

# A quality improvement approach in co-developing a primary healthcare package for raising awareness and managing female genital schistosomiasis in Nigeria and Liberia

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Received 4 April 2022; revised 8 July 2022; editorial decision 5 August 2022; accepted 27 September 2022

**Background:** Girls and women living in endemic areas for urogenital schistosomiasis may have lifelong vulnerability to female genital schistosomiasis (FGS). For >2 decades, the importance of FGS has been increasing in sub-Saharan Africa, but without established policies for case detection and treatment. This research aimed to understand the level of FGS knowledge of frontline health workers and health professionals working in endemic areas and to identify health system needs for the effective management of FGS cases and prevention of further complications due to ongoing infections.

**Methods:** Workshops were conducted with health workers and stakeholders using participatory methods. These workshops were part of a quality improvement approach to develop the intervention.

**Results:** Health workers' and system stakeholders' knowledge regarding FGS was low. Participants identified key steps to be taken to improve the diagnosis and treatment of FGS in schistosomiasis-endemic settings, which focused mainly on awareness creation, supply of praziquantel, development of FGS syndromic management and mass administration of praziquantel to all eligible ages. The FGS intervention component varies across countries and depends on the health system structure, existing facilities, services provided and the cadre of personnel available.

**Conclusion:** Our study found that co-developing a new service for FGS that responds to contextual variations is feasible, promotes ownership and embeds learning across health sectors, including healthcare providers, NTD policymakers and implementers, health professionals and community health workers.

**Keywords:** female genital schistosomiasis, health systems, health worker training, participatory research, primary healthcare, quality improvement.

## Introduction

Girls and women living in endemic areas for urogenital schistosomiasis may have a lifelong vulnerability to female genital schistosomiasis (FGS). Approximately 56 million girls and women in sub-Saharan Africa (SSA) are estimated to be affected by FGS.<sup>1</sup> This condition occurs when girls and women are repeatedly exposed to *Schistosoma haematobium* parasites through percutaneous contact with infected water sources.<sup>2</sup> Upon maturation of schistosome worms, schistosome eggs become trapped within genital tissues, causing localised and systemic inflammation as well as tissue-specific damage to the reproductive organs and genitalia. A lack of preventative treatment, limited alternatives to the river as a key source of water and delays in seeking and receiving treatment for FGS symptoms can worsen clinical outcomes associated with the condition.<sup>3-5</sup> These include subfertility, infertility, anaemia, cervical cancer, miscarriage, ectopic pregnancy and increases in infant and maternal mortality.<sup>6-8</sup> Collectively, FGS can lead to severe psychosocial and economic consequences, particularly in some parts of Nigeria and Liberia where the social status of women is often associated with fertility and reproductive capacity. For example, through stigmatisation, FGS sufferers may lose their home and relationships owing to health implications from FGS or from incorrect assertions from misdiagnosis with sexually transmitted infections (STIs).<sup>9</sup> A low level of awareness of FGS among health workers enforces this vicious cycle, resulting in many cases of FGS being undiagnosed and mismanaged within primary care, as FGS symptoms often overlaps STIs.<sup>10,11</sup>

Treatment strategies for tackling urogenital schistosomiasis, like other preventable neglected tropical diseases (NTDs), are currently via mass drug administration (MDA) campaigns that predominantly target school-age children. Programmatic challenges to reaching out-of-school children and adults means that girls and women are often missed and their risk of FGS accumulates through time.<sup>11-13</sup> However, MDA treatment with praziquantel of school-age girls dramatically reduces the development of FGS in adolescence and adulthood. Consequently, the World Health Organization (WHO) released a policy brief<sup>4</sup> recommending the extension of deworming coverage for schistosomiasis and soil-transmitted helminths to adolescent girls and women of reproductive age for prevention of these two diseases in these groups.<sup>4</sup> Structural barriers and social norms, such as household washing and low decision-making power of women, disproportionately increase women's exposure to fresh water and disease, alongside low health-seeking behaviours, making FGS a gendered health issue.<sup>14,15</sup> Thus addressing FGS becomes central to supporting progress toward universal health coverage (UHC) and in addressing multiple Sustainable Development Goals (SDGs), including 3, 5 and 10 concerning well-being, human rights and sexual and reproductive health of girls and women.<sup>16</sup>

For >2 decades, the importance of FGS has been raised in SSA, but without established policies or protocols for case detection and treatment pathways.<sup>2</sup> More so, high endemicity for urogenital schistosomiasis is indicative of the significant FGS disease burden among girls and women.<sup>17,18</sup> The WHO NTD Roadmap 2021–2030 calls for better integrated interventions to address NTDs using sustainable and existing health infrastructures.<sup>19</sup> The WHO also recommends that girls and women with symptoms of FGS and recent percutaneous contact with freshwater in any

endemic region should be considered for FGS treatment with praziquantel through the primary healthcare (PHC) system.<sup>20</sup>

