

[FIG] TOGETHER TO END FEMALE
GENITAL SCHISTOSOMIASIS



**THE TIME
IS
NOW**

**ADDRESSING THE UNMET NEEDS
OF WOMEN AND GIRLS IN AFRICA
THROUGH FGS INTEGRATION**

A CALL TO ACTION ON FGS TO PROTECT MARGINALISED WOMEN AND GIRLS FROM SERIOUS SRH COMPLICATIONS, HIV AND CERVICAL CANCER

Female genital schistosomiasis is estimated by the WHO to affect as many as 56 million women and girls, primarily in sub-Saharan Africa. Although a clinical manifestation of a neglected tropical disease, FGS is also a neglected sexual and reproductive health rights (SRHR) issue. It can result in severe sexual and reproductive health (SRH) complications and is increasingly associated with an FGS/HIV/HPV syndemic in which disease interactions exacerbate underlying susceptibility. Despite the urgency, SRH service providers and most communities know little, if anything, about FGS. This policy brief urges stakeholder support to address key gaps identified by countries to address the needs of these women and girls.

We call on stakeholders to:

- Ensure health financing mechanisms support integration of FGS into health services
- Develop policy, technical and clinical guidance on FGS and FGS integration and facilitate technical assistance where needed



SCHISTOSOMIASIS AND FEMALE GENITAL SCHISTOSOMIASIS

FGS results from schistosomiasis (or bilharzia). *Schistosoma haematobium* is a parasitic worm found in freshwater across sub-Saharan Africa and some parts of the Middle East and North Africa, and is the schistosome species that causes urogenital schistosomiasis. The worms infect a person who comes into contact with contaminated water and lay eggs that move through the blood system. The eggs often lodge in the pelvic area, causing FGS. Chronic FGS infection happens when the eggs become trapped in tissues and organs along the genital tract, including the uterus, vaginal wall, vulva and/or cervix, causing inflammation, lesions and severe complications such as ectopic pregnancy, miscarriage and infertility. FGS symptoms include significant pelvic pain, vaginal discharge, painful intercourse, post-coital bleeding and genital itching and burning.

The lack of access to safe water and sanitation services increases the risk of FGS, with women and girls facing a disproportionate risk due to household chores and gender norms.

Schistosomiasis, which can result in FGS, can be treated with a single dose of praziquantel. FGS symptoms improve and can completely resolve with early treatment. Chronic lesions may persist after treatment even if symptoms improve.

HIGHLIGHT : DEVELOPMENT OF THE MINIMUM SERVICE PACKAGE FOR FGS INTEGRATION

As part of a Children's Investment Fund Foundation (CIFF) funded project, Frontline AIDS and its partners developed a minimum service package (MSP) as a programmatic guide for FGS integration into SRHR interventions, which will be piloted in Kenya.

The MSP was developed to help government, public health practitioners and programmers in schistosomiasis endemic countries to practically integrate FGS into existing SRHR interventions. The MSP covers interventions for FGS integration across four components: health literacy, screening and diagnosis, treatment and care and social inclusion and equity. The MSP serves as programmatic guidance for FGS and SRHR integration, which has been a gap until now. Implementation of the MSP should support countries to increase training for healthcare workers and integrate FGS services into SRH, which would ultimately support the documentation of FGS cases – which would increase as FGS services are integrated into SRH service delivery.

This minimum service package is currently being tested through a study led by LVCT Health in nine sites across three counties in Kenya.

Frontline AIDS/Denis Mwangi/2023



Nancy Ogweche is an SRH nurse in Homa Bay, Kenya

Women wash clothes and utensils at the lake in Homa Bay, Kenya



Frontline AIDS/Denis Mwangi/2023

FGS: A SILENT HEALTH THREAT

FGS often goes undiagnosed due to the lack of training for health personnel and a lack of knowledge at all levels from the community upwards.

It is often misdiagnosed as a sexually transmitted infection (STI) or even cervical cancer, which contributes to unnecessary clinical procedures, poor treatment outcomes and the risk of antimicrobial resistance (AMR). Misdiagnosis can also result in further marginalisation. This knowledge gap contributes to lack of evidence on the burden of FGS.

These gaps in evidence and knowledge contribute to and are exacerbated by the absence of clear normative guidance at the international level.

Often, women and girls affected by FGS are already marginalised, living in conditions of poverty and lacking access to quality health care services.

FGS also interacts with, and compounds, the many health and social issues that particularly affect women and girls. These complications can lead to social isolation and a heightened risk of mental health issues, including depression, stigma and discrimination, and gender-based violence.

Despite praziquantel being an effective and inexpensive medication for the treatment of schistosomiasis and the prevention of FGS, it is often only distributed through mass drug administration, primarily in school-aged children, and not regularly available in primary health care settings, making this SRH service difficult to access.

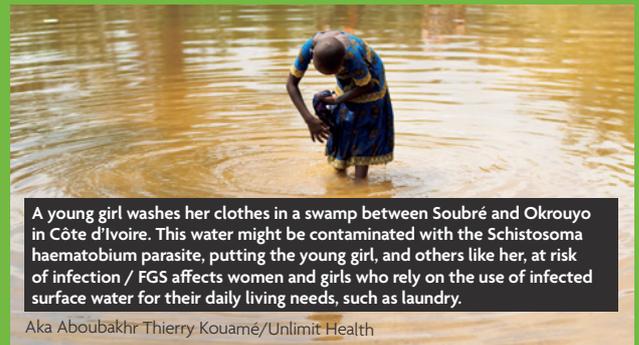
AN OPPORTUNITY FOR IMPROVING HEALTHCARE SERVICES FOR WOMEN AND GIRLS

Addressing FGS is a **human rights issue**. A focus on FGS helps to highlight areas in which women and girls face barriers to accessing healthcare services; it is therefore a useful entry point for **improving equity and quality services**, and consequently as a way of improving trust in, and uptake of, healthcare services among women and girls. All affected women and girls need access to measures for preventing, diagnosing and treating FGS as an integral part of comprehensive SRH services. Achieving universal health coverage will require that FGS services, including treatment and prevention, are included as an essential component of SRH programmes and HIV and cervical cancer strategies in all endemic countries.

