OPEN LETTER

# REVISED The first BILGENSA Research Network workshop in Zambia: identifying research priorities, challenges and needs in genital bilharzia in Southern Africa

[version 2; peer review: 3 approved, 1 approved with reservations]

Rhoda Ndubani[1], Olimpia Lamberti[2], Anna Kildemoes[3], Pytsje Hoekstra[3], Jennifer Fitzpatrick[1], Helen Kelly[2], Bellington Vwalika[4], Bodo Randrianasolo[5], Amy Sturt[6,7], Seke Kayuni[8], Augustine Choko[8], Nkatya Kasese[1], Eyrun Kjetland[9,10], Takalani Nemungadi[9], Sibone Mocumbi[11], Anna Samson[12], Elizabeth Ntapara[13], Anifrid Thomson[13], Elizabeth Danstan[14], Chido Dziya Chikwari[14,15], Kevin Martin[2,14,16], Ibrahim Rabiu[17], Gifty Terkie[17], David Chaima[18], Manuel Kasoka[4], Karoline Joeker[19], Louise Thomsen Schmidt Arenholt[19-21], Peter Leutscher[19,21], Russel Stothard[8], Oliva Rabozakandria[5], Anouk Gouvras[22], Tendai Munthali[23,24], Grace Hameja[25], Paul Kanfwa[4], Halwindi Hikabasa[23], Helen Ayles[1,2], Kwame Shanaube[1*], Amaya L. Bustinduy[2*]

[1]Zambart School of Medicine, Lusaka, Zambia
[2]Department of Clinical Research, London School of Hygiene and Tropical Medicine (LSHTM), London, UK
[3]Department of Parasitology, Leiden University Medical Center, Leiden, The Netherlands
[4]Department of gynaecology, University of Zambia, Lusaka, Lusaka Province, Zambia
[5]Association K'OLO VANOVA, Antananarivo, Madagascar
[6]Infectious Diseases Section, Veterans Affairs Healthcare System, Palo Alto, USA
[7]8. Division of Infectious Diseases and Geographic Medicine, Stanford University, Stanford, California, USA
[8]Department of Tropical Disease Biology, Liverpool School of Tropical Medicine, Liverpool, UK
[9]Discipline of Public Health Medicine, Nelson R Mandela School of Medicine, College of Health Sciences,, University of KwaZulu-Natal, Durban, KwaZulu-Natal, South Africa
[10]Department of Infectious Diseases, Norwegian Centre for Imported and Tropical Diseases, Oslo, Norway
[11]Manhiça Health Research Centre (CISM), Maputo Central Hospital, Maputo, Mozambique
[12]Department of Behavioral Sciences, School of Public Health, Catholic University of Health and Allied Sciences, Mwanza, Tanzania
[13]Mbeya Medical Research Centre (MMRC), National Institute of Medical Research, Mwanza, Tanzania
[14]Biomedical Research and Training Institute, Harare, Harare Province, Zimbabwe
[15]The Centre for Sexual Health and HIV/AIDS Research Zimbabwe, Harare, Zimbabwe
[16]Department of Global Health and Infection, Brighton and Sussex Medical School, Brighton, UK
[17]Department of Community Medicine, Gombe State University, Gombe, Gombe, Nigeria
[18]Department of Pathology, School of Medicine and Oral Health, Kamuzu University of Health Sciences, Blantyre, Malawi
[19]Department of Clinical Medicine, Aalborg University, Aalborg, Denmark
[20]Centre for Clinical Research, North Denmark Regional Hospital, Hjoerring, Denmark
[21]Department of Obstetrics and Gynecology, North Denmark Regional Hospital, Hjoerring, Denmark
[22]Global Schistosomiasis Alliance, London, UK
[23]School of Public Health, University of Zambia, Lusaka, Lusaka Province, Zambia
[24]Department of Public Health, Ministry of Health, Lusaka, Zambia
[25]Department of Neglected Tropical Diseases, Ministry of Health, Lusaka, Zambia

*

Equal contributors

**v2** **First published:** 10 Jul 2024, **9**:360
https://doi.org/10.12688/wellcomeopenres.22429.1
**Latest published:** 11 Apr 2025, **9**:360
https://doi.org/10.12688/wellcomeopenres.22429.2

## Abstract

Female genital schistosomiasis (FGS) and male genital schistosomiasis (MGS) are gender-specific manifestations of urogenital schistosomiasis. Morbidity is a consequence of prolonged inflammation in the human genital tract caused by the entrapped eggs of the waterborne parasite, *Schistosoma (S.) haematobium.* Both diseases affect the sexual and reproductive health (SRH) of millions of people globally, especially in sub-Sahara Africa (SSA). Awareness and knowledge of these diseases is largely absent among affected communities and healthcare workers in endemic countries. Accurate burden of FGS and MGS disease estimates, single and combined, are absent, mostly due to lack of awareness of both diseases and absence of standardized methods for individual or population-based screening and diagnosis. In addition, there are disparities in country-specific FGS and MGS knowledge, research and implementation approaches, and diagnosis and treatment. There are currently no WHO guidelines to inform practice. The BILGENSA (Genital Bilharzia in Southern Africa) Research Network aimed to create a collaborative multidisciplinary network to advance clinical research of FGS and MGS across Southern African endemic countries. The workshop was held in Lusaka, Zambia over two days in November 2022. Over 150 researchers and stakeholders from different schistosomiasis endemic settings attended. Attendees identified challenges and research priorities around FGS and MGS from their respective countries. Key research themes identified across settings included: 1) To increase the knowledge about the local burden of FGS and MGS; 2) To raise awareness among local communities and healthcare workers; 3) To develop effective and scalable guidelines for disease diagnosis and management; 4) To understand the effect of treatment interventions on disease progression, and 5) To integrate FGS and MGS within other existing sexual and reproductive health (SRH) services. In its first meeting, the BILGENSA Network set forth a common research agenda across *S. haematobium endemic* countries for the control of FGS and MGS.

## Keywords

Female genital schistosomiasis, FGS, male genital schistosomiasis, MGS, Schistosoma haematobium, research, needs, priorities, Southern Africa

**Open Peer Review**

**Approval Status** ✓ ? ✓ ✓

| | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| **version 2** (revision) 11 Apr 2025 | ✓ view | | | ✓ view |
| **version 1** 10 Jul 2024 | ? view | ? view | ✓ view | ? view |

1. **Joseph Osarfo**, University of Health and Allied Sciences, Ho, Ghana
2. **Ogechukwu Benedicta Aribodor**, Nnamdi Azikiwe University, Awka, Nigeria
3. **W. Evan Secor**, Centers for Disease Control and Prevention, Atlanta, USA
4. **Leora N. Pillay**, Frontline AIDS, Cape Town, South Africa

Any reports and responses or comments on the article can be found at the end of the article.