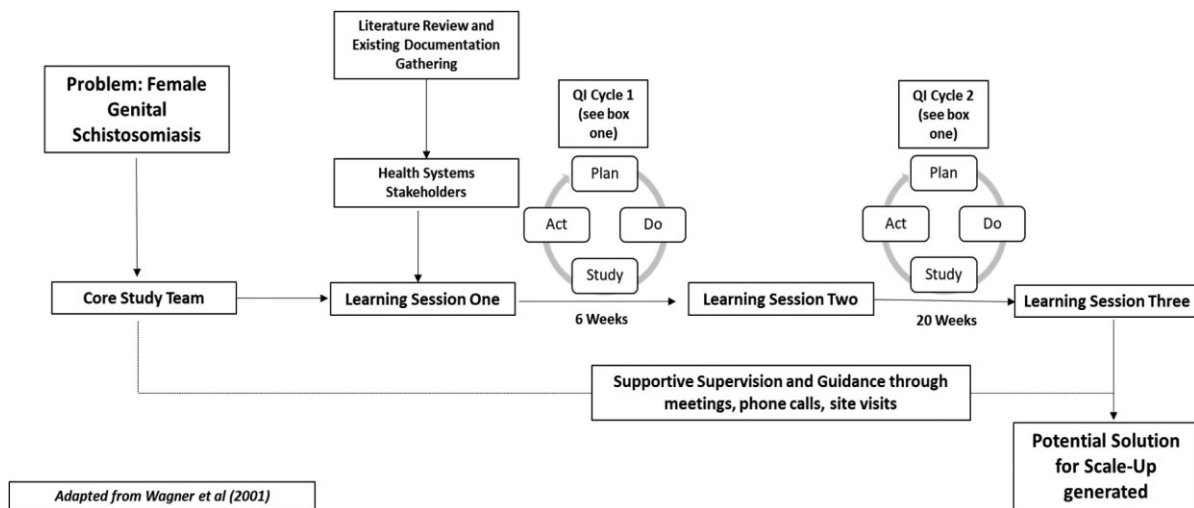
While standard annual praziquantel cannot fully reverse lesions resulting from FGS once they are formed, it can prevent further progression of the disease, hence early and regular treatment of girls and women with symptoms of FGS is advised.<sup>21</sup> Therefore, as we move towards mainstreaming of NTD services into health systems,<sup>19</sup> timely diagnosis and treatment of FGS through the PHC system should be considered as an essential service or priority intervention for integration,<sup>22</sup> alongside supportive strategies for well-being, which may address the psychosocial impacts of disease.

Operationalising the diagnosis, treatment and management of FGS at the PHC level is met by multiple health system challenges including a lack of point-of-care diagnostic tools, limited availability of praziquantel outside of MDA campaign periods and limited awareness among health workers and communities.<sup>22</sup> Furthermore, where steps have been taken to address these diagnostic and treatment capacity gaps, they have seldom been evaluated. For example, the WHO developed a pocket atlas to support health workers for diagnosis and treatment of FGS.<sup>20</sup> However, efforts to operationalise the atlas are unclear and its reliance on specialist staff and gynaecological equipment such as colposcopy for diagnosis renders its implementation challenging across many resource-limited settings. Strengthening the evidence base of how to address these ongoing health system challenges is essential to develop context-specific strategies that can support the integration of FGS services within the PHC system and to ensure that many girls and women do not continue to remain undiagnosed, stigmatised and untreated. Thus there is a call to embed diagnostic and treatment strategies for FGS within PHC settings to address the increasing disease burden and treatment gap through implementation research. At the time of conceptualization and commencement of this study in 2019 there was no published work or implementation research detailing how to operationalize the diagnosis, treatment and management of FGS at the PHC level. Most studies focused on describing the epidemiology of FGS to raise awareness.<sup>3,5</sup>

As a result of dialogue and awareness raising through the COUNTDOWN Consortium, drawing on learnings from a Ghanaian situational analysis,<sup>11</sup> programme managers from the Liberian Ministry of Health and the Nigerian Federal Ministry of Health, with research partners in Liberia (University of Liberia–Pacific Institute for Research and Evaluation) and Nigeria (Sightsavers), requested that we work together to better understand how to address challenges related to the diagnosis, treatment and management of FGS.

To this end, we explore a quality improvement (QI) approach using plan, do, study, act (PDSA) cycles to support health system strengthening through the development of an integrated package of care for FGS to be used at PHC facilities in areas highly endemic for schistosomiasis in Liberia and Nigeria.

The QI approach promotes real-world, context-specific solutions to implementation problems through the co-production of health system knowledge and learning.<sup>23,24</sup> The approach provides an opportunity for dialogue and interaction between frontline health workers (FLHWs) and more senior health system decision makers for shared learning of skills and experience,



**Figure 1.** Study pathway (adapted from Wagner et al.<sup>31</sup>).

leading to better-quality health service delivery. The QI approach is an iterative model of continuous learning and modification, involving stakeholders at different levels of the health system. Participation is central to co-developing solutions to implementation challenges versus the dominance of top-down health systems design. This approach allows immediate uptake of research findings while simultaneously embedding change within health systems for sustainability.<sup>25,26</sup>

In this article we describe the outcomes of the ‘plan’ phase of the first PDSA cycle from implementing a QI approach. The plan phase consists of an initial workshop aimed at increasing health provider and health system stakeholder (HSS) awareness of FGS in Liberia and Nigeria. The subsequent ‘do, study, act’ phases consist of co-developing an integrated care package that will later be rolled out in PHC facilities, evaluated and reported in succeeding papers. Here we present the first steps and the formal processes in developing this intervention for FGS. The following research questions were considered for this aspect of the study: What is the level of knowledge of FLHWs and health professionals working in schistosomiasis-endemic areas in Ogun State regarding FGS? What does the health system need to put in place to be able to effectively manage cases of FGS and prevent further complications due to infections with schistosomiasis?

## Methods

### Study design

The study applied a QI approach using PDSA cycles with participatory research methods with the aims of understanding and documenting health worker and systems knowledge of FGS in Liberia and Nigeria; educating health system decision makers, NTD leads, specialists and FLHWs on FGS and potential diagnosis and treatment options; and co-designing an intervention to be piloted in endemic communities.

