstacles to Cervical Screening**

*The ROSE team in Malaysia designed a locally adapted screening program that addresses women's concerns: fear of pain, embarrassment, inconvenience and negative perception on any benefits by harnessing best practice. Using a simple self-sampling kit, women now provide a sample in privacy and register for an app-based test result and follow up with the health care team in minutes. ROSE also reduces the health facility work load and brings cost efficiencies while providing women with access to the state-of-the-art test and rapid follow up when needed. "We are of course very happy with the news that that 99% of women would use ROSE again and 94% would recommend ROSE to a friend. In particular, I am amazed at the follow up, proving the impact this new service will have on cervical cancer" says Professor Yin Ling Woo, lead of the program, "looking at the small percentage of women that get the news that they have a positive test only 4.99% in our assessment of 4188 women, we are reaching over 90% of women with positive tests and look to retain this acceptance and follow up rates as we scale up nationally". For more information click [here](#)*

*"This report from Malaysia and other examples of taking advantage of great e-health tools such as this one in [Zambia](#), show how knowledge about cervical cancer services and the ability to engage and access them will be improving in the coming years. This is both an opportunity for the younger generation to get involved and make sure these new approaches are as good as they can be, as well as encouragement for women to be empowered by these new tools to take control of their own health" says Julie Torode, Director of Special Projects at The Union For The International Cancer Control (UICC).*

**Even a single screening test after the age of 30 in a woman's lifetime can make a big difference. Even though there is no data to back this up, some believe that this is especially important for women living with HIV.<sup>7</sup>**

*Cervical cancer is the leading cause of cancer related morbidity and mortality for women in Tanzania. The Tanzania Network of Women Living with HIV (TNW+) have been building awareness of cervical cancer screening amongst women living with HIV since 2014. Phase 1 of TNW+'s work was supported by Pink Ribbon Red Ribbon through UNAIDS with technical support from the Tanzania Health Promotion Service. The objective was to build knowledge capacity of peer educators on cervical cancer prevention. Phase 2, which ended September 2018 was to reach 70% of women living with HIV in 10 districts (9752 women). TNW+ has 60 women living with HIV trained as facilitators who have reached 30 out of 189 districts in Tanzania. RESULTS: 17,018 women received information; 13,104 women were screened, and 475 women received treatment with cryotherapy; 12 women received Leep services and approximately 83 women were referred to the cervical cancer Ocean Road Cancer Institute, Dar es Salaam for follow up. "Meaningful involvement of local leaders made our work successful and a large number of women were reached by women living with HIV ourselves." Joan Chamungu, Executive Director TNW+.*

# Cervical Cancer Affects Our Socio-Economic Lives

Women living with HIV, especially those of us with compromised immune systems, are up to five times more likely to develop cervical cancer than women who do not have HIV.

HIV and cervical cancer intersect and disproportionately affect women in LMICs.<sup>2</sup> For example, women living with HIV in South Africa have 10 times higher cervical cancer rates than in the general population.<sup>20</sup> Other dimensions of intersectionality include, but are not limited to our age, race, ethnicity, disability, poverty, where we live, our key population status as women who use drugs and female sex workers, sexual orientation, livelihood, economic status, the way society and law regulate and criminalise our behaviour, and many other variables, including violence against us.

This is why we keep talking about ourselves as women living with HIV in all our diversity. These are key factors to be taken into consideration in an effective and ethical response to cervical cancer prevention and treatment.<sup>21,22</sup> All of these different aspects can also make women more vulnerable to cervical cancer, in higher income countries. For example, in one study researchers found that a woman's risk of dying in the USA is higher than previously believed, due to errors in calculations such as inclusion of women with hysterectomies or women over the age of 65, a typical cut-off-point for screening services. The paper pointed to disparities within the population also, stating that "black women in the United States are dying from cervical cancer at a rate 77 percent higher than previously thought while white women are dying at a rate 47 percent higher than previously reported."<sup>23</sup>

Although access to HPV vaccine has increased over the years, very few of us are aware of the risks around HPV. Similarly, most of us do not have access to essential screening and early diagnosis services.<sup>24</sup> This is especially true for women of same sex orientation, trans men (who are not seen as vulnerable), sex workers and women who use drugs (whose labour and behaviour is criminalised or stigmatised), women with disabilities and adolescent girls and young women. We also note with concern that there seems to be a lack of documentation relating to how cervical cancer is experienced by women living with HIV in all our diversity, and a complete lack of our engagement at many levels. Despite the need, cervical cancer prevention has, for the most part, been left out of sexual and reproductive health services for women living with HIV in many LMICs.<sup>3</sup>

