working together



to eliminate schistosomiasis

GLOBAL SCHISTOSOMIASIS ALLIANCE

PROGRESS AND ACTIVITY 2022-2023

From the GSA Executive Team



"Central to the Global Schistosomiasis Alliance is our firm belief that by working together we will reach our elimination targets sooner. We unite stakeholders at all levels to increase commitment, knowledge and encourage long term investment" Dr David Rollinson Director of GSA

As an all-inclusive coalition, the GSA works to mobilise the growing momentum to control and eliminate schistosomiasis. GSA is made of our members, for our members, and it is their work that is presented in this progress and activity report.

- Strengthen and diversify cross-sectoral partnerships
- Support stakeholder participation and leadership
- Advocate for schistosomiasis elimination



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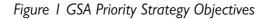


Introduction

Central to the Global Schistosomiasis Alliance is our firm belief that by working together we will reach our elimination targets sooner. We unite stakeholders at all levels to increase commitment, knowledge and encourage long term investment. Early data from WHO shows that the COVID 19 pandemic had a negative impact on the distribution of praziquantel treatments across Africa, most likely caused by the school closures, and many countries are working hard to regain the momentum. Schistosomiasis is notorious for bouncing back if control measures are not sustained. We must respond rapidly and find the best ways of reducing prevalence of schistosomiasis and reducing the associated suffering for all age groups.

The GSA strategic plan (2022-2025) outlined our priorities, which closely align to the WHO 2030 Roadmap and the earlier GSA Schistosomiasis Action Plan. Our five focus areas and associated actions will act as the template for our future activities as reported here. It is with the aim of enhancing and improving current methods of control that our Working groups and Work Streams, together with our website and many outreach activities bring together the many different strands of schistosomiasis control.





The International Task Force for Disease Eradication (ITFDE) in 2022 concluded that intersectoral cooperation is vital for schistosomiasis elimination and reinforced the need for coordinated action and partnerships amongst health, water, agriculture, animal and education sectors (WER9804-4150). By bringing the schistosomiasis community together and encouraging cross-cutting and cross-sector activities the GSA aims to be a key player in helping to achieve the WHO Roadmap targets. Here we present the many and diverse activities that took place in 2022 and our plans for 2023.



Vision, Mission & Approach

The GSA is an all-inclusive coalition to mobilise the growing momentum to control and eliminate schistosomiasis. It is constituted as a diverse partnership of public health programmes, academic and research institutions, international development agencies and foundations, non-governmental organizations, private sector companies and advocacy and resource-mobilisations partners. Our alliance is not limited to partner organizations but also includes individuals, research groups and different networks, collaborating together as a community to control and eliminate schistosomiasis.

Diversity, equity, and inclusion are at the core of who we are and what we do. Our commitment to these values is unwavering – across all of our network's activity, around the world. They are central to our mission of eliminating schistosomiasis as a public health problem and to our impact as an alliance.

In this progress and activity report we highlight some of the key outputs from our activities in 2022 and operational strategy for 2023. These outputs and plans are organised using the 5 Strategic Priority Objectives of the GSA 4-year strategy.

We would like to acknowledge the dedicated work and commitment the GSA members and partners have contributed to driving forward these outputs. Our members are the GSA and it is their work that is presented in this progress and activity report.

Vision - Elimination of schistosomiasis.

Mission - To be the leading advocate for schistosomiasis elimination.

Approach - To lead and coordinate a multi-stakeholder platform consisting of public and private sector partners across the globe, contributing to schistosomiasis elimination as a public health problem and the ultimate goal of sustained interruption of transmission.

Figure 3 GSA Vision, Mission and Approach



Focus areas	Actions
Resources, Capabilities & Knowledge Development	 Promote, support and strengthen schistosomiasis technical and operational capabilities
Monitoring and Evaluation	 Facilitate and strengthen ways to measure progress and evaluate interventions Enable learn & adapt approaches to current and future challenges, Meet verification/validation requirements for schistosomiasis elimination as a public health problem and interruption of transmission.
Integrated solutions to schistosomiasis elimination	 Enhance practices and improve the quality of services, promoting targeted, context & evidence driven interventions, including preventive chemotherapy, snail control and environmental management, WASH, behaviour change communication and health education and cross-sector collaborative interventions.
Diagnostics	 Promote development and adoption of diagnostics to support M&E for MDA, test & treat, surveillance and to facilitate the integration of SCH into all levels of the health system.
Innovation, Integration & Cross-cutting action	 Promote basic, clinical & operational research, to engage with innovations and novel tools from different sectors, Encourage collaborative research to facilitate cross- cutting and cross-sector approaches for sustainable elimination of schistosomiasis.

