One Health Society.

ADVOCACY GUIDE FOR

Female Genital Schistosomiasis (FGS)

A Toolkit for Civil Society Organizations

This guide has been prepared to provide practical advocacy guidance, tools, and lessons drawn from experience to civil society organizations working on Female Genital Schistosomiasis (FGS) and related neglected tropical diseases.

The findings, interpretations, and recommendations expressed in this guide are those of One Health Society and do not necessarily reflect the official policies or positions of the Ministry of Health of Tanzania, or of the government officials, institutional partners, or individuals acknowledged herein.

This is a working document, offered as a first edition based on experience to date. One Health Society welcomes feedback from readers and partner organizations to strengthen future editions.

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Abbreviations

Abbreviation	Meaning
CHW	Community Health Worker
CPD	Continuing Professional Development
CSO	Civil Society Organization
ECSA-HC	East, Central and Southern Africa Health Community
FGS	Female Genital Schistosomiasis
FIG	Female Genital Schistosomiasis Integration Group
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
HPV	Human Papillomavirus
MDA	Mass Drug Administration
MoH	Ministry of Health
MGS	Male Genital Schistosomiasis
Mwele-DOA	Mwele Malecela Days of Action
NGO	Non-Governmental Organization
NTD	Neglected Tropical Disease
OHS	One Health Society
PLHIV	People Living with HIV
PMO-RALG	Prime Minister's Office - Regional Administration and Local Government
RCH	Reproductive and Child Health
SRH	Sexual and Reproductive Health
STIs	Sexually Transmitted Infections
TAMSA	Tanzania Medical Students Association
WASH	Water, Sanitation and Hygiene

Preface

This guide is offered by One Health Society (OHS) as the frontline civil society organization working systematically on Female Genital Schistosomiasis (FGS) in Tanzania. It bridges years of foundational OHS advocacy in the neglected tropical diseases (NTDs) sector with the specific, high-impact strategies and lessons developed under the Mwele Malecela Days of Action (MweleDOA) program, which has driven FGS engagement within the national and regional neglected tropical diseases space.

This is a field-tested set of methods, drawn from campaigns, coalitions, briefs, and digital initiatives carried out in that time, so that other CSOs in Tanzania and beyond do not have to build an FGS advocacy strategy from zero. Each section describes what was done, and closes with an **"Adapt This"** box, translating the method into a general principle another CSO can apply to their own context, disease priority, or country.

The goal in publishing this guide extends beyond FGS itself. Many neglected diseases share the same underlying problem: they are real, treatable, and burdensome, yet invisible to the health workers, policymakers, and communities who could act on them. The staged advocacy approach, the cross-sectoral framing methods, the co-creation model, and critically the way government has been engaged at every level, from programme design through implementation, are intended to be adapted by CSOs advocating for other neglected diseases facing similar recognition and integration challenges.

Milestones at a Glance

Before diving into the methods behind them, here is a snapshot of the activities and results this guide draws on. Each is described in full later in the guide, with the method behind it broken down for reuse.

Milestone	What it means
Media features	FGS coverage in The Citizen, Daily News, and a Swahili-language interview on TBC Taifa — reaching audiences beyond English-speaking policy circles.
Co-design session	A youth and SRH advocate co-design session produced a published, named advocacy brief that now anchors engagement with the Ministry of Health.
100+ medical students trained	A training workshop with the Tanzania Medical Students Association (TAMSA) – Kairuki reached over 100 future clinicians on general knowledge on FGS.
200+ participants, 17 countries	A global policy and practice webinar brought together policymakers, researchers, and Ministry of Health leadership from 17 countries.
ECSA-HC Youth Summit	Engagement on World NTDs Day earned public endorsement of FGS from the ECSA-HC Director General, elevating the advocacy to a regional table.
FIG membership	Sustained multi-platform engagement led to formal recognition as a member of the Female Genital Schistosomiasis Integration Group.
#FGSchallenge	A peer-driven digital initiative engaged more than 32 health professionals and medical students in sharing evidence-based FGS messages.
Sign language content partnership	A partnership with a sign language interpreter made core FGS information directly accessible to Deaf and hard-of-hearing audiences.
Commemoration-day campaigns	FGS messaging carried across World AIDS Day, HPV Awareness Day, World Water Day, Nane Nane (Farmers' Day) and World NTD Day, each reframed for a different audience of stakeholders.

The rest of this guide breaks each of these down into a replicable method, with an **"Adapt This"** prompt so another CSO can apply it to their own context.

How to Use This Guide

This guide is organized to be used as a whole or in parts, depending on where an organization is in its own advocacy journey.

- Starting from zero? Begin with Sections 1 through 4 — they build the case for why FGS (or a comparable neglected condition) deserves attention, and help define a clear, staged advocacy ask before any activity is planned.

- Already advocating, but looking to strengthen methods? Sections 5 through 11 walk through specific, replicable methods — co-creation, cross-sectoral platform strategy, gender considerations, government partnership, commemoration-day planning, digital advocacy, and disability inclusion; each with a worked example and an ***"Adapt This"*** box.

- Ready to scale up or report to funders? Sections 12 and 13 cover risk assessment and monitoring, evaluation, and learning — useful before expanding activity or preparing a funder or government report.

- Need practical templates to act quickly? Section 14 (Toolkit) collects every checklist, worksheet, and template referenced earlier in one place.

- Working on a different neglected disease entirely? Section 15 speaks directly to adapting the whole model beyond FGS.

Each ***"Adapt This"*** box is designed to be used as a working tool — the questions inside are meant to be answered in writing, ideally by a small planning team, before moving to the next section.

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SECTION 1

WHY FGS NEEDS COLLECTIVE ADVOCACY

Female Genital Schistosomiasis (FGS) remains one of the most under-recognized conditions affecting the sexual and reproductive health of women and girls in schistosomiasis-endemic settings. FGS is preventable and can be treated if diagnosed early, yet millions of women and girls go undiagnosed because health systems, policymakers, and even health providers are not aware of FGS or do not routinely think to look for it.

What Is FGS?

FGS is a condition caused by Schistosomiasis, a neglected tropical, parasitic disease caused by parasitic worms living in freshwater snails. People become infected when their skin comes into contact with contaminated water during everyday activities such as washing, bathing, or swimming.

How it is transmitted: **an infected person passes parasite eggs in urine or stool → the eggs reach fresh water and infect freshwater snails → the snails release larvae into the water → the larvae penetrate human skin on contact.**

When Schistosoma haematobium eggs travel to the genital organs, they cause Genital Schistosomiasis. In women and girls, this is Female Genital Schistosomiasis (FGS); the equivalent condition in men and boys is Male Genital Schistosomiasis (MGS).

FGS is not sexually transmitted. It results from water contact, which can start as early as childhood, with damage caused by eggs trapped in the genital tissue — and symptoms sometimes not appearing until years later.

Symptoms include: vaginal itching, pain during sex, pelvic pain, bleeding between periods or after sex, abnormal vaginal discharge, lower abdominal pain and infertility

Complications include: infertility, subfertility, ectopic pregnancy, miscarriage, premature birth, increased risk of infection including HIV and HPV infection, stigma due to misdiagnosis, unnecessary treatment and painful intercourse.

FGS is preventable and can be treated if diagnosed early.

Schistosomiasis in numbers

More than 700 million people at risk of infection

Over 200 million currently infected

At least 90% of those requiring treatment live in the African Region.

Schistosomiasis is the second most prevalent tropical, parasitic disease in the world after malaria, with more than 700 million people at risk of infection globally and over 200 million currently infected, the majority in low- and middle-income countries. At least 90% of those requiring treatment live in the African Region. Across sub-Saharan Africa, an estimated 56 million women and girls are affected by FGS, a direct consequence of Schistosoma haematobium infection. Tanzania carries the second highest schistosomiasis burden in Africa, with 115 district councils considered endemic, particularly around major water bodies and farming communities.

Why it matters

FGS is associated with infertility, ectopic pregnancy, chronic pelvic pain, and an increased risk of HIV and HPV infection. Because its clinical manifestations—such as abnormal vaginal discharge, burning, and contact bleeding—mirror sexually transmitted infections (STIs), women and girls with FGS face profound social stigma, accusations of infidelity, and discrimination within their communities and healthcare settings.

This is what makes FGS a powerful advocacy issue rather than a narrow clinical one: it sits at the intersection of HIV and cervical cancer prevention, adolescent health, sexual and reproductive health and rights (SRHR), gender equity, and water, sanitation, and hygiene (WASH). An advocate does not need to convince a Ministry of Health, a donor, or a parliamentarian to care about a new disease. Instead FGS can be positioned directly inside priorities they already fund, prioritize, and commit to.

Why Women and Girls Bear the Burden of FGS

While schistosomiasis is historically mischaracterized as a disease that primarily affects men and boys due to fishing or recreational swimming, the reality for women and girls is driven by a distinct set of gendered risks.

Infection risk is directly tied to the gendered division of labor around water. From early childhood and throughout their lives, women and girls carry out routine household and livelihood responsibilities like collecting water, washing clothes, bathing children, and farming. For example, in agricultural regions such as rice-farming communities, women make up the majority of the workforce standing in contaminated water. Even in fishing communities where men and boys have high exposure on boats, women face continuous exposure at the water's edge while processing fish, fetching water, or washing household items. FGS is not an accidental health issue that happens to affect women more, but rather a direct product of gendered labor.

However, the disproportionate impact of FGS extends far beyond initial water contact. It is deeply worsened

by gender and power imbalances that dictate how health care is accessed and delivered. At the household level, women and girls often lack the financial autonomy to pay for clinic visits or the decision-making power to seek care independently. This is compounded by heavy caretaking responsibilities. A woman often cannot simply choose to visit a hospital; she must first negotiate who will look after the children, cook the meals, and manage the household in her absence. These domestic demands, combined with the barrier of out-of-pocket expenses and the need to secure permission from male partners, cause severe delays in seeking medical attention.

When women finally reach a health facility, they encounter an entirely new structural barrier: clinical bias. Because medical training often reinforces the idea that schistosomiasis is a male occupational disease, health workers rarely suspect it in female patients. Instead, when a woman presents with pelvic pain or vaginal discharge, clinicians default to testing for sexually transmitted infections or reproductive cancers. This gender blind spot means that women and girls are systematically misdiagnosed and left untreated for years. This prolonged neglect allows the parasite's eggs to permanently trap themselves in reproductive tissues, turning a treatable infection into a lifelong, irreversible case of FGS.

The health-system gap

The root of the health-system gap begins earlier than the consultation room. Pre-service and in-service training for health workers rarely includes FGS as a condition to actively screen for, which means clinicians move through their careers without ever being taught to recognize it. The direct result is that health workers remain effectively blind to FGS even when it is present in front of them.