A QI approach was selected for this study, as it applies a rigorous methodology to evaluate systemic changes to patient

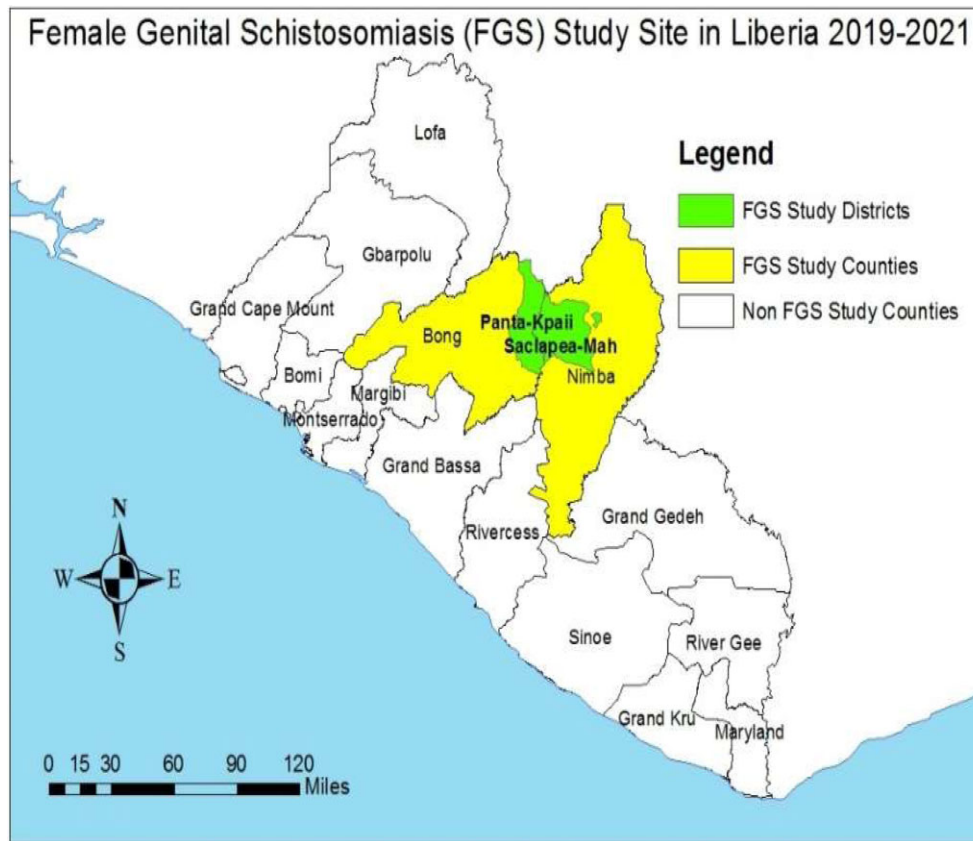
care processes to improve patient outcomes and the safety and value of the care delivered.<sup>27</sup> QI approaches utilise a PDSA cycle that provides a structure for iterative testing of changes across a four-stage learning approach. This allows for rapid assessment and flexibility to adapt and change according to feedback to ensure a fit-for-purpose solution.<sup>28-30</sup> This approach thus allows for the development of a more nuanced implementation framework at each level of the health system and can facilitate more rational use of limited resources, while building evidence for change within natural settings and engaging stakeholders in the implementation of change for sustainability.<sup>28</sup>

Figure 1 presents our study pathway, which was adapted from Wagner et al.<sup>31</sup> This involves the implementation of three PDSA cycles. Each PDSA cycle is separated and informed by participatory learning sessions during which intervention plans are collaboratively developed and adapted. PDSA cycle 1 is informed by learning session 1 and is designed as a pilot process to strengthen the capacity and skills of the core research team and co-researchers as they move into PDSA cycles 2 and 3.

However, in this article we present only the findings from learning session 1 and the plan stage of the first QI cycle.

### Study settings

In Liberia, the study communities are across two districts, Panta-Kpai and Saclepea-Mah (Figure 2), which have a prevalence of urogenital schistosomiasis of 82.74% and 61.69%, respectively (Liberia Ministry of Health<sup>32</sup> report, 2012). Study communities are adjacent to the Saint John River and have agriculture and fishing as their economic mainstays, with rice being a common cash crop. Rice paddies in Liberia are reported to have a high density of aquatic snails that transmit urogenital schistosomiasis.<sup>33</sup> The study communities in Nigeria are across two local government areas (LGAs) in Ogun State, Abeokuta North and Odeda, with an estimated prevalence of urogenital schistosomiasis of 84% and 67%, respectively (Nigeria Ministry of Health<sup>34</sup> report, 2009). These communities are adjacent to the Oyan River dam (see Figure 2), which has been reported as a foci for schistosomiasis



**Figure 2.** Map highlighting study county location.  
Source: Liberia Schistosomiasis mapping 2012–2015.

**Table 1.** Participants for the knowledge and awareness workshops

Group	Role	Nigeria (n = 30)	Liberia (n = 27)
HSSs	Representatives from national and state NTD programmes (decision makers and lead clinicians)	9	7
	Representatives from other state divisions supporting women’s health	NA	7
	Representatives from regional NTD programmes (LGAs and districts)	2	2
	Technical/academic partners	1	2
Local health providers	Local facility-level FLHWs, including nurses, midwives, traditional birth attendants and community health volunteers	18	9

transmission and cases of FGS have been confirmed in these communities.<sup>2</sup>