Figure 4 GSA Priority Focus Areas and Associated Actions



Progress 2022

Resources, Capabilities & Knowledge Development

Knowledge sharing

The GSA focused on strengthening knowledge development, dissemination and discussion of the new WHO normative guidance and policy briefs, Female Genital Schistosomiasis and women's health, sharing good practices on integration with health services and cross-sector and cross-disciplinary coordination and collaboration. This was done through:

• Webinars

GSA organised 4 webinars in 2022 with ISNTD as part of the ISNTD-GSA webinar series [Figure 5]



Figure 5 ISNTD-GSA Webinars 2022



- Workshops
 - ICOPA (August 2022). The GSA contributed to two sessions and a social networking opportunity for schistosomiasis researchers.
 - NTD NGO Network annual meeting (September 2022). The GSA was involved in two workshops on mainstreaming NTDs into health services and Putting the NTD road map into action (more information in the sections below) and GSA led on the <u>NNN SCH-STH Disease Specific Group</u> meeting focusing on the <u>WHO deworming adolescent girls and women of</u> <u>reproductive age policy brief</u>, the <u>WHO guideline for human schistosomiasis</u>, WHO STH guidance and the new WHO Technical Advisory Group for schistosomiasis and soil-transmitted helminthiasis (TAGSS) and associated subgroups [slides and recording available here].
 - COR NTD (October 2022). A workshop on Surveillance for NTDs: Lessons learned and cross-disease implications.
 - XIV International Symposium on Schistosomiasis in Brazil (November 2022).
 A GSA session on schistosomiasis research.
 - The <u>Genital Bilharzia in Southern Africa Network (BILGENSA) workshop</u> (December 2022).
- Leveraging working groups, work streams and special groups (GSA Ambassadors and the Genital Schistosomiasis Community of Practice) to disseminate information and opportunities for discussion and training on guidance, policy briefs, technical training, good practice and research in progress. We strengthened the community of practice elements of these groups by enabling discussion and exploration of new strategies and research through talks and opportunities to discuss different aspects of schistosomiasis elimination.
- Creating communication and engagement opportunities across different sectors that influence schistosomiasis: examples from 2022 include bringing schistosomiasis to the International Social and Behaviour Change Communications Summit, a collaboration with water sector through the Engineering Working Group members, <u>School Meal Coalition</u> and collaboration with the Research Consortium for School Health and Nutrition.





Strengthening funding for schistosomiasis interventions, research and development and capacity-building



Access to treatment & diagnostic tools, and integration of schistosomiasis, including female genital schistosomiasis into health services

Multisector engagement and coordination to strengthen schistosomiasis prevention, with a focus on behaviour change.

Figure 6 - GSA key communications themes and call to action 2022

Communication and Advocacy

The following events and opportunities were leveraged to raise the profile of schistosomiasis and the key messages highlighted in Figure 5:

- Launch of the first UN recognised World NTD Day
- Launch of the new WHO Guideline for the control and elimination of human schistosomiasis
- Launch of the WHO Deworming women of reproductive age and adolescent girls policy brief
- International Women's Day
- Kigali Summit on malaria and NTDs
- International AIDs conference
- World Water Week conference
- Social and Behaviour Change Communication Summit



Increased reach of our communications and network

- GSA <u>Newsletters and Bulletins</u>: Schisto Bulletin newsletter, covering schistosomiasis news circulated every 3 months. Trial Schistosomiasis Research Update bulletin and adhoc announcements to mailing list.
- Mailing list increased from 582 at the start of 2022 to 679 at Q1 of 2023 (April 2023). Engagement figures show that 44% of our subscribers are highly engaged, 14% moderately engaged and 39% are not very engaged. This is a good level of subscriber engagement for our industry. Top locations for subscriber engagement are Netherlands, Kenya and Nigeria.
- LinkedIn: Our current followers are 588, up from 347 at the start of 2022, 38% of followers are from Research, Education & Healthcare backgrounds.
- Twitter: Followers have increased from 2897 at the start of 2022 to 4104 start of 2023.
- Website reach: User numbers increased from 21,127 at the end of 2021 to 22,308 be the end of 2022 (5.59% increase).