**Corresponding author:** Rhoda Ndubani (rhoda@zambart.org.zm)

**Author roles: Ndubani R**: Writing – Original Draft Preparation; **Lamberti O**: Writing – Original Draft Preparation; **Kildemoes A**: Writing – Review & Editing; **Hoekstra P**: Writing – Review & Editing; **Fitzpatrick J**: Writing – Review & Editing; **Kelly H**: Writing – Review & Editing; **Vwalika B**: Writing – Review & Editing; **Randrianasolo B**: Writing – Review & Editing; **Sturt A**: Writing – Review & Editing; **Kayuni S**: Writing – Review & Editing; **Choko A**: Writing – Review & Editing; **Kasese N**: Writing – Review & Editing; **Kjetland E**: Writing – Review & Editing; **Nemungadi T**: Writing – Review & Editing; **Mocumbi S**: Writing – Review & Editing; **Samson A**: Writing – Review & Editing; **Ntapara E**: Writing – Review & Editing; **Thomson A**: Writing – Review & Editing; **Danstan E**: Writing – Review & Editing; **Chikwari CD**: Writing – Review & Editing; **Martin K**: Writing – Review & Editing; **Rabiu I**: Writing – Review & Editing; **Terkie G**: Writing – Review & Editing; **Chaima D**: Writing – Review & Editing; **Kasoka M**: Writing – Review & Editing; **Joeker K**: Writing – Review & Editing; **Arenholt LTS** : Writing – Review & Editing; **Leutscher P**: Writing – Review & Editing; **Stothard R**: Writing – Review & Editing; **Rabozakandria O**: Writing – Review & Editing; **Gouvras A**: Resources, Writing – Review & Editing; **Munthali T**: Writing – Review & Editing; **Hameja G**: Writing – Review & Editing; **Kanfwa P**: Writing – Review & Editing; **Hikabasa H**: Writing – Review & Editing; **Ayles H**: Writing – Review & Editing; **Shanaube K**: Investigation, Supervision, Writing – Review & Editing; **Bustinduy AL**: Conceptualization, Funding Acquisition, Resources, Supervision, Writing – Review & Editing

**Competing interests:** No competing interests were disclosed.

**Grant information:** This work was supported by Wellcome [204928, https://doi.org/10.35802/204928].
*The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.*



**How to cite this article:** Ndubani R, Lamberti O, Kildemoes A *et al.* **The first BILGENSA Research Network workshop in Zambia: identifying research priorities, challenges and needs in genital bilharzia in Southern Africa [version 2; peer review: 3 approved, 1 approved with reservations]** Wellcome Open Research 2025, **9**:360 https://doi.org/10.12688/wellcomeopenres.22429.2

**First published:** 10 Jul 2024, **9**:360 https://doi.org/10.12688/wellcomeopenres.22429.1

**REVISED** **Amendments from Version 1**

We would like to thank the reviewers and editorial team for their valuable feedback. In response, we have made the specific changes to the manuscript to improve its clarity and quality

In the **Abstract**, we revised the description of the diagnostic challenges by adding a reference to the lack of awareness of both FGS and MGS. We kept the term "waterborne" for *Schistosoma* transmission, aligning with its extensive use in relevant literature.

Throughout the manuscript, we refined language for clarity and accuracy as requested by the reviewers. For example, we replaced "sperm consistency" with "semen consistency". We have also added additional relevant references, including the FAST package as a key training and awareness tool for FGS.

Additionally, in response to the reviewers' comments, we clarified why some topics, for example WASH interventions, were not included in the manuscript, noting that these were not discussed during the BILGENSA workshop. We have also acknowledged gaps such as stigma, misdiagnosis, and the lack of integration with WASH and HIV programmes.

These changes aim to accurately reflect the complexity of FGS and MGS research and ensure that the manuscript provides a comprehensive summary of the workshop discussions alongside key gaps requiring further attention.

**Any further responses from the reviewers can be found at the end of the article**

## Introduction

Female and male genital schistosomiasis are gender-specific chronic manifestations of urogenital schistosomiasis, a waterborne parasitic disease caused by the blood fluke *Schistosoma (S.) haematobium*[1,2]. Globally, female genital schistosomiasis (FGS) affects an estimated 20–56 million girls and women, mostly in sub-Saharan Africa (SSA)[2]. Male genital schistosomiasis (MGS), is[1,3–5] estimated to affect between 1% and 20% of males at risk[1]. Prevalence of FGS and MGS, is extrapolated from a small number of studies and underestimate the true burden of disease[1,2]. To date, only approximately 15,000 girls and women in endemic settings have been assessed for FGS[1,3]. MGS is also understudied and only six African countries (Madagascar, Nigeria, Egypt, Zimbabwe, Zambia, and Ghana) have conducted MGS studies.

The FGS and MGS epidemiology is closely related to the distribution and transmission dynamics of the parasite *S. haematobium*[6,7]. Individuals are exposed to the parasite through skin-contact with larvae (cercariae) in contaminated freshwater sources[6,7]. Inside the human host, parasites mature into adults and reside in the blood vessels where they produce eggs[6,7]. While some eggs are excreted in urine, others become lodged in the urinary and genital organs, inducing granulomatous inflammation, and pathological changes[2,8,9]. Eggs entrapped in the genital organs can result in adverse reproductive health outcomes, organ dysfunction, and reproductive morbidity[1]. FGS is a disease of inequality and needs to be approached with a gendered lens due to the distribution of household chores that put women and girls at disproportionate risk[10]. Importantly, in cross-sectional studies, there was strong evidence that FGS was associated with prevalent HIV and high-risk (HR-) human papillomavirus (HPV), the primary etiological agent of cervical cancer[2,7,10,11]. No epidemiological study has evaluated the association between MGS and HIV. *S. haematobium* induced inflammation in the male genital tract is hypothesized to increase HIV-1 viral load shedding in semen and contribute to HIV-1 transmission[12]. Work from Madagascar showed *S. haematobium* egg excretion in semen is associated with leukocytospermia and elevated inflammatory cytokines[13]. Further work in participants with MGS showed some evidence of a decline in semen viral load after praziquantel treatment ($p = 0.08$)[14]. These findings may lend biological plausibility to an association of MGS with HIV transmission, but further research is needed. Despite these significant health impacts, awareness of FGS and MGS is largely absent in *S. haematobium*-endemic settings.

Clinical manifestations of FGS and MGS are non-specific and often overlap with those of other sexual and reproductive health (SRH) conditions[2,15]. And clinical signs and complications are much more prevalent in women compared to men. Girls and women with FGS report symptoms including abdominal pain, vaginal bleeding, and genital itching[2]. These are often attributed to other sexually transmitted infections (STIs) by both healthcare workers and the patients, leading to overlooking FGS and unnecessary treatment of STIs[2]. Symptoms of MGS include changes in semen consistency, presence of blood in semen, coital and ejaculatory pain, abnormal ejaculates, and erection discomfort or dysfunction[1]. Compared to FGS, the level of morbidity associated with MGS in endemic areas remains largely understudied, with most of the evidence coming from individual case reports and post-mortem studies[1]. The stigma and misconception associated with these symptoms further contribute to the challenges of underreporting and incorrect diagnosis of FGS and MGS in endemic areas[1].