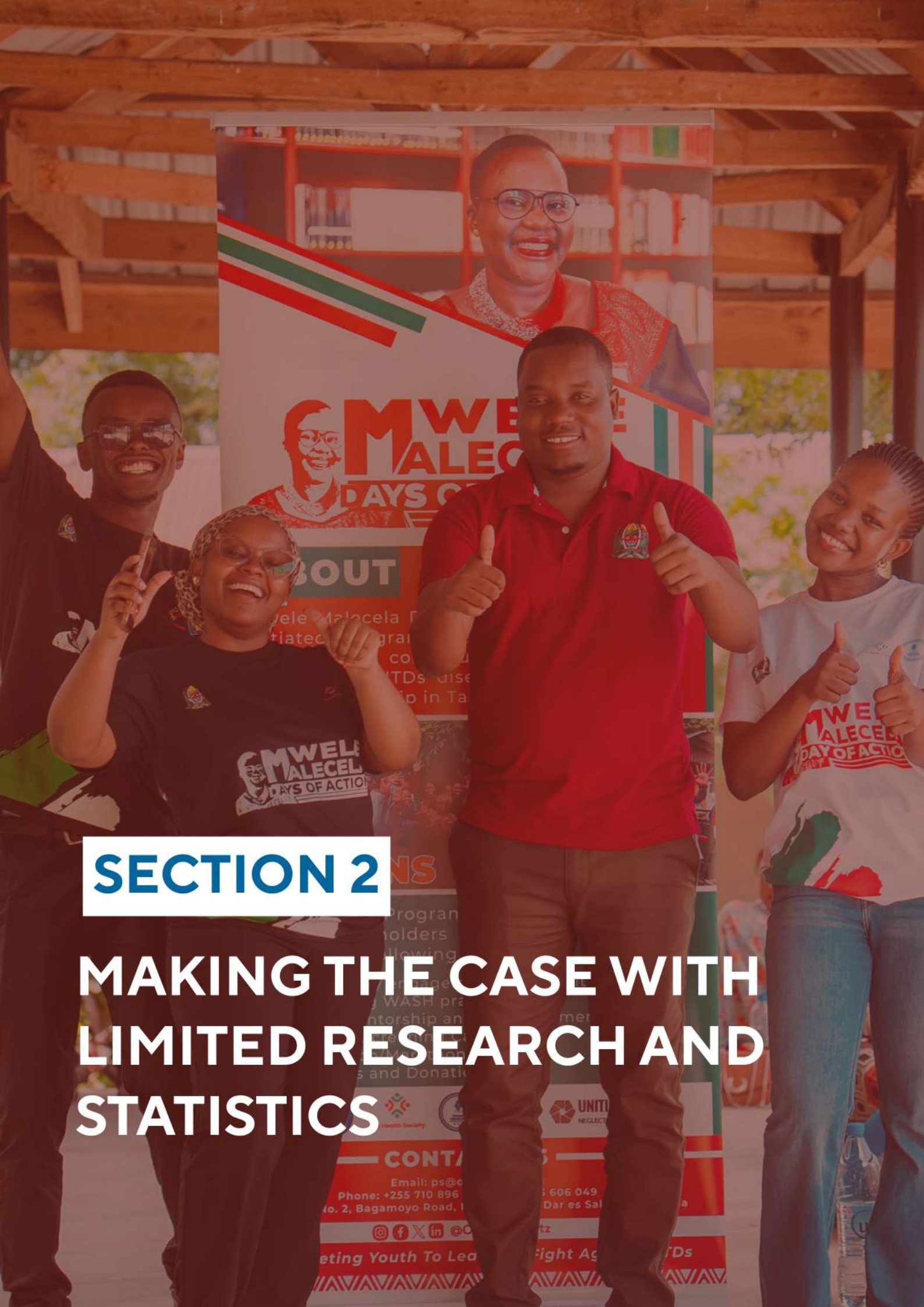
Because FGS symptoms can resemble sexually transmitted infections (STIs) or other reproductive conditions, this training gap translates directly into misdiagnosis: women and girls are frequently treated repeatedly for the wrong condition without the underlying cause ever being addressed. The consequences extend beyond physical health; delayed diagnosis and persistent symptoms can contribute to stigma, emotional distress, relationship difficulties, and reduced health-seeking behaviour.

This is the opening argument for any audience: girls and women are already in contact with the health system through family planning, antenatal care, maternal and adolescent health services, HIV services, and cervical cancer screening — and FGS is being missed at every one of those touchpoints. The ask is not to build new programmes, rather to respond to the needs of women and girls through equitable, comprehensive and integrated healthcare services.

Adapt This

What larger, already-funded agenda does your issue intersect with? Lead your case with that intersection — a standalone burden number rarely moves an audience that has never heard of the condition.

Where are the people you're trying to reach already showing up in existing services, and what is currently being missed at that encounter?



SECTION 2

MAKING THE CASE WITH LIMITED RESEARCH AND STATISTICS

A recurring obstacle in advocating for a historically neglected condition is the absence of robust local prevalence data. It is common to treat missing statistics as evidence that a disease is not a priority.

The core argument

Health workers have not been finding FGS in large numbers because they have not been looking for it — not because it is not there. Where schistosomiasis is endemic, and where women and girls report symptoms consistent with FGS, absence of routine screening produces absence of data, and absence of data is then mistaken for absence of disease. Making this distinction explicit, repeatedly and plainly, has been central to opening conversations with sceptical audiences.

Using the evidence that does exist

Rather than waiting for Tanzania-specific prevalence studies, OHS built the early case on the best available local, regional and global research — including established estimates by UNAIDS and WHO that FGS affects an estimated 56 million women and girls across sub-Saharan Africa, and published evidence linking FGS to increased HIV and HPV risk — combined with Tanzania's confirmed schistosomiasis burden as the second highest in Africa, with 115 endemic district councils. This made it possible to build a credible, evidence-based case for local relevance and risk without overstating what local data could show, while being explicit that this was extrapolation from regional evidence to argue for local investigation.

Turning the data gap itself into an ask

The absence of local statistics was treated as an actionable advocacy ask in its own right, for investment in local screening, surveillance, and operational research. This reframes a seemingly disqualifying gap into a concrete, fundable request that stakeholders can act on — a research or surveillance commitment is often an easier initial "yes" for a Ministry department or donor than a full service-integration commitment, and it directly produces the local data that later-stage advocacy will need.

Guarding against overclaiming

Regional and global data should be presented as exactly what it is — evidence of plausibility and risk that justifies looking, not proof of local prevalence. Conflating the two can undermine credibility with technical and clinical audiences who will notice the gap immediately. Good practice is to pair every regional statistic with an explicit statement that local data collection is a current priority need — turning the acknowledgment of a limitation into part of the advocacy message itself.

Adapt This

Does your issue also lack local statistics? Build your early case on the best available regional or global evidence now, rather than waiting — and state plainly that this is what you are doing.

Are you naming the mechanism behind the data gap every time you present evidence? Distinguishing "not looked for" from "not present" is often what shifts a sceptical audience from dismissal to curiosity.

Can your data gap itself become a specific research or surveillance ask? It is often a faster institutional "yes" than your ultimate integration ask, and it builds the evidence base later-stage advocacy will need.

SECTION 3

ADVOCATING WITH LIMITED RESOURCES

With modest resources and no prior national precedent to draw on, the campaign transformed into a recognized regional voice within about a year. In that time: a youth and SRH advocate co-design session produced a named, published advocacy brief; a training workshop reached over 100 medical students through the Tanzania Medical Students Association; a global webinar drew more than 200 participants from 17 countries; engagement at the ECSA-HC Youth Summit earned public endorsement from the Director General; a peer-driven digital initiative engaged 32 health professionals and students; and earned media coverage, including a Swahili-language television interview, carried the message beyond policy circles.

Every method described in this guide was carried out with modest resources, not a large advocacy budget. This is worth stating plainly, because resource scarcity is often treated by CSOs as a reason to delay advocacy until funding arrives. This experience points the other way: early, low-cost groundwork is what generated the credibility that later attracted resources, support, and collaboration — not the reverse. The lessons below describe how.

Lesson 1: Starting where you are

None of the earliest activities required significant funding. A co-design session needs a room, a facilitator, and a clear question. A digital challenge needs a personal anchor moment and a small seed group of participants willing to post. A training workshop with a medical students' association leverages a partner's existing membership and venue. Each of these produced a tangible output — a named, citable brief; a documented training reach; a hashtag with measurable participation — well before any significant funding was in place.

Lesson 2: Opening doors through early groundwork

Each low-cost activity became evidence of credibility and momentum to point to in the next conversation. A published co-design brief with named contributors provided something to bring into a Ministry meeting. A documented training of over 100 medical students provided something to cite when approaching the Human Resources for Health Conference. Consistent presence and visible outputs across these small, low-cost activities are what led to formal recognition as a member of the Female Genital Schistosomiasis Integration Group (FIG) — a form of institutional standing that could not have been requested directly or purchased with a larger initial grant; it had to be earned through demonstrated, sustained work.

Lesson 3: Building and joining networks

An organization does not need to originate every network it needs; identifying and joining the right existing ones can be as valuable as building new coalitions from scratch (see Section 6 for the fuller coalition-building method). Some of these were built directly — the relationship with TAMSA, the coalition formed around the co-design session. Others were joined — membership in FIG, and engagement with established bodies such as Uniting to Combat NTDs and the Global Schistosomiasis Alliance, brought access to technical credibility, global speakers, and regional platforms that would have taken years to build independently.

The sequencing this implies

This experience suggests a deliberate order: use minimal resources to produce a small number of credible, well-documented outputs; use those outputs to open institutional and donor conversations; use the resulting resources and partnerships to scale what already works, rather than to originate the work in the first place. Waiting for substantial funding before beginning tends to delay the very evidence of traction that funders and institutional partners look for before committing support.

Adapt This

What is the lowest-cost version of each method in this guide that you could run this month? A small co-design session, a modest training with an existing partner, a simple digital challenge — treat it as a real first output, not a placeholder until “real” funding arrives.

Are you documenting every early activity, even the small ones? Numbers reached, named contributors, and resulting materials are the currency that opens the next, better-resourced conversation.

Which existing networks could you join rather than build? A relevant coalition, alliance, or technical group may already exist and be open to a CSO joining, rather than requiring one to be built from nothing.

