LEARNING PACK

FEMALE GENITAL SCHISTOSOMIASIS:
A GUIDE TO INFORM EQUITABLE SCHISTOSOMIASIS CONTROL EFFORTS IN GHANA

COUNTDOWN
Calling time on Neglected Tropical Diseases

Sensitizing teachers using the UNITING to COMBAT NTDs Schistosomiasis/FGS flyers

HOW TO USE THE LEARNING PACK

This pack presents a summary of exploratory qualitative research methods and findings from frontline health implementers and communities conducted by the COUNTDOWN research team in Ghana.

The **COUNTDOWN** project brings together neglected tropical disease (NTD) researchers, policy makers, practitioners and research specialists to generate new knowledge and assemble necessary information about the realities of increasing the reach and impact of NTD treatment campaigns in different country contexts. The specific aim of the Ghana project is to improve on the capacity of the Ghana Health Service to establish an integrated NTD programme capable of delivering interventions to prevent, control, eliminate or eradicate neglected tropical diseases by the year 2020.

This Learning Pack serves as a guide for stakeholders in the health sector by highlighting cross-cutting issues in the treatment of women and girls in schistosomiasis-endemic areas. It presents a wide range of perspectives and recommendations about female genital schistosomiasis (FGS) from members of several endemic communities. It specifically includes the perspectives of those involved in the prevention of schistosomiasis through mass drug administration (MDA), and the treatment of female reproductive health issues including FGS. The evidence presented is from one district but it may be validated by NTD Programme staff and implementing partners who work throughout Ghana and beyond.

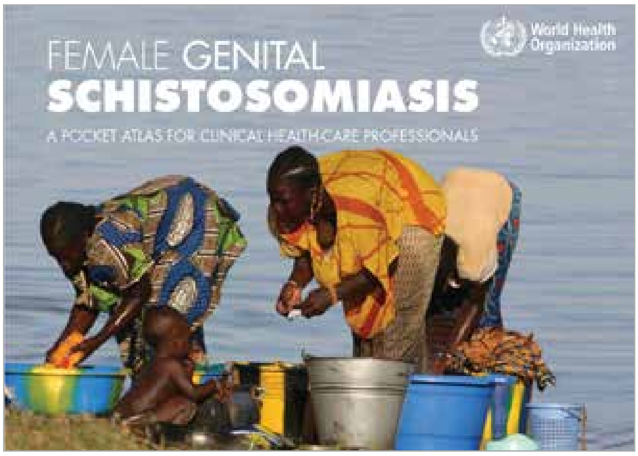
This resource is intended to raise awareness among decision-makers such as the NTD Programme specifically, and the Ghana Health Service more broadly, along with implementing partners. The guide sheds light on issues that are important to communities. It is designed to lead to discussion, validation of the issues presented, and changes to program implementation and policies. Suggested actions to address gaps in the prevention and treatment of schistosomiasis are highlighted that will require coordinated efforts and collaboration.

The findings of this research are published in the following paper:
Kukula VA, MacPherson EE, Tsey IH, Stothard JR, Theobald S, Gyapong M (2019) A major hurdle in the elimination of urogenital schistosomiasis revealed: Identifying key gaps in knowledge and understanding of female genital schistosomiasis within communities and local health workers. PLoS Negl Trop Dis 13(3): e0007207. https://doi.org/10.1371/journal.pntd.0007207