There are no standardized methods for individual or population-based screening and diagnosis of FGS and MGS, resulting in substantial underreporting of their prevalence and associated morbidity[2,15,16]. Conventional diagnosis of FGS involves the use of a colposcope to visually identify FGS associated lesions[6]. This is invasive, costly and requires high-level specialized training and advanced clinical infrastructure, which are often unavailable in *S. haematobium* endemic settings[6]. In addition, visual diagnosis of FGS may lack specificity, as the FGS mucosal changes visually observed with colposcopy have been associated with malignancy and STIs[11,17]. Microscopy of semen samples is currently the most accurate diagnostic method available for MGS[1]. However, its acceptance and availability in endemic communities is hindered by local beliefs and perceptions, posing significant challenges to its widespread implementation[1]. More recent research studies in SSA countries have validate closer-to the-user strategies for FGS screening and diagnosis[15]. Community-based screening and diagnostic strategies at the point-of-care could offer a promising opportunity for surveillance at scale[2,15,18].

FGS and MGS treatment and control relies on schistosomiasis public health guidelines, which promote mass drug administration (MDA) of praziquantel, as preventive chemotherapy[19].

Although praziquantel effectively reduces urinary egg excretion, its efficacy in treating genital schistosomiasis remains uncertain due to lack of robust clinical evidence[2]. WHO recommends the rollout of MDA treatment strategies based on schistosomiasis population-based prevalence, using a 10% threshold to determine the targeted age groups for treatment[19]. Yet, this approach is likely to overlook individuals affected by FGS and MGS who are not included in the treatment programs, contributing to the ineffective control of FGS and MGS in endemic regions.

In November 2022, the first BILGENSA (Genital Bilharzia in Southern Africa) workshop, took place in Lusaka, Zambia. The aim of the workshop was to advance the field at country-level and as part of a wider strategy for the control of schistosomiasis worldwide. Researchers from various *S. haematobium* endemic countries gathered to discuss the research gaps and needs for FGS and MGS research. This paper reports the key research needs and priorities that emerged during the workshop.

## The BILGENSA Research Network

The BILGENSA Research Network was a multi-country workshop held on the 9th and 10th of November 2022 in Lusaka, Zambia. The workshop aimed to establish a collaborative multidisciplinary network to share expertise and advance clinical research on FGS and MGS across *S. haematobium* endemic countries. The workshop was conducted over two days and used a hybrid approach with delegates and discussion both in-person and virtually. Over 150 researchers specializing in FGS, MGS, HIV, STIs and cervical cancer (CC) from around the globe attended the workshop. Attendees with a specialty in schistosomiasis research represented diverse research areas including disease epidemiology, diagnostics, parasitology, program implementation, and qualitative research on disease awareness. Delegates from *S. haematobium* endemic countries, including Zambia, Zimbabwe, Tanzania, Nigeria, South Africa, Madagascar, Ghana, Malawi, and Mozambique attended the workshop in Lusaka, Zambia.

The event was hosted by Zambart (https://www.zambart.org.zm), a Zambian research institution with extensive experience in HIV, TB, and SRH research. Sessions were held in English and translated in French for online participants. The workshop's aim and objectives are presented in *Extended data*, Figure 1[20]. The workshop was conducted over two days (*Extended data,* Text 1). Day one comprised of didactic sessions in which participants presented in-country FGS and MGS research, as well as sharing their country's perceived research priorities, challenges, and needs. The afternoon sessions were interactive with participants grouped in their respective countries to discuss country-specific research priorities (*Extended data,* Text 1). At the conclusion of Day One, outcomes of the interactive session were shared with the wider group. During Day Two, participants discussed the diagnostic opportunities and challenges for genital schistosomiasis and integration within SRH services. Specific interventions suggested included integrating FGS within existing cervical cancer, and FGS/MGS within HIV care screening programs (*Extended data,* Figure 1). We identified common themes that emerged during the workshop.

## Research needs and priorities identified in the workshop

During the BILGENSA workshop, endemic countries reported being at different stages in advancing FGS and MGS research. Despite these differences, common themes identified across countries include lack of expertise in identifying and correctly diagnosing FGS/MGS, and lack of disease awareness. The scarcity of available diagnostics and specialized equipment and health facilities infrastructure are notable hurdles. Another limitation is the limited number of trained clinicians available with specific expertise in FGS screening and identification. All country delegates reported limited availability of routine treatment with praziquantel, a drug not commonly found in clinics in SSA[21]. Further common issues include lack of financial resources from the ministry of health (MoH) to support community education and mobilization. There is a clear need for *enhanced collaboration* across countries and sectors.

Following the identification of the above challenges, the research priorities, and strategies to address them set forth by country delegates, as follows (Figure 1/Table1).

### Raising knowledge and awareness of FGS and MGS

During the workshop, delegates highlighted the urgent need to increase awareness and education on FGS and MGS in endemic settings through community engagement and sensitization programs. Community-wide campaigns should be initiated to disseminate information on the diseases' etiology, modes of transmission, symptoms, and prevention strategies. These campaigns can leverage existing community structures and engagement programs, to ensure all members of the community are included. It is imperative to provide additional training to healthcare workers in *S. haematobium* endemic regions on the acquisition, screening, and treatment of FGS and MGS. This training could be integrated into ongoing educational programs for Neglected Tropical Diseases (NTDs) and SRH[3,22]. The development of training manuals, standard operating procedures (SOPs) and standardized guidelines for the diagnosis and treatment of FGS and MGS are necessary to ensure effective disease control. An FGS training document for the community and healthcare workers, as well as a manual about raising awareness on FGS using drama, have recently been developed as a first step towards increasing education about and information on the disease, respectively[23–25]. In contrast, the lack of knowledge and awareness of MGS has not yet been adequately addressed.

Recent qualitative research in Cameroon, Tanzania, and Ghana highlighted a significant gap in knowledge and awareness on FGS among communities and healthcare workers[26–28]. Girls and women have reported limited knowledge on the mode of transmission, symptoms, and potential risk factors associated with FGS[26–28]. Simultaneously, healthcare workers often incorrectly diagnosed FGS, confusing its symptoms with those