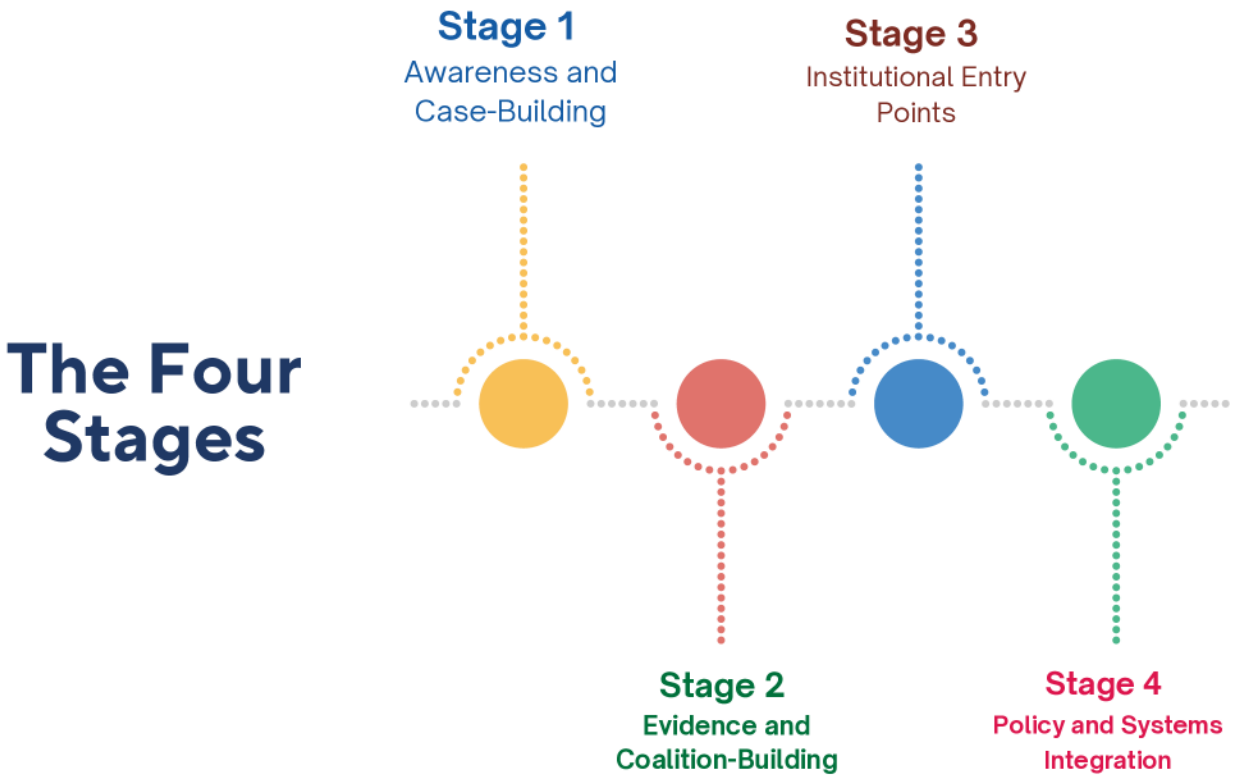
SECTION 4

DEFINING YOUR ASK – A STAGED, STRATEGIC APPROACH

Every advocacy effort should be able to state its ultimate ask in one sentence. OHS's is:

"FGS should be integrated into sexual and reproductive health (SRH) services and primary healthcare."

But stating the ask is the easy part. For a condition that health workers, communities, and policymakers are not yet familiar with, going straight to that final ask rarely works — you cannot request systems-level integration of something your audience does not yet recognize as real, common, or relevant to them. Reaching the end goal requires a deliberate, staged approach, and defining that staging from the very beginning of your advocacy strategy is one of the most important planning steps a CSO can take.



Stage 1 — Awareness and Case-Building

Before anyone will act on FGS, they need to believe it is real, common, and connected to something they already care about. This stage is not about asking for policy change; it is about earning attention and credibility. Framing is everything here — the same fact ("FGS increases HIV risk") can open a door with an HIV programme officer that a purely parasitological framing ("FGS is caused by Schistosoma haematobium") cannot.

Stage 2 — Evidence and Coalition-Building

Once an audience is willing to engage, the next step is to convert attention into an evidence base and a coalition that can carry the message forward. This is where methods like co-design sessions (Section 5) and named, citable advocacy briefs do their work — they turn "***we've heard of FGS***" into "***we have a documented, credible case and named allies behind it***."

Stage 3 — Institutional Entry Points

With evidence and allies in place, advocacy shifts to concrete, bounded institutional asks: adding FGS to a training curriculum, a screening checklist, a referral pathway, or a conference agenda. These are asks a single institution can say yes to without needing a national policy change — and each one builds a precedent for the next.

Stage 4 — Policy and Systems Integration

Only once Stages 1–3 have built familiarity, evidence, allies, and institutional precedent does full systems-level integration — national guidelines, financing lines, HMIS indicators — become a realistic ask. Arriving here without the earlier stages typically results in a well-written policy brief that no one is primed to act on.

Adapt This

Can you state your own ultimate ask in one sentence? Write it now, before doing anything else — everything you plan should trace back to it.

Have you mapped your own version of these four stages against your specific health system and country context? Resist the temptation to skip to Stage 3 or 4 because evidence already exists globally — local unfamiliarity usually means local Stage 1 and 2 work is still needed, even for a well-documented condition.

Framing for buy-in from non-NTD stakeholders

The hardest part of Stage 1 is that FGS advocacy usually has to reach people who do not work in NTDs at all — WASH officers, SRH programme staff, HIV programme managers, cervical cancer screening coordinators. None of them will act on an NTD framing alone. Each needs the case made in terms of what they already measure and fund.

Stakeholder	What they already prioritize	FGS framing hook
WASH sector	Water access, sanitation infrastructure, hygiene behaviour change	FGS as a documented reproductive-health consequence of unsafe water contact — evidence that WASH investment has a payoff beyond diarrhoeal disease prevention
SRH services	Family planning, antenatal care, adolescent-friendly services	FGS as an unrecognized cause of the infertility, pelvic pain, and repeat "STI-like" presentations already seen in their client base
HIV programmes	Reducing HIV incidence, especially among adolescent girls and young women	FGS as a biological risk multiplier for HIV acquisition — FGS screening and treatment as an HIV-prevention intervention and co-morbidity

Cervical cancer screening	Early detection of HPV and cervical cancer	FGS as a catalyst for HPV progression and a barrier to accurate cervical cancer diagnosis — Integrating FGS care into cervical cancer prevention and management
NTD / MoH programmes	MDA coverage and NTD elimination targets	FGS as the missing "so what" of existing MDA — integration measures and communicates the SRH payoff of a programme they already run
Education sector	School health and adolescent wellbeing	FGS awareness and referral embedded within Comprehensive Sexuality Education (CSE), school health clubs, and adolescent programming

The sequencing principle that follows from this table: ask each sector for something native to their existing mandate first — a message added to hygiene promotion materials, a question added to an intake form, a slide added to an existing training — rather than asking them to adopt or fund a new disease programme outright. Larger integration asks become realistic only after these small, sector-native asks have built familiarity and trust.

Adapt This

Have you built your own version of this table? List every non-specialist sector whose cooperation you eventually need, and write their existing priority before you write your framing hook — this ordering keeps the framing audience-centred rather than organization-centred.

For each stakeholder, what is the one small, sector-native first ask you could make before ever proposing full integration? This is usually the difference between a meeting that ends in polite interest and one that ends in a next step.

Mapping political will and progress

Beyond framing for individual stakeholders, it helps to diagnose the broader political environment before choosing an advocacy posture. Two questions matter most: how much political will currently exists for FGS or a comparable neglected condition, and how much progress has already been made toward addressing it. Plotting these two factors together produces four distinct advocacy postures, each calling for a different emphasis.

	Slow / Limited Progress	Promising Progress
High Political Will	Implementation Decision-makers are supportive but action is stalled. Focus on a small number of high-impact, cost-effective asks — e.g. one training curriculum change, one referral pathway — rather than a broad platform.	Sustaining Momentum Support and results are both strong. Focus on keeping the issue visible, documenting wins publicly, and pushing for durable systems (registries, financing lines, HMIS indicators) that outlast current champions.
Low Political Will	National Drive This is the typical FGS starting point in most countries. Focus on Stage 1 awareness and case-building (see above), using regional evidence, urgency framing, and influential early messengers to generate momentum from close to zero.	Leverage Progress Good results exist but political attention has shifted elsewhere — e.g. after a change in government or donor priorities. Focus on documenting past results publicly and making the case to protect what has already been built.

Adapt This

Where does your issue currently sit on this grid — and has it been sitting there because of the political environment, or because the advocacy approach hasn't matched the posture the environment calls for?

Revisit this mapping periodically. A change in government, a donor priority shift, or a new champion can move an issue to a different quadrant quickly, and the advocacy posture should move with it.

SECTION 5

CO-CREATION AS AN ADVOCACY METHOD

One of the most transferable tools in this experience is not a message — it's a method: convening the people affected by an issue to co-design the advocacy asks, rather than writing them on their behalf.

What was done

In April 2026, OHS conducted a youth co-design and engagement session with sexual and reproductive health (SRH) advocates in Tanzania to explore opportunities for integrating FGS into SRH services for adolescent girls and young women. Discussions aimed to identify barriers affecting awareness, prevention, diagnosis, treatment access, and health system responsiveness, using a gender-responsive and One Health lens.

What came out of it

- Awareness gaps — young people described substantial awareness gaps within communities and among themselves; many noted that FGS remains unfamiliar despite communities being generally aware of schistosomiasis, contributing to delayed care-seeking and missed prevention opportunities.
- Missed service encounters — girls and young women already access healthcare through adolescent-friendly services, reproductive health clinics, school health programmes, HIV services, and maternal health platforms, yet FGS is rarely considered during routine service delivery.
- Provider capacity and stigma — participants believed healthcare workers require additional support to recognize symptoms, reduce misdiagnosis, and strengthen referral pathways.

The resulting policy recommendations

These now anchor OHS's advocacy with the Ministry of Health: integrating FGS into adolescent and youth-friendly health services, reproductive and child health services, cervical cancer screening programmes, and community outreach platforms; strengthening provider training through both pre-service and in-service education; prioritizing youth-led approaches such as peer education, school health clubs, and digital platforms; and strengthening multisector collaboration between health, water, sanitation, education, and community systems.

Why this method works as advocacy — not just research

- It builds legitimacy — a brief with named youth and SRH advocate contributors carries different weight in a policy meeting than an NGO position paper.
- It builds a coalition before you need one — everyone in the room becomes a co-owner of the resulting asks, and a natural messenger when the brief circulates.
- It surfaces asks that resonate, because they come from lived proximity to the health system, not from a technical committee.

