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No more neglect

Female genital schistosomiasis and HIV

Integrating sexual and reproductive health interventions to improve women's lives

Contents

Foreword

Tedros Adhanom Ghebreyesus, Director-General, World Health Organization
Winnie Byanyima, Executive Director, Joint United Nations Programme on HIV/AIDS

Neglected tropical diseases continue to affect people who live under dire socioeconomic conditions in the poorest parts of the world — people who the global health and development community have promised not to leave behind. Female genital schistosomiasis (FGS), a manifestation of schistosomiasis, is a waterborne neglected tropical disease of poverty affecting 56 million African women and girls. Yet FGS remains underreported, under- and misdiagnosed and largely untreated.

FGS is a silent and neglected epidemic, affecting the same people who carry a disproportionate global burden of HIV and cervical cancer. FGS exemplifies the experiences of marginalized women and girls, who face multiple and intersecting health, sociocultural, environmental and economic challenges.

Human schistosomiasis (commonly known as snail fever or bilharzia) remains a significant public health problem in many tropical settings, mainly in Africa and the Middle East. At least 228 million people require treatment for schistosomiasis, and up to 659 million people are at risk, at any one time.

FGS results from untreated infection with *Schistosoma haematobium* acquired through contact with contaminated freshwater bodies used by rural communities, particularly women and girls, for their daily chores and livelihoods. Signs of FGS include vaginal bleeding, genital ulcers, pain and dyspareunia. FGS can gradually evolve towards reproductive organ damage characterized by sub-fertility or infertility, ectopic pregnancy, spontaneous abortion, premature birth, low birth weight and maternal death. Furthermore, there is concern and biological plausibility that FGS increases susceptibility to HIV. Research and information on FGS-related stigma and discrimination are sparse.

The suffering of women and girls living with FGS is avoidable. Chronic lesions can be prevented by regular treatment with praziquantel when started at an early age and continued throughout life. Since 2007 the Merck Praziquantel Donation Program has led to the provision of over 700 million tablets to treat schistosomiasis. Yet these efforts have been undermined by health-system challenges.

Sub-Saharan adolescent girls and young women (aged 15-24 years) also carry a disparate burden of vulnerability to HIV. Every week an estimated 6200 new HIV infections occur in this age group alone, with sub-Saharan African girls accounting for the majority of new infections. An alarming 7 in 10 young women in this region do not have comprehensive knowledge about HIV. Information measuring young women's agency and power in making decisions about their own health is similarly concerning.

At the same time, women from lower — and middle — income countries bear a disproportionate burden of cervical cancer. This is an avoidable tragedy, as cervical cancer is one of the most preventable and curable forms of cancer. Yet every year, more than half a million women are diagnosed with cervical cancer, and more than 300 000 women die from the disease.

Nine of 10 women who die from cervical cancer are from poor countries. Women living with HIV are four to five times more likely to develop invasive cervical cancer, are more vulnerable to persistent human papillomavirus infections, and can develop pre-cancerous lesions faster.

The unacceptable and disparate global burden of disease borne by African women and girls highlights the gaps and inequalities in access to vital health services. To break this cycle of inequality and ensure that women and girls thrive, we need integrated services for HIV and sexual and reproductive health and reproductive rights, to improve access, efficiency and redress these global, regional and national disparities.

Against this backdrop this report highlights the need for universal health coverage with integrated services for prevention, care and treatment for schistosomiasis, HIV and cervical cancer, along with socioeconomic development and the advancement of gender equality. To meet our obligations to the most vulnerable women and girls, we must join together to move from neglected to prevented.

Abbreviations

FGS	female genital schistosomiasis
HPV	human papillomavirus
PEPFAR	United States President's Emergency Plan for AIDS Relief
SDG	Sustainable Development Goal
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Executive summary

Approximately 56 million girls and women in sub-Saharan Africa are estimated to be affected by female genital schistosomiasis (FGS). FGS is a manifestation of the neglected tropical disease schistosomiasis (also known as snail fever or bilharzia) *(1)*. It is caused by parasitic worms called schistosomes. Human schistosomiasis is transmitted in areas where fresh water is contaminated with schistosome larvae.

Of the estimated 220 million people requiring preventive chemotherapy for schistosomiasis, more than 90% live in Africa *(1,2)*. The two major forms of schistosomiasis are intestinal and urogenital. *Schistosoma haematobium* is the species most commonly associated with urogenital schistosomiasis, whereas intestinal schistosomiasis may be caused by five species: *S. guineensis*, *S. intercalatum*, *S. japonicum*, *S. mansoni* and *S. mekongi*. Approximately two-thirds of all cases of schistosomiasis are attributed to infection with *S. haematobium*.

Schistosoma haematobium eggs cause inflammation and lesions in the urinary and reproductive organs. When the eggs lodge in the genital tract they cause genital schistosomiasis. Although the disease occurs in men and boys, it has a disproportionate impact on women and girls. The symptoms of FGS include vaginal discharge, bloody discharge, bleeding or spotting after intercourse, genital itching or burning sensation, pelvic pain, and pain during or after intercourse. Potential complications of FGS include infertility, spontaneous abortion or ectopic pregnancy, involuntary urination when coughing, laughing or jumping, genital ulcers, and tumours or swelling in the vulva, vagina or cervix. FGS is characterized by irritation of the vaginal walls and ulcers in the cervix, which may increase a woman's risk for acquisition and transmission of HIV. FGS is also characterized by the formation of granulomas around schistosome eggs in the vaginal mucosa; the cells in these granulomas have a high density of the receptors that HIV requires to enter the cell. Genital ulcers of any kind are associated with an increased risk of HIV acquisition and transmission.

Schistosoma haematobium lesions in children can be reversed by treatment, thus preventing FGS *(3)*. Lesions of the lower genital tract are much more difficult to treat in adulthood. Regular praziquantel treatment during childhood and adolescence at a cost of US$ 0.08 per tablet *(4)* and delivered in large-scale programmes is cost-effective. It has been estimated that 70 million children at risk of *S. haematobium* infection could be treated at a cost of US$ 22 million annually. The World Health Organization (WHO) strategy for control of schistosomiasis is routine mass administration *(5)* of praziquantel to school-aged children, who are at greatest risk for schistosomiasis infection because of their immature immune systems *(6)*.

Programmes for prevention through routine mass administration of medicine and treatment should also include other interventions, including initiatives to change behaviour and engaging community health-care providers. Water, sanitation and hygiene programmes are other key components of a sustainable schistosomiasis control strategy and can reduce the effect of FGS on sexual and reproductive health, as such

programmes contribute to preventing reinfection. Engaging communities and civil society, including sexual and reproductive health and rights organizations and networks of women living with HIV, is also critical to the success of FGS prevention programmes, as a lack of knowledge and understanding of FGS within communities and among local health workers can be a significant hurdle in the elimination of FGS. Furthermore, established community organizations are an important ally with regard to advocacy, communication, and increasing demand for and acceptability of programmes. Simple, clear messaging and communications materials on schistosomiasis and FGS prevention, treatment and care are important tools and must be made available (7). Given the associations between HIV and FGS, and considering that African women and girls bear a disproportionate burden of both health issues, existing HIV prevention and treatment programmes can play a strategic role with regard to scaling up FGS prevention and control.

