Note for the record: Webinar on Women Living with HIV and Cervical Cancer

1. Introduction

Salamander Trust recently received funding from UNAIDS to bolster civil society's advocacy, communications and consultations with women living with HIV and partners on two key issues: *Dolutegravir* (DTG) and cervical cancer. On November 20th Salamander Trust organised a webinar on **Women Living with HIV and cervical cancer.** Click here to listen to the webinar and click here for the Salamander slides and here for the UNAIDS slides. Special thanks to Dr Deborah von Zinkernagel, Director, Community Support, Social Justice and Inclusion, UNAIDS for joining this webinar and providing an introduction.

2. Background

The WHO 2017 Consolidated Guideline on the Sexual and Reproductive Health and Rights (SRHR) of women living with HIV is a ground-breaking document, which upholds the rights of women in several key areas. Since 2013, Salamander played a major role facilitating the global values and preferences survey on the SRHR of women living with HIV. This fed into the development of the new consolidated guideline. As part of this process, WHO Department of Reproductive Health and Research asked Salamander to develop a checklist tool (currently being updated), to support women in countries to ensure the full implementation of the guideline. This tool has now been endorsed by the heads of 5 UN agencies.

3. Reason for this work

UNAIDS has now asked Salamander to take this process further. No matter how great the guideline is, women continue to face challenges in accessing treatment options and services. This is evident by the fact that cervical cancer affects over half a million women and kills more than a quarter of a million women each year. One woman dies of cervical cancer every two minutes and women living with HIV are 4-5 times more vulnerable to developing cervical cancer. In 2018, approx. 570,000 women were diagnosed with cervical cancer and 266 000 women died of the disease. Nearly 90% of these women live in lower and middle income countries in Africa, parts of Asia, and Latin America and the Caribbean. Women with compromised immune systems are far less likely to clear having Human Papilloma Virus (HPV), which causes cervical cancer; and women living with HIV are more likely to develop pre-invasive lesions that can, if left untreated, quickly progress to invasive, life-threatening cervical cancer.

> HPV is one of the most common STIs worldwide and is transmitted via skin-to-skin and sexual contact (including vaginal, anal and oral penetrative and non-penetrative sex). Approx. ½ of all sexually active men and women will contract a type of HPV at some point during their lives. HPV prevalence varies widely between regions - SSA (24%), eastern Europe (21%) and Latin America (16%) have the highest rates of HPV. In 2012 analysis showed that a woman's overall vulnerability to acquiring HIV doubles if she has HPV of any kind. Among women living with HIV, HPV prevalence rates are higher, reaching levels as high as 80% in Zambia and 90–100% in Uganda. 15 types of HPV are recognized as high-risk or cancer-causing genital HPVs: HPV 16 is the most prevalent type detected in HPV-associated cancers, followed by HPV 18. **Together, HPV 16 and 18 cause about 70% of cervical cancers worldwide**. *Facts presented in the UNAIDS slides on this webinar*

Values and preferences

Women respondents participating in the GVPS articulated that cervical cancer screening for women living with HIV should be included in a standardized package of holistic, quality, woman-friendly, confidential, non-discriminatory and integrated HIV and SRH services, including in resource-limited and rural settings, and in restricted settings, such as prisons and detention centres *(37)*.

4. What we will produce

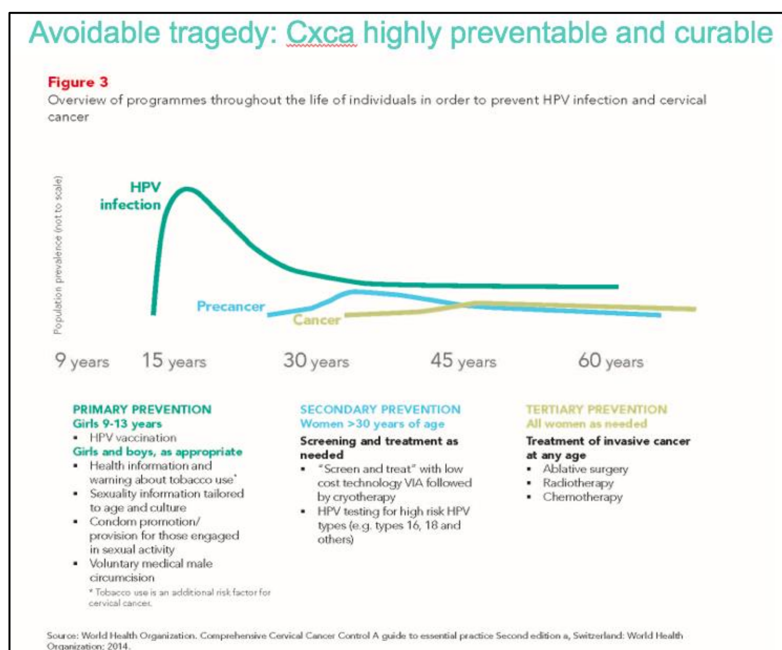
As an outcome of our work the following is to be delivered before the end of this year:

- Create an advocacy brief that can be owned by women living with HIV to move access forward before the end of this year. This will highlight recommendations to: governments at the national level; technical partners such as UNAIDS and WHO to strengthen messaging and actions to support it; and reflect and communicate diverse realities, priorities and rights of women living with HIV around cervical cancer related prevention, treatment and services.
- Set up a virtual sharing platform (probably on whats app as this is easy for many women to engage) where information on what is happening can be shared in real time and support and linkages can be made across countries and regions.
- Develop a series of 15-minute podcasts called The WHAVE (Women with HIV: Advocates, Voices, Empowered). These will be recorded by women living with HIV from around the world and will include a specific podcast on cervical cancer.
- Support those most active to join as national or regional coordinators of this work.

5. Key issues presented by UNAIDS (Dr Peter Godfrey-Faussett, Senior Science Adviser and Ms Kreena Govender, Programme Officer, Human Rights and Gender)

5.1 Key points raised by UNAIDS and WHO include:

- Intersectionality (including, but not limited to race, ethnicity, where women live, age, poverty, health status, disability, and violence) is key in the response to cervical cancer. All of these different aspects make women more vulnerable to cervical cancer.
- A 2017 US study (data from 2000-2012) found that black women are dying from cervical cancer at a rate 77% higher than previously thought, and white women are dying at a rate 47% higher than previously thought. Racial disparity seen in cervical cancer death rates for black and white women was underestimated by 44%.
- 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.



- There are many strains of HPV – transmitted in various ways. HPV is common – especially in those who are sexually active. Most people who are sexually active acquire HPV and rates are highest amongst young women. Many people's bodies naturally recover from HPV infection however, this is less common in women with compromised immune systems.
- Cervical cancer is the final stage of HPV. Over time, HPV affects the lining of the cervix and the cells become pre-cancerous. This can be a long process and can also reverse itself. Once the lesion becomes cancerous, it is difficult and expensive to treat so the emphasis has been on early diagnosis during pre-cancerous stages. Effective vaccines have to be administered before HPV is able to enter the body - prior to sexual activity.

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5.2 Cervical Cancer Vaccinations

- Despite vaccinations becoming more available and screening – women are still developing cervical cancer and we need to continue to advocate for treatment for those who do develop cervical cancer.
- **The vaccination offers protection for up to 8 – 10 years. The schedule depends on the age of the vaccine recipient**:
    - Females under 15 years at the time of first dose: a 2-dose schedule (0, 6 months) is recommended.
    - If the interval between doses is shorter than 5 months, then a third dose should be given at least 6 months after the first dose.
    - Females 15 years and above at the time of first dose: a 3-dose schedule (0, 2, 6 months) is recommended.
- A 3-dose schedule is necessary for people who are immunocompromised and/or living with HIV.
- Boys who are vaccinated are also protected but given the overall costs involved, vaccines are prioritised for adolescent girls and young women as the most important population to protect.

5.3 Early diagnosis - screening and treatment

- Pap Tests are most reliable, can be costly and are not widely available, in many parts of the world. A smear is taken, transferred to a slide and reviewed and interpreted by a qualified technician – looking specifically for cancerous cells.
- Visual Inspection with Acetic Acid (VIA) is simple and uses vinegar to detect small cellular changes in the cervix. This requires an internal examination - someone who knows how to do this and is able to provide a private space. The healthcare provider swabs vinegar, (acetic acid), on the cervix and looks for areas that change colour. VIA seems an excellent cervical cancer screening method especially in low-resource settings. It works well in situations where Pap smears and HPV tests are not available due to lack of expertise or high per-test cost. This can all be done in one visit unless it is an advanced case. The down side is that it is not as accurate as the Pap test. It requires training, privacy and health care services but is the mostly widely used and effective way to detect cervical cancer.
- What will become the gold standard is to use HPV nucleic acid detection (similar to detect DNA and RNA tests in HIV). This can be done by the woman herself and at home but it requires the technology to detect the HPV gene. The actual test kits are becoming more and more available. If a positive HPV result is found, then the person needs to return to the clinic for treatment and/or referral. The good side is that those whose test shows no HPV do not need to do anything for another three years and this then frees up health providers to support those who do need treatment. To understand more about treatment options on slide 7 of the UNAIDS presentation.