COUNTDOWN
Calling time on Neglected Tropical Diseases

THE PROBLEM OF FEMALE GENITAL SCHISTOSOMIASIS

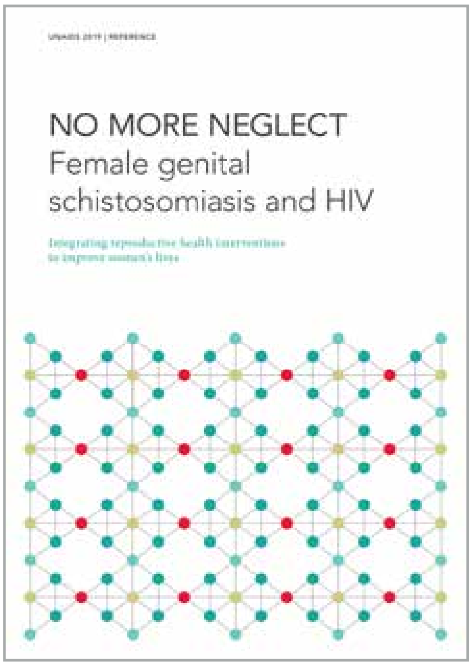
Female Genital Schistosomiasis (FGS) is a form of schistosomiasis that may be the **most common gynecological condition in schistosomiasis-endemic areas**[1]. It occurs when schistosome eggs lodge in female reproductive organs including the vagina, cervix, uterus, fallopian tubes and ovaries[2]. The eggs cause painful lesions which increase the risk of viral infections, especially HIV and the human papillomavirus (HPV), the main cause of cervical cancer[3]. Studies show that women with FGS may have a 3-4 times greater risk of contracting HIV[4-6]. Eventual complications of FGS can include genital ulcers, tumors, subfecundity, infertility, miscarriages, and ectopic pregnancy[7].



FEMALE GENITAL
SCHISTOSOMIASIS
A POCKET ATLAS FOR CLINICAL HEALTH-CARE PROFESSIONALS

World Health Organization

Up to 56 million women in Sub-Saharan Africa are currently suffering from FGS, according to the WHO. They may be experiencing symptoms including vaginal discharge, bloody discharge, bleeding or pain during or after intercourse, and genital itching or burning. Most of these cases are undiagnosed, and some are misdiagnosed as sexually transmitted infections and treated with medicines that are ineffective against schistosomiasis[8]. In endemic countries, the WHO recommends that the diagnosis of FGS must be considered for all women and girls with urogenital symptoms who have had contact with fresh water. FGS is diagnosed by visual inspection, which may be aided by the WHO **Female Genital Schistosomiasis: A Pocket Atlas for Clinical Health-care Professionals.**



NO MORE NEGLECT
Female genital
schistosomiasis and HIV

All women and girls who are exposed to infested water are at risk of FGS. Children and adolescents have been observed to have a higher trend of reinfection, requiring frequent treatment with praziquantel. WHO recommends preventive chemotherapy (mass treatment) of entire communities in endemic areas. UNAIDS and the WHO are also calling for increased advocacy for schistosomiasis treatment of adolescent girls and women with praziquantel, and integration of schistosomiasis treatment in HIV prevention. Complementary health education, WASH, and vector control interventions are also recommended.

Schistosomiasis is addressed in Ghana primarily through annual school-based mass drug administration (MDA), but MDA coverage has fallen well below the 75% coverage target in recent years. While there are information, education, and communication materials designed by the NTD Programme for schistosomiasis education in communities, none of them mention FGS or address symptoms specific to females. FGS is not currently covered in either pre-service or in-service training for community health workers, midwives, nurses, or clinicians in Ghana and health workers are not aware of the Pocket Atlas.

THE RESEARCH APPROACH

The COUNTDOWN project explored community and health provider perceptions about female genital schistosomiasis to identify gaps in knowledge and opportunities to strengthen prevention and treatment. The research took place in 16 communities along Lake Volta in the Shai-Osudoku District between June and August 2017. Participants were chosen purposively using the principle of maximum variation to ensure a wide range of perspectives was included.

Data collection methods:

- 75 semi-structured interviews
- 18 focus group discussions

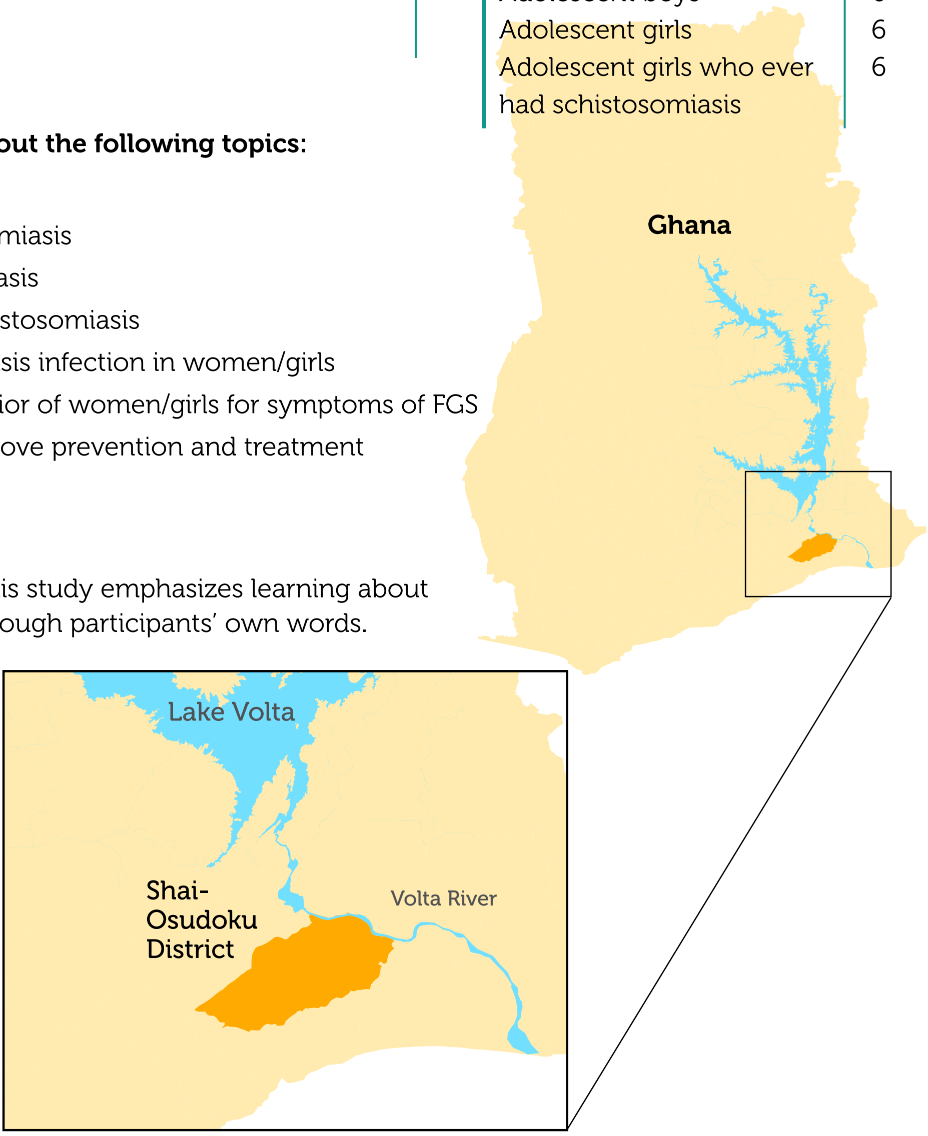
Community Focus Group Discussions	18	Health Provider Interviews	33	Community Member Interviews	42
Adult men	2	Nurses	5	Teachers	6
Adult women	3	Reproductive health clinic nurses	6	Traditional birth attendants	4
Adolescent boys	2	STI clinic nurses	4	Medicine sellers	2
Adolescent girls	5	Midwives	10	Opinion leaders	3
Boys in school	2	Community health officers	5	Adult men	4
Girls in school	2	OBGYNs	3	Adult women	5
Mixed school group	2			Adolescent boys	6
				Adolescent girls	6
				Adolescent girls who ever had schistosomiasis	6

Participants were asked about the following topics:

- What is schistosomiasis
- How people get schistosomiasis
- Symptoms of schistosomiasis
- Who is most at risk of schistosomiasis
- The effect of schistosomiasis infection in women/girls
- Health care seeking behavior of women/girls for symptoms of FGS
- What can be done to improve prevention and treatment

Analysis Approach

The exploratory design of this study emphasizes learning about community perspectives through participants' own words. Researchers used an iterative approach during data collection to gain continued feedback on concepts and themes. They reviewed data on a daily basis to search for patterns and emerging themes, which were incorporated into subsequent interviews and used to develop the thematic coding framework.