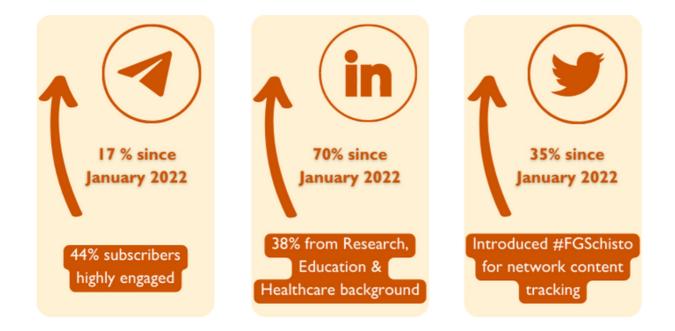


Figure 7 - GSA social media performance highlights January 2022 to April 2023



Language & accessibility

- GSA continued to integrate French and other languages where possible into its communications:
- Provided French interpretation for webinars, and for meetings such as the NNN SCH-STH DSG.
- Increased the number of GSA communications that offer both languages, including email updates and minutes/documents for the GSA groups and newsletters that go to the GSA mailing list.
- Supported translation into other languages were possible.

Website

Website review with action plan for improved visibility & traffic - phase I:

- In seeking improvement to the GSA website platform and network collaboration for the elimination of schistosomiasis, we have engaged Manta Ray Media in a project to improve the GSA network members area, including the taxonomy linked to individual accounts to enable better search experience for members. The <u>GSA network members</u> area is now a searchable directory of schistosomiasis experts and practitioners.
- Additional web pages were created for the GSA work streams (Diagnostics, Snails & Malacology), the Genital Schistosomiasis Community of Practice and the <u>Female Genital Schistosomiasis Integration Group</u> (FIG).
- Further work is being done to link the GSA network members with the <u>GSA</u> <u>working group pages</u>.



Monitoring & Evaluation

M&E Working Group

- The <u>Monitoring & Evaluation WG</u> (42 members) continued to share information, opportunities and tools through the shared emailed address and through meetings. Key items covered:
 - Information sharing on SCH specific meetings, conferences, publications etc
 - Toolbox forum agenda item at M&E WG meeting- introduction and/or knowledge exchange on M&E tools and development for SCH e.g. WHO Technical Advisory Group for Schistosomiasis and STH and sub-groups, Schistosomiasis Oversampling Study (SOS).

COR NTD workshop Surveillance for NTDs

• <u>Surveillance for NTDs: Lessons learned and cross-disease implications</u> - lessons learned and cross-disease implications, defining and discussing whether passive or active approaches are better suited for NTD surveillance and whether there remains a role for syndromic approaches. <u>Report available here</u>.

Integrated solutions to schistosomiasis elimination

GSA Ambassadors

 The 13 members of the <u>GSA Ambassadors</u> group met 3 times in 2022 to discuss the WHO SCH recommendations, approaches to monitoring and evaluation and, in a joint meeting with the <u>Kikundi Community of Practice for NTD</u> <u>Programme Managers</u>, on Monitoring Drug Efficacy for schistosomiasis.



Implementation Working Group

- Focus of meeting: The 13 members of the <u>GSA Implementation Working Group</u> met on the 10th May 2022 to discuss the new WHO recommendations set out in the <u>WHO guideline document for human schistosomiasis</u>, to understand the demand and supply of treatment, how to prioritise treatment, how countries are responding to the recommendations, and discuss potential short-term solutions to help coordinate the first steps in implementing the new guideline and recommendations.
- Joint NNN workshop with ITI on Putting the NTD road map into action: Exploring lessons learned as NTD programs operationalize evolving strategies and address challenges to achieving final mile goals [<u>Report available</u>]
- Chairs presented experiences and challenges on operationalizing the guidelines at the NNN SCH-STH DSG meeting in September 2022 [Recording and slides available here]

Behaviour Change and Health Education Working Group

Bringing Behaviour Change (BC) experts together in the NTD-SCH space to bring greater visibility of ongoing initiatives in the BC space / Identified gaps and shared lessons learnings:

- Shared information through email and meetings, learnt about the Bilharzia Storytelling project in Kenya.
- Manuscript submitted: "Behaviour change interventions for the control and elimination of schistosomiasis: A systematic review of evidence from low- and middle-income countries".
- Panel discussion at the SBCC Summit "Multisector action to enable social and behaviour change for the elimination of schistosomiasis, a water-borne Neglected Tropical Disease".



