



Female Genital Schistosomiasis Society of Nigeria: a model for local action

Case study presentation

Summary

Over the last six months, an emerging group of Nigerian Health Workers has launched the Female Genital Schistosomiasis Society of Nigeria. These health care providers by leading local action in promoting FGS awareness have created a growing momentum to tackle FGS across the country and has the potential to steer change throughout Sub-Saharan Africa.

Female genital schistosomiasis (FGS) is the most common female reproductive neglected tropical disease in Sub-Saharan Africa. The level of awareness of FGS is quite low among health workers and communities. Even when FGS cases are suspected and referred, lack of understanding and knowledge amongst health care providers frequently results in misdiagnosis and improper treatment. There is a need for a linking specialist, healthcare workers, researchers, teachers, and students in the reproductive and community health sectors to increase awareness of the disease, improve diagnosis, enhance the index of suspicion and encourage treatment for and prevention of FGS to decrease the burden of FGS and its morbidities and complications. To this end, the Nigerian FGS Society was created to address these challenges by:

- creating a platform for bringing together ideas across all sectors of care and the healthcare workforce;
- facilitating the transfer of ideas and resources across healthcare workers and communities;
- enabling a local unified front for combatting FGS, increasing its awareness to ultimately achieve its elimination.

Click [here](#) to watch Dr. Hameedat Omoyele-Abdussalam and Dr. Ibrahim Rabiú tell the story of the emergence of the FGS Society of Nigeria.

Highlights achieved by the Society:

1. Establishment of Nigerian FGS Network and expansion to the FGS Society of Nigeria
2. Formal registration of Female Genital Schistosomiasis Society of Nigeria with Corporate Affairs Commission (CAC)
3. FGS awareness creation by:
 1. Conducting training on FGS in tertiary hospitals covering 83% (5 of 6) geo-political zones in Nigeria;
 2. Facilitating linkages and network among health professional through WhatsApp messages;
4. Cross-sector FGS engagement by mobilizing global, national and local

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The emergence: from Network to Society

The Idea:

In May of 2021, several Nigerian health practitioners had the opportunity to participate in an online training workshop on FGS as part of the FGS Accelerate Scale Together (FAST) Package Project conducted by Bridges to Development and The Geneva Learning Foundation earning certification as FGS Scholars. As part of this training, the Scholars developed action plans to address FGS within their local context. Recognizing the significant burden of FGS in Nigeria, the Nigerian Scholars came together to establish a Nigerian FGS Network to strengthen each other's work and help build a greater response to the national challenge.

The Nigerian FGS Network was initiated in October 2021 using a WhatsApp group as the primary network platform. The original idea was to link both the FGS Scholars in Nigeria and a growing group lectured by the Scholars to create awareness about FGS. The original group of 11 physicians participating in this nascent network quickly became more than a social group and as the idea grows more ambitious, the group decided to create a more formal FGS Society in Nigeria.

The Pathway: from Network to Society

To move from an informal FGS Network connected through a WhatsApp group to a more formal FGS Society, the founding members needed to execute several activities:

- 1) Identify and connect with motivated health care workers with the common goal to address FGS
- 2) Identify a platform to facilitate interactions
- 3) Layout mission, vision, and strategy to attract and grow membership
- 4) Structure the society with a governance framework and revisit mission and vision statements
- 5) Formalize the establishment of the society with authorities
- 6) Plan and Implement Activities

Network Building

The establishment of the Society helped transfer ideas and resources across a large population of like-minded specialists in a cost-effective way. It created a local unified front for combatting FGS, increasing its awareness to enhance appropriate, diagnosis, prevention, and treatment to effectively control or even eliminate this disease. Connecting via WhatsApp proved to be convenient and necessary during the COVID-19 pandemic when most physical interactions were largely interrupted due to restrictions that had been placed.

Considering Nigeria's geography and the COVID-19 pandemic, the network structure became a viable and creative way to:

- access healthcare professionals and the general public in Nigeria;
- promote and facilitate FGS training;
- strengthen each other's work within the Network;
- build a greater, unified response to the national challenge of FGS.