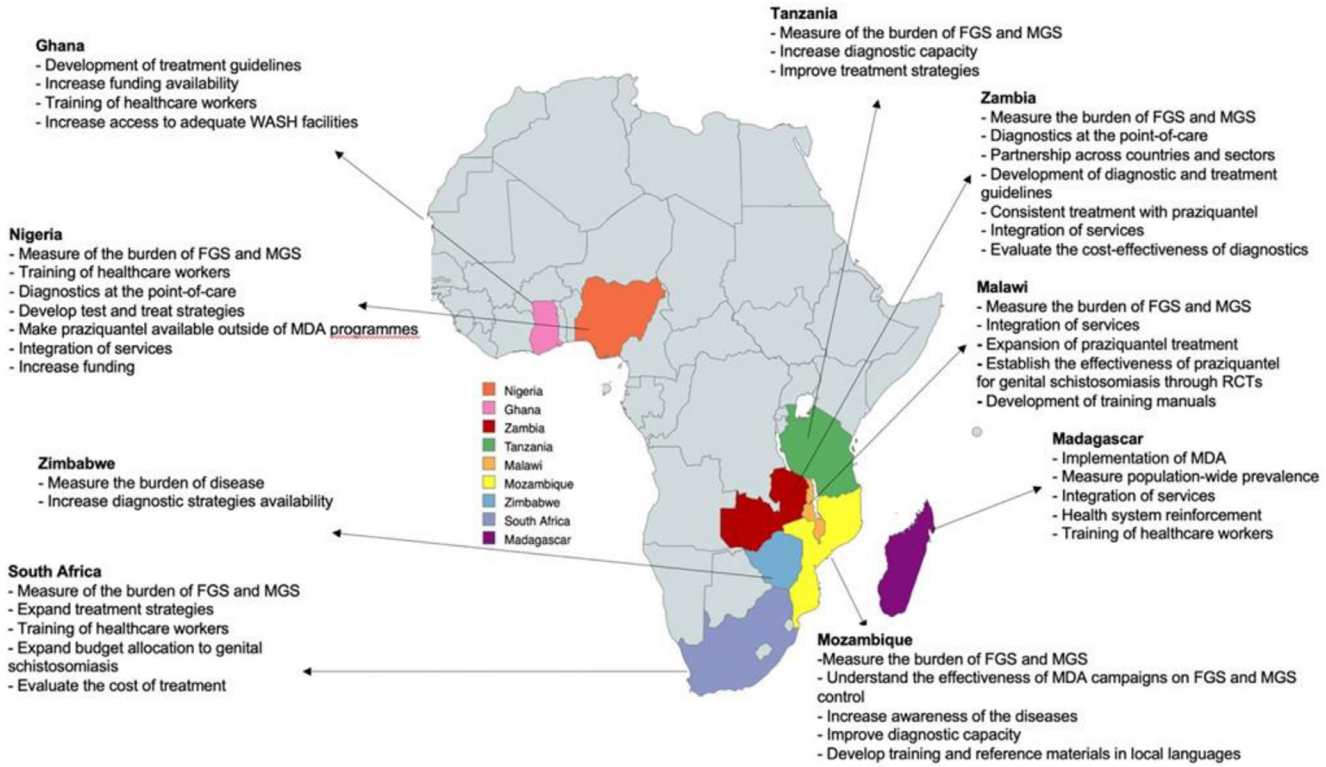


**Figure 1. Map showing the countries represented during the BILGENSA Research Network and their research needs and priorities to advance research on female genital schistosomiasis (FGS) and male genital schistosomiasis (MGS).**

**Table 1. Summary of the recommendations for future research discussed during the BILGENSA Research Network to address the female genital schistosomiasis (FGS) and male genital schistosomiasis (MGS) research needs and priorities in endemic settings.**

| Research need | Recommendations for future research | |
|---|---|---|
| | FGS | MGS |
| **Raising awareness and knowledge** | Provide further training to healthcare workers and patients on etiology, transmission, symptoms, screening, and management | Develop and disseminate educational and training material |
| **Improving diagnostic capabilities** | Validate and implement decentralized and field-deployable screening and diagnostic strategies for community-based surveillance at scale.<br>Evaluate the scalability and cost-effectiveness of different screening and diagnostic strategies | Develop and validate accessible, scalable, and low-cost molecular test. |
| **Developing standardized treatment guidelines** | Conduct randomized control trials (RCTs) to evaluate the effectiveness of praziquantel for FGS and MGS<br>Develop and implement FGS/MGS specific treatment guidelines. | |
| **Integration of SRH screening strategies** | Evaluate the integration of FGS within the wider schistosomiasis and SRH control guidelines. | Identify potential opportunities for integration of MGS into ongoing HIV interventions |
| **Surveillance and monitoring** | Develop routine and integrated surveillance of FGS<br>Increase collaborative efforts and financial resources available to implement and expand FGS and MGS control strategies. | |

of other STIs[26–28]. This results in the unnecessary STI treatment and contributes to the stigma faced by affected individuals seeking care in public health facilities[2]. The FAST package was designed as training curriculum to educate healthcare providers at different levels about FGS and engage teachers to improve coverage of MDA for schistosomiasis control[28]. further action is necessary to implement additional programs aimed at raising awareness and disseminating information and education on FGS among affected populations and healthcare workers, to effectively control and manage schistosomiasis. Further work is needed to develop educational material for MGS.

### Improving diagnostic capabilities in-country

Many countries reported limited diagnostic capacity for FGS and MGS with some (such as Nigeria, Tanzania, and Malawi) relying solely on *S. haematobium* antigen, antibody, and pathogen-based diagnosis. Although these methods serve as a useful proxy, they have reduced sensitivity for FGS and MGS diagnosis as they do not confirm genital involvement[1,2]. An additional common challenge identified across countries was the limited number of clinicians trained in colposcopy to identify FGS specific lesions, leading to a bottleneck in diagnosis.

Given the limited resources available in *S. haematobium* endemic countries, the BILGENSA Research Network highlighted the importance of decentralizing diagnostic methods for FGS. This includes bringing screening closer to the user for community-based surveillance at scale[2]. *Hand-held colposcopy* has been proposed as a more scalable diagnostic strategy compared to traditional colposcopy[2,17,29]. Hand-held colposcopes can be operated by primary healthcare workers (midwives), are mobile, cheaper and, rechargeable[2,17,29]. Furthermore, novel approaches for analysis of colposcopic images include using artificial intelligence visual reading algorithms to overcome some of the FGS diagnostic barriers including the lack of trained clinicians to identify FGS lesions and the subjectivity of FGS visual diagnosis[29]. Community-based screening and testing using *home-based self-sampling* and *point-of-care (POC) diagnostics* has also been proposed as a closer-to-the-user strategy for surveillance at scale[15]. Previous studies have shown the feasibility, acceptability, and cost-effectiveness of home-based genital self-sampling for cervical cancer screening, which has the potential to increase coverage by reaching women less likely to attend screening in clinic. A recent study in Zambia validated the use of genital self-sampling as a feasible, accurate, and feasible method for community-based screening of FGS[15,30]. As part of the study they successfully piloted a rapid and portable recombinase polymerase assay (RPA) for FGS diagnosis[15,31]. The RPA is a POC molecular assay which has high specificity, meaning detecting *S. haematobium* DNA in genital specimen confirms an FGS diagnosis[31,32]. The promising results from these studies emphasize the need for further applications of these screening and diagnostic techniques across different endemic settings.

In contrast to FGS, there is limited research on novel MGS screening and diagnostic methods[5]. Accessible and low-cost molecular tests are urgently needed to address the diagnostic challenges associated with MGS. For both FGS and MGS, future research should evaluate the cost-effectiveness, scalability, and performance of field-deployable molecular assays designed for point-of-care applications. These efforts are crucial for advancing the implementation of decentralized diagnostic strategies, ultimately contributing to more effective and accessible community-based surveillance of FGS and MGS.