The aim of this brief is to raise awareness about schistosomiasis and FGS and their potential effects on increasing HIV vulnerability, particularly among adolescent girls and young women in sub-Saharan Africa, who are also among those most affected by the HIV epidemic *(8)*. Building on WHO policy and the Consolidated Guideline on Sexual and Reproductive Health and Rights of Women Living with HIV *(9)*, which upholds that "an integrated approach to health and human rights lies at the heart of ensuring the dignity and well-being of women living with HIV", integrating FGS prevention and control with existing sexual and reproductive health and HIV services could contribute to improving the long-term health and well-being of women and girls in the African region. This brief is also useful for decision-making at the global, regional and national levels, supporting the design and implementation of programmes, mobilizing resources and resource allocations, and investing in high-quality integrated programmes that meet the specific sexual and reproductive health and rights and HIV needs of women and girls—thereby contributing to achievement of the Sustainable Development Goals (SDGs), particularly good health and well-being (SDG 3), gender equality (SDG 5) and reducing inequality (SDG 10).

This brief includes recent scientific evidence on the association between HIV and FGS and epidemiological data showing that treatment of schistosomiasis in childhood may prevent future HIV transmission. More research and evidence are needed, however, to fully understand the links between the two diseases, the sociocultural and economic barriers to FGS prevention and control, and FGS-related stigma and discrimination that hinder access to services.

Partnerships between epidemiologists, researchers, health and gender ministries, policy-makers, nongovernmental organizations, community health workers, the private sector, and community and civil society partners will be important to better understanding the links and ultimately improve the sexual and reproductive health outcomes of women and girls affected by HIV and FGS.

There are a number of actions that policy-makers at all levels can take to address the health and well-being of women and girls in all their diversity:

- Promote the synergies among programmes for schistosomiasis and FGS prevention and control with existing HIV and sexual and reproductive health and rights programmes, including services for family planning, treatment of sexually transmitted infections and human papillomavirus, and cervical cancer prevention and control.
- Leverage HIV and other sexual and reproductive health and rights platforms to increase understanding of FGS prevention and control and to improve awareness about and uptake of the WHO policy on schistosomiasis.
- Mobilize and engage civil society and community organizations, including networks of women living with HIV and sexual and reproductive health and rights advocates, in the design, implementation and monitoring of FGS programmes to support community outreach to raise community awareness and demand creation.
- Make long-term investments in training, biomedical infrastructure, research and human resources for successful implementation of FGS prevention and control programmes.
- Conduct more research on the links between FGS and HIV, the effects of early treatment of FGS on reducing HIV infection, the sociocultural and economic barriers to FGS prevention and control, and FGS-related stigma and discrimination that hinder access to services.

The target audiences for this brief are ministries of health and gender; policy-makers; nongovernmental organizations; health-care workers; civil society and community organizations, including sexual and reproductive and rights health activists and women living with HIV; and potential private-sector partners.

Key messages

"MILLIONS OF YOUNG WOMEN IN SUB-SAHARAN AFRICA ARE AT RISK OF FEMALE GENITAL SCHISTOSOMIASIS (FGS), HIV INFECTION AND CERVICAL CANCER, AND THE PREVALENCE OF FGS IS UNDERESTIMATED."

Female genital schistosomiasis is a neglected tropical disease that affects the most vulnerable communities

Schistosomiasis is prevalent in tropical and subtropical areas in communities of poor people without access to potable water or adequate sanitation. It is common in rural areas and in underdeveloped urban areas where communities rely on open surface water sources such as rivers, streams and lakes for work or daily chores.

It is estimated that > 200 million people require preventive treatment for schistosomiasis worldwide. About 90% of these live in sub-Saharan Africa *(8)*, of whom an estimated 20 million are adolescent girls aged 12-19 years *(7)*.

Female genital schistosomiasis is currently underdiagnosed, with grave implications for women's sexual and reproductive health

Up to 56 million women in sub-Saharan Africa have FGS. FGS results from entrapment of schistosome eggs in the vagina, cervix, uterus, fallopian tubes or vulva *(10)*. When FGS is untreated, it frequently damages the reproductive organs irreversibly *(11-13)*, and can lead to infertility, ectopic pregnancy or maternal death *(3,14)*. The signs and symptoms of FGS are often mistaken for those of cervical cancer or sexually transmitted infections, and misdiagnosis can lead to multiple visits to health-care professionals, with an increased burden on the patient and the health-care system.

Praziquantel is the only medicine that can treat schistosomiasis. It is included in the WHO List of Essential Medicines. Since 2007 the German pharmaceutical company Merck, through the Merck Praziquantel Donation Program has donated approximately 700 million praziquantel tablets through WHO to endemic countries to implement large-scale preventive treatment of school-aged children.

Women living with female genital schistosomiasis are at greater risk of HIV infection and poor sexual and reproductive health

Gender inequalities, including the epidemic of gender-based violence, fuel the HIV epidemic among women and girls.

Globally in 2017 there were 720 000 adolescent girls aged 15-19 years living with HIV; 87% of these were living in sub-Saharan Africa. Every week, an estimated 6200 girls and young women aged 15-24 years acquire HIV, with sub-Saharan African girls accounting for the majority of new infections. Yet an alarming 7 in 10 young women in this region do not have comprehensive knowledge about HIV. Evidence from locations with high HIV prevalence in sub-Saharan Africa suggests that intimate partner violence increases HIV vulnerability, and that violence (or the fear of violence) is associated with lower treatment access rates, lower treatment adherence rates, and lower rates of viral suppression among women and girls *(15)*.

In this region, AIDS-related conditions are the second leading cause of death in adolescent girls and young women who are 44% more likely to acquire HIV than their male counterparts *(16)*.

FGS is characterized by weakness of the vaginal mucosa an d ulcers in the cervix, leading to contact bleeding during sexual intercourse, which is thought to increase a woman's risk for HIV acquisition, in the same way that ulcerative sexually transmitted infections increase susceptibility to HIV infection *(17-19)*. Cross-sectional studies in Mozambique, the United Republic of Tanzania and Zimbabwe showed that adult women with FGS were three to four times more likely to be living with HIV than women without FGS *(10,20-23)*. Adolescent girls with FGS had a higher proportion of HIV receptors on their genital tissue cells than those without FGS *(24)*.

Female genital schistosomiasis can be prevented at low cost

FGS usually starts in childhood and can become a chronic debilitating disorder. Women who have been treated with praziquantel at least once before age 20 years are 50% less likely to develop FGS later in life *(25)*.

WHO recommends several annual rounds of praziquantel treatment in childhood to prevent urogenital schistosomiasis *(26)*. Since 2007 the pharmaceutical company Merck has donated praziquantel through WHO to endemic countries for large-scale preventive treatment of school-aged children *(27)*. Since the beginning of the programme, approximately 700 million tablets have been provided free of charge. In 2012 Merck pledged to increase its annual donation to 250 million tablets a year, enough to treat 100 million school-aged children annually. At a cost of US$ 0.08 per tablet and an average of 2.5 tablets required per child, the cost per treatment will be only US$ 0.20 per school-aged child.

Prevention and treatment of female genital schistosomiasis is an issue of social justice and sexual and reproductive health and rights

The mainstay of schistosomiasis control is routine mass administration of medicine, usually for school-aged children, in which participation and compliance are based on informed parental consent and WHO guidelines *(1,26)*. Yet, there exists significant gender disparities and inequalities in access to education and schooling. According to UNESCO, in 2016 at least half of youth between the ages of 15 and 17 in sub-Saharan Africa were not in school. In total, more than 93 million children and youth of primary and secondary school ages are out of school across the region. Furthermore, across sub-Saharan Africa, 9 million girls will never attend school compared to 6 million boys, a disparity which starts at an early age in the region, where 23% of all girls compared to 19% of all boys are out of primary school. Mass administration of medicines, for schistosomiasis and FGS prevention and control, should therefore take into account these gender disparities and ensure outreach to girls both in and out of school.