As the network thrived, other strategies for interactions were put in place to enhance communication, attract membership, and have a more ambitious impact, including:

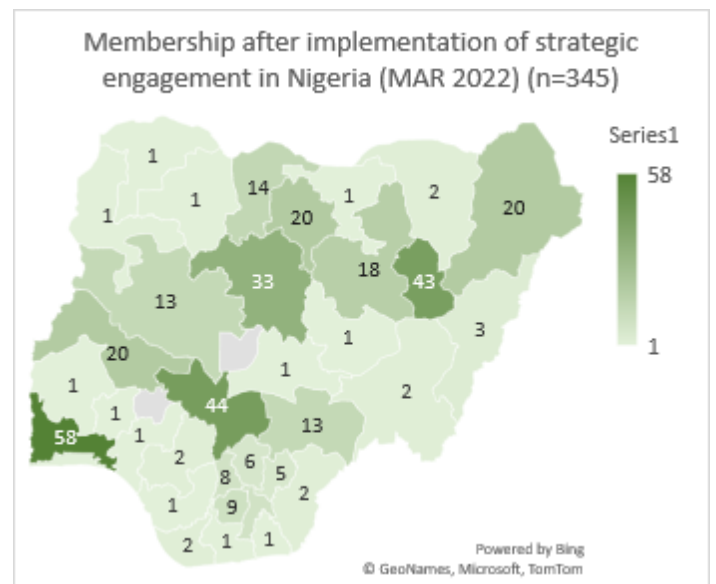
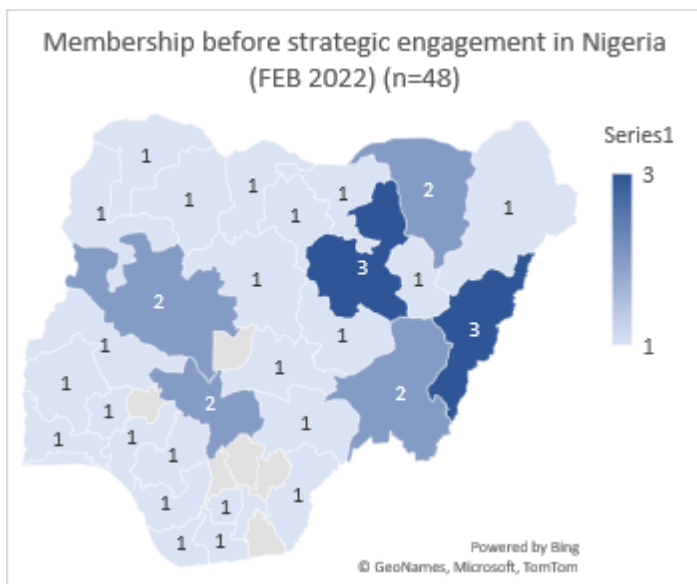
1. Establishing a regular cadence of physical and virtual meetings
2. Calling assemblies
3. Connecting via phone calls

4. Connecting via WhatsApp messages
5. Creating Telegram group for the Society
6. Promoting FGS training
7. Liking the Society and the FGS cause to leadership: global partners, national program managers and national professional bodies.

Ultimately, these activities allowed the Society to grow in its reach across the country in an efficient manner as seen below.

Geographical Reach and Society Presence in Nigeria

The strategic planning for engagement, pilot sensitization activities, together with the launch activities were able to demonstrate a **618.75% increase** in membership. The Society is now active in **five of the six geopolitical zones**, over **36 states**, and **773 local government areas (LGAs)**, and grew to a total of **345 members**.



Mission and Vision

At the initial formation of the Network, the vision for the group was to improve awareness of FGS among healthcare professionals and the general public. As the Network expanded to a Society the idea evolved. After several rounds of iterations with the members, a new mission, vision and values were set.

FGS Society of Nigeria mission is:

To eliminate FGS and related infectious diseases and cancers in Nigeria and the world over by:

1. Partnering with relevant stakeholders in Nigeria and the world over
2. Connecting with partners active in NTDs to help build FGS into programming in Nigeria
3. Creating awareness about FGS among healthcare professionals and the general public
4. Linking Nigerian practitioners to others working in FGS beyond Nigeria to share knowledge and best practices
5. Conducting research about FGS and related diseases in Nigeria and beyond Nigeria
6. Actively searching for FGS cases across communities in Nigeria
7. Treating FGS cases using existing praziquantel treatment program in Nigeria
8. Recording FGS cases in a database
9. Managing FGS cases Under -One-Roof with HIV and cervical cancer in the community
10. Developing a school curriculum on FGS to be used in schools of healthcare professionals
11. Commemorating the annual World NTD Day in Nigeria with special attention on FGS.