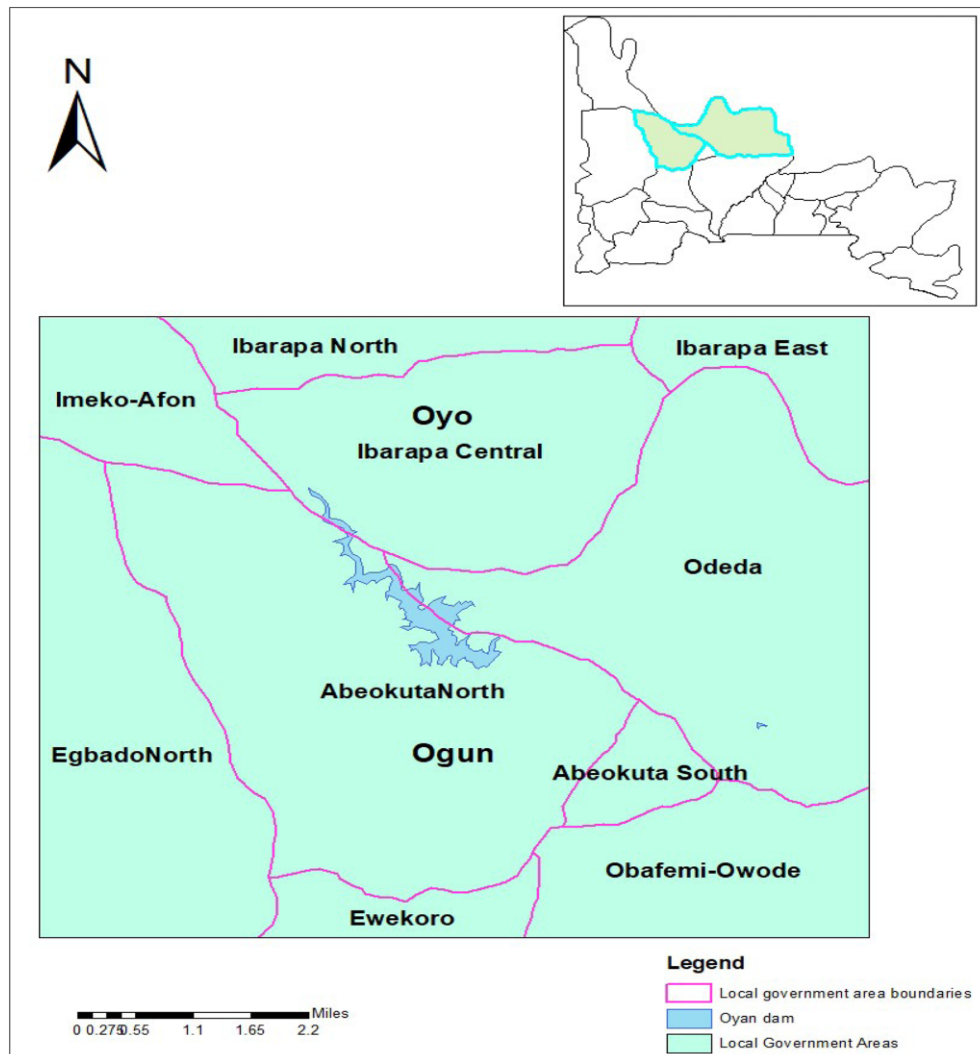
**Data collection**

*Sampling and recruitment*

Health workers and HSSs were purposively selected in the two countries based on their role in PHC and/or women’s health, availability and willingness to take part in the study. Tables 1

and 2 present the stakeholders who were selected and participated in the workshops based on initial discussions with NTD policymakers about who was essential to include.

Two participatory workshops were conducted to collect data. In preparation for these workshops, researchers conducted a literature review to identify peer-reviewed and grey literature, including policy documents and strategies that focus on case detection, referral, clinical and psychosocial management processes for FGS and community-based case detection and



**Figure 3.** Map of Ogun State with the study area expanded to show the waterbody. Source: Produced by AO using ArcGIS 10 software.

syndromic management systems for other diseases such as respiratory conditions and STIs.

#### Workshop 1

This workshop was aimed at elucidating the level of knowledge and understanding of the FLHWs and HSSs (health professionals and health policymakers) (see Table 1) about FGS before sensitization. FLHWs and HSSs were then encouraged to conceptualise the steps required to provide care for girls and women with symptoms of FGS.

**FGS knowledge** Participants shared their knowledge and experience about FGS using health scenarios prompted by questions regarding symptoms, diagnosis, treatment and prevention. Following this, a presentation on FGS was delivered to update their knowledge.

**Health-seeking pathway** Participants engaged in participatory research using health-seeking pathways (Liberia) and the stepping stones method (Nigeria)<sup>35</sup> to identify the systematic steps that are needed to support girls and women with symptoms of FGS without being stigmatized.<sup>36</sup> The participants applied new knowledge gained from the presentation on FGS and their experience as health workers and discussed the steps needed to address the challenge. The results from this workshop and the literature review fed into the second workshop.

**Stakeholder mapping** Stakeholder mapping was conducted to identify relevant health staff and HSSs who are likely to contribute to the development and implementation of this study, promote and sustain activities and outcomes and be affected by the process and/or outcome of this study. These HSSs were then invited to form an FGS QI team who spearheaded the development of the FGS care package

**Table 2.** Participants for the intervention development workshops based on the stakeholder mapping (FGS quality improvement team)

Group	Role	Nigeria (n = 22)	Liberia (n = 33)
HSSs	Representatives from the state NTD programme, including decision makers and lead clinicians	17	7
	Representatives from other state divisions supporting child and women's health	1	7
	Representatives from regional NTD programmes (LGAs and districts)	1	2
	Technical/academic partners	1	2
Local health providers	Local facility-level FLHWs, including nurses, midwives, traditional birth attendants and community health volunteers	2	9

### Workshop 2

The second workshop aimed to collaboratively develop an intervention for the management of FGS at the PHC level. The participants were divided into two groups; each group initially focused on a particular stage of the intervention, which was later agreed upon in the wider group. The QI team had two subsequent working sessions to assemble tools into manuals and conduct reviews.<sup>37,38</sup> In-depth interviews were conducted with selected participants to obtain their perceptions of the intervention development process.

### Data management and analysis

Data were collected by research assistants with at least a bachelor's degree and having experience in qualitative data collection. In addition, we provided capacity strengthening in qualitative and participatory health research approaches, including the QI cycle, specific to the study. These research assistants were supported on a daily basis by country research leads who are holders of a master's degree (Liberia) or a PhD (Nigeria) and social scientists (PhD) from the UK with extensive knowledge and experience in the methods used. All the sessions were audio recorded and the recordings were then transcribed verbatim (translated in Nigeria from Yoruba to English as appropriate) and reports were produced in both contexts. Deductive analysis was conducted by coding the transcripts and reports alongside the health-seeking pathway steps, including diagnosis, treatment, referral and counselling. Inductive analysis was also conducted to identify any additional themes raised in the two workshops. Coding and analysis were carried out using NVivo 12 software (QSR International, Hawthorn East, VIC, Australia), applying the five stages of the framework approach to qualitative analysis (i.e. familiarization, identifying a thematic framework, coding/indexing, charting, mapping and interpretation).