*"A few years ago I had an abnormal pap test and after having a biopsy on my cervix, I was told it was CIN 1. The doctor told that because I was living with HIV they were going to keep a close eye on this and I should come back for another test in six months. I went back a year later and the cells had changed to CIN 2. The doctor told me to come back in six months. I was busy with work so I only went back a year later and the result was now CIN 3. The doctor was angry that I had not gone back. I was trying to have a baby at the time and they then told me that I had to wait as they had to remove the 'bad' cells before they became cancerous. They did remove these using a conisation. After 8 weeks we were allowed to start trying for the baby. That was 7 years ago. I have a screen done once a year and the results have since then come back as normal. If I had not detected the precancer and done something about it I would have had a whole lot more to deal with! Access to health care should not be a privilege available to only a few – All women should have this." Sophie Dilmatis - living with HIV, Zimbabwe*

# The Global Response To Cervical Cancer

“Since 2006, globally, one third of countries have introduced HPV vaccination in the national vaccination schedule. However, large inequities exist: while 70% of high-income countries have introduced HPV vaccination, only 20% of middle-income and 6% of low-income countries have done so.”<sup>25</sup>

The World Health Organisation (WHO) 2017 Consolidated guideline on the SRHR of women living with HIV highlights the need for sexually transmitted infections (STI) and family planning services to be integrated within HIV care settings.<sup>26</sup> In May 2018, Dr Tedros, WHO Director General made a [global call for action](#)<sup>27</sup> towards the ‘elimination’<sup>iii</sup> of cervical cancer’ as a public health concern. The call has led to support from all our countries to develop a global strategy to accelerate action against cervical cancer, with the ambition of achieving this goal in every country within the 21st century.

[The Cervical Cancer Elimination Initiative](#) includes seven UN agencies WHO, International Atomic Energy Agency (IAEA), International Agency for Research on Cancer (IARC), UNAIDS, UNFPA, UNICEF and UN Women and an increasing number of partner organisations such as the Clinton Health Access Initiative and the Union for International Cancer Control (UICC), GAVI, UNITAID, USAID, the Global Fund to Fight AIDS, TB and Malaria, and the World Bank. Under this initiative the WHO-led Secretariat leads seven working groups (WGs) which will identify and support accelerators for implementation and scale up of national services, as well as supporting a number of high burden countries. To keep up to date with progress click [here](#).

The framework of the new global strategy towards elimination of cervical cancer as a public health concern will be open for consultation in the coming months. Three global priorities are emerging and were shared on a January 2019 UNAIDS [#BeTeamWomen](#) Facebook live session, as follows:

- **High coverage of the HPV vaccination of girls.** The target is to reach **90% coverage of girls by age 15 in each country by 2030**. WHO estimate that currently only 10-15% of 9-14 year old girls globally are protected by HPV vaccination.
- **High screening coverage of women at 35 and 45 years of age with follow up and treatment for cervical precancer available.** The target is to **have screening coverage to 70% by 2030**.
- **High treatment coverage with 90% of women identified with a cervical lesion be treated by 2030.** Here importantly, the emphasis is on appropriate follow up of women with screen positive results (precancer or cancer) or of women with symptoms.
- **Reducing mortality through not only prevention but also early diagnosis and treatment of invasive cervical cancer.** Linking people to care once cervical cancer has been diagnosed, including palliative care, available to all women. The impact target **is to reduce mortality by 30% by 2030**. This means increasing the numbers of women who are diagnosed at early stage disease, and their access to treatment, surgery and radiotherapy in particular.

Although we have heard about possible WHO regional consultations to review the text of this global commitment, it is unfortunate that there does not yet appear to be any accessible articulation of the role and space of civil society in this plan, especially for women and girls living with HPV and/or living with more advanced conditions. In particular, in this context, with the extra challenges that HPV poses for women living with HIV, we would strongly advocate for meaningful involvement of women living with HIV in the global processes. We are glad to see that UNAIDS is taking a lead on this<sup>28</sup> and look forward to next steps from UNAIDS and WHO, including critical funding to ensure community responses, which are essential to success.

iii This is an unfortunate use of language. In the world of HIV, we have specifically pointed out that such language can often be turned from focus on the medical condition onto people with the condition – with potential negative consequences for the people concerned.

# Conclusions and Recommendations for Cervical Cancer Prevention and Treatment for Precancerous Cells

**Conclusions:** No one sector of society can on its own end cervical cancer as a public health concern. We also know that investment must focus on prevention and early detection of precancers and cervical cancer at early stage of disease. We call for a holistic collaborative approach to the issue and to ensure that this is part of a package of care that all women living with HIV in all our diversity have access to. We call on women living with HIV, health care providers, policy makers, our UN Partners and global funding initiatives to support us to end cervical cancer. Review our recommendations on how you can work collaboratively to contribute to and support other sectors to end cervical cancer for all of us. We remind you of your SDG commitments and especially call on you to include women living with HIV in all our diversity meaningfully, in your own policies and programming.