5.4 More resources are available here

- HPV, HIV and cervical cancer: leveraging synergies to save women's lives
- Cervical Cancer Screening of Women Living with HIV Infection: A Must in the Era of Antiretroviral Therapy
- HPV Information Centre

"Cervical cancer is a disease of social inequality. Cervical cancer is one of the most unequal diseases in the world!" Dr Peter Godfrey-Faussett.

- In May 2018, Dr Tedros, WHO Director General made a global call for action towards the 'elimination of cervical cancer' as a public health concern. The aim is to develop a global strategy to support approaches that can achieve this ambitious goal in every country within the

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21st century. There are seven working groups (WGs) formed under WHO-led Secretariat: (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; and (7) Research.

- These working groups go beyond 7 UN agencies (WHO, IAEA, IARC, UNAIDS, UNFPA, UNICEF and UN Women), to include others such as GAVI, UNITAID, Pink Ribbon Red Ribbon, the Union for INT Cancer Control, the Global Fund including civil society. UNAIDS is co-chairing WG 2 with UICC and is engaged with all WGs.
- A review meeting scheduled for early December is setting incremental and long-term 'elimination' targets.
- The targets and modelling highlight the timescale. Vaccination interventions will only have great impact decades from now, when girls currently being vaccinated have grown older. Keeping up the momentum is challenging. There are simply not enough vaccines being produced, now that the demand has increased. GAVI has brought down the cost of vaccines from approx. $100 to $4 per vaccine. In the meantime, the focus is on increasing vaccination, increased access to pre-cancer screening and decreasing death rates.

6. **Key issues presented by WHO** (Dr Paul Bloem, Expanded Programme on Immunization Plus)

- HPV vaccines protect against 70-90% of all cervical cancers specially HPV 16 and 18, which cause 70% of the cervical cancer. Due to cross protection WHO considers all three currently available vaccines (bivalent, quadrivalent, & nonavalent) as equally effective.
- WHO recommends vaccinating girls aged 9-14, before they become sexually active. This includes two doses up to 14 years of age and three for those who are 15 year of age and older or living with HIV.
- While sustained protection has been shown to last up to 12 years, the vaccine is thought to protect women over various decades or lifelong. Therefore, no booster dose is currently recommended.
- When high coverage of the vaccine in girls is achieved (>80%), the knock on effect is that boys' profit from equal protection through the strong herd[1] immunity this vaccine offers.
- HPV vaccines do not protect against all strains of HPV hence screening remains necessary and important.
- Regarding targets – there are long term and short term targets. The long term targets will be put before Member States to adopt (this will be around tracking incidence). Regarding the shorter term targets if we want to have impact we need to vaccinate now so that by 2025 or 2030 all countries have introduced the vaccine.
- This year we have seen 4 new countries introduce vaccines – including Ethiopia, Tanzania, Zimbabwe, Senegal, with Malawi following in January. They will be followed by nine other countries in Africa and some countries in Asia. We need to focus on low-income countries and GAVI will be essential for this.

7. **Key points presented by the Global Fund** *(Heather Doyle Senior Coordinator, Gender, Strategy, Investment & Impact Division (SIID)).*

How does the Global Fund support countries in all of this especially given that the Global Fund can't dictate what countries decide to do?

- About two years ago the Global Fund passed the policy on coinfections and comorbidities – and this specifically calls out HPV and cervical cancer as priorities.

[1] To know more about the heard immunity, visit this site http://vk.ovg.ox.ac.uk/herd-immunity

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- The Global Fund funds screening and treatment where this aligns with the national policy guidelines. The support provided has mostly focused on supporting coordination of national guidelines implementations. In Tanzania, funding went into operationalising the national guidelines.
- The Global Fund recently signed grants which have just started and, within those, where we have the most potential for impact in preventing and/or treating cervical cancer, particularly for women living with HIV, is in Southern and Eastern Africa.
- Within the 13 priority countries that received catalytic funding for adolescent girls and young women, there has been a concerted effort to provide adolescent girls and young women with a comprehensive package of services to reduce infections and also to ensure services. Some of this includes screening for cervical cancer. The WHO focus is important and the Global Fund would like to play more of an active role in the working groups. The biggest opportunities are to work with PEPFAR in Southern Africa and possibly West Africa.

8. Questions and Discussion

Question: you explained that it was for economic reasons that HPV vaccines are prioritised for girls and not boys. Not giving boys the HPV vaccination could be seen as blaming girls alone for acquiring an STI and as a missed opportunity and it would be good to understand how countries that ended cervical cancer approached this and if they did the same thing?
Answer: This is an interesting question. The emphasis is on using the HPV vaccine to prevent cervical cancer. In South Africa, the UK and Australia the messaging has tried to market this as a vaccine to prevent cervical cancer and messaging plays down the fact that this is a sexually transmitted infection as parents don't want to acknowledge that their daughters are sexually active. Epidemiologically the direct beneficiaries are women who develop cervical cancer and vaccinating boys is shown in the models to have less impact. (NB Voluntary Medical Male Circumcision (VMMC) reduces the chance of men and boys acquiring HPV, and sexual partners of men who are circumcised are less likely to be HPV positive). Currently there are not enough HPV vaccines for everyone.