## Results

### FGS awareness and understanding

FLHWs and HSSs reported low levels of knowledge regarding FGS, with most stating that this was the first time they had heard of the condition. HSSs agreed that there was limited education

on FGS in medical education, which contributed to a lack of awareness.

*'When somebody tell me say "my last pepee [urine] is bloody" then I will tell the person... maybe you get schisto because that schisto can cause that problem... but I never knew actually that genital err... discharge, ulcer to the private part, that was schisto'. (Workshop 1, Liberia)*

FLHWs and HSSs had encountered patients with FGS symptoms during their medical practice but had diagnosed it as another condition because of its overlapping symptoms with other health conditions, such as STIs or genital cancers, and subsequently issued medicines that reportedly did not resolve the condition.

*'There was no proper diagnosing of FGS all of those condition coming to the health facility was either diagnosis as chronic infection or STI and some of them had been treated with strong antibiotic, and they continue coming with the same condition...'. (FLHW, Workshop 1, Liberia)*

*'The lesions that we saw in the cervix, that we might be thinking could be as a result of... early-stage cervical cancer'. (HSS, Workshop 1, Nigeria)*

Despite low levels of awareness of FGS, there was good awareness of schistosomiasis, however, there were common misunderstandings among some FLHWs. For example, an assumption that schistosomiasis is a male-related disease, therefore if a women or girl presents with blood in her urine, it is assumed to be related to the menstrual period, spotting or intermenstrual bleeding. Schistosomiasis was further assumed in Nigeria to be transmitted through oral routes, i.e. drinking contaminated water or the ingestion of snails, through dogs urinating or through sexual intercourse. Hence recommendations for prevention can also be incorrect, such as caging dogs, purifying drinking water or using sexual protection.

*'In my own area, they call it "Atosi Aja." They believe before you could have it, hmmm, you're going to urinate near where a dog has urinated'. (FLHW, Workshop 1, Nigeria)*

Participants reported that girls and women may be reluctant to seek healthcare for FGS due to fears of stigmatization, with the assumption that it may be viewed as an STI or other serious infection, as it affects the genital area. They explained that this impact would more likely be felt in a community where issues about sexual and reproductive health are treated with high sensitivity, especially when it concerns women or girls.

*'Stigmatization is possible and then of course, the women will not want to open up because everything that has to do with sexuality, gender issues, most of the time, because of our clan, we are very sensitive we tend to recline'.* (HSS, Workshop 1, Nigeria)

### Key ways to improving diagnosis and treatment of FGS

The result from the health-seeking pathway activity highlighted the steps to be taken to improve diagnosis and treatment of FGS. These are described below.

#### *Design and provide information, education and communication materials for community awareness*

Participants reiterated the need for information, education and communication materials in local languages posted in strategic locations, including health facilities, to create awareness in the community and emphasizing the need to communicate that 'FGS treatment is free'.

#### *Supply health facilities with praziquantel*

Participants identified that praziquantel is not currently available in the health facilities unless there is a deworming programme ongoing, thus a regular supply would need to be available for case management of patients who present to the health facilities. They emphasized the importance of having the drug reliably available for treatment at all times.

*'It is frustrating if one has to present at the health facility and you are told the drugs are not here, go to another place'.* (HSS, Workshop 1, Nigeria)

#### *Develop syndromic management procedure*

In the absence of point-of-care diagnostic equipment, FLHWs stated that the symptomatic diagnosis of FGS with opportunities for further testing or treatments based on the symptoms presented would be feasible at the PHC level. They highlighted the steps a suspected patient with FGS symptoms will need to go through, including assessment of signs and symptoms, clinical history, demographics, residence location, recent exposure to fresh water, laboratory investigation (where possible) and treatment. Health professionals suggested the development of standard operating procedures for the diagnosis and treatment of FGS.

*'If we could have something like syndromic management, so that when you have, even apart from the signs and symp-*

*toms ... look at the social demographic features, you want to know location, exposures and all of those point, they [procedure] will [be] just like the STI syndromic management'.* (HSS, Workshop 1, Nigeria)

#### *Develop and deliver training methods and appropriate tools for FLHWs at the PHC level*

Participants mentioned the need to sensitize and train PHC level FLHWs, including nurses, midwives and community health service supervisors, to be able to effectively manage cases and refer severe cases to higher-level health institutions. In Liberia, participants stressed the need to train the already established cadres of community health workers, including community health volunteers (CHVs), community health assistants (CHAs) and trained traditional midwives (TTMs). These cadres were said to receive some form of motivation (financial for CHVs and CHAs) from the Liberian Ministry of Health to promote community health programmes such as patient identification and referral to health facilities and patient follow-up. The TTMs are an all-women cadre who assist women with birth issues and often refer or accompany pregnant women to health facilities for delivery. Participants stressed TTMs are trusted by community women and are often the first point of contact for women with genital issues/symptoms. This is because they are closest to the endemic communities. Participants also stressed the need to develop standard operating procedures and job aids that can be used by FLHWs.

*'The health workers should be trained to be able to recognize the symptoms, we need to be able to identify the category of the health workers that needs to be trained, the people that we find in the schistosomiasis endemic communities are what we call community health extension workers'.* (HSS, Workshop 1, Nigeria)

#### *Awareness creation on FGS among the community*

All FLHWs agreed that there is little or no awareness of FGS among health workers and community members, hence they recommend creating awareness of FGS to address potentially related stigma and enable FLHWs to recognise symptoms when girls and women living in endemic areas present for other conditions. Increasing awareness of signs and symptoms in the community would also create demand for girls and women seeking treatment for symptoms by reducing the stigma related to gynaecological issues, which are assumed to be STIs or other stigmatising conditions. Methods suggested to increase awareness included mass media, radio jingles, community workshops and seminars. The health workers mentioned that persons with FGS-related symptoms should be made aware of the consequences of delaying medical attention and allay the fears of those experiencing FGS to reduce stigmatization.