Other activities

- I. Input into the 7th INCAS meeting and considered ways of enhancing collaboration as countries emerge from the pandemic.
- 2. China Africa Cooperation on Tropical Diseases Control and Risk Assessment Conference paying attention to ongoing research and control in Egypt and China.
- 3. Members of GSA working group, work streams and GSA Ambassadors and the GS CoP are involved in the TAGSS and the subgroups on:
 - M&E Frameworks for SCH & STH
 - Guidelines and manuals for strongyloidiasis
 - Manual on control of zoonotic SCH
 - Manuals on validation of SCH and STH elimination as a public health problem (EPHP)
 - WASH and SCH-STH
 - Standardized approaches for impact surveys
 - Drug efficacy

Diagnostic Development, Adoption & Adaptation

Diagnostics Work Stream

• The <u>Diagnostic work stream</u> discussed hosting a symposium on CCA and CAA. The GSA, in collaboration with ISPiRED (LUMC) hosted a symposium on the use of CCA and CAA for schistosomiasis diagnosis in different settings looking at themes such as quality, data, access and development. The report is available here: <u>Diagnosis of schistosomiasis by CCA or CAA detecting lateral flow tests:</u> <u>Facts and challenges</u>.



Innovation, Integration & Cross-cutting action

Research Working Group

• <u>Research working group</u> (30 members) hosted two sessions at ICOPA conference on: 'Morbidity and spillover impact associated with Schistosoma infections: an updated appraisal' and "Genomic insights into schistosome biology and control".

Engineering Working Group

- The GSA, University of Cranfield and the <u>African Ministers Council on Water</u> (AMCOW) started a collaboration to look at how schistosomiasis prevention measures can be integrated into water infrastructure and management policies. The <u>Engineering working group</u> (29 members) has identified priority outputs to work on and feed into the WHO SCH-STH TAG subgroup on WASH. These include:
 - Developing a draft white paper on SCH and Water infrastructure and treatment, from WASH to agriculture.
 - Collect Case studies on water infrastructure and schistosomiasis (Mali, Senegal, Zanzibar, China)
 - Create a draft information piece on water development and schistosomiasis to share with policy makers, implementers and stakeholders involved in water development including for agriculture and energy sectors.



Snails (40 members) and Malacology (54 members) work streams

- Making connections between researchers in both laboratory and endemic settings
- Engaged members in talks from speakers, in 2022 covering:
 - Snail 3G: Genomics, Genetics, Gene-editing.
 - PCR-based diagnostic tools to detect and characterize trematode infections in snails.
 - Detecting snail borne trematode transmission using environmental DNA.
 - The microbiomes of Biomphalaria.
- Conducted survey to gather information on successes and challenges of sample sharing / permits and got good group engagement (25 responses)

Genital Schistosomiasis Community of Practice & FGS Integration Group [FIG]