Addressing FGS provides an opportunity for developing **holistic, integrated and patient-centred healthcare services for all**. FGS integration into SRH interventions provides a practical model of how holistic and integrated health programmes and services can impact on health and human rights, education attainment, economic empowerment, and gender equality, while at the same time helping to increase resilience and sustainability within health systems.

HIGHLIGHT: SCALING UP FGS PREVENTION IN CÔTE D'IVOIRE

A pilot study conducted in Soubré district, Côte d'Ivoire, showed that although there is likely to be a high risk of transmission and exposure to infection with women using infected water sources for daily activities such as farming or social activities there are no routine services available for FGS prevention or care. The medication, praziquantel, is not routinely provided in health centres and 53% of women reported that they could not access praziquantel on the same day if they needed it. Knowledge of FGS amongst health workers was low, and knowledge of FGS amongst women aged 15-29 years was negligible. The pilot provided evidence that FGS prevention services could be feasibly integrated with routine SRH services at the primary healthcare level.

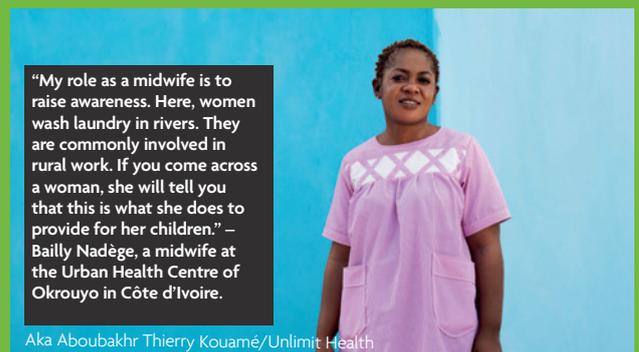


A young girl washes her clothes in a swamp between Soubré and Okrouyo in Côte d'Ivoire. This water might be contaminated with the Schistosoma haematobium parasite, putting the young girl, and others like her, at risk of infection / FGS affects women and girls who rely on the use of infected surface water for their daily living needs, such as laundry.

Aka Aboubakhr Thierry Kouamé/Unlimit Health

The Ministry of Health in Côte d'Ivoire, supported by Unlimit Health, is scaling up FGS prevention services across two districts using a combined health centre and community outreach approach. The ambition is for FGS prevention services to be provided routinely and sustainably on a national scale, alongside an integrated training programme.

A working group of national experts including the MoH NTD Programme, the MoH HIV/AIDS Programme, the MoH Mother and Child Health Programme, the Governing Body of the National Health Management Information System and research institutions will provide technical and strategic guidance on the scale-up approach. The results from the scale up in two districts, and the pilot study, will be used to inform evidence-based guidelines for the national strategy for FGS.



"My role as a midwife is to raise awareness. Here, women wash laundry in rivers. They are commonly involved in rural work. If you come across a woman, she will tell you that this is what she does to provide for her children." – Bailly Nadège, a midwife at the Urban Health Centre of Okrouyo in Côte d'Ivoire.

Aka Aboubakhr Thierry Kouamé/Unlimit Health

THE TIME IS NOW: ACTION NEEDED

URGENT STAKEHOLDER ACTION IS NEEDED TO:

ENSURE HEALTH FINANCING MECHANISMS SUPPORT INTEGRATION

- Enable integrated rather than vertical funding approaches
- Improve access to funding for HIV co-infections and finance praziquantel to be available in both campaign and healthcare settings.
- Include the financing of FGS as part of SRH programmes, including HIV prevention, HPV and cervical cancer programmes.
- Ensure resources for scaling up health system operational research for developing and testing guidance.



DEVELOP POLICY, TECHNICAL AND CLINICAL GUIDANCE ON FGS AND FGS INTEGRATION AND FACILITATE TECHNICAL ASSISTANCE WHERE NEEDED

- Recognise FGS as an SRH condition and reference it in global as well as regional and national health policies and strategies including SRH, HIV, HPV and cervical cancer, and STI policies and strategies.
- Develop technical guidance on how to plan and deliver integrated FGS services as part of routine healthcare, including women's SRH services, cervical cancer screening and HIV prevention services
- Develop curricula and resources for healthcare professionals
- Develop clinical guidance on prevention, diagnosis and treatment of FGS
- Develop clinical tools and resources for effective and integrated FGS service provision
- Develop guidance on adaptations to reporting mechanisms to enable capture of FGS-related data as part of country health management information systems
- Support coordination across initiatives to maximise learning and increase return on investments



[FIG]

The FGS Integration Group, also known as FIG, is a global coalition that is galvanising joint action across neglected tropical diseases, sexual and reproductive health and rights (SRHR), HIV, HPV/cervical cancer and WASH sectors to address the neglected and harmful condition of FGS.

FIG nurtures partnerships across the coalition and among its allies to pilot and scale up FGS integration programming. We are raising awareness of FGS to improve FGS diagnosis, treatment and prevention with and for women and girls through sustainable integration of FGS into SRHR and NTD programmes at scale.

FGS integration is a powerful opportunity to demonstrate that crosssector coordination results in systems efficiencies, high quality care, universal healthcare, and resilient and sustainable health systems for women and girls.

Email fgs.integration@gmail.com to find out more about FIG and what you can do for FGS integration