*'..., tell them that people at the community level with such conditions are not a witch, because the myth they have, is that they have some contact with demon that is making them not getting pregnant, or maybe getting sick all the time'.* (FLHW, Workshop 1, Liberia)

**Box 1.** FGS intervention components – Liberia.

The intervention manual includes an introduction to FGS (and schistosomiasis) and how to use the manual, followed by three modules: the diagnosis, treatment, and management algorithms; training guides; and monitoring and supervision tools.

**Introduction to the manual**

Participants found it useful to describe FGS and how it results from schistosomiasis at the start of the manual. This was followed by brief descriptions of disease manifestations and complications and current recommendations on diagnosis, prevention and treatment. This section ended with details on the target audience and how to use the manual.

**Diagnosis, treatment and management algorithms**

A patient pathway (Figure 1) was developed together with the supporting documents below to support each level of the algorithm:

- Job aids and community referral forms for community health workers
- Symptom checklist and environmental risk assessment for screening health workers
- Guides on genital speculum examination and images of potential FGS-related lesions for health professionals who practice speculum examination
- Eligibility criteria and treatment guides for praziquantel
- Guides on communication and counselling with women and girls diagnosed, including psychosocial support, with special attention to stigma and mental health in relation to FGS
- Possible side effects of praziquantel and management at the PHC facility level
- Criteria for the severity of disease and referral forms for higher-level health facilities

**Training**

This section was developed to guide the QI team and higher-level health workers to roll out a cascaded training of peers and collaborators across all levels of the health system. The training materials included a training programme, training agenda, training guides and assessment of trainees. The training guides have participatory exercises that foster peer learning, such as group discussions and role plays.

**Monitoring and supervision**

This section provides tips for planning and facilitating monitoring and supervision that is supportive, alongside tools such as reporting forms and checklists to assist the process.

*Prevention of FGS through MDA of praziquantel to all eligible ages*  
HSSs mentioned that cases of FGS could be prevented through MDA of praziquantel to all eligible ages in communities where schistosomiasis prevalence is >50%, as outlined in the WHO schistosomiasis control guide. Hence they emphasized the need to follow the WHO recommendation on schistosomiasis control to prevent FGS.

FLHWs also emphasized the need to encourage compliance with MDA of praziquantel for school-age children. They reported that several parents did not allow their children to participate in the previous MDA of praziquantel due to fears of side effects.

*'We have several communities in Ogun state that are 80%, and they don't have access [to praziquantel], only the school children are treated if at all ... so it is also important for us to ensure that the WHO treatment protocol for schistosomiasis is implemented'.* (HSS, Workshop 1, Nigeria)

**Development of the intervention**

In the development of the intervention, the QI team considered critically the health system structure, the existing facilities, the services provided and the cadre of personnel available at the PHC level. Hence the interventions developed in both countries were similar in principle and content but differed in the terminology used and implementation structure. In this section we describe the content of the intervention for each country (Box 1 and

Box 2) and participants' feedback on intervention development process and materials.

**Participant feedback on intervention process and materials***Collaborative QI approach*

The QI team facilitated discussions during the workshops, drafted the intervention manual and facilitated the amendment and adoption process. Participants described the process of manual development as challenging, interactive, participatory and engaging. As co-developers of the intervention, they felt a sense of fulfilment and project ownership and were optimistic about the project roll-out.

*Actually, the workshop was interactive, trust me, we learnt a lot, especially, with the group discussion. Because with my group the people who were there even listened to me you will see that my group was on top of things'.* (National-level stakeholder, Liberia)

*'...people from different departments, the gynecologists department, the pediatrician department, officers from local government level and other people from the state level so we come together, so everyone began to put in their best, bring in suggestions, opinions, and at the end of the day, there are some that we gathered and there are some*



**Box 2.** FGS intervention components – Nigeria.

Two FGS intervention documents were developed in Nigeria. One is the health workers training guide for managing FGS in PHC and the second document is a training manual that contains a set of activities the trainer must follow to effectively communicate the content of the training guide to participants. The training guide consists of an introduction section, followed by six sections that focus on diagnosis, treatment and management of FGS, follow-up, health education and counselling to prevent stigma, reporting and documentation, monitoring and supervision tools and sensitization strategies.

**Introduction to the training guide** focusses on the aim and objective of the guide, schistosomiasis and how it is transmitted, the manifestations and how it results in FGS. This is followed by an overall flow diagram of the care pathway for persons with FGS-related symptoms.

The **Diagnosis** section consists of five tools to support the diagnosis of FGS, its severity and other conditions. This includes an initial symptom questionnaire, environmental risk assessment, complications of FGS/other conditions checklist, vaginal discharge colour chart and follow-up questionnaire.

The **Treatment and management of FGS** section consists of the treatment pathway, eligibility criteria, inclusion and exclusion criteria for praziquantel treatment and monitoring of side effects.

**Follow-up** consists of a questionnaire to check if the patient's condition has improved based on initial symptoms reported and if there is need for referral for further investigation and care.

The **Health education and counselling to prevent stigma** section highlights what needs to be communicated to the FGS patient and the necessary communication skills for addressing any potential stigma and to promote open discussion.

The **Reporting and documentation** section consists of information on the importance of documentation and tools development for reporting and documentation of cases of FGS seen and managed. This includes the outpatient register (from the health system), FGS appointment card, FGS register and the referral form (from the health system).

The **Monitoring and supervision tools** for FGS include a monthly reporting form and supervision checklist.

**Sensitization strategies** presents the various proven platforms that can be used to create awareness about FGS and the availability of the FGS intervention at the PHC level.