An approach based on sexual and reproductive health and rights and human rights must also include principles of non-discrimination, equality and accountability.

All individuals have a right to the highest attainable standard of health. Health-care and services should be available, accessible, acceptable, of good quality, and free from stigma and discrimination *(28,29)*. Schistosomiasis is a neglected tropical disease, and therefore a human rights issue, typically endemic among the poorest, most marginalized communities, reflecting social inequalities in health and lack of access to high-quality sexual and reproductive health services *(30,31)*.

Health systems must deliver high-quality gender-sensitive integrated HIV and sexual and reproductive health and rights services, including for FGS. The Convention on the Elimination of all Forms of Discrimination Against Women established access to health-care, including reproductive health, as a basic right *(32)*. Full realization of women's right to health can be achieved only when governments fulfil their obligations to respect, protect and promote women's fundamental human right to health-care. To eliminate discrimination against women in health-care, health legislation, plans and policies must address conditions that are hazardous to women's health. While any demographic group, irrespective of age or gender, that is in contact with unsafe water is at risk of schistosomiasis infection, social roles and gender norms place different groups of men, women, boys and girls at different risks. The gender roles of women and girls in households, such as washing clothes and dishes and collecting water for household consumption, places them in almost continual contact with water *(7)*. At the same time, women and girls, in particular adolescent girls and young women aged 15-24 years, are also at higher risk of HIV in sub-Saharan Africa: in eastern and southern Africa, young women acquire HIV 5-7 years earlier than their male peers. In 2017 there were on average 6200 new HIV infections among girls and young women aged 15-24 years every week. In eastern and southern Africa, there were 2.4 HIV infections among young women aged 15-24 years in 2018 for every 1 infection among young men of the same age; in western and central Africa, there were more than twice as many HIV infections among young women than young men *(33)*. In areas with high HIV prevalence and endemic schistosomiasis, FGS may contribute to this gendered dynamic and the disproportionate burden of HIV on young women and adolescent girls. Understanding the gendered risks and vulnerabilities of women and girls is important when developing strategies and implementing programmes for schistosomiasis prevention and control *(7,34)*. Recognizing that women and girls often face layered and intersecting socioeconomic and health issues, the global health community and policy-makers and health systems must deliver high-quality, gender-sensitive integrated HIV and sexual and reproductive health and rights services, including for FGS. A rights-based gendered approach to FGS prevention and control will ensure that communities in areas endemic for schistosomiasis not only have access to diagnosis and treatment but also are aware of how to prevent the disease, including understanding the signs and symptoms. Building on lessons learned from the HIV response, information should be disseminated in affected areas, including through existing health and comprehensive sexuality programmes. Engaging civil society and community networks, including networks of women living with HIV and sexual and reproductive health and rights advocates, is key.

Partnerships, integrated programmes, and expansion of interventions are needed

Effective mass administration of medicine programmes reduce morbidity from all types of schistosomiasis and their sequelae. Such programmes are usually conducted in partnership with ministries of gender, health and education, schools, nongovernmental organizations, the pharmaceutical industry and national governments *(34)*.

An effective control programme requires a comprehensive human rights-based approach, emphasizing the principles of community participation and informed consent. It may also be linked systematically to other health promotion interventions including vaccination campaigns, in particular HPV vaccination.

FGS is rarely mentioned in medical textbooks or literature on HIV transmission and genital inflammation *(16,35)*. Existing programmes on sexual and reproductive health and rights and HIV could be used to inform medical professionals, affected communities and civil society organizations, including networks of women living with HIV, about FGS prevention and control. Programmes such as Determined, Resilient, Empowered, AIDS-free, Mentored and Safe Women (DREAMS), a joint initiative between the United States President's Emergency Plan for AIDS Relief (PEPFAR), the Bill & Melinda Gates Foundation, the Girl Effect, Johnson & Johnson, Gilead Sciences and ViiV Healthcare in 14 African countries (Botswana, Cote D'Ivoire, Eswatini, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe) and Haiti, could be used to create synergy in advocacy, communication and services for the prevention and control of FGS.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) Youth PACT, a vibrant coalition of more than 80 organizations working collaboratively and strategically in the global HIV response, could be leveraged to advocate among and mobilize support from youth networks and organizations. Information on FGS could also be included in comprehensive sexuality education in schools.

Schistosomiasis prevention for preschool children could be integrated into programmes for child health services, such as when their weight is monitored and when they are vaccinated, dewormed and given micronutrient supplements.

Integrated services for HIV and schistosomiasis prevention can be extended to include primary prevention for cervical cancer—human papillomavirus vaccinations for girls aged 9-13 years before sexual debut *(36)*.

Control of FGS also entails interrupting the cycle of transmission of infection. Ensuring safe water supplies and reducing contact with infected water sources, whether for work, daily chores (Figure 1) or recreation (Figure 2), is the long-term solution to the prevention of urogenital schistosomiasis. Water, sanitation and hygiene education is therefore a critical component of an integrated control and elimination strategy *(37)*.

Holistic layered approaches that address the multiple and intersecting health, socioeconomic and environment issues faced by women and girls, combined with medical interventions, will be the most effective. Poverty, gender inequality, stigma and discrimination, and poor access to education, which undermine women and girls' sexual and reproductive health, must also be addressed.

Figure 1.
Schistosomiasis can be transmitted at sites where women wash clothes

Photo: Håvard Holme

Figure 2.
Infants and young children are exposed to a risk of schistosomiasis when playing

Photo: Håvard Holme

Research and development are crucial

Further research, investigation and evidence are needed on the associations between FGS and HIV and on the treatment of FGS lesions, as chronic genital lesions cannot be reversed with the standard single-dose regimen of praziquantel *(38)*. Non-invasive objective diagnostic methods should be found. The optimal timing of treatment for prevention of genital lesions and HIV infection should be established, with a long-term study on how the lesions can be reversed and on how treatment of chronic calcified lesions and severe inflammation affect the risk of HIV acquisition and disease progression. The clinical and histological courses of *S. haematobium* infection should be explored. Early and late lesions should be identified to provide the right treatment and inform patients correctly.

Research on the sociocultural, economic and environmental barriers to women accessing FGS prevention, treatment and care and FGS-related stigma should be conducted in order to inform and guide design and implementation of programmes and services.

Actions for stakeholders

Stakeholders at all levels, and particularly policy-makers, can undertake a variety of actions to improve the prevention of FGS and HIV infection:

- Increase mass administration of medicine for schistosomiasis to "leave no one behind", by ensuring participation including in programme design, implementation, monitoring and informed community consent.
- Where necessary, integrate sexual and reproductive health and rights and HIV programmes and services, including for the prevention, care and treatment of HIV, cervical cancer and FGS.
- Use existing health-care delivery systems, including for HIV and cervical cancer prevention and control, to increase FGS prevention, screening and treatment, and to address possible discrimination in health-care settings and stigma associated with sexual and reproductive conditions.
- Improve awareness through increased advocacy and communications about FGS, human papillomavirus, cervical cancer and HIV among key affected communities through age-appropriate, youth-friendly sexuality education programmes in and out of schools, women-centred campaigns, and programmes among medical and health professionals.
- Improve training and capacity-building of medical, community and health-care professionals on FGS prevention and control, including identification of symptoms and treatment.
- Implement water, sanitation and hygiene programmes concomitantly with biomedical interventions for FGS.
- Leverage existing HIV programmes to increase knowledge and awareness of FGS among affected communities and their health-care providers.
- Support research to improve the diagnosis and clinical management of FGS, in combination with or independently of HIV infection.
- Advocate for clinical trials to strengthen evidence on the links between FGS and HIV infection.
- Conduct research on community perceptions of interventions to control schistosomiasis and FGS.