### Developing standardized treatment guidelines

Treatment recommendations for FGS and MGS follow schistosomiasis public health guidelines, which promote mass drug administration (MDA) of praziquantel (typically offered at 40mg/kg), as preventive chemotherapy[2]. Praziquantel is an effective treatment for urinary schistosomiasis, but the evidence on its effectiveness for treating FGS and MGS remains limited. To date, only a small number of observational studies evaluated the performance of praziquantel for the treatment of FGS, and there have been no studies on its effectiveness for MGS[2]. In endemic settings, treatment programs are determined by the schistosomiasis prevalence[19]. The World Health Organization (WHO) recommends annual praziquantel treatment for all individuals aged two years and older in communities where the prevalence of egg-patent *Schistosoma* infection is 10% or greater[19]. In contrast, for communities with a prevalence below 10%, a test-and-treat strategy is advised[19]. Despite these guidelines, some countries, such as Mozambique and Tanzania, reported that MDA programs exclusively target school-aged-children (SAC), leaving older individuals and adults with limited access to treatment. Additionally, access to and uptake of praziquantel still remain a challenge[33]

During the BILGENSA workshop, participants highlighted the need to expand FGS and MGS treatment strategies. There was a call for randomized control trials (RCTs) to evaluate the effectiveness of praziquantel for the treatment of FGS and MGS[2]. Results from these trials will play a pivotal role in the development of effective treatment protocols and guidelines[2]. Mapping surveys should also be conducted to assess the impact of MDA programs on the prevalence of FGS and MGS in endemic settings and to facilitate an assessment of MDA coverage in rural areas and among hard-to-reach-populations. These efforts are critical for improving treatment accessibility and effectiveness of control strategies in endemic regions.

### Integration of SRH screening strategies

FGS and MGS surveillance are not yet included in wider schistosomiasis or SRH control strategies[2,3]. Existing HIV and cervical cancer programs have been identified as opportunities to integrate FGS surveillance into the SRH agenda[2,3,18]. Healthcare delivery systems already in place for HIV and cervical cancer prevention and control can be used to increase access to FGS screening and treatment services[2,3,18]. An integrated home-based screening and testing package for different SRH conditions, including FGS, could be made available to individuals in *S. haematobium* endemic settings[2,15]. This is currently being validated in an ongoing study in Zambia which aims to assess the feasibility and acceptability of an integrated home-based approach for multi-pathogen

genital screening, including FGS, HPV, Trichomonas and HIV[34]. In addition, FGS screening using hand-held colposcopy could be integrated into the existing cervical cancer screening programs[17,35]. In contrast, for men, there is still a need to identify potential opportunities for integration of MGS screening and control into ongoing HIV interventions. An integrated approach presents an opportunity to increase screening coverage of genital schistosomiasis while developing comprehensive policy frameworks that addresses the disease burden of FGS, MGS, HIV, and cervical cancer. Ultimately, this will accelerate the attainment of universal health coverage by strengthening different levels of the health system.

### Surveillance and monitoring

FGS has been financially neglected, resulting in limited funding available for advancing research and control of these diseases across endemic settings. The shift from campaign-based programs to routine and integrated surveillance of FGS requires further financial resources and sustainable collaborations between sectors. Across countries, participants of the BILGENSA Research Network highlighted the need to increase collaborative efforts and financial resources available to implement and expand FGS control strategies. SRH programs have been proposed as a plausible platform for integration of FGS surveillance within national health systems and information systems. This still requires improved FGS diagnostics, and better understanding of the spatial distribution of disease.

## Conclusions

FGS and MGS are specific genital tract manifestations of urogenital schistosomiasis. These diseases have been largely neglected and under-researched in *S. haematobium* endemic countries. The BILGENSA Research Network was created to bring together researchers and experts from different Southern African countries working on FGS, MGS, within the wider SRH landscape. Common research gaps identified across *S. haematobium* endemic countries included the lack of disease knowledge and awareness, scarcity of availability diagnostic methods, limited availability of routine screening and treatment, and lack of financial resources to support community education and mobilization. Key priorities identified included improving awareness and knowledge around genital schistosomiasis, increasing surveillance-at-scale by developing decentralized screening and diagnostic guidelines, and exploring the effectiveness of integration of control strategies within the broader schistosomiasis and SRH agendas. These actions are paramount for the control and elimination of these diseases in affected communities.

## Data availability

There is supplementary material associated with this manuscript which can be accessed here: 10.5281/zenodo.11930643. The following supplementary material are included:

- Figure 1: Schematic figure presenting the aims and objectives of the BILGENSA Research Network
- Text 1: Description of the proposed activities conducted during the BILGENSA Research Network
- Table 1: Agenda for the BILGENSA Research Network



### Underlying data

No underlying data are associated with this study.

### Extended data

Zenodo: The first BILGENSA Research Network Workshop in Zambia; Identifying Research Priorities, Challenges and Needs in Genital Bilharzia in Southern Africa. https://doi.org/10.5281/zenodo.11930644[20]

This project contains the following extended data:

- Supplementary document_12.06.2024.docx (Figure 1: Schematic figure presenting the aims and objectives of the BILGENSA Research Network, Text 1: Description of the proposed activities conducted during the BILGENSA Research Network, Table 1: Agenda for the BILGENSA Research Network)



### Acknowledgments

The BILGENSA Research Network initial workshop was hosted by Zambart with partners from the London School of School of Hygiene and Tropical Medicine (LSHTM), Global Schistosomiasis Alliance (GSA) and Leiden University Medical Centre (LUMC). The online event was organized by the GSA who also facilitated the French translation of the event as well as all the speaker's slides. The workshop and travel grants were funded by the Wellcome Trust Strategic Award, ISSF-3 to Prof. Bustinduy.

## References

1. Kayuni S, Lampiao F, Makaula P, *et al.*: **A systematic review with epidemiological update of Male Genital Schistosomiasis (MGS): a call for integrated case management across the health system in sub-Saharan Africa.** *Parasite Epidemiol Control.* 2019; **4**: e00077.
PubMed Abstract | Publisher Full Text | Free Full Text

2. Bustinduy AL, Randriansolo B, Sturt AS, *et al.*: **An update on Female and Male Genital Schistosomiasis and a call to integrate efforts to escalate diagnosis, treatment and awareness in endemic and non-endemic settings: the time is now.** *Adv Parasitol.* Elsevier, 2022; **115**: 1–44.
PubMed Abstract | Publisher Full Text

3. Engels D, Hotez PJ, Ducker C, *et al.*: **Integration of prevention and control measures for Female Genital Schistosomiasis, HIV and cervical cancer.** *Bull World Health Organ.* 2020; **98**(9): 615–24.
PubMed Abstract | Publisher Full Text | Free Full Text

4. Makene T, Zacharia A, Haule S, *et al.*: **Sexual and reproductive health among men with genital schistosomiasis in southern Tanzania: a descriptive study.** Standley CJ editor. *PLOS Glob Public Health.* 2024; **4**(3): e0002533.
PubMed Abstract | Publisher Full Text | Free Full Text