Question: When do you expect to develop the targets on the reduction of cervical cancer? These would be helpful to have to plan our advocacy.
Answer: The target setting is a complex process. Ensuring that cervical cancer becomes a rare cancer will take a long time to achieve and modelling shows that even with the most optimistic expectations to scale up services it will take a long time. We need earlier targets that speak to levels of vaccine coverage, and numbers of countries vaccinating and screening. This is being discussed with the group being convened by WHO. PEPFAR is working in parallel to the WHO process and they have laid out some targets around screening in the eight African countries that have included this in their country operational plans.

Question: Regarding the third dose for women living with HIV – is that a booster shot or does it start the process of creating antibodies.
Answer: This is a booster. When this vaccine was developed it came as a three dose vaccine: one primer and then two primers. Over time it became clear that young girls do not need the third dose and then have more time between the first and the second dose, which makes the booster stronger. Sticking to the three dose regime is to prime the immune system which is sometimes weaker. The complication comes when school girls are vaccinated. There is a small cohort of girls that are living with HIV and not easily identified. This is where integration becomes essential so that those who are on treatment can get their third dose without being singled out.

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Comment: In Zimbabwe women are screened and are referred to another part of the hospital if they have pre-cancerous cells or cervical cancer. HPV screening is free if it is in government facilities but the biggest challenge comes when a woman has cervical cancer and then does not have access to any of the treatment. Women are asking what the point of screening is if we have no access to treatment. "The other issue is that women living far from the centres and when you present late, women are scolded and blamed for what is happening to them."
Comment: In Bolivia the screening is available but the surgery if needed, is so complicated for women living with HIV. We have serval women who died of cervical cancer, which is widespread in Bolivia. The issues we have is around stigma. We sent a proposal to the MoH to request that women living with HIV are offered pap tests inside HIV clinics. Many women living with HIV are unable to go to any clinic given the stigma. This has been challenging and women are lying about their HIV status to access services. The problem with most women in Bolivia is the pap test is not popular because of the stigma associated with being a woman getting touched by a male doctor. We try to get women to go early enough but women, most of them are afraid.

Response from UNAIDS to the comments: The real challenge is to screen women and diagnose them in the early stages when it is fairly easy to treat. There are ways that one can treat the cells at the surface of the cervix as it is found and is different to the invasive surgery for cervical cancer.

FINAL COMMENTS: The Global Fund is happy to have follow up discussions on country level processes. The Global Fund is in the process of producing analysis over the grants including a gender analysis of grants. This will help to get more granular information of the funding around cervical cancer, which is often embedded in the grants. They would be eager to have a discussion (perhaps supported by Women4GlobalFund) to talk about what they are funding and if we collectively feel we need to proactively fund more around cervical cancer. We need to start strategies about now and think about the opportunities that this campaign brings. The Global Fund would see most possibilities to support programmes and services in Southern Africa around cervical cancer at the right scale that would make a difference.

UNAIDS: There is a lot that women living with HIV can be doing. We need to ensure that the cervical cancer is brought into HIV platforms and the women's rights platforms such as Women Deliver. This increases advocacy, information sharing and demand creation. BETEAMWOMEN has a facebook live session on cervical cancer on January 31st.

"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 denied care because of my HIV status"

9. Webinar Participants

17 participants joined the webinar, from Africa, the Caribbean, Europe, and Latin America, including: Ms Florence Anam, Dr Gcinashe, Ms Joyce Ouma; Ms Kristen de Graaf, Ms Lahaila Dunn, Ms Olive Edwards, Ms Resty Nalwanga, Ms Violeta Ross. Representatives from UNAIDS included: Dr Deborah von Zinkernagel, Director, Community Support, Social Justice and Inclusion; Ms Kreena Govender, Programme Officer, Human Rights and Gender; Dr Peter Godfrey-Faussett, Senior Science Adviser; and Ms Kaitlin Mitchell. WHO was represented by Dr Paul Bloem, Expanded Programme on Immunization Plus and Ms Lucinda O'Hanlon. The Global Fund was represented by Ms Heather Doyle, Senior Coordinator, Gender, Strategy, Investment & Impact Division (SIID). The Salamander Secretariat was represented by Ms Alice Welbourn and Ms Sophie Dilmitis.

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