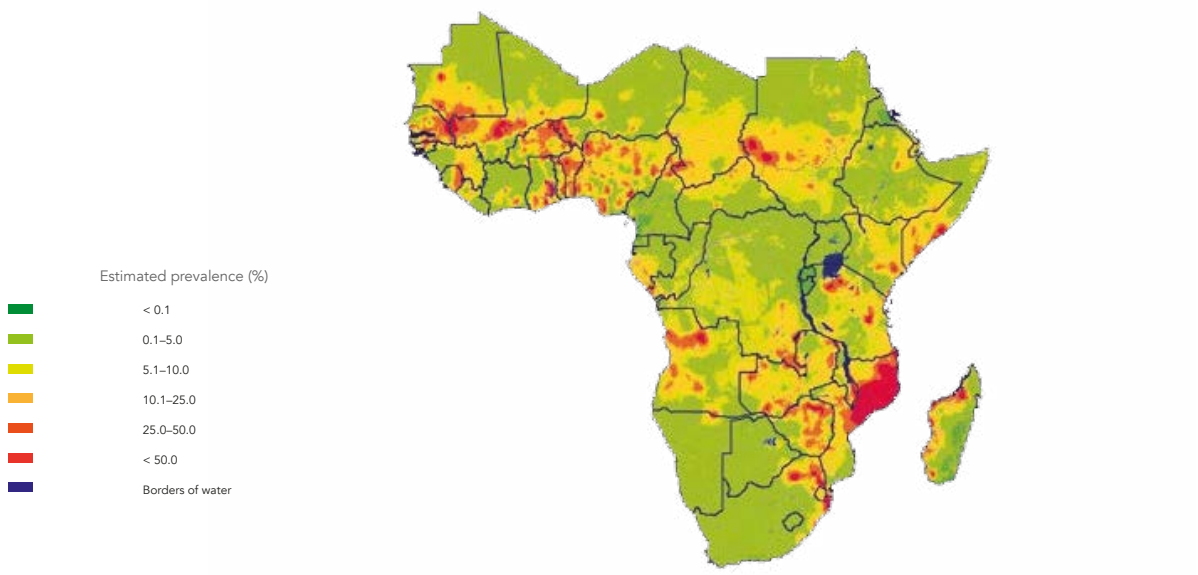
- Broaden collaboration and partnerships, including with community health-care workers and civil society, in order to scale up and support the integration of high-quality gender-sensitive services for HIV, cervical cancer and FGS prevention, control and care.
- Ensure continued engagement and leadership of civil society and communities in the design, implementation and monitoring of high-quality and acceptable integrated sexual and reproductive health and rights and HIV services, which address the multiple and intersecting needs of women and girls in all their diversity.

Global epidemiology of female genital schistosomiasis

FGS is a condition related to infection with a waterborne parasitic disease. It is caused by infection with the blood parasite *S. haematobium (39).* Transmission occurs through skin contact with larvae (cercariae) in contaminated fresh water in more than 44 countries in sub-Saharan Africa *(40).* Figure 3 shows estimates of the prevalence of *S. haematobium* in this region.

Of all women and girls infected with *S. haematobium, 75%* have lesions in the uterus, *cervix,* vagina or vulva *(41,42).* Many have genital schistosomiasis without urinary excretion of *S. haematobium* eggs.

Figure 3.
Estimated prevalence of *Schistosoma haematobium* in sub-Saharan Africa



Source: WASH and health working together: a "how-to" guide for neglected tropical disease programmes. Geneva: World Health Organization; 2019 (https://www.who.int/water_sanitation_health/publications/wash-health-toolkit/en/).

Figure 4 shows the direct association between FGS and the prevalence of urogenital schistosomiasis *(43)*. In some areas endemic for schistosomiasis, FGS may be the most common cause of genital lesions *(17)*. Very few countries have readily available data on FGS *(44)*. An estimate of 3.3 million disability-adjusted life-years attributed to all types of schistosomiasis *(45)* did not include disability associated with FGS, indicating a worrying underestimate of disability associated with this form of schistosomiasis.

Figure 4.
Association between urinary schistosomiasis and female genital schistosomiasis

Source: Adapted from Poggensee G, Kiwelu I, Saria M, Richter J, Krantz I, Feldmeier H. Schistosomiasis of the lower reproductive tract without egg excretion in urine. Am J Trop Med Hyg. 1998;59:782-3.

After exposure to infected water, larval flukes burrow into the skin, where the immature larvae take four to six weeks to mature into adult worms in the urinary bladder network of veins *(39)*. Adult female *S. haematobium* worms start to shed eggs as early as four weeks after infection. These eggs travel through the blood vessels to the pelvic and urinary organs, where some are trapped in the tissue linings and some are shed into urine, semen or vaginal secretions *(46)*. The entrapped eggs frequently cause irreversible reproductive organ damage, leading to infertility, subfertility, pain during sexual intercourse and genital symptoms *(46-49)*. Lesions can start to develop in early childhood, soon after exposure, although this has not been explored fully *(47,50)*. Both the symptoms and the complications of FGS in women can affect their mental health and social status; infertility, spontaneous abortion, and presentation of symptoms similar to those of sexually transmitted infections may be taboo in many cultures and lead to stigmatization and social exclusion.

Association between female genital schistosomiasis and HIV

An association between *S. haematobium* and HIV infection has been documented in several observational studies *(17-19)*. Cross-sectional studies in Mozambique, the United Republic of Tanzania and Zimbabwe showed that adult women with FGS were three to four times more likely to have HIV infection than women without FGS *(10,20-23)*. In a study in Zambia, schistosomiasis was associated with increased HIV infection in both sexes and higher acquisition of HIV in women *(51)*. The integration of effective prevention and treatment strategies for schistosomiasis, including in urban areas, may therefore support HIV prevention strategies in areas endemic for schistosomiasis.

Adolescent girls with FGS have a higher proportion of HIV receptors on their genital tissue cells than those without FGS *(24)*. FGS is often present before sexual debut in areas where *S. haematobium* is endemic, and several studies have shown that females with schistosomiasis are more likely to have HIV infection *(20,52)*. Two mechanisms may be responsible: (i) an increased number of HIV receptor cells in FGS lesions; and (ii) physical damage of the vaginal and cervical mucosa *(52-54)*.

FGS causes lesions in the cervix and vaginal mucosa in young women, creating ideal conditions for HIV transmission due to contact bleeding during sexual intercourse. A longitudinal study in the United Republic of Tanzania showed that women infected with schistosomes had a nearly three times greater incidence of HIV infection, although many were infected with *S. mansoni*, an intestinal infection that is also associated with genital lesions but is not the main cause of FGS *(55)*. HIV transmission through schistosomal lesions in the genital tract must be prevented. Clinicians are generally unaware of FGS and should be trained to identify signs and symptoms of this disease. To improve awareness and diagnosis of FGS, WHO has prepared an illustrated pocket guide on the clinical manifestations of FGS *(56,57)*, which should be distributed during training and awareness campaigns, used for training trainers, and incorporated into nursing and medical curricula *(57)*.