5. Kayuni SA, Alharbi MH, Shaw A, *et al.*: **Detection of Male Genital Schistosomiasis (MGS) by real-time TaqMan® PCR analysis of semen from fishermen along the southern shoreline of Lake Malawi.** *Heliyon.* 2023; **9**(7): e17338.
PubMed Abstract | Publisher Full Text | Free Full Text

6. Kjetland EF, Leutscher PDC, Ndhlovu PD: **A review of Female Genital Schistosomiasis.** *Trends Parasitol.* 2012; **28**(2): 58–65.
PubMed Abstract | Publisher Full Text

7. Sturt AS, Webb EL, Francis SC, *et al.*: **Beyond the barrier: Female Genital Schistosomiasis as a potential risk factor for HIV-1 acquisition.** *Acta Trop.* 2020; **209**: 105524.
PubMed Abstract | Publisher Full Text | Free Full Text

8. Downs JA, Kabangila R, Verweij JJ, *et al.*: **Detectable urogenital schistosome DNA and cervical abnormalities 6 months after single-dose praziquantel in women with *Schistosoma haematobium* infection.** *Trop Med Int Health.* 2013; **18**(9): 1090–6.
PubMed Abstract | Publisher Full Text | Free Full Text

9. Wall KM, Kilembe W, Vwalika B, *et al.*: **Schistosomiasis is associated with incident HIV transmission and death in Zambia.** Bustinduy AL, editor. *PLoS Negl Trop Dis.* 2018; **12**(12): e0006902.
PubMed Abstract | Publisher Full Text | Free Full Text

10. Kjetland EF, Ndhlovu PD, Gomo E, *et al.*: **Association between genital schistosomiasis and HIV in rural Zimbabwean women.** *AIDS.* 2006; **20**(4): 593–600.
PubMed Abstract | Publisher Full Text

11. Kjetland EF, Ndhlovu PD, Mduluza T, *et al.*: **Simple clinical manifestations of genital *Schistosoma Haematobium* infection in rural Zimbabwean women.** *Am J Trop Med Hyg.* 2005; **72**(3): 311–9.
PubMed Abstract | Publisher Full Text

12. Kayuni SA, Abdullahi A, Alharbi MH, *et al.*: **Prospective pilot study on the relationship between seminal HIV-1 shedding and genital schistosomiasis in men receiving antiretroviral therapy along Lake Malawi.** *Sci Rep.* 2023; **13**(1): 14154.
PubMed Abstract | Publisher Full Text | Free Full Text

13. Leutscher PDC, Pedersen M, Raharisolo C, *et al.*: **Increased prevalence of leukocytes and elevated cytokine levels in semen from *Schistosoma haematobium*-infected individuals.** *J Infect Dis.* 2005; **191**(10): 1639–47.
PubMed Abstract | Publisher Full Text

14. Midzi N, Mduluza T, Mudenge B, *et al.*: **Decrease in seminal HIV-1 RNA load after praziquantel treatment of urogenital schistosomiasis coinfection in HIV-positive men-an observational study.** *Open Forum Infect Dis.* 2017; **4**(4): ofx199.
PubMed Abstract | Publisher Full Text | Free Full Text

15. Sturt AS, Webb EL, Phiri CR, *et al.*: **Genital self-sampling compared with cervicovaginal lavage for the diagnosis of Female Genital Schistosomiasis in Zambian women: the BILHIV study.** Cools P, editor. *PLoS Negl Trop Dis.* 2020; **14**(7): e0008337.
PubMed Abstract | Publisher Full Text | Free Full Text

16. Pillay P, Downs JA, Changalucha JM, *et al.*: **Detection of *Schistosoma* DNA in genital specimens and urine: a comparison between five female African study populations originating from *S. haematobium* and/or *S. mansoni* endemic areas.** *Acta Trop.* 2020; **204**: 105363.
PubMed Abstract | Publisher Full Text

17. Sturt A, Bristowe H, Webb E, *et al.*: **Visual diagnosis of Female Genital Schistosomiasis in Zambian women from hand-held colposcopy: agreement of expert image review and association with clinical symptoms [version 2; peer review: 6 approved].** *Wellcome Open Res.* 2023; **8**: 14.
PubMed Abstract | Publisher Full Text | Free Full Text

18. Lamberti O, Bozzani F, Kiyoshi K, *et al.*: **Time to bring Female Genital Schistosomiasis out of neglect.** *Br Med Bull.* 2024; **149**(1): 45–59.
PubMed Abstract | Publisher Full Text | Free Full Text

19. World Health Organization: **WHO guideline on control and elimination of human schistosomiasis**.

20. Lamberti O, Ndubani R, Bustinduy A, *et al.*: **The first BILGENSA Research Network Workshop in Zambia; Identifying Research Priorities, Challenges and Needs in Genital Bilharzia in Southern Africa.** In: *Wellcome Open Research*. Zenodo. [Dataset]. 2024.
http://www.doi.org/10.5281/zenodo.11930644

21. World Health Organization: **The selection and use of essential medicines 2023" executive summary of the report of the 24th WHO expert committee on the selection and use of essential medicine**. 2023.
Reference Source

22. UNAIDS: **No more neglect: Female Genital Schistosomiasis and HIV**. 2019.
Reference Source

23. Countdown: **Health worker training guide for Female Genital Schistosomiasis (FGS) in Primary Health Care.** Liverpool School of Tropical Medicine, UK, 2021.
Reference Source

24. Jacobson J, Pantelias A, Williamson M, *et al.*: **Addressing a silent and neglected scourge in sexual and reproductive health in Sub-Saharan Africa by development of training competencies to improve prevention, diagnosis, and treatment of Female Genital Schistosomiasis (FGS) for health workers.** *Reprod Health.* 2022; **19**(1): 20.
PubMed Abstract | Publisher Full Text | Free Full Text

25. Blantyre Institute for Community Outreach in Malawi, Catholic University of Health and Allied Sciences in Tanzania, Zambart in Zambia: **Using Drama to Raise Awareness About Female Genital Schistosomiasis**. 2022.
Reference Source

26. Masong MC, Wepnje GB, Marlene NT, *et al.*: **Female Genital Schistosomiasis (FGS) in Cameroon: a formative epidemiological and socioeconomic investigation in eleven rural fishing communities.** Tappis H, editor. *PLOS Glob Public Health.* 2021; **1**(10): e0000007.
PubMed Abstract | Publisher Full Text | Free Full Text

27. Yirenya-Tawiah D, Amoah C, Apea-Kubi K, *et al.*: **A survey of Female Genital Schistosomiasis of the lower reproductive tract in the volta basin of Ghana.** *Ghana Med J.* 2011; **45**(1): 16–21.
PubMed Abstract | Publisher Full Text | Free Full Text

28. Ursini T, Scarso S, Mugassa S, *et al.*: **Assessing the prevalence of Female Genital Schistosomiasis and comparing the acceptability and performance of health worker-collected and self-collected cervical-vaginal swabs using PCR testing among women in North-Western Tanzania: the ShWAB study.** Ekpo UF, editor. *PLoS Negl Trop Dis.* 2023; **17**(7): e0011465.
PubMed Abstract | Publisher Full Text | Free Full Text