How to run a co-design session

- Define a narrow, answerable question. The question used here was: what are the barriers to integrating FGS into SRH services for adolescent girls and young women, and what should change? Not “what do you think about FGS” — too broad to produce policy language.
- Invite the right mix — youth/peer advocates and SRH technical advocates in the same room; the tension and overlap between lived experience and technical framing is what produces usable recommendations.
- Structure discussion around barriers first, then translate to recommendations — this avoids the session collapsing into generic “more awareness needed” statements.
- Capture direct language — quotable lines from participants and session leads become the brief's emotional register.
- Publish with named contributors and a designated contact person — this turns a session into a durable, citable artifact, not a one-off meeting.

Adapt This

What is your own narrow, answerable question about your own priority population? You don't need this exact question or these exact contributors — the method transfers directly: invite a deliberate mix of lived-experience and technical voices, and structure the session barriers-first.

Has your organization published a named, contributor-credited brief before? If not, treat your first co-design session as the moment to start — it becomes a reusable, citable asset for every advocacy conversation that follows.

SECTION 6

CROSS-SECTORAL PLATFORM STRATEGY — STACKING ENTRY POINTS

FGS advocacy cannot rely on one platform. The most productive month of advocacy work to date deliberately used four different types of platforms in succession, each building on the last.

Health workforce entry point

A partnership with the Tanzania Medical Students Association (TAMSA) – Kairuki convened a training workshop for more than 100 medical students, focused on FGS clinical presentation, its documented associations with HIV and cervical cancer, and the importance of embedding FGS within SRH services and clinical training curricula. This is the highest-leverage, lowest-cost advocacy platform available to most CSOs: today's medical students are tomorrow's clinicians, curriculum committee members, and policymakers.

Global / technical entry point

A global policy and practice webinar brought together policymakers, researchers, advocates, youth leaders, and Ministry of Health officials, reaching more than 200 participants from 17 countries. The Ministry of Health and National NTD Control Programme leadership spoke directly to the value of aligning FGS integration with national priorities. A webinar is a low-cost way for a national CSO to convene a genuinely international room — use it to bring global technical credibility into a national conversation, and national political voices into a global one.

Why did the webinar reach this audience?

Webinars are one of the most commonly used, and most commonly under-attended, advocacy tools available to CSOs. Reaching 200+ participants from 17 countries was not incidental — it was the result of ***two deliberate design choices*** made well before the event itself.

A two-axis speaker formula. Speakers were chosen to be diverse along two axes at once: by function — government, youth, research, an implementation partner, and an international funder were each represented — and by geographic scope — local (Tanzanian), regional, and global experts were each represented. Crossing both axes meant that most attendees, whatever their own role or location, saw someone on the panel who reflected their own position. A single-axis approach (for example, only varying technical expertise) tends to produce a panel that is credible but not broadly relevant to a wide audience.

A momentum-building sequence. Publicity began weeks before the webinar was even announced, using earlier activities to build anticipation and drive traffic toward it rather than treating each as a standalone event:

- A New Year teaser video signalled that myths-and-facts content, quotes, and educational videos on FGS were coming through January.
- By mid-January, the #FGSchallenge launched, sustaining engagement and visibility.
- Few days before the webinar, the TAMSA training was held and included a quiz to be answered on the organization's Instagram page — an incentive that drove traffic to the account, where the webinar was also promoted, while the training itself was used to mention the webinar directly to a room of future clinicians.
- The webinar was also shared through coalition platforms, including the Uniting to Combat NTDs Communication Working Group and the Global Schistosomiasis Alliance, which carried it in their newsletter to their own networks.

Each activity in the weeks before the webinar was doing double duty: delivering its own content and building the audience for what came next. The webinar's turnout reflects that sequence as much as it reflects the announcement itself.

Adapt This

Does your speaker list cross two axes of diversity — function and geographic scope — rather than just one?

Can you map a momentum sequence for your own next big event, using activities you're already planning? A teaser, an engagement moment, a partner training, and coalition amplification can each feed the next rather than standing alone.

Which coalition platforms could carry your announcement to audiences you can't reach directly?

Regional youth / leadership entry point

Engagement at the ECSA Health Community (ECSA-HC) Youth Summit, held on World NTDs Day, positioned FGS integration within broader regional discussions on health leadership and systems strengthening. This was arguably the single most valuable moment in this entire build-up for a condition as unfamiliar as FGS — it is the one day already guaranteed to draw an audience primed to think about neglected diseases, without requiring the advocacy itself to first explain why the topic deserves attention. Landing there just three days after the webinar meant momentum was carried forward.
That endorsement of FGS from the ECSA-HC Director General, alongside the launch of the Youth mentorship programme which includes NTDs as one of its focus areas — provided a

Health workforce policy entry point

At the Human Resources for Health Conference, hosted by the Benjamin Mkapa Foundation, participation as an exhibitor and attendee was used to raise the FGS agenda in relation to health workforce development. The ask made there was specific and structural: that FGS be included in pre-service and in-service medical training curricula. This is a template worth naming explicitly — translate an awareness goal into a curriculum or systems-design ask. “Raise awareness” is hard to fund and impossible to measure. “Add FGS to the pre-service midwifery curriculum” is a concrete, trackable institutional change.

The compounding result

As a result of this sustained technical and advocacy engagement, One Health Society – Tanzania was formally recognized as a member of the Female Genital Schistosomiasis Integration Group (FIG), strengthening collaboration with global partners advancing integrated, people-centred approaches to FGS. Formal recognition by a global coordination body is not something an organization requests directly — it is the outcome of consistent, credible, multi-platform presence over time.

Adapt This

What are your own four platform types — a workforce/training platform, a global/technical platform, a regional or youth leadership platform, and a policy/institutional platform? You may not have access to the exact platforms used here, but every country has equivalents: a national medical or nursing students' association, a regional health community, a workforce or professional body conference.

Are you prepared for the trajectory awareness → coalition → technical credibility → formal standing to take sustained presence across multiple platforms over time, rather than a single strong pitch to one gatekeeper?

Building a coalition: who else to engage

Platforms provide moments of visibility; a coalition provides sustained support between those moments. The table below covers the range of partner types worth considering for FGS advocacy specifically — not every group needs to be a core coalition member, but each should at least be considered and deliberately included or deliberately set aside.

Suggested coalition partner	Reasoning
Women and girls with lived experience of FGS	Their voices should shape messaging and asks directly, not be represented secondhand.
Organizations working on women's rights and adolescent health	Bring expertise in engaging women and girls and dispelling stigma-driven misinformation.
SRH, family planning, and maternal and child health organizations	Natural service-integration partners and co-advocates for the same service platforms.
HIV community organizations and advocates	Given the documented HIV-FGS link, a natural and often well-resourced ally with advocacy infrastructure already in place.
Youth leadership groups	Particularly important given FGS's disproportionate impact on adolescent girls and young women, and their role in digital and peer-to-peer advocacy.
Gender equality organizations	Bring expertise on engaging men and boys as allies and addressing the household-level dynamics described in Section 3.
Organizations working on men's and boys' health	Help translate the “not sexually transmitted” message credibly to male audiences.
WASH sector organizations and government WASH departments	Directly relevant given the water-contact transmission route.
NTD control programme and immunization/MDA community	The closest existing technical and delivery infrastructure.
Associations of nurses and midwives	Trusted, high-reach community health messengers with a direct role in screening and referral.
Medical professional associations and public health academics	Shape treatment guidelines and training curricula, and can fill technical evidence gaps.
Legal and human rights advocacy groups	Can frame FGS access to diagnosis and treatment as a health rights issue where useful.
Current or former parliamentarians	Bring budget-cycle knowledge and can champion FGS within legislative processes.
Religious and traditional community leaders	Influential messengers for stigma-reduction, particularly the messaging aimed at men and guardians described in Section 3.
Parent groups and school teachers	Key messengers for adolescent girls and their guardians, and a route into school health platforms.
Media	Journalists, digital platforms, and health influencers who can extend reach beyond what a coalition can achieve through direct outreach alone.

PLATFORM STACKING

TAMSA Training

Global Webinar

ECSA Youth Summit

OHS becomes FIG member

BUILDING THE BRIDGE TO FGS INTEGRATION

Adapt This

Which of these partner types are already engaged, which are missing, and which have been deliberately left out for now? Write this down explicitly rather than leaving coalition composition to happen by default.

For a small or resource-constrained CSO, which two or three partner types would add the most credibility or reach right now? Start there rather than trying to build the full coalition at once.

SECTION 7

GENDER CONSIDERATIONS IN ADVOCACY

This section addresses a different question from the one covered in Section 3. Section 3 looks at how gender dynamics shape the risks facing the population FGS advocacy is trying to reach. This section asks whether the advocacy work itself including its coalition, its messengers, its authorship — reproduces the same imbalances it is trying to correct. A companion document, the Gender-Responsive Framework for Community Engagement in Addressing FGS, covers gender-responsive engagement design at the community level in depth; this section focuses specifically on the advocacy practice covered in this guide.

Who is representing the issue

FGS disproportionately affects women and girls, yet advocacy spaces — panels, conferences, media interviews, official delegations — can easily end up dominated by male officials, technical experts, or organizational leadership, with women and girls discussed rather than heard directly.

Furthermore, because FGS involves highly private reproductive symptoms that are deeply personal and difficult to discuss openly, it is fundamental that women and girls lead this conversation. A male-dominated space cannot safely or authentically break the silence around a gynecological issue of this nature. Deliberate effort is needed to ensure women and girls, including young advocates, are present as speakers and messengers, not only as the subject of the advocacy.

Who leads and who is credited

Coalition leadership structures, named authorship on briefs, and quoted spokespeople all signal who is understood to own an issue. A coalition that is gender-balanced in membership, but led and quoted exclusively by men sends a different message than its composition suggests. Co-design sessions (Section 5) help here structurally, since named, credited contributors are built into the method — but this needs to be maintained deliberately as an issue moves into more formal institutional and policy spaces (Sections 8 and 14), where technical and government counterparts may skew male.

Whose labour is visible

Much of the groundwork described in Section 3 (advocating with limited resources) — organizing, community mobilization, follow-up — is often carried out by women and young people within an organization, while more visible representational roles go to others. Recognizing and crediting this labour explicitly, including in materials such as this guide, is itself a small gender-responsive practice.

Messaging about men and boys

Section 3 already establishes that men and boys are a necessary audience for stigma-reduction messaging. It is worth stating the complementary point directly here: engaging men and boys should be framed as engaging allies with a stake in the health and dignity of the women and girls in their lives, not as gatekeepers whose approval must be secured before women and girls can act. The distinction affects tone — invitation and shared responsibility, rather than permission-seeking — throughout every platform and message described in this guide.

Adapt This

Look at the last three public-facing advocacy moments your organization has had (panels, interviews, briefs). Who spoke, who was quoted, who was credited? Is that composition consistent with who the issue actually affects?