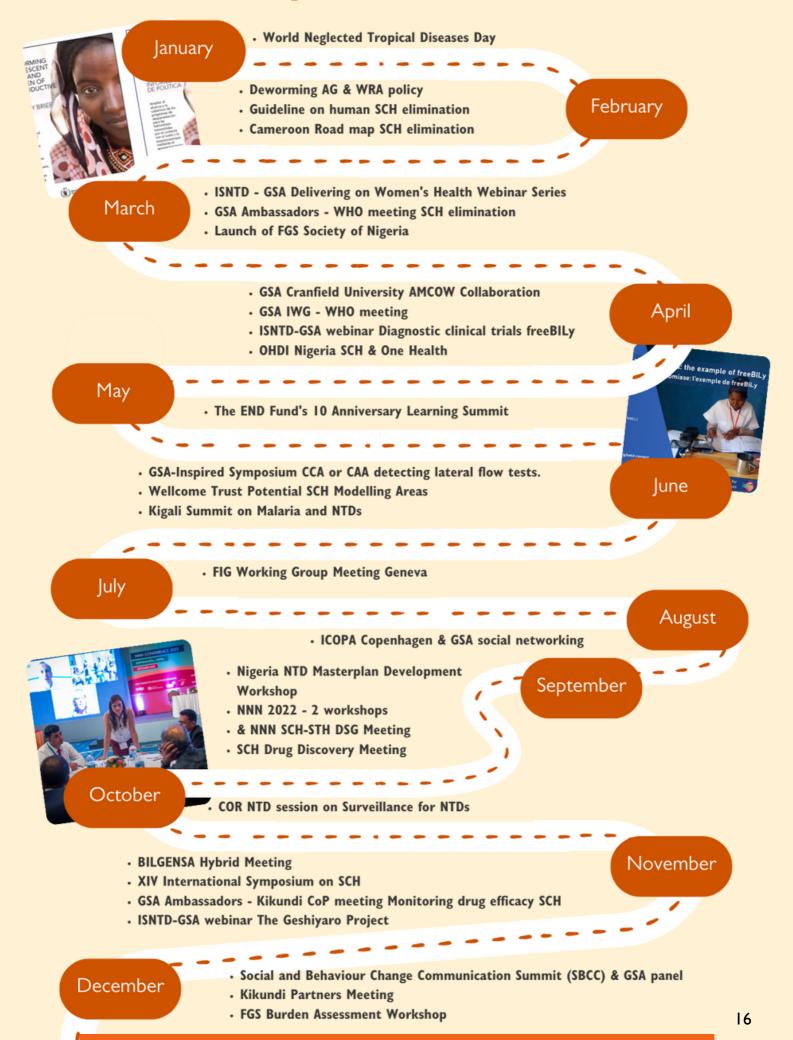
<u>Genital Schistosomiasis CoP</u> is a group of 141 members of clinical & operational researchers and healthcare practitioners (nurses, midwives, medical doctors working in Sexual and Reproductive Health Services) working on Female Genital Schistosomiasis and Male Genital Schistosomiasis, whether that is awareness raising or training health workforce. This group shared news, updates, publications, training materials and opportunities for FGS and MGS research and integration. GSA together with the FGS Integration Group [FIG] led FGS integration discussions at the NNN workshop on Cross-cutting approaches to mainstreaming NTDs.

School Meal Coalition and Research Consortium for School Health and Nutrition

 School Meal Coalition and collaboration with the Research Consortium for School Health and Nutrition led to a publication in Frontiers In Tropical Diseases: <u>A coordinated response to the needs of the learner: How deworming</u> and school meals together will contribute to the global recovery from the <u>COVID-19 pandemic</u>.



Key events 2022



Operational Strategy for 2023

Resources, Capabilities & Knowledge Development

Website improvements - phase 2

- Strengthen the "one-stop-shop" key purpose of the GSA website phase 2:
 a. Leverage user data and stakeholder feedback to review and restructure the website.
 - b. Build and strengthen members area of website.
 - c. Utilize heatmapping software (Crazy Egg) on the website to help make databased decisions and evaluations to improve user experience. Support decisions-making regarding restructure of website to promote resources, events and members area.

Knowledge and capabilities development workshops

- Leverage opportunities and collaborations across partners and stakeholders to share learnings, identify gaps and develop solutions – opportunities include: NNN, COR NTD, ASTMH and online meetings.
- Continue successful collaboration with ISNTD and the GSA webinar series, highlighting research, innovation and implementation in schistosomiasis.
- Explore opportunities to support Early Career Researchers (ECRs) through resources, capabilities and knowledge development, and through GSA groups.



Resources, Capabilities & Knowledge Development

Raising the profile of schistosomiasis, messaging and advocacy for 2023

• Key messages and calls to action will be focused on:

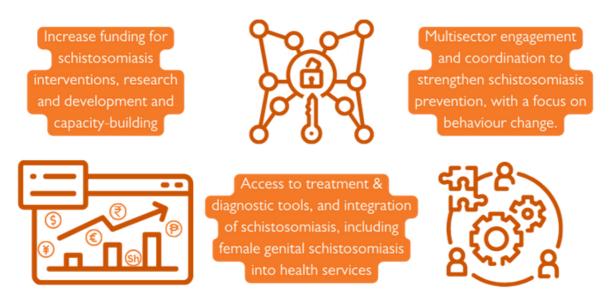


Figure 7 - GSA message and advocacy themes 2023

- The GSA will launch a series of mini animations on schistosomiasis:
 - What is schistosomiasis?
 - Act Now. Act Together. Invest in NTDs
 - Future animations to focus on women's health, snails, diagnostics, water and more
- GSA will leverage the following events and opportunities.
 - World NTD Day 2023
 - International Women's Day
 - World Health Day and the 75th anniversary of WHO developing social media comms highlighting 7 decades of schistosomiasis discovery and progress
 - Work with FIG partners raising awareness on FGS and schistosomiasis at Women Deliver
 - World Water Week



- World Toilet Day
- Human Rights Day and Universal Health Coverage Day
- And other internationally important events and advocacy opportunities.