*that is not useful and we delete from it and the algorithm'.*  
(FLHW, in-depth interview, Nigeria)

**Challenges faced during intervention development**

The novelty of FGS and managing power dynamics among groups of participants were discussed as main challenges during the development of the manual in Liberia. Participants often found it challenging to agree on one idea when multiple suggestions were made by the different individuals in the group. However, in both countries, reading and research to understand FGS and how the intervention can be designed was perceived to be time consuming.

*The challenges! the first thing I told you, this was new to a lot of us; we had to do a lot of reading, research, some of us, to see what was happening to other places and before we were able to adapt to the Liberian context what we should do here'.* (QI interview, national-level stakeholder, Liberia)

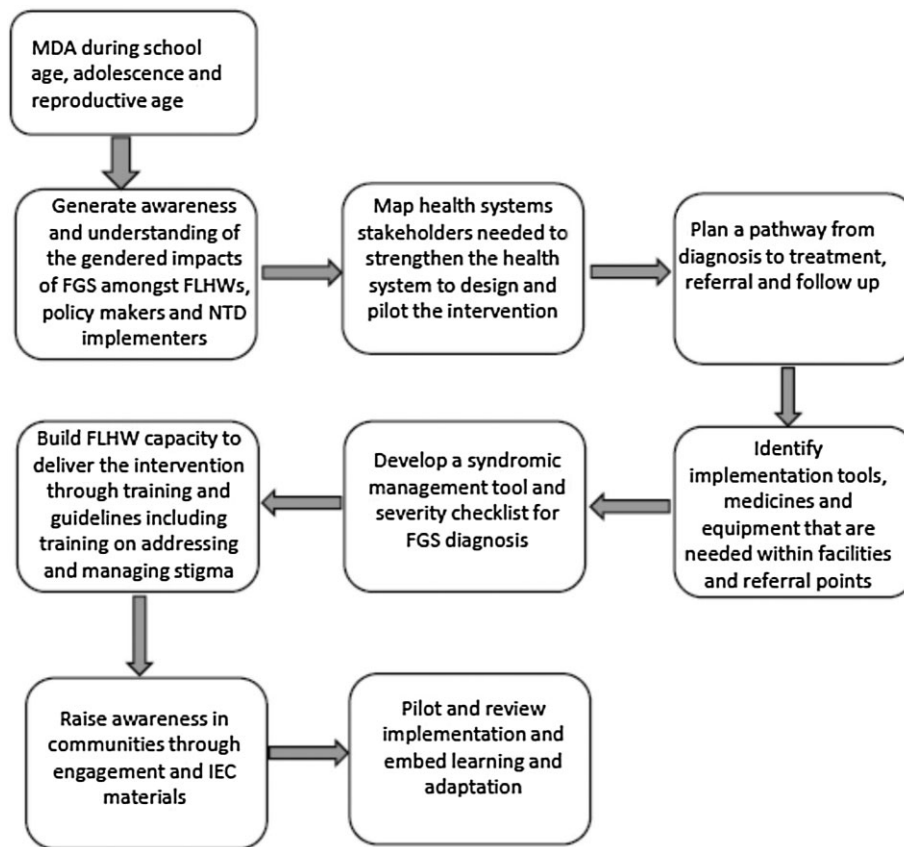
**Discussion**

This article is a seminal attempt in West Africa to address FGS by being the first published study to develop an intervention for case management of FGS at the PHC level. In this discussion we highlight the importance of having a care package for FGS at the PHC level, creating awareness about FGS among health workers and the endemic community, using a co-production approach to

solutions, having practical tools for training and FGS case management and engaging stakeholders across sectors. We also outline key steps (Figure 4) for other contexts, considering the integration of FGS care management into existing health systems, and make key recommendations for attention. Lastly, we highlight the need for prevention of FGS through extension of MDA of praziquantel to all age groups as recommended in the new WHO guideline on control and elimination of schistosomiasis.<sup>5</sup>

**Importance of implementing FGS care packages at the PHC level**

Schistosomiasis-endemic populations are often dependent on PHC, which lacks specialist or sophisticated diagnostic tools.<sup>14</sup> However, the gold standard for clinical diagnosis of FGS requires the availability of colposcopy with histopathology, both of which are not readily available in PHC facilities close to endemic regions, except in tertiary institutions.<sup>22</sup> This was confirmed in a large-scale qualitative study in Zanzibar and Tanzania and other studies from Ghana exploring community members knowledge, attitudes and practices on health-seeking behaviour for FGS who stated that 'there is a need to implement public health interventions at the community and health facility levels to, first, create awareness of FGS, its symptoms/clinical signs, diagnosis, management, and prevention and, second, encourage girls and women to seek for treatment at health facilities or that it'(p. 19).<sup>39</sup> In response to this need, a symptomatic diagnostic and treatment guide to manage FGS at the PHC level was developed,



**Figure 4.** Nine key steps to developing a contextualised FGS care pathway at the PHC level

which was considered a practical and realistic innovation that will enable the health system to respond to FGS. Developing the intervention and treatment pathway for FGS is also a timely response to several calls for the need to address the neglect of persons affected by FGS.<sup>7,21</sup> In addition, developing an intervention for FGS aligns with the goal of the WHO NTD Road Map 2030 and a step towards achieving the ‘leaving no one behind’ of the UHC as it relates to schistosomiasis control.<sup>40</sup>

### Generating awareness of communities and health systems to tackle FGS in endemic regions of Liberia and Nigeria

This study highlights that there was little or no awareness of FGS both within communities and by FLHWs and health professionals at primary and secondary healthcare levels in endemic regions of Liberia and Nigeria. In addition, the poor level of awareness and understanding of the gender dynamics of schistosomiasis found in this study and by others is one of the main reasons for the long neglect of persons affected by FGS and their inability to access needed care.<sup>12,39</sup> Through working collaboratively with HSSs and FLHWs to design an intervention and tools for integrated FGS care, this study was able to provide a space for embedded learning about the disease and to generate valuable discussions about the gendered impacts of symptoms and outcomes, including stigma.