FGS Society of Nigeria values are:

Collaboration, community engagement, equity scientific rigor and transparency

FGS Society of Nigeria Vision is:

A world free of female genital schistosomiasis and neglected tropical diseases.

Who can be part of the Society?

As the Society evolved so did its desire to reach all individuals who could help advance the Society's mission. This society is not just meant for medical professionals. Membership includes academicians and politicians' interest in ending the FGS neglect in Nigeria.

Governance Structure Building

The Society is led by an executive committee consisting of: President, Vice President I; Vice President II; Secretary General; Deputy Secretary General and Financial Secretary. Working under the executive committee, the Society established six zonal coordinators. This decentralized model of zonal coordinators mimics the decentralized Health System in Nigeria, allowing a deeper penetration in the system and improved implementation of the society activities. Moreover, since most cases of FGS are seen at the community level, this format enables a grassroots approach to address this health challenge.

Click [here](#) to find the complete organogram for the network functions for members.

Formalizing the Society with Local Authorities

The Society has been registered with the Nigerian Corporate Affairs Commission (CAC) as the Female Genital Schistosomiasis Society of Nigeria.

Why register?

The registration of the network as a society is a powerful strategy to gather attention and recognition for FGS from relevant stakeholders in Nigeria.

Society Promoted Activities

Training

Goal

The training aimed to:

- increase awareness of FGS among healthcare workers across the country;
- broadcast and share trusted FGS resources;
- recruit members of the Society;
- establish a state branch of the Society where the training is done.

Audience

Pilot training sessions were carried out in five tertiary hospitals located in five of the country's six geopolitical zones targeting health care workers.



Format

The training was delivered by a parasitologist, an obstetrician gynecologist, a public health officer and facilitated by the zonal coordinators in their respective geopolitical zone. PowerPoint-style training materials were developed using key references for FGS and adapted to the Nigerian context. The final training materials were a result of a process of several iterations between members of the Network and global experts in FGS.

Click [here](#) to watch the training recordings.

Results

The March training sessions trained over **275 health workers** across five geopolitical zones in Nigeria. This reach is helping to further reduce the current gap in awareness and knowledge on FGS.

So far so good, I use to be close to an illiterate when it come to FGS. But today I have learnt how to keep my environment clean which can help prevent FGS. This society have come up with a very good idea trying to sensitize the community on how to maintain water and proper hygiene in our environment so as to prevent this neglected diseases in our community. They are doing a very good job collaborating with medical practitioners to sensitize tertiary institution. We will support this society by disseminating the information
Inshallah

Comrade Abubakar Salihu

The society aims to continue promoting FGS training sessions to further advance awareness and knowledge to every county in Nigeria.

Society Official Launch

The FGS Society of Nigeria was officially launched on March 30th, 2022, at the University of Abuja Teaching Hospital (UATH) Gwagwalada. To watch a recording of the event click [here](#).

The launch allowed the society to:

- spread awareness of the FGS issue;
- create awareness about the existence of the Society and its mission, values and vision;
- grow audience of international, national and local partners;
- collaborate with partners internationally, nationally and locally.
- create a stronger base of support to drive the mission forward;
- generate buzz and raise visibility for the society and its mission.

Launch Day

Activities

Results

Reach

The launch event was attended by over **257 attendees**, including governmental officials, academics, health care workers, and global partners. This broad and diverse list of invitees secured a local, national and global audience, allowing the Society to enhance its base of support and recognition.

The strategic planning for engagement, the pilot programming sensitization, and the launch activities generated a 618.75% increase in membership . Meaning that by the end of the Launch, the Society included **345 people willing to promote change and end the neglect in Nigeria.**

Call to action

The Society presented their vision and strategy to the Nigerian Response for FGS at the launch. The Society Advocacy call aims to pivot the pathway to those changes (see figure below).