A small survey of women with *S. haematobium* infection indicated an association with high-grade cervical squamous neoplasia *(58)*. If this association is validated in larger studies, then control of human papillomavirus to prevent cervical cancer might have to be increased in areas endemic for urogenital schistosomiasis, with screening for FGS and preventive mass administration of medicine for schistosomiasis. Public health interventions should therefore not only be for the control of schistosomiasis but also be integrated into other health-care programmes. Table 1 shows how HIV services could be integrated with prevention and control of schistosomiasis, FGS and cervical cancer.

Table 1.
Age-appropriate health action for prevention and treatment of HIV, sexually transmitted infections, female genital schistosomiasis (FGS), human papillomavirus (HPV) and cervical cancer in regions endemic for *S. haematobium*

Life stage	Target programmes	HIV and STI interventions	SCH/FGS interventions	Opportunities for integration with selected interventions[1]		Community mobilization, education and counselling
				HIV interventions	Cervical cancer interventions	
Infants and young children < 5 years	▸ Ante/Peri- and postnatal care ▸ MCH clinics ▸ Immunization, immunization clinics and campaigns ▸ Preventive care through UNICEF's IMCI (Integrated management of childhood illnesses) e.g. integrating praziquantel for preschool children is a preventive strategy for FGS prevention		Voluntary HIV testing services Test-and-treat for urinary schistosomiasis (dipstick urinalysis for microhematuria or other[2]) for mothers and children Treatment with praziquantel of positive mothers and children[3]	Test-and-treat for urinary schistosomiasis (dipstick urinalysis for microhematuria or other) for mothers and children Voluntary HIV testing for mothers and children Treatment with praziquantel of positive mothers and children Systematic treatment in high endemic areas		HIV counselling for mothers Promotion of behavior change for schistosomiasis treatment and prevention, including safe bathing practices for infants and children HIV, schistosomiasis/ FGS and HPV/cervical cancer awareness building and information Discuss with mothers/ carers about signs and symptoms of FGS, STIs, and cervical cancer; referral to appropriate services if indicated Community-based outreach and demand generation for accessible uptake of treatment and demand for water and sanitation services including through community health clubs, community WASH management groups
Primary school children	▸ School health programmes ▸ School feeding programmes ▸ Programmes targeting non-enrolled children		Age appropriate comprehensive life skills education Regular treatment with praziquantel as part of deworming programmes (frequency according to level of endemicity and WHO recommendations) Possible extension of deworming to non-enrolled siblings Safe water and (girl-friendly and inclusive) toilets in school	Extension of deworming to non-enrolled siblings Safe water and (girl-friendly) toilets in school	HPV vaccination Possible extension of HPV vaccination to include siblings and non-enrolled children in recommended age-range in same communities	Education on schistosomiasis and other communicable and/or tropical diseases in the area Age-appropriate, comprehensive life skills education, including for HIV

1 During the high level meeting a number of additional entry points for integration of FGS interventions into SRHR and broader health services were also identified including Expanded Program for Immunization, Maternal and Child Health Clinics, School Health programs and school clubs, Water, Sanitation and Hygiene interventions.

2 Antigen-based urine dipstick under development

3 Paediatric formulation of praziquantel under development

Life stage	Target programmes	HIV and STI interventions	SCH/FGS interventions	Opportunities for integration with selected interventions		Community mobilization, education and counselling
				HIV interventions	Cervical cancer interventions	
Adolescent girls 12-19 years	▸ Secondary school health programmes ▸ other programmes targeting adolescents, both in and out of school e.g. migrant and vulnerable populations	Offer voluntary HIV testing services as appropriate; refer to health services for further care if indicated Discuss about risk of schistosomiasis; test-and-treat for urinary schistosomiasis if indicated Alternatively, regular responsive and context specific large-scale treatment in areas highly endemic for schistosomiasis Safe water and (girl-friendly and inclusive) toilets in school Age appropriate comprehensive life skills education	Query them about risk of schistosomiasis; test-and-treat for urinary schistosomiasis if indicated Alternatively: regular large-scale treatment in areas highly endemic for schistosomiasis	Catch-up HPV vaccination as appropriate		Provide youth-friendly, gender-aware and age-appropriate comprehensive SRHR education, including HIV, STIs, FGS and cervical cancer; referral to appropriate services if indicated Hygiene education, including menstrual health Age appropriate comprehensive sexuality education including counselling on condom use and safe sex practices of sexually transmitted infections Community-based outreach, including demand generation for sexual and reproductive health services
Women > 20 years	▸ Pre-natal care and MCH programmes ▸ family planning ▸ HIV screening and prevention programmes ▸ sexual and reproductive health clinics ▸ other programmes targeting women of reproductive age	Offer voluntary HIV testing services; refer to health services Discuss with women about risk of schistosomiasis; test-and-treat for further urinary schistosomiasis if indicated Evaluate additional risks and whether PrEP is indicated. Comprehensive sexual and reproductive health and rights information and services	Discuss with women about their risk of schistosomiasis; test-and-treat and refer to health services for urinary schistosomiasis further care if indicated For women with infertility, screen and treat for FGS where indicated	Promote regular cervical cancer screening/ colposcopy in appropriate age-group; provide and facilitate access to cervical cancer screening services; include screening and treatment for FGS in cervical cancer screening services		Provide information on symptoms and risks of HIV infection, STIs and FGS; Query women about signs and symptoms of FGS, STIs, and cervical cancer; facilitate referral to appropriate services if indicated Hygiene education, including menstrual health Train physicians to begin colposcopy for women at younger ages and to recognize/ diagnose and treat FGS Community-based outreach, including demand generation for FGS prevention interventions Reproductive health services engaging and strengthening existing community-based mechanisms such as women's groups, maternal and child health clinics and village health clubs

Mathematical modelling suggests that adequate prevention and control of FGS with administration of praziquantel to school-aged children should decrease the incidence of HIV infection among women and girls aged 15-24 years in high-risk areas *(3,59)*. Monitoring and evaluation of mass administration of medicine programmes should include data on FGS and HIV status in affected communities.

Currently, a person with symptoms of genital infection or infertility is managed clinically as having a sexually transmitted infection or cancer *(10,56,60)*. Diagnosis of FGS is best made from specimens taken with speculums during gynaecological examinations, such as in cervical cancer screening, including among adolescent girls and young women *(36)*. As new techniques for human papillomavirus diagnosis are introduced, health systems must be aware of the implications for diagnosis of FGS. Currently, diagnosis of FGS in sub-Saharan Africa is limited to very few referral hospitals, where expensive colposcopy is available. It will be essential to train health personnel in low-resource settings in identifying lesions *(57)*. Health workers increasingly use mobile phones for diagnosing cervical cancer *(61,62)*. Through telemedicine, remote experts can provide differential diagnoses for genital tract pathology, including FGS *(63)*. The increasing availability of smartphones in developing countries has the potential of supporting FGS diagnosis through capture and interpretation of characteristic lesions indicative of the disease *(64,65)*. In all situations issues pertaining to confidentiality, dignity and privacy are of ethical concern and must be respected.

Girls and women found to have FGS should be treated with praziquantel to prevent further disease and to decrease the number of cells with increased density of HIV-selective receptors around the schistosome egg in the genital mucosa *(24,66)*. Additionally, women experiencing infertility with a history of travel or resident in schistosomiasis endemic areas should receive praziquantel as part of their treatment protocol.

HIV and FGS surveillance can be modified to suit the needs of affected communities. In zones with a known or suspected high prevalence of schistosomiasis, sentinel surveillance sites should be established given that potentially contaminated water sources provide indication for screening adolescent girls and young women for FGS and cervical cancer which would benefit the community. HIV testing would be targeted at older girls and women, particularly those who have not been pregnant, as FGS-associated infertility means that many young women with FGS never present for antenatal care.