Does your coalition's visible leadership match its actual composition? If not, what would it take to correct that in the next round of representation, not just internally?

SECTION 8

PARTNERING WITH THE MINISTRY OF HEALTH – FROM DESIGN TO IMPLEMENTATION

A common mistake in NTD and neglected-disease advocacy is treating the Ministry of Health as a single audience to be lobbied once a brief is ready. This experience points to the opposite: sustainable integration requires working with the government as a partner across multiple internal structures, and from the earliest stages of programme design through implementation — not only at the point of a final policy ask.

Beyond the NTD Control Programme

The National NTD Control Programme is the natural technical home for an issue like FGS, and its leadership matters — Tanzania's National NTD Control Programme has underscored the value of aligning this work with national priorities and highlighted the significance of incorporating FGS screening, diagnosis, treatment, and referral into routine SRH and primary healthcare services. But because the ask is integration into SRH and primary healthcare, the NTD desk alone cannot deliver it — it does not own SRH service design, health promotion messaging, or community-level delivery. Treating the NTD Control Programme as the only government touchpoint is one of the most common reasons integration advocacy stalls after a warm initial meeting.

The Health Promotion Section

Public health messaging and IEC (information, education, communication) materials are shaped by the Ministry's Health Promotion Section, not the disease-specific programme. The Health Promotion Section at Tanzania's Ministry of Health was represented among the featured speakers at the global policy and practice webinar described in Section 6. Engaging this section early means FGS messaging has a route into official government communication channels, rather than existing only as a parallel campaign competing with government materials for the same audience.

Community and RCH programmes

Because the ultimate ask is service delivery through existing SRH and primary healthcare platforms, the Ministry's community health and reproductive and child health (RCH) structures need to be involved in shaping how integration would actually work at the point of care — not simply informed of a finished advocacy brief. Co-designing service delivery questions with these structures (which cadre screens, at which visit type, with what referral pathway) turns an abstract integration ask into something a programme officer can operationalize.

Medical professional bodies

Ministry endorsement alone does not change clinical practice. Standard treatment guidelines, pre-service curricula, and continuing professional development requirements are shaped by medical, nursing, midwifery, and specialist professional bodies — the institutions that ultimately decide what clinicians are trained to recognize and how they are expected to manage it. Engaging these bodies early is what allows an integration ask to eventually reach standard treatment guidelines rather than remaining a policy statement with no clinical pathway attached. The engagement with the Tanzania Medical Students Association (TAMSA) described in Section 6 reflects this logic at the pre-service level: reaching the professional pipeline, not only sitting practitioners.

From design to implementation, not just at the ask

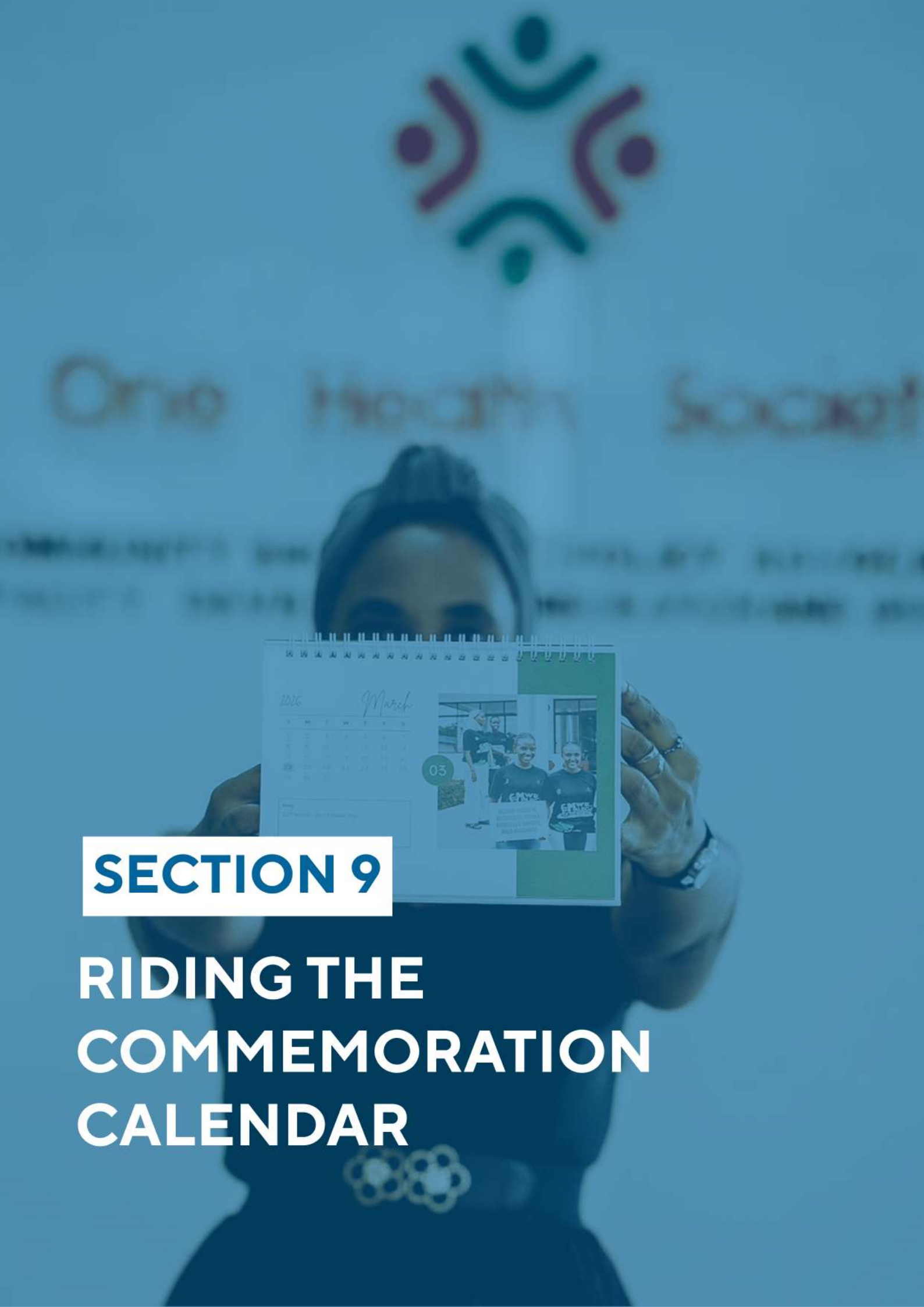
The common thread across all of the above is timing. Ministry of Health involvement has been sought from the design stage of activities — as co-panelists and speakers in OHS's own convenings, not only as recipients of finished asks — so that government voices help shape the framing and recommendations, and carry ownership of the resulting asks into implementation. A recommendation that a Ministry official helped shape in a co-design session or spoke to on a public panel is far more durable than the same recommendation delivered to them afterward in a brief.

Adapt This

Have you mapped your own Ministry of Health's internal structure? Which department is the technical home for your issue, which section controls public messaging, which section controls the service platform you want integration into, and which professional bodies set the clinical guidelines and training standards your issue would need to enter?

Are government counterparts invited as co-panelists, speakers, or co-design participants in your own events from the start, rather than only receiving finished asks? Ownership built during design carries much further into implementation.

This model is not FGS-specific — could the same structure (disease programme + health promotion + service delivery/community structures + professional bodies) apply to your own neglected or under-recognized condition?



SECTION 9

RIDING THE COMMEMORATION CALENDAR

A CSO does not need to invent a new awareness day to get visibility — it needs to find its issue's natural home inside the days that already command public and media attention. FGS has been mapped onto multiple existing commemorations, each giving a different framing and audience for the same underlying message.

Commemoration Day	Framing angle	Primary audience
World AIDS Day	FGS as an HIV risk multiplier	HIV programme officers, donors, PLHIV networks
HPV / Cervical Cancer Awareness Day	FGS–HPV/cervical cancer link	Cervical cancer screening programmes, SRH clinics
World Water Day	Transmission via water contact; WASH as prevention	WASH sector, local government, environmental agencies
World NTD Day	FGS as a core, still-neglected NTD	NTD control programmes, global health community
Nane Nane (Farmers' Day)	One Health link between agriculture, environment, and women's reproductive health	Ministry of Agriculture, rice-farming communities, agricultural livelihoods sector
Women's Day	FGS as a gender justice issue	Ministry of Gender and Social Development, Women's Rights Networks and Feminist Movements, Gender-Focused Global Donors

This is the practical value of the calendar approach: rather than competing for attention on a single "FGS Day" that doesn't yet exist in public consciousness, an organization borrows the built-in audience, media cycle, and institutional buy-in of a day people already observe — and uses it to introduce FGS to a sector that wouldn't otherwise engage with it that week. The engagement with the ECSA-HC Youth Summit described in Section 6, deliberately timed to fall on World NTDs Day, is a direct example of this — the summit's own theme and the day's global observance reinforced each other.

Planning template for other CSOs

- Build a 12-month calendar mapping every relevant commemoration day (health, environment, gender, youth) against your issue.
- For each day, write one framing sentence and identify the one audience you're trying to move that day.
- Pre-produce content at least three weeks ahead of each date — commemoration-day content dies if it's reactive.

Adapt This

What commemoration days intersect with your issue? Build your own version of this table — a nutrition-focused CSO might use World Food Day and Breastfeeding Week; a disability-rights CSO might use International Day of Persons with Disabilities and World Health Day.

For each day on your calendar, have you written a distinct framing sentence rather than repeating the same message everywhere? The specific days matter less than the practice of finding an existing high-visibility moment and framing deliberately for it.

Case Example: Nane Nane (Farmers' Day)

On Nane Nane 08.08.2026, Tanzania's National Farmers' Day, a bilingual (Swahili and English) social media campaign linked FGS to agriculture and environment, reframing it as a One Health issue rather than a health-sector-only concern. This is a direct example of the "insert into cross-sectoral platforms" method, applied to a commemoration day with no health framing at all.

The core link: rice fields make ideal habitat for the freshwater snails that transmit schistosomiasis, raising transmission risk for the women who farm them. Researchers piloting a response in Senegal introduced native Nile tilapia and African bony tongue, species that eat the snails into flooded rice paddies. The results published in Nature Sustainability (2026), with a larger follow-up trial underway.

- Reduced disease-carrying snail populations
- 25%+ higher rice yield
- Additional income from fish, for food and sale
- Improved soil fertility

Why this matters for Tanzania specifically: Tanzania carries the second-highest schistosomiasis burden in sub-Saharan Africa, and rice farming spans 6 major regions (Shinyanga, Tabora, Mwanza, Mbeya, Rukwa, Morogoro), producing roughly 3 million tonnes of rice — making Tanzania a leading African producer. An estimated 80% of the agricultural workforce is women, the majority smallholders. Women who spend hours in flooded paddies face repeated exposure to Schistosomiasis hence FGS — making agriculture a direct, if unrecognized, reproductive health issue.