Cervical cancer **can be avoided** by ensuring that all girls (irrespective of HIV status) receive the HPV **vaccine** before they become sexually active. With regular **screening**, any early development of precancerous or abnormal cells can be treated so that cervical cancer can be averted. Even if abnormal cells do develop, **early diagnosis** can prompt early **treatment** which can, in turn enable **recovery**.

For women who do develop cervical cancer, treatment options vary depending on the stage and what our countries can provide. When cervical cancer is detected in its earliest stages, surgery and radiation therapy are the most common treatment methods. Whilst there has been some progress to deliver treatment services for cervical cancer, access is poor in many low- and middle-income settings. In addition, in many countries, women are diagnosed late when treatment options are limited. We therefore call on all countries to make sure treatment services keep pace with the rising burden of cervical cancer. Because of this harsh reality we must focus our efforts on prevention and early detection.

It is essential that these key messages are shared throughout our communities, and that all people see this as their collective responsibility in our communities, health centres and policy fora to support women and girls in all our diversity to be protected against HPV and cervical cancer.

**Recommendations:** The following recommendations focus on specific audiences who have the power to ensure that we end the devastating impact of cervical cancer. Each section speaks to areas of engagement, prevention, screening and early diagnosis, treatment of precancerous cells and research.

## Women Living With HIV In All Our Diversity

In this section, we speak directly to (other) women living with HIV in all our diversity, as well as to others seeking to support our sexual and reproductive health and rights. We highlight actions towards engagement, prevention, screening and early diagnosis and treatment, including palliative care<sup>iv</sup> for our own health; and in relation to others in our community. We also discuss how we can reach out to healthcare providers, policy makers and other key actors.

If you are personally affected by any issues in this booklet, you are not alone. Many of us have had precancerous cells and/or cervical cancer. It is *not your fault* – and you are taking the right action by reading this booklet.

Sadly, one of the greatest barriers to action around HPV and cervical cancer is fear: There is fear associated with the vaccine, even though it is safe, and fear associated with the test, its implications and negative reactions experienced by some women who have HPV or cervical cancer. One study conducted in 2013 in Switzerland showed that “fear was another feeling quoted in every focus group as a reason not to attend screening. The term was used 241 times during the focus groups (a minimum of 2 times in one focus group, and a minimum of 23 times in another focus group)”<sup>27</sup>

### Engagement

- Connect with **other adolescent girls and young women and women** living with HIV around you who may attend the same clinic as you. You could discuss your fears/thoughts around HPV, precancerous cells or cervical cancer in an existing informal support group, or you could set one up to discuss it. You could read this booklet together, discuss its contents and together work out how to better support each other to take the information and suggestions forward. The right to health includes a clear understanding that all women – especially women living with HIV – be included in discussions related to our own health and lives, as countries roll out national prevention programmes.
- Work together with your community and with women’s rights groups; networks of women from key populations (sex workers and women who use drugs); or women-specific cancer organisations or perhaps even through a **community** health council. Think about who are the most marginalised girls and women who also need this information. This could help to bring visibility to this booklet and encourage a wider discussion about how your community can promote and support a community-wide girls’ vaccination and screening programme, to protect the next generation as well as all of us now. If no vaccination programme exists, use this opportunity to lobby your community health council. If one of you feels comfortable, share some of your own experiences to build understanding of the challenges faced and how these were overcome. See below for more specific ideas.

To find out more about how you can connect with a local cancer group contact the Union for International Cancer Control at [cervicalcancer@uicc.org](mailto:cervicalcancer@uicc.org)

- Share this booklet with local **health care providers** to bring their attention to the minimum standards of health care provision. The right to meaningful involvement in shaping your healthcare at local levels is clear in the 2017 WHO Consolidated guideline on the SRHR of women living with HIV. Share this booklet and discuss options with your Community Advisory Group linked to the health centre, if there is one. If not reach out to a supportive nurse or clinical officer and share this booklet and request a meeting to discuss it with local healthcare providers. All programmes and services must be rolled out in a way that safeguards our rights and addresses existing barriers to accessing services, such as stigma and discrimination and provides adequate information for us to make healthy choices.

<sup>iv</sup> Palliative care can include nursing and psycho-social care for people who are dying and their families. Provided either at home or in day-care or residential centres by voluntary or professional health providers. This usually includes pain relief.