Awareness and understanding of FGS and its dynamics is important in providing the necessary diagnosis, treatment and care for those affected.<sup>39</sup> Similar to the report in a study on FGS in Ghana, health workers assumed schistosomiasis is a disease of men and boys and did not consider schistosomiasis when a woman or girl presented at a health facility with blood in her urine, assuming it was related to menstrual cycles or other conditions.<sup>11</sup> Therefore, increasing awareness of health workers and health professionals about FGS is a major step in tackling the severe consequences of the disease and associated stigma. In addition, poor awareness and misunderstandings about causes, transmission and the impact of FGS among the endemic population is responsible for the poor health-seeking behaviour of those affected due to fear of stigmatization.<sup>41</sup>

Engaging community health workers to identify suspected cases of FGS and carrying out sensitization is therefore a major step towards reducing stigma and encouraging health-seeking behaviour. Community health workers are known to be impactful in health initiatives to improve maternal and child health.<sup>42,43</sup> However, when designing this intervention, the QI teams recognised that first FLHWs must have embedded knowledge, skills and tools to treat girls and women before community awareness drives women to facilities. Striking this balance at the beginning of the implementation period will be important for successful piloting and learning and to safeguard girls and women.

## Collaborative approaches to design, test, implement and integrate FGS care at the PHC level promotes ownership and sustainability of new interventions

This study found that co-developing a new service for FGS that responds to contextual variations at the PHC level is feasible, promotes ownership and embeds learning across health sectors, including primary and secondary healthcare providers, NTD policymakers and implementers, women's health professionals and community health workers. Engagement of health system actors using participatory research tools supported the development of potentially sustainable solutions to FGS treatment that builds on existing health system structures for training, service delivery, monitoring and supervision. This aligns with calls from the WHO in the NTD Road Map 2021–2030 for multisectoral action for diagnostics, monitoring and evaluation, access to and logistics for medicines, capacity strengthening, advocacy and funding. In addition, the road map specifies a change in operating models towards country ownership; using a QI approach ensured that researchers were facilitators in the development of the intervention.<sup>19</sup>

The QI approach identified what is needed to strengthen the health system for control and management of FGS, thus aligning with the guiding principles for quality, ethical standards and ongoing learning in implementation research, specifically by enabling flexible planning that builds on existing structures while providing opportunities for embedding change, developing relational practices within health systems and developing structures for ongoing learning.<sup>44</sup> Therefore, engaging the health system actors is likely to fast track the development and inclusion of policy and practice for the management of FGS that currently do not exist in the countries where this study was conducted. Studies have shown that healthcare innovations are more readily adopted when tailored to local contexts, which requires continuous investment and commitment of key actors, including implementers and users.<sup>45</sup> Framing research objectives to align with priorities of users and health systems, appropriate selection of stakeholders and building relationships between researchers and stakeholders are major recommendations for the sustainability of health interventions.<sup>46</sup>

Having discussed the need for early diagnosis and management of FGS and the role of the health system actors in achieving this, it is important to highlight that FGS can be prevented if all young girls and women living in schistosomiasis-endemic areas have access to praziquantel treatment early and to safe water and sanitation.<sup>3,4</sup> It is therefore expedient that schistosomiasis control/elimination programmes in endemic countries work out methods for ensuring that the recommendations from the WHO released in 2022 on deworming of adolescent girls and women and schistosomiasis control and elimination be fully implemented.<sup>4,5</sup> Also, integration of praziquantel treatment with other routine health services targeted at girls and women to prevent FGS should be considered in areas where schistosomiasis is highly endemic.<sup>4</sup>

### Limitations of the study

The strength of this research was in the engagement of committed health system actors who were passionate to develop

solutions for people suffering from FGS. However, coronavirus disease 2019 limited the number of face-to-face meetings and made it hard to work together but were limited due to travel restrictions.

## Conclusion and next steps

The findings from this study have provided information that could be useful for addressing the neglect of persons affected by FGS. Increasing the knowledge and understanding of health workers at all levels of the health system is the first step, along with awareness creation in the endemic community. Engaging health system actors in the development of contextualised care packages at the PHC level will ensure country ownership, which in turn may enable sustainability of the intervention, including policy development and the allocation of resources. A document that can assist FLHWs in the diagnosis and management of FGS at the PHC level has been developed by and for them, which will be piloted and evaluated to determine its effectiveness. Finally, implementing the WHO recommendation to extend MDA coverage from  $\geq 2$  y of age, including pregnant women from the second trimester, will go a long way towards preventing the morbidities associated with FGS and its eventual elimination.

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**Authors' contributions:** ASO and RT conceived the study. ASO, KO, RT and LD designed the study. AKB, MMN, ASO, VOF, JBA, HP and KO were involved in data collection and analysis. All authors were involved in the implementation and evaluation of the study. ASO and MMN drafted the manuscript. KO and HP critically revised the manuscript for intellectual content. UFE, IYS, MAK-E, FOS, OJN, KKK and SI further revised the manuscript. All authors read and approved the final manuscript.

**Acknowledgements:** We thank each member of the QI team for their contributions to the study and manuscript development. We would also

like to thank the management of the LGA for allowing healthcare workers to participate in this study.

**Funding:** This work was supported by UK AID within the UK Foreign, Commonwealth and Development Office (grant 6407).

**Competing interests:** None declared.

**Ethical approval:** This study was approved by the Liverpool School of Tropical Medicine (LSTM) Research Ethics Committee and the National Health Research Committee of Nigeria (NHREC/01/01/2007-17/02/2020) for the study conducted in Nigeria. For the Liberia study, LSTM Research Ethics Committee and the Institutional Review Board at the University of Liberia. Participants were invited via letter prior to the workshops and a participant information sheet was sent for them to read and understand the objective of the study. On arrival at the workshops, researchers provided informed written consent.

**Data availability statement:** The data that support the findings of this study are available upon reasonable request.

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