"One Health. One Intervention. One Field." This framing complements existing schistosomiasis control strategies by addressing the environmental conditions that allow disease transmission to take hold in the first place — opening a route into the Ministry of Agriculture and farming communities that a purely clinical framing could not reach on its own.

The campaign was produced bilingually from the outset, in Swahili and English, so that farming communities; not only English-language health and policy audiences, could engage with it directly.

Adapt This

What non-health, non-NTD commemoration day intersects with your issue's environmental or occupational risk factors? Farmers' Day, World Environment Day, and similar days can open sectors that health-only messaging never reaches.

Is there an environmental or agricultural intervention that could reframe your NTD as a livelihoods issue as well as a health issue?

Are your commemoration-day materials produced in the language spoken by the sector you're trying to reach, not only the language your usual health-sector audience uses?

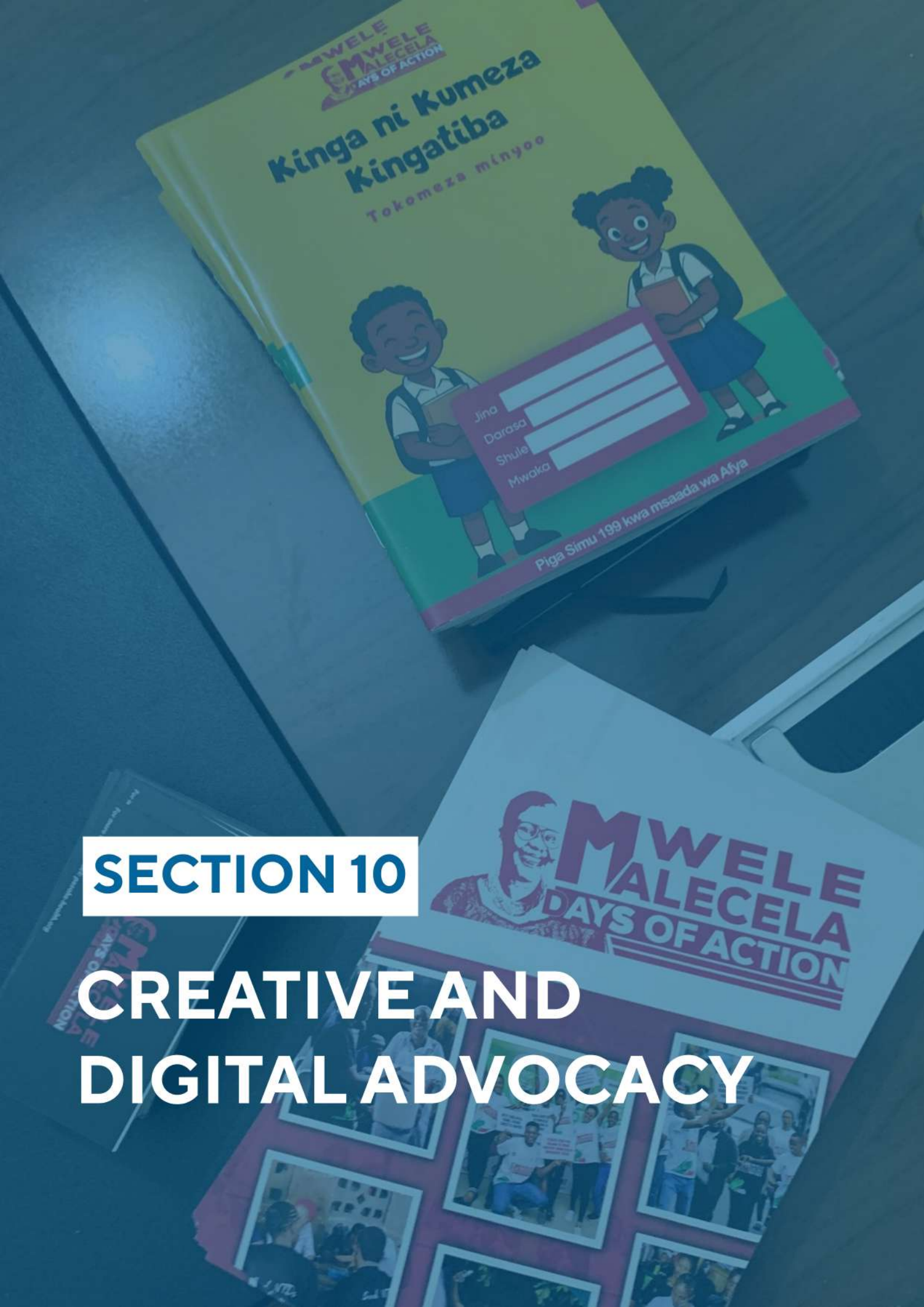
CASE EXAMPLE: NANE NANE DAY

The HOOK

The EVIDENCE

The OUTCOME

Why Tanzania Should CARE



SECTION 10

CREATIVE AND DIGITAL ADVOCACY

Technical briefs move institutions. They rarely move public awareness on their own. This work uses a four-track content strategy.

Track 1: Peer-driven digital challenges

The #FGSchallenge digital advocacy initiative engaged more than 32 health professionals and medical students in disseminating evidence-based FGS messages across digital platforms, complementing formal policy dialogue with peer-to-peer reach among current and future health practitioners. The format's strength was its informality and personal framing rather than a polished institutional campaign — it invited participation rather than just broadcasting a message, and it specifically activated health professionals and students as messengers, which lends the content clinical credibility it wouldn't have from a general public account.

Practical guidance for replicating a "challenge" format

- Anchor it to something personal and low-stakes (a birthday, a personal commitment, a simple visual or written prompt) rather than a heavy institutional ask — participation should feel easy and social.
- Target a specific, reachable seed audience first (health professionals and medical students, in this case) rather than the general public — credibility spreads outward from a credible core group more effectively than the reverse.
- Pair every challenge post with one accurate, shareable fact — the format is the hook; the fact is the payload

Track 2: Local-language public content

Technical/English-language material serves policy and donor audiences; separate, simplified local-language content is needed for public-facing awareness, particularly in the communities where exposure risk is highest. Keep these as genuinely distinct content tracks rather than translating one into the other — the framing, tone, and even the core message often need to differ.

Track 3: Healthcare influencer partnerships

Identifying and briefing healthcare professionals with existing public followings extends reach into audiences a formal NGO account cannot access on its own, while keeping the underlying content medically accurate — the briefing step matters, since influencer content only works for the movement if it doesn't require later correction.

Track 4: Earned media coverage

Owned channels (a CSO's own social accounts, briefs, and websites) only reach audiences already paying attention. Earned media coverage secured in independent outlets extends reach into audiences who would never encounter FGS content otherwise, and carries a credibility that self-published content cannot match on its own. FGS coverage in The Citizen and Daily News reached general newspaper readerships beyond the SRH and NTD sectors, while a Swahili-language interview on TBC Taifa reached an audience entirely outside English-language policy and donor circles — arguably the most accessible piece for locals. Pitching a story to local media costs little beyond preparation time, and a credible spokesperson, but the audience it unlocks is difficult to reach any other way.

- Prepare a short, plain-language pitch and one or two spokespeople who can speak accessibly, not only technically, about the issue.
- Prioritize at least one local-language outlet alongside English-language ones — the reach difference can be substantial, as with the TBC Taifa interview.
- Treat earned media coverage as citable evidence of traction, the same way a published brief or training reach is used elsewhere in this guide (see Section 3, Section 13).

Track 5: Leveraging social media trends

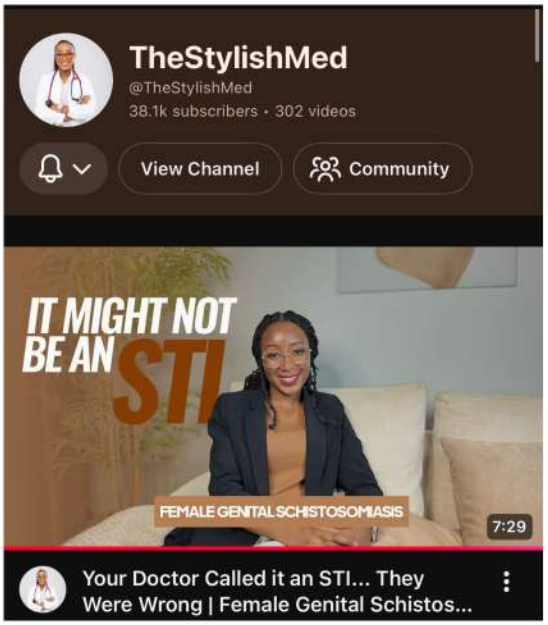
To capture attention entirely outside traditional public health circles, partners can deploy a high-impact strategy that aligns health communication with real-time cultural moments, ongoing digital trends, and high-visibility public events. This track translates intricate epidemiological data into the immediate conversational landscape of the public; allowing programs to hijack existing momentum and massive digital traffic though three core adaptive pillars:

- ***Trend & Meme Hijacking:*** Monitoring digital trends, viral challenges, and memes to rapidly wrap public health facts inside formats that are already capturing attention.
- ***Metaphorical Translation:*** Mapping FGS dynamics directly onto the rules, terminology, or visual layout of the chosen event to lower the technical barrier for non-medical audiences.
- ***Disruptive Themed Aesthetics:*** Reformatting static clinical advice into the visual style, graphics, and emotional tension of the surrounding event, prompting interaction from younger, non-medical demographics who traditionally bypass routine public health announcements

CREATIVE ADVOCACY

#FGSchallenge

Local Language Content



Influencer Partnership

Media Coverage

Implementation Case Example: The World Cup Strategy

During our implementation, the global World Cup tournament was underway—creating a digital landscape dominated by global trends, live-match memes, and intense public focus. The campaign integrated directly into the trends by framing FGS content using football analogies:

The ***"Referee" Analogy for Health Workers:*** Primary healthcare workers were framed as referees on the pitch who must "make the right call" on accurate FGS screening before permanent complications occur.

By Leveraging Shared Momentum: Inserting evidence-based health messaging directly into the timelines of broad public celebrations, seasonal gatherings, or global tournaments where audiences are already actively looking to engage, comment, and share

Practical Guide for Partner Adoption:

1. **Establish a Trend-Watch System:** Assign communication leads to monitor national/global event calendars (e.g., music festivals, sport tournaments, holiday trends) and viral social media audio or meme formats. CAUTION: be careful to choose the trends that do not compromise ethics of health communication or promote dangerous behavior
2. **Build a Metaphor Matrix:** Brainstorm how your core health messages can be analogized to the chosen event (e.g., mapping FGS diagnostic barriers onto a concert's "gatekeeping" or a holiday's "traditions").
3. **Execute Rapid-Response Content:** Design quick-turnaround templates that mirror the event's visual branding, ensuring you launch content exactly while public engagement is at its peak.