FINDINGS

- Schistosomias is associated with bloody urine, and the local word for the disease means "blood in the urine." Men, women, and some community-based health workers believe that women do not get schistosomiasis or are less at risk for it because they do not report the cardinal symptom ''urinating blood.''
- Women and girls are believed to get the disease through sexual contact with infected males.

> **"...I have never heard the girls complain about urinating blood, it is only the boys. Girls have some kind of defense against the schistosomiasis from the lake that affects the boys, only the men can pass it to them." – FGD school boy's group**

S. haematobium is the cause of urogenital schistosomiasis in both males and females. Women and girls are infected by skin contact with infested fresh water.

Schistosomiasis is not sexually transmitted.

- Community perceptions of how and why FGS is transmitted often went beyond biomedical explanations to include socio-cultural beliefs:

> **"Married women and girls who sleep with married men, God always punishes them with schistosomiasis." – IDI Teacher**
>
> **"Children who disrespect their elders by making fun of them or insulting them are cursed with urinating blood." – Vignette school pupil**

- Regarding women/girls understanding of their symptoms in relation to FGS, they had no idea about the existence of FGS and could not relate their symptoms to possible FGS.

> **"Since we were young, we have always suffered vaginal itching, lower abdominal pains and irregular bleeding, but we were never told at the clinic that we had 'muozim', they always give us pills and we go home and add the local herbs." – FGD adult women**

Education about FGS, Dormeliam SDA Primary School

FINDINGS CONTINUED

KNOWLEDGE GAPS — HEALTH WORKERS

- Some key groups including nurses, midwives and teachers, had never heard of FGS and were not able to describe the symptoms:
  - Health workers lacked the knowledge and capacity to effectively diagnose and treat FGS.
  - Teachers lacked the capacity to educate the school pupils on the disease.
- Health workers confused the symptoms of FGS and STIs, leading to stigmatization of young girls when they seek care.

- Health workers thought that boys were more likely to contract schistosomiasis than girls:

> **"I have worked here for 12 years and have never seen a girl report with bloody urine. It is always the boys. I do not think girls get the disease from the lake like the boys." – IDI midwife**

> **"I do not see how females will get schistosomiasis and we will not know. This is because when you get it, you have to pass bloody urine and females have never passed the bloody urine and reported to our clinics. Even our report shows that it is only the boys who get it. Is this FGS caused by a different organism?'' – IDI midwife**

It is estimated that at least 1/3 of women have FGS in communities where there is schistosomiasis.


FGS sensitization with teachers, Kadjanya Basic Schools

FINDINGS CONTINUED

PREVENTION — MASS DRUG ADMINISTRATION

- Parents, teachers and adolescents attending school felt that there was inadequate information on the drugs given to children during the school MDA.
- There was concern that the health service did not inform the community when the drugs were going to be given in the schools.

……

- Students said the teachers and nurses told them the drugs were for treating intestinal worms rather than schistosomiasis, leading to confusion and concern.

> **"If the medicines they give in the school is to treat against the bloody urine, then it is very good but because we the parents are not informed, our children do not take it."**
>
> – **IDI Queen Mother**

In Ghana, school-based MDA includes drugs to treat and prevent soil transmitted helminths as well as schistosomiasis.

FGS community sensitization, Asutuare

FINDINGS CONTINUED

PREVENTION — OTHER INTERVENTIONS

- Some community members recommended limiting access to the water because it is the source of schistosomiasis.

- Communities clearly expressed their need for clean water sources and sanitation. Existing boreholes and standpipes were either broken or had user fees that people could not afford.
- Several community leaders said that medicine should be given to everyone who needs it.