Communications

- Newsletter
 - Schisto Bulletin newsletter, covering schistosomiasis news circulated every 3 months.
 - Frequent Schistosomiasis Research Update bulletin.
 - Adhoc announcements to mailing list.
- Social Media Channels to promote animations, calls to action, resource and tool dissemination and events. Use to increase website visibility and traffic.
- Language: Continue to strengthen communications in French. Look at how to engage with Lusophone stakeholders.

Monitoring and Evaluation

- Review and redefine purpose and scope of the M&E working group Questionnaire to be sent to working group members. Potential of questionnaire to ESPEN/WHO, donors.
- Explore opportunities for workshops on M&E good practice & tool development, e.g. NNN and COR NTDs.
- Liaise and disseminate findings from the Schistosomiasis Oversampling Study (SOS)

Integrated solutions to schistosomiasis elimination

GSA Ambassadors

• Build the GSA Ambassadors network and hold 2-3 meetings on a priority of their choice. Continue collaboration with Kikundi Community of Practice and other networks.



Behaviour Change and Health Education Working Group

- Liaising/Coordinating with other intersectoral groups WASH/Health Education sector to join forces and identify synergies to support WHO NTD Roadmap
- Develop a SCH BCHE research agenda, liaising with other groups too (WHO TAG, NNN).
- Invite members to share their work/findings/ongoing BC projects to share experiences and lessons learned.

Implementation Working Group

• Promote discussions in relations to WHO schistosomiasis guidance and tools.

Other activities

• Support members of the GSA feeding into the WHO TAGSS and subgroups

Diagnostic Development, Adoption & Adaptation

Diagnostics Work Stream

- The group will collate protocols for sample collection and storage and diagnostic tests. These will be uploaded to the GSA Diagnostic resource collection.
 - Collecting and making available protocols for the collection and storage of samples for testing and archiving, to be shared via the <u>GSA Diagnostic</u> <u>collection webpage</u>.
 - Updating the communication/information piece on commercially available diagnostics document, and
 - Drafting a list of research priorities for schistosomiasis diagnostics



Innovation, Integration & Cross-cutting action

Research Working Group

 This group will focus on Early Career Researchers. The GSA will hold online, informal consultation meetings with ECRs to capture their feedback and their ideas on how the GSA platform and network can be better leveraged to support ECRs across countries. The RWG will review these ideas and guide the GSA on what can be taken forward to support ECRs, with ECRs leading these activities where practical.

Engineering Working Group

 Focus on drafting a white paper/publication on SCH and Water infrastructure and treatment, from WASH to agriculture, drawing on lessons learnt from the collected case studies on water infrastructure and schistosomiasis (Mali, Senegal, Zanzibar, China), and the feedback back and information gathering from AMCOW stakeholders.

Snails and Malacology Work Streams

- Snails workstream: Preparing snail specimen molecular protocols using DNA and RNA extraction, to upload to the GSA website for open access for researchers. These protocols will be updated on a 'version' basis. A meeting will be organised to discuss protocol collection and curation on the <u>GSA website</u>.
- Malacology workstream: Organise a Malacology standalone meeting with a
 programmatic element potentially inviting talks from the NALA Foundation on
 snail mapping, the Rwanda Biomedical Centre on integrated mosquito and snail
 surveys and control, ATRAP project on fieldwork protocols for snail collection
 through citizen science.
- Members across the two work streams will discussing developing concept note for a Snail mapping guide proposal and snail atlas.



Genital Schistosomiasis Community of Practice and FGS Integration Group [FIG]

- Strengthen Community of Practice, increase knowledge sharing and lessons learnt.
- Build on momentum around FIG and Women Deliver to call for integration of and investment in FGS prevention, diagnosis and treatment in health services that reach women and girls.