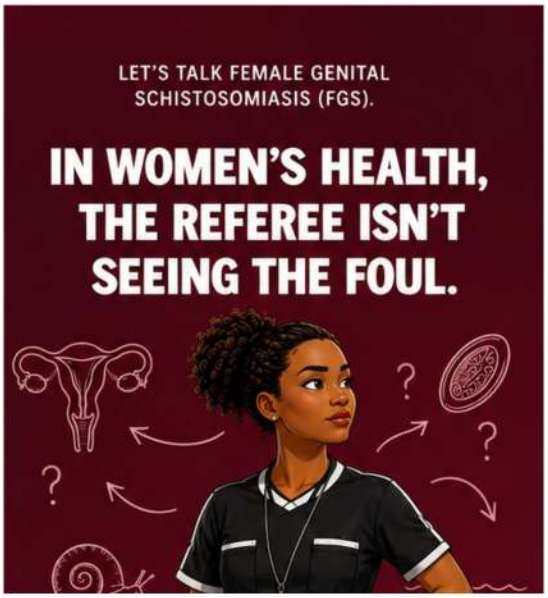
Adapt This

What personal, low-stakes moment could anchor a challenge for your issue? You don't need a birthday or this exact format — seed it with a small credible group before opening it to the public, and pair every post with one accurate fact.

Have you decided your own three content tracks? What serves policy/donor audiences, what serves the general public in local language, and who your credible messenger partners could be.

What global tournament, viral meme, or trends is currently capturing your target audience's attention, and how can you map your advocacy messaging onto its rules, trends, or roles to hijack that momentum?

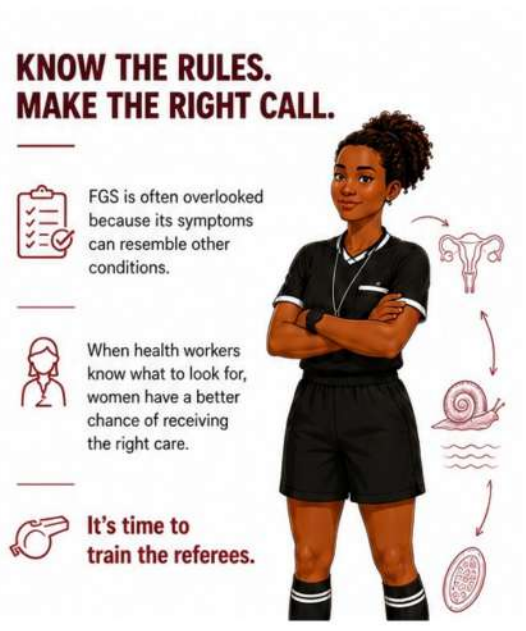
CASE EXAMPLE: WORLD CUP



The Gap

The WHY?

The EVIDENCE



The WAY FORWARD

SECTION 11

DISABILITY INCLUSION AND ACCESSIBILITY

Content strategies that reach a wide public audience can still exclude people with disabilities by default if accessibility is not designed in deliberately. This is a distinct content track from the four described in Section 10, not a variation on one of them.

Sign language content as a case example

A partnership with a sign language interpreter was established to prepare FGS content in sign language, making core information accessible to Deaf and hard-of-hearing audiences directly, in their primary language, rather than through subtitles alone. This distinction matters for a topic like FGS: sign language is often the first language of Deaf individuals, and subtitle-only content requires literacy in a second, written language to access sensitive health information — an extra barrier on a topic where privacy and comprehension both matter.

Why this matters specifically for a stigma-sensitive SRH topic

General accessibility guidance often stops at "add captions." For a condition carrying the stigma risks described in Section 3, accessibility has an added dimension: dignity and independence. A Deaf woman or girl who can access FGS information directly, in sign language, does not need to rely on a hearing family member to translate a sensitive reproductive health topic on her behalf — which matters both for privacy and for the same guardian-response risks described in Section 3.

How the partnership was approached

- Accessibility expertise was brought in as a partnership rather than attempted in-house — a qualified sign language interpreter, rather than a general content team improvising translation.
- Core factual content (what FGS is, how it relates to water contact, that it is not sexually transmitted, where to seek screening) was prioritized for sign language translation first, rather than every piece of content produced.
- Sign language content was treated as a distinct production, not a subtitle track layered onto existing video — reflecting that sign language and the spoken/written language it accompanies are different languages with different grammar, not a direct word-for-word mapping.

Extending beyond sign language

Sign language interpretation addresses one specific accessibility need. Other considerations worth deliberate attention include plain-language versions of technical content for audiences with intellectual or learning disabilities, screen-reader-compatible digital materials for people who are blind or have low vision, and physical accessibility of any in-person community engagement venues. Not every CSO will be able to address all of these at once — the sign language partnership here is offered as a model for how to start with one accessibility gap, done well and in partnership with the relevant expertise, rather than attempting a comprehensive accessibility overhaul immediately.

Adapt This

Which disability communities are least able to access your current content, and what is the single highest-impact accessibility gap to address first?

Do you have a partnership with relevant disability-specific expertise (a sign language interpreter, a disability-led organization) for that gap, rather than attempting it without that expertise in-house?

SECTION 12

RISK ASSESSMENT

Advocacy for a stigmatized, poorly understood condition carries risks that go beyond the usual advocacy concerns of funding or political attention. Some of the risks can affect the populations being advocated for directly, not only the organization doing the advocacy. A short, honest risk assessment, revisited periodically rather than done once, is a necessary companion to the methods described in this guide

A simple risk register

A lightweight, living document is more useful than an exhaustive one-time risk assessment. At minimum, track:

Risk ID	Risk	Risk Category	Who/What it could affect	Likelihood	Impact	Risk Grade	Mitigation already in this guide
R1	Public awareness activities launched before stigma-mitigation messaging is established	Population protection / safeguarding	Women, girls, families, and community relationships	Medium	High	High	Sequence awareness campaigns alongside stigma-mitigation messaging, particularly targeting men, husbands, guardians, and community gatekeepers (Section 3).
R2	Awareness activities conducted where screening, referral, or treatment pathways are unavailable	Service access / health system trust	Community members, affected women and girls, CSO credibility, health system trust	Medium	High	High	Link awareness activities to functioning referral pathways and confirm service availability before demand-generation activities (Sections 5 and 9).
R3	Use of personal stories, testimonials, or images without adequate consent or protection of identity	Safeguarding / ethical risk	Women and girls affected by FGS, families, communities	Low–Medium	High	High	Obtain informed and ongoing consent; avoid identifiable information; apply safeguarding principles when documenting lived experiences.

Risk ID	Risk	Risk Category	Who/What it could affect	Likelihood	Impact	Risk Grade	Mitigation already in this guide
R4	Limited precedent for FGS advocacy results in unintended consequences or reputational challenges	Organizational / first-mover risk	CSO credibility and broader FGS advocacy efforts	Medium	Medium–High	High	Document lessons, use evidence-based approaches, seek technical review, and distinguish individual activities from the broader FGS agenda.
R5	Pursuing too many advocacy platforms or events without sufficient capacity to deliver quality engagement	Organizational capacity risk	CSO credibility, partner confidence, advocacy effectiveness	Medium	Medium	Medium	Prioritize strategic platforms where the organization can demonstrate consistent engagement and follow-through rather than maximizing activity volume (Sections 3 and 6).
R6	Regional or global evidence presented as local prevalence estimates without adequate qualification	Evidence credibility risk	Technical stakeholders, policymakers, professional audiences	Medium	Medium–High	High	Clearly distinguish global/regional evidence from local data; apply evidence communication guardrails and acknowledge data limitations (Section 2).
R7	Changes in government leadership, health priorities, or donor interests reduce political attention to FGS	External environment / political risk	Advocacy momentum, policy engagement, programme sustainability	Medium	High	High	Regularly reassess political-will mapping and adapt advocacy strategies as stakeholder priorities change (Section 4).
R8	Dependence on a single government champion or institutional contact	Relationship / sustainability risk	MoH engagement, institutional partnerships, advocacy continuity	Medium	High	High	Build relationships across multiple Ministry departments, technical units, professional bodies, and stakeholder groups rather than relying on one individual (Section 7).
R9	Coalition loses momentum after a specific campaign or advocacy event	Partnership / coalition risk	Coalition effectiveness, collective advocacy efforts	Medium	Medium	Medium	Define ongoing partner roles, maintain communication structures, and establish shared priorities beyond individual campaigns (Section 6).

Adapt This

Which of these risks are most live for your organization right now, and which mitigation from this guide already addresses it? Write this down as a short, dated document, not a one-time exercise.

Who reviews and updates this risk register, and how often? A risk register nobody revisits is not meaningfully different from having none.

SECTION 13

MONITORING, EVALUATION, AND LEARNING

Advocacy is not a linear process, and its results are not always immediately visible. A simple monitoring, evaluation, and learning (MEL) approach that is tied directly to the staged-ask model in Section 4; helps distinguish activity from actual progress, and gives funders and partners evidence that advocacy is producing results, not just events.

Three levels of indicator

- **Output indicators:** what was done including trainings held, briefs published, platforms engaged, participants reached. These are the easiest to count and the least persuasive on their own.
- **Outcome indicators:** what changed as a result Institutional recommendation adopted, Curriculum revised to include FGS, Coalition members independently using common advocacy messages, Health workers routinely screening for FGS after training, Facilities integrating FGS into SRH services
- **Impact indicators:** The longer-term health and societal changes to which the intervention contributes, such as reduced FGS prevalence, improved quality of life for women and girls, or reduced HIV vulnerability associated with FGS. These indicators are often influenced by multiple factors and usually require routine surveillance or population-level data to measure reliably.

Indicators mapped to the staged-ask model

Stage (Section 4)	Example output indicators	Example outcome indicators
Stage 1: Awareness and case-building	Platforms engaged; Media products disseminated ; co-design session held	Stakeholders citing FGS unprompted; framing adopted in others' materials
Stage 2: Evidence and coalition-building	Brief published; coalition meetings convened	Brief cited by others; coalition partners advocating independently
Stage 3: Institutional entry points	Institutional asks submitted (e.g., curriculum updates, referral pathways, clinical checklists)	Asks granted; pilots or trainings adopted by the institution
Stage 4: Policy and systems integration	Policy asks submitted; meetings with MoH departments	FGS integrated into institutional training or pilot programmes

Wherever possible, pair an output indicator measuring advocacy or awareness activities with an outcome indicator measuring whether those activities contributed to changes in knowledge, access, behavior, or institutional practice. For example, track the number of people reached through an awareness activity alongside referral completion rates at the nearest facility.