Shaping the vision for FGS response in Nigeria		
Leadership, Management & Governance for FGS <ul style="list-style-type: none"> Assured national ownership, drive and commitment Develop and incorporate into national NTD strategy, budget and structures for National FGS response plan Coordinate with relevant sector and direct resources and expertise where needed 	FGS Financing <ul style="list-style-type: none"> Mobilize resources through advocacy from donors and increase domestic funding at national and sub-national levels Implement an accountability framework for judicious use of scarce resources. Leverage on funding from other sources (programmes/projects) to support FGS response 	Human resources for FGS <ul style="list-style-type: none"> Develop capacities and competencies for FGS across all levels. Develop and implement an integrated supportive supervisory/mentoring visits Both at National & Sub-national level have a core team of experts on FGS programming
FGS product inventory <ul style="list-style-type: none"> Develop, implement, an effectively integrated supply chain management to ensure access to quality-assured NTD medicines and other products and assured effective last mile distribution 	FGS infrastructures <ul style="list-style-type: none"> Strengthened at-point-of-care diagnostics. Support massive ACSM Integrate FGS response into NTDs and other service delivery 	FGS intelligence <ul style="list-style-type: none"> Develop and implement an M&E framework for FGS (data collection and management, analysis, mapping, impact assessments, surveillance and reporting systems)



Website Development

The FGS Society [webpage](#) is a knowledge-sharing and action space for people working and interested in FGS in Nigeria.

Why a website?

The platform promotes discussion, knowledge distribution, and the latest FGS best practices and announces the FGS training and events promoted by the society. The website also works as a showcase to attract members and promote and advance the society's mission.

Lessons Learned

Through the process of developing and launching the Nigerian FGS Society, several lessons were learned that can help inform other countries interested in addressing the burden FGS in their communities:

- Empowering problem-solving at the local level is a powerful and engaging tool to implement change.
- Enabling health providers to lead change in Nigeria is a catalyst for positive FGS conversations and action.
- Health care workers are willing to learn and take action, establishing a Society may work as a possible enabler and promoter to fill in the training gap for FGS.
- Decentralization of activities and governance allowed a deeper penetration into the system and improved the implementation of the Society's goals. Moreover, since most cases of FGS are seen at the community level, this format enabled a grassroots approach to address this health challenge and made it possible to exponentiate the Societies' growth and geographical penetration within Nigeria.

Remaining Challenges:

- The Society believes that investing in FGS awareness will facilitate the advocacy strategy to obtain government buy-in and the resource allocation necessary to beat FGS in Nigeria. Therefore, gathering resources to promote FGS awareness and advocacy activities remains the main challenge to sustain activities.

Want to connect with the FGS Society of Nigeria? Reach us via e-mail or WhatsApp:



You can contact us anytime

+234 803 605 8782, +234 803 570 0965

fgssocietyofnigeria@gmail.com

Appendix A

Governance Structure

Executive Committee

The President shall preside over all proceedings of the Society. The President shall preside over Executive Council Meetings and he/she shall also sign the minutes of the Council Meetings. The President in consultation with the Council Members shall interpret the provisions of the constitution and decide any doubtful points.

The Vice President: In the absence of the President, one of the Vice Presidents shall perform his/her duties. For these purposes, the Vice President I will take precedence over the Vice President II. In the absence of the President and the two Vice Presidents, a member chosen by the meeting shall perform the duties.

Secretary-General: The Secretary-General shall handle all correspondence and shall keep the minutes of the Society and Council. He/she shall notify new members of their election. He/she shall notify the Financial Secretary of all changes in members' addresses. He/she shall arrange with the President the order of proceedings at the meetings.

The Deputy Secretary-General shall assist the Secretary General to carry his/her duties.

The Financial Secretary shall receive all monies due to the Society and make all payments ordered by the Council. The Financial Secretary shall keep an account for all such receipts and payments and submit a report to the Annual General Meeting

Zonal coordinators

The zonal coordinators coordinates the states under their jurisdiction and report to the national body. Their function includes:

- addressing challenges faced by the states;
- reporting to the national body and intervene in issues beyond the reach of the state;
- supervising and supporting states under their jurisdiction;
- representing the Society in their zone thereby reducing cost of executive officers traveling long distance.