One treatment with praziquantel in childhood or adolescence has been shown to have a clear but moderate effect on lesions and bleeding in adulthood *(66)*. Another study showed a significant decrease in HIV cell receptors in adolescents treated with praziquantel *(24)*. This and other work suggests that mass administration of medicine for adolescents before sexual debut should be a priority *(26,67)*.

Successful integration of prevention and control of FGS into HIV programmes depends on increasing community awareness and meaningful engagement of civil society and community organizations in the design and implementation of high-quality and acceptable integrated sexual and reproductive health, HIV and FGS programmes.

Case studies

Eight large studies attempted to decrease HIV transmission by treating sexually transmitted infections *(64-69)*. Although many studies have shown an association between sexually transmitted infections and HIV infection, only one of the prospective randomized control trials showed an effect of sexually transmitted infections on HIV incidence *(62)*. In nearly all study sites, schistosomiasis was a possible unidentified cause of genital lesions. Unfortunately, colposcopy was not performed, missing an opportunity to link FGS to HIV transmission *(13)*.

Attitudes and knowledge about this poorly diagnosed, often stigmatizing disease must be investigated, as lack of understanding of the severity of the disease may lead to low uptake of mass administration of medicine programmes.
The community should be engaged at every level in the prevention and control of schistosomiasis as a factor in preventing HIV infection, so they understand the value of mass administration of medicines, especially for adolescents.

In Ghana, for example, community workers and local health workers were not aware of the impact of schistosomiasis on women and girls, and community members had not heard of FGS as a specific disease. They were convinced that schistosomiasis resulting in symptoms in girls and women, such as blood in the urine, could be acquired only by sexual transmission from males *(7)*. An ecological association has been reported between long-term exposure to schistosomal infection and infertility *(68)*, another highly stigmatized sexual and reproductive issue requiring sensitivity and community engagement and the sensitization and training of health-care workers.

Community leaders at all levels including community health workers, nongovernmental organizations, women's organizations, networks of women living with HIV, and youth groups are important partners. These groups can support community outreach, advocate and raise awareness, mobilize support for demand creation, and amplify the call for high-quality integrated programmes that address the multiple and layered sexual and reproductive health and rights and HIV needs of women and girls.

HIV prevention in adolescent girls and young women

Adolescent girls and young women aged 15-24 years in sub-Saharan Africa continue to bear a disproportionate burden of new HIV infections globally, with about 6200 new HIV infections every week, 5500 of which are in young sub-Saharan African women and girls *(69)*. Gender inequality and inequity in access to vital sexual and reproductive health and rights services, lack of rights, and gender-based violence drive the HIV epidemic.

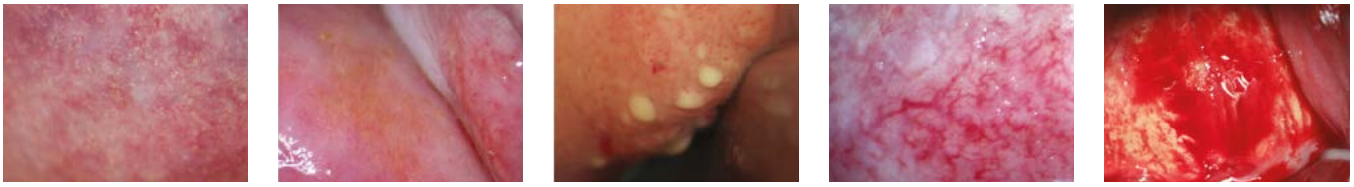
Despite some progress, young people still lack the knowledge they require to protect themselves from HIV *(30,70)*. In surveys in 35 countries in sub-Saharan Africa, only 36% of young men and 30% of young women correctly identified ways of preventing sexual transmission of HIV and rejected misconceptions about HIV transmission *(30)*. Furthermore, about 75% of young women aged 15-19 years reported they could not make decisions about their own health. In Ghana the treatment-seeking behaviour of adolescent boys and girls when they suspected symptoms of schistosomiasis differed markedly. Girls were more reluctant to seek care and voiced concerns about the cost of treatment and stigmatization, noting that when they attended a clinic with symptoms similar to those of sexually transmitted infections, they were reproved by the health professionals *(7)*. Strategies to prevent FGS in adolescent girls as a means of preventing HIV will have to overcome barriers to care. In the same study, misinformation from the health service and teachers that the medicines given to children during school mass administration were to treat intestinal worms rather than schistosomiasis led to confusion and concern. Limited engagement with the community and lack of clarity about purpose can be barriers to prevention of FGS and potential HIV transmission in adolescents *(7)*.

UNAIDS has called for a 75% reduction in HIV transmission by 2020, a 90% reduction by 2030 from the 2010 baseline, and high coverage of voluntary medical male circumcision, condom distribution, use of pre-exposure prophylaxis, needle-syringe programmes and opioid substitution therapy. Improving enrolment and keeping girls in school can also protect girls against HIV and FGS, as schools are currently the main sites for schistosomiasis treatment. Comprehensive sexuality education programmes in schools increase knowledge about pregnancy, HIV, sexually transmitted infections, risky behaviours and sexuality, and improve attitudes towards sexual and reproductive health *(71)*. Including FGS in comprehensive sexuality education will benefit adolescent girls and young women. Youth-friendly sexual and reproductive health and rights services are also critical to meeting the UNAIDS goals for reducing HIV transmission. In view of the many challenges women and girls face throughout their lives, a multisectoral approach to ending AIDS by 2030 must include these complex challenges.

Prevention, diagnosis and care of female genital schistosomiasis

Experts agree that one of the following three mucosal findings, together or separately, in people in areas endemic for *S. haematobium* may be adequate for diagnosis for FGS (Figure 5): sandy patches appearing as single or clustered grains, homogeneous yellow areas, or *rubbery* papules *(64)*. Frequently, abnormal blood vessels and contact bleeding are also seen. Some lesions may resemble those of cancer *(56,72)*. A definitive diagnosis is made by identification of these FGS-defining lesions, often seen only under a magnifying device such as a colposcope or digital camera. The WHO FGS pocket atlas and a clinical poster are freely available for improving recognition and surveillance of FGS *(56,57)*.

Figure 5.
Colposcopic images of female genital schistosomiasis



i – Grainy sandy patches

ii – Homogeneous yellow patch

iii – Rubbery papules

iv – Abnormal blood vessels

v – Severe contact bleeding

Photos: Elisabeth Kleppa, Bodo Raniandrasolo and Eyrun Kjetland.

Praziquantel, the only anti-schistosomiasis medicine available, is effective in killing adult worms *(73)*. Its use in mass treatment (Figure 6) is the current WHO-recommended strategy. In a study on adult genital schistosomiasis, however, a standard single-dose of praziquantel was found to have no effect on the inflammatory lesions of FGS once they have formed and developed for a few years *(66)*. Currently, the only way to prevent FGS is therefore by preventing infection with schistosomes.

In a rural village in north-western United Republic of Tanzania, a 19-year-old girl attended a clinic complaining of irregular menstrual bleeding for the past 6 months. She also had bloody urine. A pelvic examination showed an irregular mass measuring approximately 4 × 7 mm on the face of the cervix. The medical team took a biopsy and sent part of it to the pathology laboratory at the referral hospital. The doctor crushed a small portion of the biopsy to examine it for schistosome eggs and found hundreds. The pathology department found no evidence of cervical dysplasia or cancer. The girl was treated with praziquantel and followed up over 18 months. Her cervical lesion regressed, the eggs in her urine cleared, and her irregular bleeding stopped. She now has two young children and is doing well.