Tracking awareness activities without assessing whether they translated into improved access, service uptake, or other meaningful changes is one of the most common MEL gaps in advocacy work generally, not only in FGS advocacy.

A simple MEL cycle

- Set two or three indicators per stage before an activity begins, not after.
- Review progress on a fixed schedule (e.g. quarterly) with the coalition, not only internally.
- Feed findings back into the staged-ask plan explicitly — a stalled Stage 3 ask may mean returning to Stage 2 coalition-building rather than pushing harder on the same ask.
- Document both what worked and what did not; a negative or stalled result is still useful data for the next activity and for other CSOs adapting this guide.

Adapt This

What are your two or three indicators for the stage you are currently working in? If you cannot name them, that is a sign to define them before the next activity, not after.

Is there at least one outcome indicator linked to every awareness output you track? Counting activities, audiences reached, or materials produced alone will not show whether knowledge, behavior, institutional practice, or service access changed.

SECTION 14

TOOLKIT

A. Co-design session facilitation guide

- Pre-session: define the single research question; identify 15–25 participants split between lived-experience/youth advocates and SRH technical advocates; prepare 3–4 guiding discussion prompts organized around barriers, not solutions.
- During session: barriers discussion (45–60 min) → recommendations discussion (45–60 min) → closing reflections/quotable statements (15 min).
- Post-session: draft brief within 2–3 weeks while momentum and quotes are fresh; circulate to named contributors for review before publishing; publish with full contributor list and a named contact person.

B. Advocacy brief template (structure)

- Title and framing tagline
- Context and purpose of the brief (why this session, who convened it)
- Background and burden data (with sources)
- Conceptual framing (e.g., One Health / gender-responsive lens)
- What participants identified (barriers, organized thematically)
- Policy recommendations (specific, institution-addressed)
- Conclusion with a quotable closing statement
- Contributors and contact information

C. Conference / platform “insertion” checklist

- What is this platform's stated theme, and what is the most credible one-sentence bridge to your issue?
- Who is the platform's convening institution, and what is their existing relationship (if any) to your sector?
- What is the single ask or message you want carried out of the room — not five asks, one?
- Is there a named individual from the host institution you can secure a quote or public statement from?

D. Ministry of Health stakeholder-mapping worksheet

- Disease/technical programme: who is the responsible officer, and what are their current priorities and targets?
- Health promotion section: who controls public messaging and IEC materials relevant to your issue?

- Community / RCH / service delivery structures: who would need to co-design the actual point-of-care model?
- Relevant professional bodies: which associations or councils set treatment guidelines, curricula, or CPD requirements for the cadre you need to reach?
- For each, note: current level of engagement, one small design-stage role they could play, and one implementation-stage role they could play.

E. Commemoration-day content calendar

Build using the Section 9 table; assign production leads and deadlines at least three weeks before each date.

F. Digital-challenge relaunch format

- Choose a personal, low-stakes anchor moment.
- Draft one accompanying factual message (under 280 characters) per post.
- Seed with a small credible group (health workers, students) before opening to general public participation.
- Track simple metrics: number of participants, reach, and any resulting media pickup.

G. Influencer briefing template

- One-page fact sheet (burden, symptoms, treatment, integration ask)
- 2–3 pre-approved key messages
- Do/don't list for medical accuracy (e.g., avoid conflating with STIs without context)
- Contact for fact-checking before publication

SECTION 15

ADAPTING THIS MODEL FOR OTHER CSOs AND COUNTRIES

Beyond FGS: applying this to other neglected diseases

This guide is written from FGS experience, but the underlying problem — a real, treatable, burdensome condition that remains invisible to health workers, policymakers, and communities — is common to most neglected tropical diseases and many other under-recognized health conditions. A CSO working on a different neglected disease can use this entire guide as a template: define your own staged ask and stakeholder framing table (Section 4), build your case despite limited local research (Section 2), advocate with limited resources (Section 3), map your own Ministry of Health structure and professional bodies (Section 8), and build your own platform, calendar, and content strategies (Sections 6, 9, 10).

What's Tanzania-specific

- The Mwele Malecela Days of Action (Mwele-DOA) programme, implemented by One Health Society, was the pioneer initiative in Tanzania to work systematically on FGS, and the activities described throughout this guide are drawn from it. The programme is named in honour of Dr. Mwele Ntuli Malecela, the Tanzanian scientist and former WHO Director of the Department of Control of Neglected Tropical Diseases, whose career was devoted to elevating neglected diseases onto national and global agendas. Other CSOs could look for their own local scientific or health leadership legacy to anchor a similar programme identity.
- Specific burden figures (115 endemic district councils) and specific institutional partners (TAMSA) are local; the categories of partner (medical student associations, regional health communities such as ECSA-HC) are transferable to most East and Southern African contexts.

What's directly transferable

- Making the case despite limited local research and statistics (Section 2)
- Advocating and building groundwork despite limited resources (Section 3)
- Defining a staged ask and a stakeholder framing table before launching any activity (Section 4)
- The co-design-to-brief method (Section 5)
- The platform-stacking sequence: workforce → global/technical → regional/youth → policy (Section 6)
- Attending to who represents, leads, and is credited for the advocacy itself, not only who it is designed to reach (Section 7)

- Mapping and engaging government across departments and professional bodies, from design through implementation (Section 8)
- The commemoration-calendar approach (Section 9)
- The five-track content strategy and peer-challenge format and trend hijacking (Section 10)
- Partnering with disability-specific expertise to close one accessibility gap at a time (Section 11)
- A risk register anticipating harm to the population being advocated for, not only organizational risk (Section 12)
- A staged-ask-linked monitoring, evaluation, and learning approach (Section 13)

A note on sustainability

Every method in this guide is oriented toward the same outcome: durable ownership by the systems and institutions that will ultimately have to sustain integration long after any single CSO's project funding ends. Co-designed briefs, government co-panelists, professional body engagement, and curriculum-level asks all share this logic — they embed the work in institutions built to outlast a project cycle, rather than leaving it dependent on continued NGO presence.

Minimum viable version for a resource-constrained CSO

If you cannot resource a full programme immediately, start with:

1. Writing your one-sentence ask, staged plan, and a first map of who in the Ministry of Health you need at the table (Sections 4 and 8).
2. Building your early case on the best available regional evidence while naming your local data gap as an ask in itself (Section 2).
3. One low-cost co-design session with 10–15 participants producing a 2-page brief (Section 5).
4. Mapping your issue onto your national NTD Day and one other existing SRH/HIV commemoration (Section 9).
5. One peer-driven digital challenge seeded with health workers or students you already have relationships with (Section 10).

This sequence alone builds the foundation — a clear ask, a credible case even without local statistics, government-connected legitimacy, a citable evidence artifact, a public visibility moment, and a credible messenger network — that everything else in this guide, and the resources it eventually attracts, builds on.

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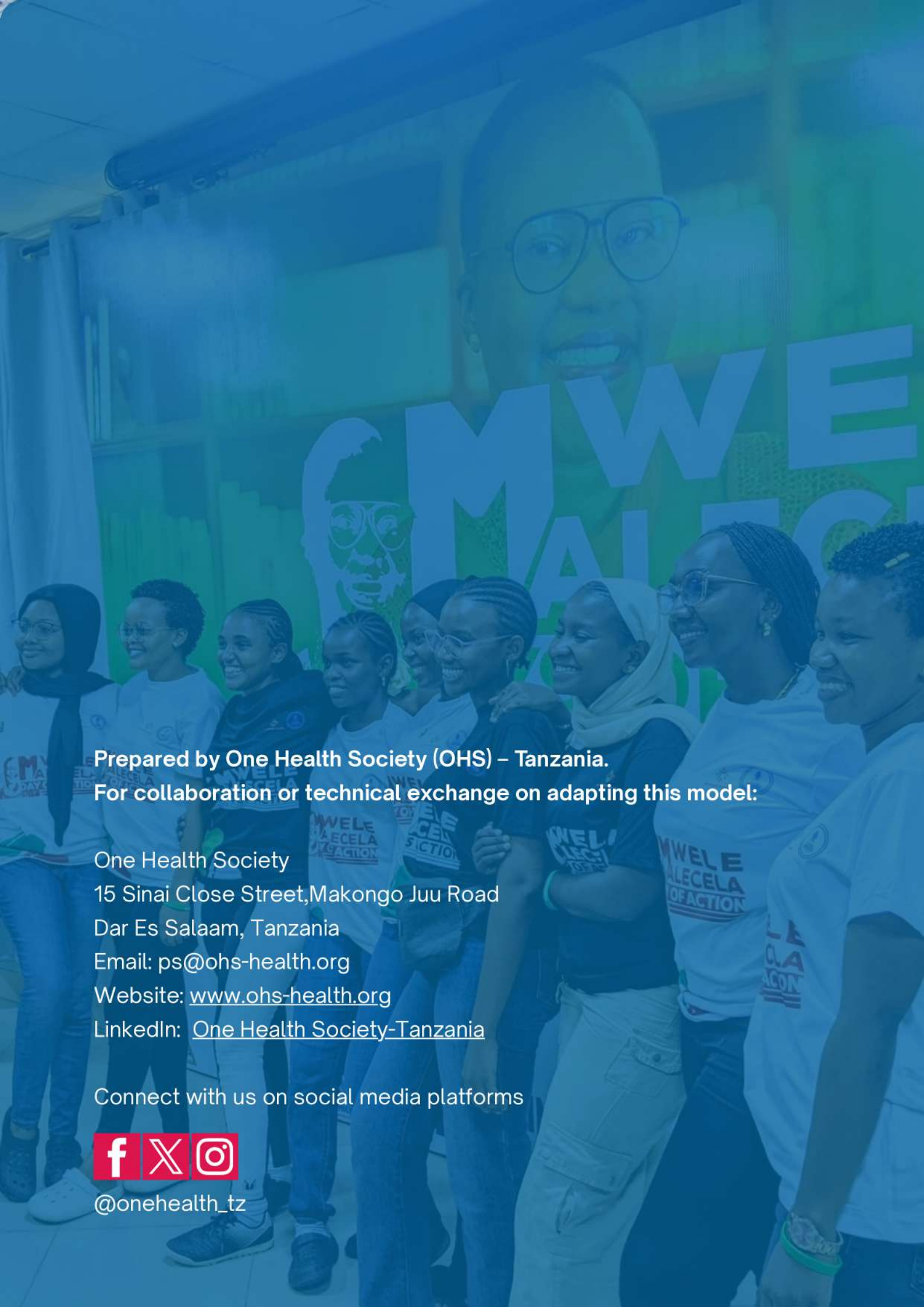

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