- Programme implementers must include the very women they are trying to reach (be they women living with HIV, adolescent girls and young women or women from key populations) in the development and implementation of programmes and services and give equal consideration to where the barriers to access lie. See below for more specific points.
- Share this booklet with **local or national leaders**: write to your Member of Parliament or lobby parliament or Ministries of Gender, Health, Education and Labour to find out more about what is happening in your own country or district: and how women living with HIV and adolescent girls and young women are engaged or not.
- In your discussions address any fears that may exist around the safety of the vaccine. The HPV vaccine is SAFE. To learn more about this from a trusted source click [here](#).
- Gather a group to engage with the **media** to discuss how you would prefer they share information on cervical cancer and bring visibility to national programmes for women and adolescent girls and young women. See below for examples.
- Understand who is **investing** in your country to provide services: and where the entry points are for women living with HIV at national and local levels to engage and influence how programmes and services are rolled out. Engage your national UNAIDS, WHO, UN Women, UNFPA, UNICEF and other technical partners, and share your concerns. Find out how they can convene women living with HIV and support community advocacy.
- Connect migrants, incarcerated women, or women who are internally displaced or affected by other **instabilities** to UNHCR, OHCHR. Find out what services are provided by your local Family Planning Association, and other sexual and reproductive health and/or women's rights organisations. Identify who else you can engage with.
- Advocate for a seat at the table at the **global** level and request that UN partners provide an update on the UN Joint Global Programme on cervical cancer Prevention and Control in the six focus countries: Bolivia, Tanzania, Morocco, Myanmar, Uzbekistan, Mongolia and how women living with HIV are deliberately being engaged and are empowered to participate.
- Link to a network or organisation that is conducting community-based monitoring and see if you can engage in monitoring and **accountability** mechanisms for access and quality of services for women living with HIV around HPV and cervical cancer.

## Prevention

- If you are an adolescent girl and young woman, and especially if you are living with HIV, do what you can to access the HPV vaccine from your school or health centre. When you have had this, you will be protected from HPV strains which cause most of the cervical cancer. However, remember it is important to go for regular screening throughout your life – especially once you have become sexually active.
- Build demand for the HPV Vaccine! As adolescent girls and young women gather your friends and peers to talk about the HPV vaccine for girls and how best you can raise awareness in your community. Share and discuss this document and find ways to advocate/promote vaccination campaigns especially for girls who do not have access through schools.<sup>30</sup> Highlight the fact that the HPV vaccine and regular screening can detect the abnormal cell formation and greatly reduce the chances of developing cervical cancer. You could also discuss key concerns and/or experiences of the HPV vaccine; having pap smears or VIA tests. Here are some helpful tips from a North American site about [these fears](#).

## Screening

- Ensure you are able to access regular screening. If you have never been for a check-up then try to address the reason for not going. If you do not have access or are afraid then please go back to the engagement section above and try to access supportive networks.
- Discuss with a group of your peers both personal and health service reasons why you and/or some of your peers may not be having regular screening. If some people are embarrassed to speak openly, then use an anonymous comments box where people can write, and a facilitator can discuss each issue raised in general. Invite a trusted NGO or network who can support this group to document and raise these concerns with your community, healthcare providers and policy makers. For more on how to organize your advocacy click [here](#).
- Assess if there is community recognition and action to ensure regular screening is available. Are women in your community able to access HPV screening? If not, what are the barriers and how can your community support women to overcome them? Make sure all women in your community can access screening for cervical cancer at least once for every woman (30-49 years). If you cannot, write to your MP and other local key leaders, to inform them that you do not have access and lobby them to change this.

## Early Diagnosis

- Remember that you are not alone and that it is great that you have had a screening. Your result might mean that you have abnormal cells that may need to be dealt with. This does not mean that you automatically have cervical cancer. If the test shows precancerous cells, your health care provider will suggest steps to stop cancer from developing.
- Please read the section below for healthcare providers to see what services you should be able to access. If services aren't there, turn to your peer group for support.
- If you are diagnosed with cervical cancer the doctor should talk to you about what treatment options are available in your country.

## Treatment

- Create a system with adolescent girls and young women and/or older women to build the care and support needed to cope with abnormal test results and to follow through with next steps, whatever these may be.
- Demand to be involved in building referrals systems to address the care and support needs after adolescent girls and young women and/or older women receive an abnormal test result.
- Ensure that the wider community understands the different stages, as described above on page 2 (CIN 1; 2; 3); and that women facing news of abnormal cells or more are given all the encouragement and support needed to access further care.

“Decisions about treatment options should consider your age, overall health, and your personal preferences [about having children in the future]. Depending on the type and stage of your cancer, you may need more than one type of treatment. For the earliest stages of cervical cancer, either surgery or radiation combined with chemotherapy may be used. For later stages, radiation combined with chemo is usually the main treatment.” For more information visit the [American Cancer Society](#) for easy to read information.