In 2017 about 40% of people in the world who required treatment were reached, and 61% of school-aged children in areas endemic for schistosomiasis received preventive chemotherapy *(1)*. There is a global shortage of praziquantel *(74)*, however, and paediatric formulations are still lacking *(75)*. The amount of praziquantel procured in addition to that donated has dropped significantly. If this trend continues, only

Figure 6.
Mass drug administration at a school in South Africa

Photo: Håvard Holme

250 million donated tablets will be available globally in 2020, which would cover all school-aged children but only 30% of the global need. The 2020 goal for schistosomiasis control is to achieve at least 75% coverage of preventive chemotherapy for all at-risk populations. Although 285 million praziquantel tablets were available in 2016, only 263 million were available in 2017, which was less than 50% of the amount required to treat all people who required preventive chemotherapy for the disease. The increase in the number of tablets of praziquantel donated by Merck to 250 million per year coincides with a decrease in donations from other sources, apparently due to lack of funds and the extension of national programmes *(74)*. Bottlenecks in the availability and distribution of praziquantel must be removed, as dispensing praziquantel tablets remains an underused opportunity to prevent HIV infection *(26,67)*.

As in HIV testing and care programmes, FGS diagnosis and care must move closer to the most affected communities to make access equitable. A tool for affordable diagnosis of FGS in the community might include a visual point-of-care device coupled with self-testing strategies for the detection of *S. haematobium*.

Sexual and reproductive health is a fundamental human right and essential for the health and well-being of women and girls in all their diversity. FGS has a disproportionate impact on women and young girls living in poor rural communities and in urban areas without adequate sanitation or access to safe water, mainly in Africa and

Female genital schistosomiasis: an issue of gender, sexual and reproductive health and rights and social justice

the Middle East. These populations also frequently lack access to appropriate medical care, including basic sexual and reproductive health and rights services. SDG 3 seeks to ensure universal access to sexual and reproductive health, including information and education, and the integration of reproductive health into national strategies and programmes by 2030.

Individuals can realize their right to sexual and reproductive health only if they have access to comprehensive information about health risks and their vulnerability to the adverse consequences of their condition and access to medicines to eliminate or reduce such risks. Yet, to date, there is no targeted national programme for detecting people with FGS, informing patients, managing the chronic consequences, or actively preventing new cases of FGS.

Access to safe potable water and adequate sanitation are critical in preventing and reducing the risk of infection. Women and girls, especially in rural areas, depend on open water sources and are susceptible to contracting schistosomiasis daily. Rural communities known to be endemic for schistosomiasis should have access to information on the disease, the signs and symptoms of FGS, prevention and treatment of schistosomiasis and FGS, and the importance of hygiene. Any intervention should therefore be based on community engagement, from design, to implementation, to monitoring of programmes.

National programmes should address the socioeconomic and gender inequalities experienced by women and girls that increase their vulnerability to HIV, cervical cancer and neglected tropical diseases, including FGS, concomitantly through holistic and multisectoral programmes. Multilateral and bilateral agencies engaged in improving sexual and reproductive health, especially for women, that promote policies and programmes aligned with rights-based approaches are natural allies in promoting the integration of HIV, cervical cancer, and FGS prevention and control programmes.

Lessons learned from three decades of the HIV response and AIDS activism, including the meaningful engagement of civil society, should inform the development and scale-up of high-quality integrated programmes and services, including those that address HIV, cervical cancer, and FGS prevention, diagnosis, treatment, and control. Networks of women living with HIV and the women's rights movement, which have united and fought for services and an HIV response rooted in human rights, sexual and reproductive health, and rights and social justice, are powerful advocates. As with the HIV response, civil society and community groups are critical partners for raising community awareness and amplifying the demand for health services and commodities.

Promotion of gender-sensitive analyses of health-care and its delivery by civil society and nongovernmental organizations will result in simple, relatively inexpensive approaches to treating children and improving long-term sexual and reproductive health, especially for young women and girls.

Initiatives such as DREAMS and the Youth PACT (a vibrant coalition of more than 80 organizations in solidarity, working collaboratively and strategically in the global HIV response) are vital to address young women's sexual and reproductive health needs. Partners beyond the scientific and medical community should be engaged, especially women's civil society and community organizations. Innovative outreach, including through social contracting, social media, radio and other information channels, should be leveraged for broad community outreach and to share clear, concise, inclusive and acceptable messaging on FGS prevention, diagnosis, treatment and care.

Programme integration and alliances

The SDGs, the 2016-2021 UNAIDS Strategy and the 2016 High-level Meeting on Ending AIDS provided significant opportunities to break down the silos and build bridges among movements, programmes and services to reach all women and girls with comprehensive sexual and reproductive health and rights services, including for HIV, cervical cancer and FGS.

The WHO road map on accelerating work to overcome the global impact of neglected tropical diseases *(26)* led to unprecedented international commitment and created momentum that could be harnessed to tackle schistosomiasis and HIV infection jointly. Subsequent plans should include more specific targeting of FGS as a potential risk factor for HIV acquisition, which would be aligned with global work to address women's health issues comprehensively *(76)*.

Affordable point-of-care colposcopes would also benefit cervical cancer screening programmes. In addition, FGS prevention and control should include research on the impact of mass administration of medicine and innovative approaches. Training of the health-care workforce to provide comprehensive treatment, care and support is essential, including by leveraging technology and creating platforms for virtual trainings and support. Addressing schistosomiasis and FGS in children and adolescents could provide an opportunity to prevent new HIV infections, especially among adolescent girls and young women.

Various groups should be brought together, such as the United Nations Children's Fund and other agencies that provide preventive care for children under five years of age *(77)*. UNAIDS and PEPFAR *(78)* should advocate for the uptake of WHO mass administration of medicine programmes and include information about urogenital schistosomiasis and FGS in their educational materials to improve awareness of the risk of HIV infection *(79)*.

The number of new HIV infections in people aged 15-19 years in sub-Saharan Africa calls for a broad approach to reducing the incidence among adolescent girls *(79)*. New international commitments to control neglected tropical diseases, such as the London Declaration on Neglected Tropical Diseases and the Global Partners meeting *(80)*, could be used to bring FGS to the fore in national public health agendas. More funds are required to integrate programmes and research on the reproductive health challenges posed by neglected tropical diseases, HIV and other causes.