> **"We need toilet facilities so that people will stop going to the toilet in the river. They also need to give us boreholes and pipe water so that we will not go into the water to get the disease."**
>
> **– FGD male**
>
> **"I think there should be a community-wide screening of girls and when found with the infection, they should be treated immediately."**
>
> **– IDI community health nurse**

FGS community sensitization, Adakope

FINDINGS CONTINUED

Health Facilities

- Women and girls who had schistosomiasis said they were stigmatized by health providers when they reported their symptoms.
- Symptoms such as vaginal itching after bathing in the lake, vaginal discharge, pain during urination, painful menstruation and weakness were common symptoms girls and young women experience.
- These symptoms were mostly tagged as STIs and treated as such with no mention of schistosomiasis and its prevention.
- Adolescent girls and young women reflected that health providers chastised them and accused them of sexual promiscuity with long counselling sessions instead of investigating and treating them for their symptoms.

FGS can be present without urinary schistosomiasis. It is diagnosed by visual inspection of the cervix.

> **"When I reported to the clinic with bloody urine, vaginal itch, discharge and lower abdominal pains, they referred me to the family planning clinic where the nurse asked me the last time I had sex, number of men I slept with and told me the symptoms was STI. She gave me some medicine and told me to abstain from sex. But I have never had sex in my life, I am only 14 years then. The medicine she gave me did not work and I finally went to the drug store where they treated me for my symptoms."**
>
> **– IDI adolescent female**

Herbal Treatments

- Women are less likely to receive appropriate treatment due to stigma and a lack of understanding of the symptoms of FGS.
- On treatment-seeking behaviors, women/girls preferred seeking care from traditional medicine practitioners (?) and medicine peddlers because of fear of stigmatization.
- Community members, especially women and girls, relied on home remedies, community medicine sellers, and herbalists to treat their symptoms.

> **"The white man's tablets are difficult to swallow and sometimes it gives you bad effects. I don't use it for my children when they urinate blood. I use the herbs and it works well."**
>
> **– IDI male opinion leader**

> **"As for me, the moment I saw blood in my feces and itching vagina, I told my mother and she gave me some herbal mixture to drink and insert in my vagina and I was okay within 3 days. My friend used the clinic medicine for months and it did not improve." – FGD adolescent girls group**

Herbal treatments may alleviate symptoms of FGS, but they will not stop the disease from progressing, increasing the risk of HIV infection, cervical cancer, reduced fertility, and complications of pregnancy.

HOW DOES GENDER INFLUENCE OUR RESPONSE TO SCHISTOSOMIASIS?

Differences in behavioral norms between women and men put them at different risk for schistosomiasis

Women and girls are more likely to use groundwater for domestic tasks such as bathing children and washing clothes, whereas men may be exposed to groundwater due to livelihood activities like fishing. Differences in exposure should be explored and taken into account when designing interventions targeting women and girls.

Schistosomiasis affects women's and men's bodies differently

Women may have FGS without having urinary schistosomiasis (blood in the urine). They experience symptoms due to infection with S. haematobium that men do not, such as vaginal itching and discharge, painful menstruation, and painful sex. Women with untreated FGS are at risk of spontaneous abortion and infertility or reduced fertility, which are associated with stigma, abandonment, and depression[8].

Stigma impedes health-seeking behavior—especially for women and girls

Because FGS symptoms are also the symptoms of some STIs, women and girls avoid seeking treatment for fear of stigma[8]. Their fears are reinforced by the stories of other women who were assumed to have an STI when they had schistosomiasis. Social norms surrounding sexual behaviour—such as those barring sexual activity among adolescent girls or unmarried women—make the suspicion of an STI especially stigmatized[9].