## Health Care Providers & Programmers

As women living with HIV we expect, as part of minimum standards, that healthcare centres must have full **information** that we require about HPV vaccines and screening and that this be available for all women and children who access any health-care facility, either for themselves or for a family member.

This is especially important for women living with HIV who access health care for HIV treatment. Youth-friendly information should also be available in paediatric clinics, so that girls can access information for themselves.

## Engagement

- Engage women living with HIV to act as community-based experts. Work with women living with HIV to create a strong community network that brings women into contact with health care, as part of integrated nationwide SRH and HIV service provision.

## Screening

Screening services should include the following considerations:

- **Location:** Where can cervical cancer screening be accessed? Is there a private room where this can happen, which preserves confidentiality? Is there equal access for women with mobility issues? Screening should also be available in restricted settings, such as prisons and detention centres.
- **Personnel:** Who is conducting the test (male or female)? Has s/he been trained to be aware of the many fears and other challenges facing women living with HIV who are also coping with this?
- **Enabling environment:** Women should be supported if they find the speculum (instrument that is inserted into the vagina to conduct the screening) painful. If women are in pain, then they should have access to pain relief or other medications. In some countries, women can access ibuprofen beforehand, or be given a course of oestrogen pessaries ahead of their screening to reduce the pain when they do have the test.
- **Providing support:** In your own context - what are the real costs of annual screening for women living with HIV? For many women, there are transport, and child-care costs, as well as time off work and often permission to travel from a partner is required. Have these been taken into consideration when planning location and frequency of services?<sup>29</sup> Bring attention to any barriers to accessing services to the notice of your managers and/or policy makers, to provide effective and ethical prevention and treatment programmes for cervical cancer.
- **Addressing challenges:** Can cervical cancer screening and preventive therapy be integrated with other reproductive health services? Can a 'one-stop / single visit' approach be developed?<sup>32, 33</sup>
- **External check:** Even if VIA is not available, health care providers can check the outside of the vagina and anus for lesions which are often visible but not detected and treated early.<sup>34</sup>
- **Include men:** Men must also be visually checked by health care providers each time they visit the clinic for any annual or other check-up linked to HIV treatment. There is rising concern, in particular, for the numbers of men who have sex with men who have HPV-related oral and throat cancers. It is also essential to provide services to transgender men. This box below is from the 2017 WHO Consolidated guideline on the SRHR of women living with HIV and highlights considerations for transgender men.

### Box 4.6: Key considerations on cervical cancer for transgender men living with HIV

- Transgender men who retain their female genitalia often miss out on cervical screening and other sexual health services, as they may not seek out or may be excluded from those services. As a result, they face increased risk of ovarian, uterine and cervical disease.
- Following total hysterectomy, if there is a history of high-grade cervical dysplasia and/or cervical cancer, a Papanicolaou test of the vaginal cuff can be performed annually until three normal tests are documented, and then every two to three years.
- Following removal of ovaries, but where the uterus and cervix remain intact, WHO cervical screening guidelines for natal females can be followed. This may be deferred if there is no history of genital sexual activity. It is important to inform the pathologist of current or prior testosterone use, as cervical atrophy can mimic dysplasia.

Source: WHO, 2016 (10).

## Treatment

- Ensure that, in addition to whatever treatment is available, all women who are screened and found to have abnormal or precancerous cells should receive adequate counselling. This should include the following:
  - Information to understand disease progression and that an abnormal test result does not mean cancer but could mean early stages of cell changes;
  - Support for women to secure further appointments or to enable any referrals to happen;
  - Offer of all the options available for follow-up screening and/or treatment;
  - Full answers to questions and concerns with appropriate information;
  - Assurance that women in need of and/or accessing follow up screening and/or treatment have access to funded peer support and are connected to other women living with HIV who have experiences of cervical cancer.
- Follow up to ensure that women get the follow-up screening and/or treatment and that they are linked to funded peer support and connected to other women living with HIV who have experiences of abnormal cells or cervical cancer.

## National Policy

- Effective responses are grounded in effective national policies that address key priority needs and rights of women and girls in all our diversity.
- All national policy should fully address the SRHR of women living with HIV<sup>33</sup> and adolescent girls and young women by providing screening services for all women, especially women living with HIV, adolescent girls and young women who are sexually active and sex workers.
- National Policy guides a countries operational regulations, guidelines, norms, and standards and must address all the key issues highlighted in this booklet – especially issues around how intersectionality increases barriers to accessing services.
- A critical component of the right to health requires that governments ensure access to a range of available screening services and treatments that are best suited to the individual woman.
- As a minimum we expect the following:

## Engagement

We request a seat at the table. We would like to be deliberately and meaningfully engaged in all of the points mentioned directly above, to ensure that effective responses are grounded in our realities, and that screening services and treatments are best suited to our needs and priorities. This is in line with the WHO 2017 Guideline on the SRHR of women living with HIV.