Programme integration

Integration of programmes will require various approaches, including economic empowerment, improving girls' access to secondary education, integration of HIV services with sexual and reproductive health and rights services, comprehensive sexuality education, community mobilization, risk-reduction communication, prevention of gender-based violence, stigma-reduction programmes and access to justice *(81)*. Bringing safe water sources to communities, enhancing the status of adolescent girls and young women through formal and informal education, and providing accessible affordable health-care to communities are all required to improve the health and well-being of women, girls, and broader communities. To address the inequalities inherent in the epidemics of FGS, cervical cancer, and HIV among young women in sub-Saharan Africa, the following steps should be taken for the scale-up of high-quality integrated programmes and services, which address the multiple and intersecting socioeconomic and health needs:

- Increase multisectoral collaboration and partnerships among ministries and government departments, such as ministries of health, education, gender, and water and sanitation, and engage community and civil society partners, the private sector, the United Nations and other development partners for FGS prevention and control.
- Partnerships with communities through relevant community structures and community engagement are central to an FGS response, including elements of leadership, participation, real power-sharing and coordinated community action. Lessons can be drawn from the HIV response, programmes targeted at adolescent girls and young women, and the WHO Community Engagement Framework for Quality, People-centred and Resilient Health Services *(82)*.
- Increase mass treatment with praziquantel to cover all school-aged children in areas in which schistosomiasis is endemic. Treatment should be extended to adults in endemic areas and made available free of charge in health facilities for case management.
- School HIV programmes should include education about urogenital schistosomiasis and FGS. Information about early treatment, especially before sexual debut, should be shared with parents, and demand should be created for mass administration of medicine programmes in schools. Policy-makers, public health officials and health-care providers should advocate for praziquantel treatment of school-aged children, and public-private partnerships should be strengthened to ensure praziquantel is consistently available.
- Services for HIV, cervical cancer, sexually transmitted infections and antenatal care are natural platforms for including diagnosis, treatment and prevention of FGS. Integration of urogenital schistosomiasis diagnosis within women's and men's services for sexual and reproductive health is an important first step. A comprehensive approach must include increased community and health worker knowledge and awareness in areas endemic for urogenital schistosomiasis.
- Given the association between FGS and cervical cancer, health-care providers in charge of screening and prevention programmes should consider the greater risks of HIV acquisition linked to FGS and the higher rates of cervical cancer among people living with HIV.
- Mass administration of medicines is currently managed mainly by public health officials, neglected tropical disease control programmes and school nurses *(83-86)*. While information is provided to the communities offered mass treatment, information on FGS is usually not included *(86-88)*. Carefully formulated information should be provided on the risks for FGS and the concurrent elevated risk of HIV acquisition.

This would give parents, adolescent girls and young women information that might influence their decision to join such programmes; they might also be asked whether they know their HIV status and be given the opportunity to test for HIV if appropriate *(89)*.

More research, data (qualitative and quantitative) and analyses are needed to design programmes and understand the needs, diagnosis and treatment pathways of women and girls, their understanding of the symptoms of FGS, and barriers to accessing services. Existing initiatives by the neglected tropical diseases community shows how social scientists design and manage programmes: (i) identify stakeholders' perspectives; (ii) understand the context; (iii) understand stakeholders' knowledge; and (iv) identify how stakeholders want to be engaged *(90)*.

Civil society and community partners, including women living with HIV, sexual and reproductive health and rights advocates, women's and youth groups, traditional birth attendants and community health workers, are natural allies in appropriate advocacy and mobilizing demand for FGS prevention and treatment.

Cervical cancer screening programmes, family planning programmes, sexual and reproductive health programmes, and age-appropriate management of schistosomiasis are not currently linked or integrated. Doing so would maximize efficiency and improve health outcomes *(45)*. Without a multifaceted approach, from communities up to national policy-makers, FGS cannot be eliminated.

As the continuum of the disease starts in childhood and progresses into adulthood *(73,91)*, schools, routine vaccination programmes, deworming programmes, community centres, antenatal clinics and women's advocacy groups should be involved. Sexually transmitted infection clinics, human papillomavirus vaccination clinics, cervical cancer screening programmes, and HIV testing and counselling centres across sub-Saharan Africa should collaborate and offer services for FGS diagnosis and treatment.

A strong suspicion and a preoperative diagnosis of FGS can avoid unnecessary surgery for suspected cervical cancer, while also preventing HIV transmission, avoiding misdiagnosis of sexually transmitted infections and reducing repeat visits to the health system. Health-care professionals should receive routine training and facilitated with access to an affordable easy-to-use diagnostic tool suitable for low-resource settings, which remains a priority.

Prevention through mass administration of medicine and treatment should complement other interventions to combat FGS, including water, sanitation and hygiene *(37)*. This comprises changing behaviour and the environment, social inclusion and treatment. Communities should be made aware about how infection occurs in order to change their attitudes to use of unsafe water. Community leaders should be educated about the dangers of untreated schistosomiasis and its links to HIV infection so that they are open to interventions and will support mass administration of medicines through school programmes. The environment should be changed by ensuring access to reliable, affordable, sustainable water to prevent or reduce contact with surface water and facilitate personal hygiene. Community groups should be encouraged to practise good hygiene and advocate for and facilitate the use alternative safe water sources.

The aim of social inclusion is to ensure meaningful participation of all representatives of the community, so that all interventions are approved by those affected and to build an enabling environment and programming for community agency, ownership and action. Similar to the HIV response and responses from the neglected tropical diseases community, ensuring social inclusion will also combat the discrimination and stigma attached to FGS, which is frequently misdiagnosed as a sexually transmitted infection. Relevant education will also contribute to disease control and address misinformation.

Public health action and research for integration of female genital schistosomiasis and HIV programmes

The following activities are recommended *(89)*:

- Extend mass administration of medicine for schistosomiasis for school-age children to women of reproductive age, with creation of awareness, community participation in local treatment programmes, and informed consent.
- Ensure schistosomiasis control programmes follow WHO guidelines that include praziquantel treatment for pregnant women and woman of child-bearing age who are at risk of schistosome infection.
- Extend integration of prevention, care and treatment services to HIV infection, cervical cancer and FGS, and their impacts on reproductive health throughout the life-course.
- Improve awareness, health education and communication about FGS and HIV in communities endemic for both.
- Develop training curricula for medical professionals on FGS, and integrate training with that for HIV and cervical cancer screening.
- Forge interdisciplinary public-private partnerships to develop appropriate and affordable clinical diagnostic tools and make these more readily available in field settings.
- Use HIV programmes to increase knowledge about FGS and integrate prevention services into affected communities and their health-care providers.
- Use health-care delivery systems to extend FGS prevention, screening and treatment. Address possible discrimination and stigma.
- Advance gender equality and the sexual and reproductive health and rights of all girls and women.

A number of research questions should be addressed. In epidemiology, these include:

- Validation of global and national estimates of the prevalence of FGS.
- The disease burden of FGS in women living with HIV.
- Any association between HIV and the severity of FGS disease, and whether severity is affected by the degree of HIV-related immune suppression.
- Whether FGS is associated with an increased risk of HIV infection, at primary acquisition or at secondary transmission.
- Whether the rates of mortality, infertility and cervical cancer are increased in women coinfected with HIV and *S. haematobium*.

For diagnosis of FGS, research is needed to find a rapid point-of-care diagnostic test that does not require a gynaecological examination. FGS diagnosis should be integrated with diagnostic tests for sexually transmitted infections, including syndromic algorithms used in low-resource settings.

Research questions with regard to treatment include the following:

- The effectiveness of praziquantel in the treatment of FGS in HIV-positive and HIV-negative women in terms of cure, recurrence, mortality and infertility.
- Whether antiretroviral treatment improves the outcomes of FGS, such as cure, recurrence or infertility rates in women with HIV and FGS coinfection.
- Whether antiretroviral treatment is associated with an increased incidence of FGS-associated immune reconstitution inflammatory syndrome reactions, their severity, their effects, and how they can be managed.
- Whether regular treatment with praziquantel in school-aged girls reduces the incidence of HIV infection in endemic communities.
- Identification of praziquantel treatment regimens in school-aged girls that reduce the prevalence of FGS in endemic communities.

Research is also needed on approaches to integrating FGS care for women living with HIV into clinical protocols and public health programmes.

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UNAIDS
Joint United Nations
Programme on HIV/AIDS

20 Avenue Appia
1211 Geneva 27
Switzerland

+41 22 791 3666

unaids.org