29. Holmen SD, Kleppa E, Lillebø K, *et al.*: **The first step toward diagnosing Female Genital Schistosomiasis by computer image analysis.** *Am J Trop Med Hyg.* 2015; **93**(1): 80–86.
PubMed Abstract | Publisher Full Text | Free Full Text

30. Rutty Phiri C, Sturt AS, Webb EL, *et al.*: **Acceptability and feasibility of genital self-sampling for the diagnosis of Female Genital Schistosomiasis: a cross-sectional study in Zambia [version 2; peer review: 2 approved].** *Wellcome Open Res.* 2020; **5**: 61.
PubMed Abstract | Publisher Full Text | Free Full Text

31. Archer J, Patwary FK, Sturt AS, *et al.*: **Validation of the isothermal *Schistosoma haematobium* Recombinase Polymerase Amplification (RPA) assay, coupled with simplified sample preparation, for diagnosing Female Genital Schistosomiasis using cervicovaginal lavage and vaginal self-swab samples.** Santos VS, editor. *PLoS Negl Trop Dis.* 2022; **16**(3): e0010276.
PubMed Abstract | Publisher Full Text | Free Full Text

32. Archer J, Barksby R, Pennance T, *et al.*: **Analytical and clinical assessment of a portable, isothermal Recombinase Polymerase Amplification (RPA) assay for the molecular diagnosis of urogenital schistosomiasis.** *Molecules.* 2020; **25**(18): 4175.
PubMed Abstract | Publisher Full Text | Free Full Text

33. Tuhebwe D, Bagonza J, Kiracho EE, *et al.*: **Uptake of Mass Drug Administration programme for schistosomiasis control in Koome Islands, Central Uganda.** Garcia-Lerma JG, editor. *PLoS One.* 2015; **10**(4): e0123673.
PubMed Abstract | Publisher Full Text | Free Full Text

34. Shanaube K, Ndubani R, Kelly H, *et al.*: **The Zipime-Weka-Schista study protocol: a longitudinal cohort study of an integrated home-based approach for genital multi-pathogen screening in women, including Female Genital Schistosomiasis, HPV Trichomonas and HIV in Zambia.** Under review.

35. Søfteland S, Sebitloane MH, Taylor M, *et al.*: **A systematic review of handheld tools in lieu of colposcopy for cervical neoplasia and Female Genital Schistosomiasis.** *Int J Gynaecol Obstet.* 2021; **153**(2): 190–199.
PubMed Abstract | Publisher Full Text | Free Full Text

# Open Peer Review

## Current Peer Review Status: ✔ ? ✔ ✔

**Version 2**

Reviewer Report 07 May 2025

https://doi.org/10.21956/wellcomeopenres.26419.r122124



✔ **Leora N. Pillay**
Frontline AIDS, Cape Town, South Africa

No further comments. Happy with the revisions.

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** I lead advocacy for FGS integration.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 26 April 2025

https://doi.org/10.21956/wellcomeopenres.26419.r122125



✔ **Joseph Osarfo**
Department of Community Health, University of Health and Allied Sciences, Ho, Ghana

have looked at it and I am content that it represents an improvement over the initial submitted manuscript.

I am grateful to the authors for addressing my comments.....although I still think the last sentence in the second paragraph of the 'Introduction' should have been referenced.

***Competing Interests:*** No competing interests were disclosed.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

**Version 1**

Reviewer Report 21 August 2024

https://doi.org/10.21956/wellcomeopenres.24710.r91915



?

**Leora N. Pillay**
Frontline AIDS, Cape Town, South Africa

The open letter summarises the BILENGSIA workshop held in 2022 and speaks to the research needs that were identified by countries. It is an interesting summary of what was discussed at this workshop and highlights the research questions and needs identified by countries.

Introduction:
The introduction is comprehensive and provides a good summary of MGS and FGS.

The intro speaks to how gaining semen samples from men to test for MGS is hindered by cultural beliefs and perceptions, posing challenges. A gap identified in the introduction is that nowhere is it acknowledged the invasiveness of colposcopy and how cultural beliefs can impact the screening and diagnosis of FGS.

The introduction also lacks important information on FGS as a gendered issue as a result of the disproportionate risk that women and girls face due to the split of household chores.

Research needs and priorities identified in the workshop:
The first need identified was 'Raising knowledge and awareness of FGS and MGS' which included the proposed topics for community awareness and sensitisation. These topics are purely clinical around the disease's etiology, modes of transmission, symptoms and prevention strategies but do not tackle stigma, discrimination around the overlap with STI symptoms and the possibility of gender based violence for women and girls. Whilst this may not have come up in the workshop itself, it should be acknowledged as a gap and must be included in any community awareness of FGS.

Additionally, integration with NTDs and SRH is mentioned but there seems to be no mention of WASH as part of work on prevention in communities and community awareness which is concerning. These gaps should be discussed somewhere in the open letter.

Integration with HIV programmes for both MGS and FGS came up in the workshop, but thinking

around how this integration could take place for MGS seems really lacking and something to highlight as needing action.

Information and health literacy on MGS seems to be a large gap but the open letter doesn't go into detail as to why this is the case and what the proposed actions are.

Improving diagnostic capabilities in country:
An important element to note as a gap is the invasive way that FGS that is diagnosed for women and girls. We should be searching for new ways to diagnose FGS without a colposcopy, but also ensure that it is acknowledged and information is given to women about the process etc. to ease any concerns/worries.

Conclusion
The conclusions section should sum up the workshop discussions but also acknowledge remaining gaps and possible next steps.

**Is the rationale for the Open Letter provided in sufficient detail?**
Yes

**Does the article adequately reference differing views and opinions?**
Partly

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**
Yes

**Is the Open Letter written in accessible language?**
Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**
Partly

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** I lead advocacy for FGS integration.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

Reviewer Report 20 August 2024

https://doi.org/10.21956/wellcomeopenres.24710.r91910

**W. Evan Secor**
Centers for Disease Control and Prevention, Atlanta, Georgia, USA

The formation of the BILGENSA Research Network and the accompanying report on the first workshop are very encouraging to see. The workshop participants have been deeply engaged in female and male genital schistosomiasis and identified important priorities for future work. The report on the workshop reads well although some light copy editing could be in order to correct typographical errors and reduce redundancies that likely resulted from different authors for the different sections. The only thing really missing from the report is "what's next" for the BILGENSA Research Network to keep the momentum up. Are there plans for another workshop in the coming year or perhaps meeting in conjunction with another planned conference? There appears to be an intent to develop harmonized protocols for field-deployable screening and diagnostics strategies; how will these be shared with other researchers and ministries of health? One other small question--how are men defined to be "at risk" of MGS (introductory paragraph)?

**Is the rationale for the Open Letter provided in sufficient detail?**
Yes

**Does the article adequately reference differing views and opinions?**
Yes

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**
Yes

**Is the Open Letter written in accessible language?**
Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**
Partly

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** Multiple aspects of laboratory and field research on schistosomiasis.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 15 August 2024

https://doi.org/10.21956/wellcomeopenres.24710.r91907

?