## Prevention

- All schools must have HPV vaccine programmes in place for girls - and ideally boys (see box on page 9).
- Cervical cancer education (including information on the values of HPV vaccination and screening) should be available to all young people in schools as part of comprehensive sexuality education (CSE) programmes.
- All girls and boys should know that the vaccination and regular screening are key ways to prevent and detect precancerous cells and address this before it becomes cervical cancer. Adolescent girls and young women out of school, especially those living with HIV also need to access the HPV vaccine and the health information about its importance.
- Leverage group discussions to strengthen or create community approaches to ensure all girls have access – in ways that minimize any stigma, discrimination or fear around the vaccine.

## Integration of Healthcare Services

- Provide training for health care professionals to ensure that they fully uphold and respect the rights of women living with HIV and adolescent girls and young women.
- Provide comprehensive integrated SRH and HIV services, to maximise cost-effectiveness and minimise women's practical treatment access costs.<sup>34</sup> See below this box in the 2017 WHO Consolidated guideline on the SRHR of women living with HIV, which highlights the need for integration (our highlights added).

### NEW good practice statements on integration of services

**GPS A.4: Women living with HIV should have access to integrated and tailored comprehensive\* sexual and reproductive health (SRH) and HIV services.**

**GPS A.5: Women living with HIV should be included in the design and delivery of these services.**

\* As defined in WHO's 2004 *Reproductive health strategy to accelerate progress towards the attainment of international development goals and targets*, comprehensive SRH services include the following: improving antenatal, perinatal, postpartum and newborn care; providing high-quality services for family planning, including infertility services; eliminating unsafe abortion; combating sexually transmitted infections including HIV, reproductive tract infections, cervical cancer and other gynaecological morbidities; and promoting sexual health (65).

## Screening and Early Diagnosis

- Policy needs to include all the points which are detailed in the section above, that speaks to the minimum standards expected for services from health care providers.
- Now is the time for governments to address legal issues and prejudices around age of consent. No young women - especially those living with HIV and who are sexually active - should risk being turned away because of age, when they are acting responsibly in trying to access screening - or any-services.

## Treatment

- Provide treatment access for both precancerous abnormal cells and for more advanced cervical cancer. This is essential given the global statistics outlined in this booklet. All national and district policies must align with the 2017 WHO Consolidated guideline on the SRHR of women living with HIV. This states that women living with HIV, including adolescent girls and young women, in all our diversity, are meaningfully involved in policy development and roll-out. Practices which directly or indirectly affect our choices, including barriers to treatment and services - whether they concern access to HIV treatment options, to contraceptive options or to screening for cervical cancer - undermine human rights and have grave consequences, not only for our mental and physical health but in all spheres of our lives.
- Ensure that all women who are screened and diagnosed are fully linked to treatment of precancer so that all women have the continuity of care that they need.
- Improve access to definitive cancer treatment and effective palliative care for women who have not been able to access and benefit from prevention efforts.

## The Cervical Cancer Elimination Initiative and Donors

Across the seven working groups (WGs) we make the following recommendations:

### Engagement

We request a seat at the table. We would like to know how women living with HIV and adolescent girls and young women are deliberately being meaningfully engaged in policy that directly affects our lives at global, regional and national levels. We also request an update from the UN Joint Global Programme on cervical cancer Prevention and Control on key countries including the six focus countries: Bolivia, Tanzania, Morocco, Myanmar, Uzbekistan, Mongolia.

The seven WGs are:

- 1 Strategic Documents and Action Plan;
- 2 Advocacy Communications, and Civil Society Mobilization and Engagement;
- 3 Recommendations;
- 4 Impact Modelling, Costing and Financing;
- 5 Increasing Access to Interventions;
- 6 Monitoring and Surveillance;
- 7 Research

As governments commit to end cervical cancer and as WHO hosts regional consultations to review the text of this global commitment, which will be available online in the coming weeks, women living with HIV in all our diversity would like to be engaged in this process. For more information visit the [\(UICC\) website](#); [the UNAIDS website](#) and [the WHO website](#).

### Prevention, Screening and Early Diagnosis

Neither of the WHO 2013 or 2014 documents on screening and treatment of precancerous lesions for cervical cancer prevention adequately addresses the many key issues which are the structural drivers that are highlighted in this booklet. We understand that the review and update of the WHO guidelines on cervical cancer, including for women living with HIV, is in process. We hope this will be updated in line with the 2017 WHO Consolidated guideline on the SRHR of women living with HIV, and with this booklet.