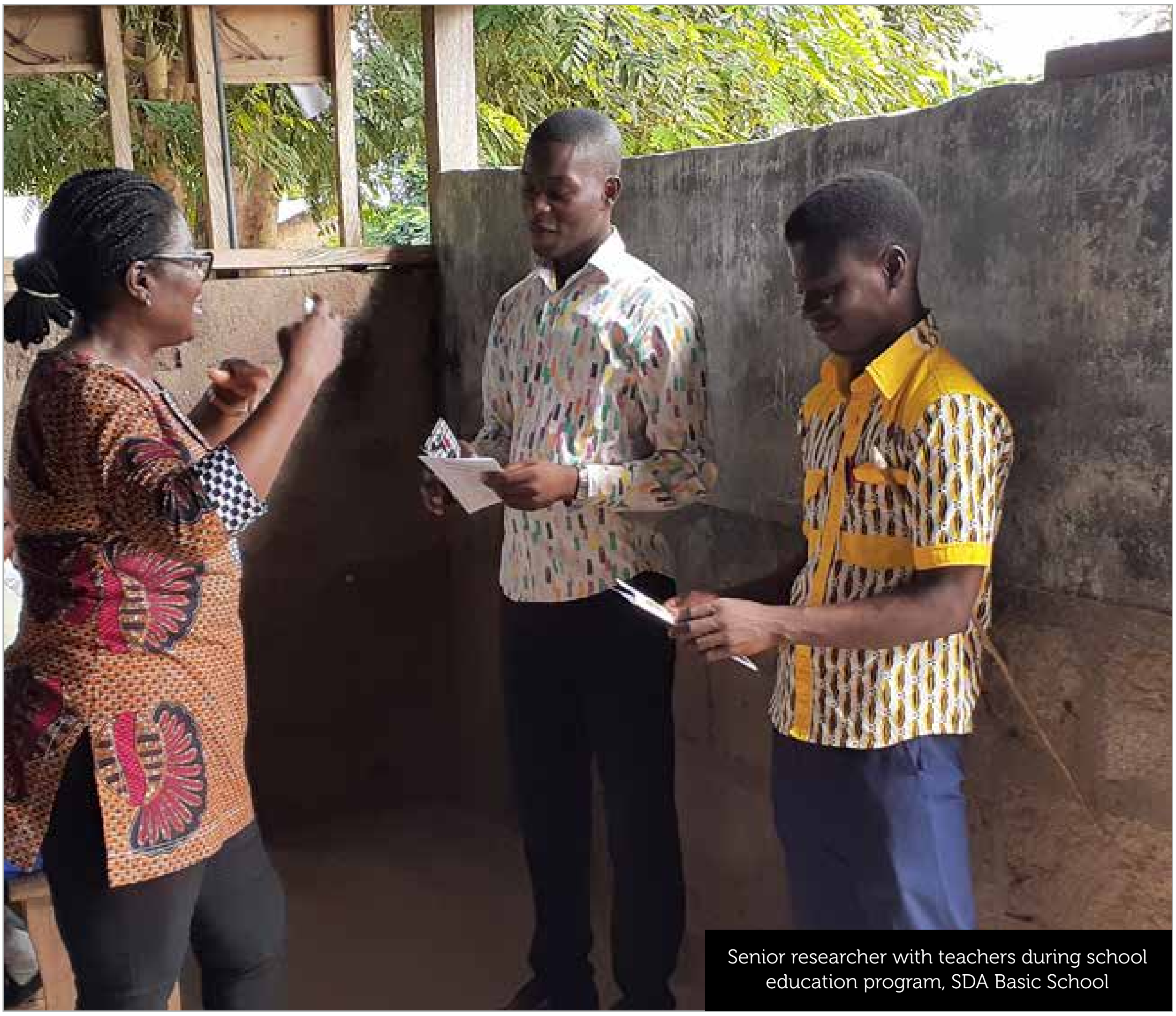
Misconceptions about schistosomiasis in women and girls lead to under-diagnosis and disease progression

The gynecological symptoms of FGS lead health workers to use the STI treatment guidelines instead of considering that women may have schistosomiasis. In communities where schistosomiasis is endemic, it is estimated that between 33-75% of women have FGS, yet few of these cases are diagnosed correctly[10]. Over time, FGS does more damage to reproductive organs that may be irreversible. Treatment with praziquantel kills adult worms but may not heal established lesions caused by schistosome eggs[11].