Organization and Governance

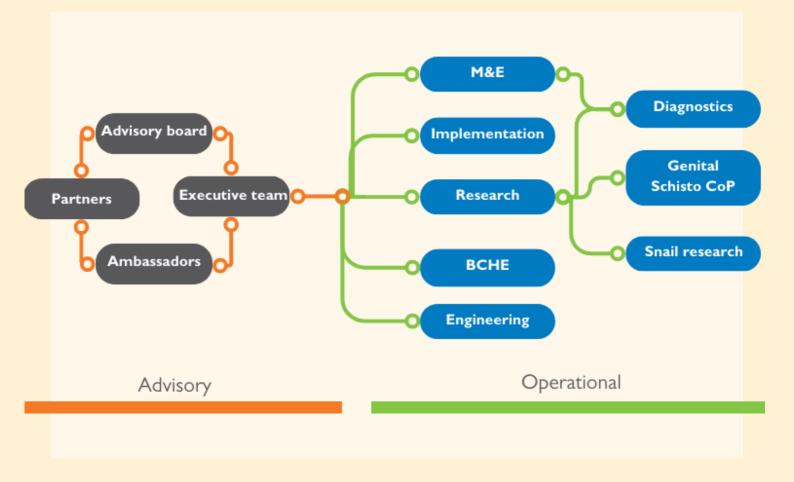


Figure 8 - GSA Network and community

The GSA is managed by an Executive Team and oversees and supports the GSA Working Groups (WG) and Work Streams (WS). Working Groups and Work Streams bring together relevant experts and stakeholders, drawn from the partner organizations and from other organizations, research groups and programmes, to produce tangible outputs addressing specific challenges or barriers to schistosomiasis control and elimination as identified in the GSA Schistosomiasis Action Plan.



The working group outputs are aimed at accelerating progress towards the WHO roadmap goals and beyond. The GSA Executive Team works with the Working Group Chairs to develop an annual operational strategy and plan and consults with the WHO NTD Department on a regular basis.

The alliance also has a network of GSA Ambassadors who are GSA points of contact in endemic countries and advise on progress being made and challenges being faced in-country with regard to the control and elimination of schistosomiasis. They contribute to discussions to determine actions required by the schistosomiasis community and feedback on their experience and concerns to the community via the GSA and fellow Ambassadors. The annual operational strategy and progress report is reviewed by the GSA Advisory Board.



Glossary

- AG Adolescent Girls
- ASTMH American Society for Tropical Medicine and Hygiene
- BCHE Behaviour Change Health
 Education
- BC Behaviour Change
- CIFF Children's Investment Fund Foundation
- CDC USA Center of Disease Control
- CHOGM Commonwealth Heads of Government Meeting
- COR NTD Coalition for Operational Research for NTDs
- CoP Community of Practice
- ECTMIH European Congress Tropical Medicines and International Health
- ESPEN Expanded Special Project for Elimination of NTDs
- FGS Female Genital Schistosomiasis
- FIG FGS Integration Group
- GSA Global Schistosomiasis Alliance
- ICOPA International Congress of Parasitology
- ISNTD International Society for Neglected Tropical Diseases
- MDA Mass Drug Administration
- M&E Monitoring and Evaluation
- NIPD China National Institute for Parasitic Diseases
- NTDs Neglected Tropical Diseases
- NNN NTD NGO Network
- OHDI One Health and Development Initiative

- OR Operational Research
- PC Preventative Chemotherapy
- SCI Schistosomiasis Control Initiative Foundation
- SCH Schistosomiasis
- STAG Strategic and Technical Advisory Group
- STH Soil-transmitted helminths
- Swiss TPH Swiss Tropical Medicine and Public Health Institute
- TAGSS Technical Advisory Group on Schistosomiasis and Soil-transmitted helminthiasis
- USAID U.S. Agency for International Development
- WASH Water, Sanitation and Hygiene
- WISER Water Infrastructure for Schistosomiasis Endemic Regions
- WG Working Group
- WHA World Health Assembly
- WHO World Health Organization
- WHO HQ WHO Headquarters in Geneve, Switzerland
- WHO AFRO WHO Regional Office for Africa
- WHO EMRO WHO Regional Office for Easter Mediterranean
- WHO SEARO WHO Regional Office for South-East Asia
- WHO WPRO WHO Regional Office for Western Pacific
- WRA Women of Reproductive Age



working together

to eliminate schistosomiasis



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