We strongly recommend that future WHO guidelines on cervical cancer highlight the following:

- Enabling legal environments are essential and allow women in all our diversity to access services irrespective of our HIV status, identity or profession. No person should risk being turned away because of age, or criminalised/prosecuted when it comes to accessing health services and this must be explicit if Universal Health Coverage (UHC) is to be achieved.
- Integrate services so that women can access sexual and reproductive health services along with HIV and TB treatment if necessary, and so that children can also access services at the same time as their mothers (such as the HPV vaccine) to meet their health needs. Health services must modify working hours so that services are accessible to women in all their diversities (especially women with childcare challenges and family/work responsibilities during the day) and for girls in schools.
- The global response to HIV and cervical cancer must continue to build political commitment around the integration of health services and work with governments and communities to improve women's health as part of efforts to end AIDS by 2030 and to end cervical cancer as a public health concern. This will be essential if the UN is to support governments to deliver on key commitments made in the SDGs to leave no one behind.
- We trust that the forthcoming WHO Guideline on self-care which will include a section on self-sampling for screening, will include, or make appropriate reference to, all the points above.

## Funding

We acknowledge the efforts of the Global Fund to Fight HIV, TB and Malaria, PEPFAR, GAVI, Unitaid and others to work towards ending cervical cancer. Much more funding needs to be driven towards scaling up access to HPV vaccination, expanding screening and ensuring equitable access to treatment and palliative care services.

There are currently only two suppliers of the HPV vaccine. These are Merck MSD and GlaxoSmithKline (GSK), who have not been able to meet the required demand from GAVI and other multilaterals and Governments. The current cost of the HPV vaccine ranges from between \$4.50 and \$193 across different countries<sup>37</sup> due to patent monopolies. Access to the HPV vaccine could be greatly improved if governments and multilateral organisations had access to a generic version, which could be produced for as little as \$0.50-\$0.60 per dose.<sup>38</sup> There are a few generic versions in the pipeline but, due to the time required to establish adequate manufacturing capacity and conduct necessary testing for quality control and regulatory purposes, these generics will take 3-5 years to be introduced to the market. In the meantime:

- Governments, multi-laterals and donors should encourage Merck MSD and GSK to scale-up its capacity in order to meet the coverage demand. Prevention efforts should allow for new approaches such as HPV nucleic acid detection to reach women in communities. Our countries are facing huge funding challenges and are forced to make decisions on priorities. It is unacceptable that in Uganda, the baseline lifetime screening rate for cervical cancer is reported to be between 4.8% and 30%.<sup>39, 40, 41</sup> We use this example, but this could be many of our countries. We also highlight the inequities in access within countries and call for attention for marginalised populations.
- Funding for research could also develop less invasive tests. See more about funding for research below. Engaging women in research would also help to increase understanding of why screening is important and would thereby increase the demand for and take-up of cervical cancer screening.
- Financially support our work: The 'right to health' is an important component of a human rights approach to cervical cancer. Among many other determinants this includes the right to sexual and reproductive health services and access to information, as well as the resources to act on that information. The health care system alone cannot possibly address all social and economic barriers to services, and therefore we desperately need the community – to support this work.
- With regard to the emerging Global Strategy and targets, when will governments ratify their commitment to these, and what will their follow-up involve? How will women in communities be engaged? The targets enable us to know what is expected in our countries. They will help us to hold our governments accountable and ensure that resources are allocated where they are most needed. However, funding for community activism will be an essential component to success.

## Employers

Employers also have an important role to play and should ensure the following to support women:

- Allow flexibility in working hours so that women can take time off, when needed, to access healthcare services.
- Ensure all employees have full access to regular and updated information and support about the importance of screening; and the means to access it regularly.
- Provide adequate health leave for women and men who require treatment.

## Media

- There are examples of how mass media has promoted health messages and there is some evidence to show that awareness can grow through social media.<sup>42</sup> Some reviews concluded that mass media campaigns can be effective in improving health-related behaviours when combined with other strategies.<sup>43</sup>
- The box on the next page highlights examples of effective media strategies that could be replicated in other parts of the world.

One example of good practice is when a UK government body, Public Health England, met with all national newspapers and other media to explain the public health importance of the HPV vaccine for girls. The information provided persuaded them all that HPV vaccines are protective of girls' and young women's health, and do not promote early sexual activity. All the newspapers and diverse radio and TV channels took part, affirming their support for the campaign when it was launched by the government. This was an effective way to reach a wide diversity of people across England. There has been a routine schools-based programme ever since, with over 85% of girls vaccinated.<sup>44 45</sup> However, the momentum has to be maintained as one-off campaigns are rarely enough.

One of the widest-read papers in the UK has a #cheersforsmeas campaign, which encourages women to have regular pap smears.<sup>46</sup> This campaign is linked to the memory of a celebrity, Jane Goody, who died from cervical cancer in 2009 and courageously used her own experience to campaign about it before she died. It also features the relatives of others who have died more recently. The campaign emphasises the value of screening and encourages women to go. Can you develop similar campaigns in your country?