Interventions must be tailored to the special needs of women

Women and girls can be protected from schistosomiasis by education about the disease that addresses the gendered differences in risk and routine provision of praziquantel for women and girls who are at risk. Facilities should also be stocked with praziquantel for women who present to a health worker with symptoms, and health workers better prepared to diagnose FGS. Finally, access to improved water sources is essential in the fight against FGS.

Informal discussion with pupils on FGS, Natriku



Senior researcher with teachers during school education program, SDA Basic School

ACTING ON THE EVIDENCE

Summary of Challenges and Suggested Actions

Challenge	Suggested Action
There are many misconceptions about schistosomiasis and women. Community members say that women and girls do not get schistosomiasis or that they get schistosomiasis through sexual contact	Design FGS educational materials for adult community members Develop educational materials for children about FGS that can be used in schools Implement appropriate community strategies to target women's groups, traditional women leaders, community medicine sellers, community-based health volunteers and traditional birth attendants for effective community education and engagement
Teachers did not know about FGS	Train teachers about FGS
Parents, teachers, and school children said they need more information about MDA, including when it will take place and that it is for schistosomiasis as well as intestinal worms	Ensure that MDA is well advertised in communities ahead of time and that community sensitization includes information about schistosomiasis and FGS
Women and girls were unaware of FGS and report that they treat its symptoms with traditional medicine	Design strategies and interventions to meet the needs of women and girls for greater awareness, prevention, and access to friendly diagnosis and treatment of FGS
Community members want to reduce their exposure to infected water but do not have universal access to clean water	Work with WASH stakeholders to develop gender-sensitive interventions that consider the roles and responsibilities of women that put them into contact with water

> **"There is no such disease for women. Only boys have this disease that causes bloody urine. It is only in boys."**
> **– IDI traditional birth attendant**

> **"I think the ladies can only get it when the boys give to them... But since you are asking these questions, it implies that the girls also suffer from the disease."**
> **– IDI teacher**

ACTING ON THE EVIDENCE CONTINUED

<table>
<tr><th colspan="2">Summary of Challenges and Suggested Actions</th></tr>
<tr><th>Challenge</th><th>Suggested Action</th></tr>
<tr><td>Community members were concerned that not everyone has access to medicine for FGS</td><td>Consider expanding annual MDA for schistosomiasis to target pre-school children, young women and out of school girls</td></tr>
<tr><td colspan="2">"Why do you give the treatment to only school children if the disease is in the water and everyone gets it? Next time make sure everyone gets the treatment.." – IDI teacher</td></tr>
<tr><td>Health workers use STI treatment guidelines for symptoms like vaginal discharge and itching, which are also symptoms of FGS</td><td>Add FGS screening and treatment to national guidelines, such as sexual and reproductive health service delivery guidelines, and the national STI treatment algorithm</td></tr>
<tr><td colspan="2">"When young girls or women come to the clinic with vaginal discharge or vaginal itching, painful urination and weakness, we use the STI treatment guidelines to treat them." – IDI community health worker</td></tr>
<tr><td>Health workers lacked the resources and capacity to effectively diagnose and treat FGS</td><td>Provide the sexual and reproductive health clinics with the WHO FGS Pocket Atlas
Provide health workers with praziquantel
Design in-service training on how to screen and diagnose FGS for sexual and reproductive health care providers</td></tr>
<tr><td>Few health workers were familiar with FGS, its symptoms, or its treatment</td><td>Design in-service training on how to screen and diagnose FGS for sexual and reproductive health care providers
Feature FGS in training and workshop agendas at all levels of the health system and at district, regional and national review meetings for effective visibility and responsiveness
Review and update curricula to include FGS in trainings for:
• Clinicians
• Nurses
• Midwives
• Community health workers</td></tr>
</table>

CONCLUSION

The findings are intended to provide policy makers and programme implementers with valuable information on key areas for strengthening policy and practice to address FGS. Documented knowledge gaps point to the need for educating communities and health workers. The findings show that current approaches toward sensitization, MDA, and treatment of schistosomiasis are leaving women and girls behind. Meeting these key areas will go a long way in improving the health and well-being of women and girls.