**Ogechukwu Benedicta Aribodor**
Nnamdi Azikiwe University, Awka, Nigeria

General Remarks:
This manuscript offers significant insights into the research priorities, challenges, and needs related to genital bilharzia (schistosomiasis) in Southern Africa and other *Schistosoma haematobium*-endemic countries. The first BILGENSA Research Network workshop highlighted critical areas requiring attention and advancement. However, several corrections and additions are needed to enhance clarity and accuracy:

**Full Meaning of BILGENSA:** The acronym BILGENSA is introduced in the title. Providing the full meaning of BILGENSA would guide readers and enhance understanding of the network's scope and relevance.

**Terminology in the Abstract:** The term 'waterborne' used to describe *Schistosoma haematobium* is incorrect. Please rephrase that the infection is associated with snails infected with *S. haematobium* in aquatic habitats, or use 'freshwater parasite'. This correction should be made consistently throughout the manuscript.

**WHO Guidelines:** The statement regarding the absence of WHO guidelines for female genital schistosomiasis is inaccurate. Refer to the WHO document Female Genital Schistosomiasis: A Pocket Atlas for Clinical Health-Care Professionals. While guidelines for female genital schistosomiasis are available, there are no established guidelines for male genital schistosomiasis (MGS).

**Diagnostic Challenges for MGS:** It is important to discuss the variability in clinical manifestations of MGS. The diverse presentation of symptoms, which can be subtle or overlap with other conditions, complicates the development of standardized diagnostic approaches. Highlighting these challenges provides crucial context for understanding why standardization in MGS diagnosis is lacking.

**Impact of Stigma and Misconceptions:** Include a discussion on how stigma and misconceptions related to the symptoms of MGS and FGS further complicate accurate diagnosis and reporting. These factors contribute to underreporting and incorrect diagnoses in many endemic areas. Additionally, cultural and religious constraints, especially where discussing female genital issues is taboo, exacerbate these challenges. For further information, refer to [Aribodor OB *et al.* (2024[1]].

**Diagnostic Methods for FGS:** Note that invasive diagnostic methods such as colposcopy are generally used only for sexually active girls and women. Jacobson et al. (2021) suggest employing syndromic diagnosis for virgins. The reliance on invasive techniques can be a significant barrier to diagnosing FGS in those who do not meet the criteria for these procedures.

**Adolescent Communication Preferences:** Address the role of adolescents' preferences in

discussing their sexual health. (Aribodor OB *et al.* (2023[2]). Reluctance to share sensitive information due to privacy concerns, stigma, or lack of trust can impede accurate diagnosis and treatment of FGS and MGS. Improving communication barriers is essential for effective diagnostic practices and care.

**FAST Package Training Manual:** Refer to the training manual developed by the FAST package (https://fastpackage.org/), which provides valuable insights for diagnosing FGS. However, it is noted that this manual does not cover MGS, highlighting the need for additional resources and standardization efforts specifically for MGS.

**Need for Low-Cost Molecular Tests:** Emphasize the urgent need for accessible, low-cost molecular tests for MGS that can function without electricity, given the frequent power supply issues in schistosomiasis-endemic communities. Such tests would greatly improve diagnostic capabilities in resource-limited settings and enhance health outcomes.

Thank you.

**References**

1. Aribodor OB, Azugo NO, Jacob EC, Ngenegbo UC, et al.: Assessing urogenital schistosomiasis and female genital schistosomiasis (FGS) among adolescents in Anaocha, Anambra State, Nigeria: implications for ongoing control efforts.*BMC Public Health*. 2024; **24** (1): 952 PubMed Abstract | Publisher Full Text
2. Aribodor OB, Mogaji HO, Surakat OA, Azugo NO, et al.: Profiling the knowledge of female medical/para-medical students, and expertise of health care professionals on female genital schistosomiasis in Anambra, South Eastern Nigeria.*PLoS Negl Trop Dis*. 2023; **17** (2): e0011132 PubMed Abstract | Publisher Full Text

**Is the rationale for the Open Letter provided in sufficient detail?**

Yes

**Does the article adequately reference differing views and opinions?**

Yes

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**

Partly

**Is the Open Letter written in accessible language?**

Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**

Yes

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** Parasitology and Public Health Parasitology with a specific focus on

schistosomiasis. I have extensive experience in researching the epidemiology, diagnostics, and treatment of schistosomiasis, particularly Female Genital Schistosomiasis (FGS). I am familiar with the challenges faced in endemic regions and have actively contributed to the development of FGS competencies, having been trained as a scholar in this area. My expertise enables me to critically evaluate methodologies and findings related to schistosomiasis research and to provide valuable insights aimed at improving diagnostic and treatment approaches.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

Reviewer Report 09 August 2024

https://doi.org/10.21956/wellcomeopenres.24710.r91912



?

**Joseph Osarfo**
Department of Community Health, University of Health and Allied Sciences, Ho, Ghana

**General Comments**
I think this report presents a true reflection of challenges, needs and research priorities in genital schistosomiasis in the participating endemic countries (although I suspect Ghana would benefit also from studies to evaluate the burden of FGS and MGS). It is well written and I recommend it is accepted for indexing after the authors have addressed the few comments below;

**Abstract**

1. "*Accurate burden of FGS and MGS disease estimates, single and combined, are absent, mostly due to the absence of standardized methods for individual or population-based screening and diagnosis*."

   I daresay that a bigger problem is whether it is diagnosed at all, especially FGS....before a debate on the methods of diagnosis ensues. I think the sentence preceding the extracted text above supports my point.

2. *"Morbidity is a consequence of prolonged inflammation in the human genital tract caused by the entrapped eggs of the waterborne parasite, Schistosoma (S.) haematobium."*

   Describing 'Schisto' as waterborne poses a problem. 'Waterborne' will typically be used to describe an infection obtained from drinking water contaminated with human faeces or urine. Schistosomiasis is described as 'Water-based' as the parasite lives at some point in an intermediate host that lives in water.

**Introduction**

1. *"……Others become lodged in the urogenital and genital organs,…."* I would think the term 'urogenital' covers both the urinary and genital pathways and repeating 'genital organs' is somewhat of a tautology.

2. 2nd paragraph, last sentence needs citation(s).

3. "Symptoms of MGS include changes in sperm consistency,……." Is it sperm consistency or semen consistency??

4. Are the authors aware of the following education and training document on schisto? Schistosomiasis and Female Genital Schistosomiasis (FGS): a booklet for educators [Internet]. TheFAST Package; 2022. Available from: eliminateschisto.org , https://fastpackage.org/wp-content/uploads/2022/04/Teachers_Guide_FAST_Package.pdf

**Is the rationale for the Open Letter provided in sufficient detail?**
Yes

**Does the article adequately reference differing views and opinions?**
Yes

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**
Partly

**Is the Open Letter written in accessible language?**
Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**
Yes

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** infectious diseases and epidemiology, health systems strengthening, malaria in pregnancy

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**