## Research

Last but by no means least, research must continue – especially around how women living with HIV are accessing services and how our lives are affected by HPV and cervical cancer.<sup>47</sup>

Countries need to be smarter around how they collect data on cervical cancer programmes and look at overlaps with sex- and age disaggregation, as well as collecting data that speak to nuances. For example: are there sex workers who use drugs who are able to access cervical cancer screening?; women who use drugs?; trans\* sex workers who are also young?; etc. The data quality should speak to these nuances and not assume that 'key populations' or 'women and girls' or 'people who use drugs' are mutually exclusive or static groups.

Quantitative data should include further data on the socio-economic dimensions of HPV and cervical cancer and how these inequalities can best be addressed. The quality of quantitative data should also be examined to ensure that accurate diagnoses are being achieved, especially in rural areas, where service gaps most need to be filled.

Qualitative data: girls' and women's own experiences of HPV vaccination; of screening; and of early (and later) diagnosis and treatment need to be documented. In particular, feared and/or actual barriers (such as travel cost, violence, stigma, pain) and enablers (such as supportive, well-trained health staff) facing girls and women living with HIV, including sex workers and women who use drugs, should be researched.

The ALIV[H]E Framework sets out an approach to holistic research, which combines formal and participatory quantitative and qualitative data collection. This offers the opportunity for women and girls most affected by these issues to be meaningfully involved in the whole research process, so that our own priorities can be articulated and included as indicators of effective and ethical programmes and policies. This is in line with the 2017 WHO Consolidated guideline on the SRHR of women living with HIV, which states:

### **6.2.1 Women living with HIV as equal partners in research**

Research about women living with HIV should be conducted with, by and for women living with HIV, as equal research partners. Research that is pursued and funded in this area should include justification for why it is important to women living with HIV.

- 1 Comprehensive cervical cancer control: a guide to essential practice. Geneva: World Health Organization; 2014 ([http://apps.who.int/iris/bitstream/10665/144785/1/9789241548953\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/144785/1/9789241548953_eng.pdf), accessed 6 March 2017).
- 2 Huchko MJ, Maloba M, Nakalembe M, Cohen CR. The time has come to make cervical cancer prevention an essential part of comprehensive sexual and reproductive health services for HIV-positive women in low-income countries. *J Int AIDS Soc.* 2015;18(Suppl 5):20282. Published 2015 Dec 1. doi:10.7448/IAS.18.6.20282
- 3 Ebony Johnson, Be Team Women, Facebook Live Session: [An Avoidable Tragedy: Eliminating cervical cancer as a public health concern](#)
- 4 Cervical cancer common amongst African women, WHO, <https://www.afro.who.int/news/cervical-cancer-common-amongst-african-women>
- 5 Kelly H, Weiss HA, Benavente Y, de Sanjose S, Mayaud P, ART and HPV Review Group. Association of antiretroviral therapy with high-risk human papillomavirus, cervical intraepithelial neoplasia, and invasive cervical cancer in women living with HIV: a systematic review and meta-analysis. *Lancet HIV.* 2017;5(1):e45-e58.
- 6 Dr Peter Godfrey-Faussett, Senior Science Adviser, Be Team Women, Facebook Live Session: An Avoidable Tragedy: Eliminating cervical cancer as a public health concern
- 7 Bloem P, Ogbuanu I. Vaccination to prevent human papillomavirus infections: From promise to practice. *PLoS Med.* 2017;14(6):e1002325. Published 2017 Jun 27. doi:10.1371/journal.pmed.1002325
- 8 Key barriers to women's access to HIV treatment: A global review, AVAC, Athena Network, Salamander Trust, 2017 <http://www.unwomen.org/-/media/headquarters/attachments/sections/library/publications/2017/key-barriers-to-womens-access-to-hiv-treatment-a-global-review-en.pdf?la=en&vs=3431>
- 9 Globocan 2018 (published by IARC), Estimated age-standardized incidence rates (World) in 2018, cervix uteri, females, all ages – click here
- 10 Subtotal versus total hysterectomy [https://www.cochrane.org/CD004993/MENSTR\\_subtotal-versus-total-hysterectomy](https://www.cochrane.org/CD004993/MENSTR_subtotal-versus-total-hysterectomy)
- 11 HPV, HIV and Cervical Cancer - Leveraging synergies to save women's lives. UNAIDS. 2016, <http://www.unaids.org/en/resources/documents/2016/HPV-HIV-cervical-cancer>
- 12 Preventing deaths from cervical cancer - Unitaid <https://unitaid.org/call-for-proposal/preventing-deaths-from-cervical-cancer/#en>
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