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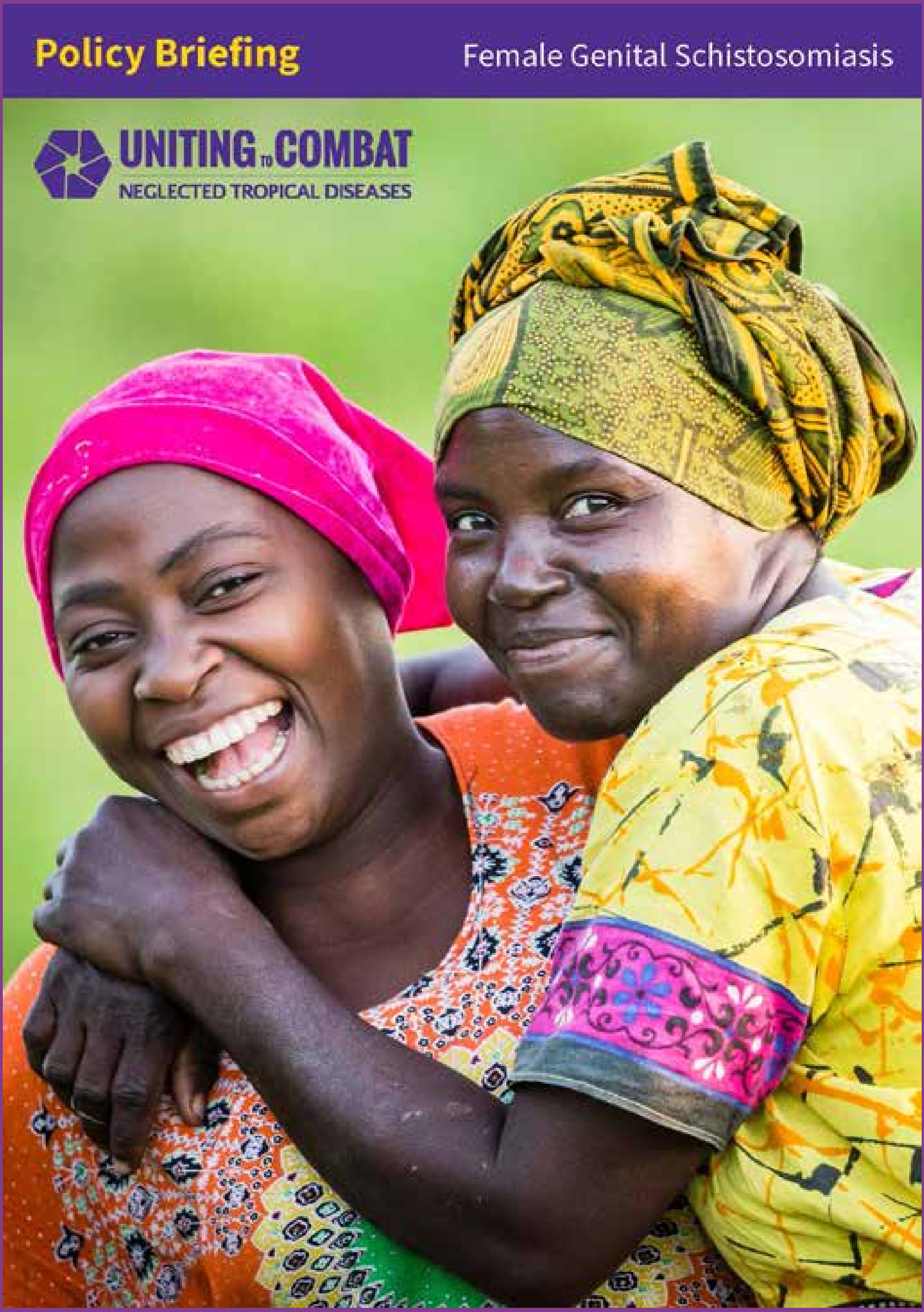
Policy Briefing

Female Genital Schistosomiasis

UNITING TO COMBAT
NEGLECTED TROPICAL DISEASES

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