

NEWSLETTER

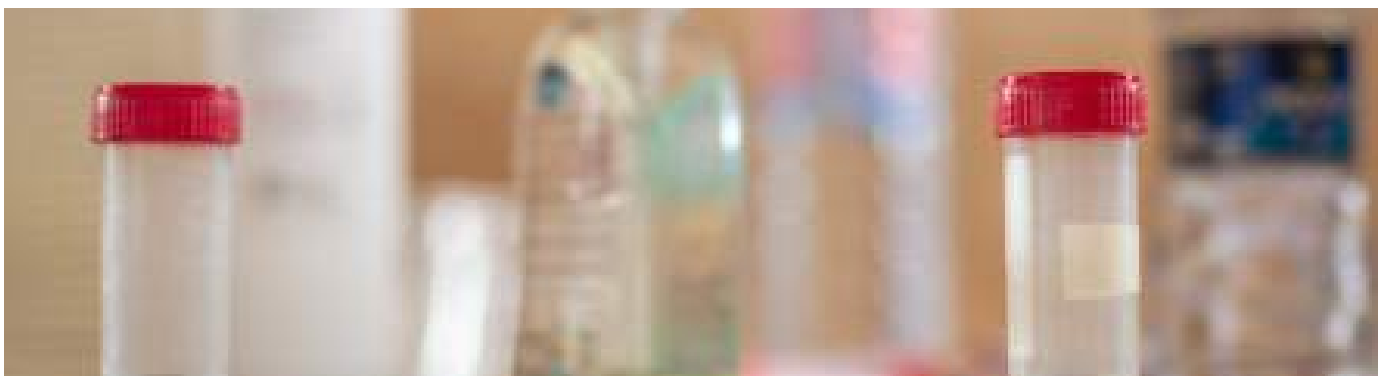


I Did Not Think I Had the Right to Speak It Aloud" — Women Break the Silence on FGS

For the first time in her life, a 56-year-old Auntie Afua, from Pataase- Tsetsekaasum a community along the Kakum River described symptoms she had hidden for nearly a decade: blood in her urine, pelvic pain, discomfort during intimacy. She believed the illness would eventually take her life, and that she would die without ever speaking its name.

Her story surfaced during a community conversation facilitated by the BCRC schistosomiasis project, where researchers described the symptoms of female genital schistosomiasis (FGS) in language that resonated with women's lived experiences. "When they described those things, I started crying. Not because I was sad—because someone finally saw me," she said.

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I Did Not Think I Had the Right to Speak It Aloud" — Women Break the Silence on FGS



FGS remains one of the most underdiagnosed manifestations of schistosomiasis. Globally, an estimated 20 to 56 million women and girls in Africa may be living with the condition, yet symptoms are routinely mistaken for sexually transmitted infections or other gynaecological disorders. In Ghana, where schistosomiasis is endemic across large rural areas, the silence is compounded by stigma that reads vaginal bleeding as moral failure. "If you say you are bleeding, they look at you as if you have done something wrong," Afua explained. "So I kept it inside. I waited for it to finish me."

The stigma around symptoms that suggest sexual activity or promiscuity ensures that disclosure is dangerous. Young girls internalise shame before they have language for what they feel. The burden, then, is not merely parasitic but structural, gendered, and perpetuated by health systems that seldom ask the right questions.

Expert say, women are treated for ailments they do not have, repeatedly, while parasitic eggs lodged in the reproductive tract sustain a quiet, chronic inflammation that erodes tissue, fertility, and hope.

Researchers at the BCRC said they are responding with a deliberate strategy: community screenings led by trained nurses, colposcopy referrals where clinically indicated, and facilitated spaces where women can share experiences without judgment. The director of the centre Prof. Samuel Kyei frames it as a methodological shift: "We are not just looking for the parasite. We are learning to listen to the women who have lived with its consequences."

The project lead, Prof. Akwasi Anyanful, says this is only the beginning. As more women come forward, their narratives will feed directly into surveillance tools, clinical training materials, and community engagement strategies—ensuring that the next woman who sees blood does not think she is already dead.

Praziquantel, the drug used in mass treatment campaigns, kills the adult worm but cannot reverse years of undiagnosed genital damage, nor can it erase the psychosocial scars of having suffered in silence. Dr. Mustapha Amodu, the public health expert on the project, says: "The psychosocial scars of enduring this for all these years, in addition to the genital scars, will remain." What finally broke Afua's silence was not a diagnostic tool but a different kind of intervention: researchers who arrived in her community not only with ultrasound probes but with the intention to listen.

Play as Prevention — The Oware Game That Teaches Children to Outsmart a Parasite

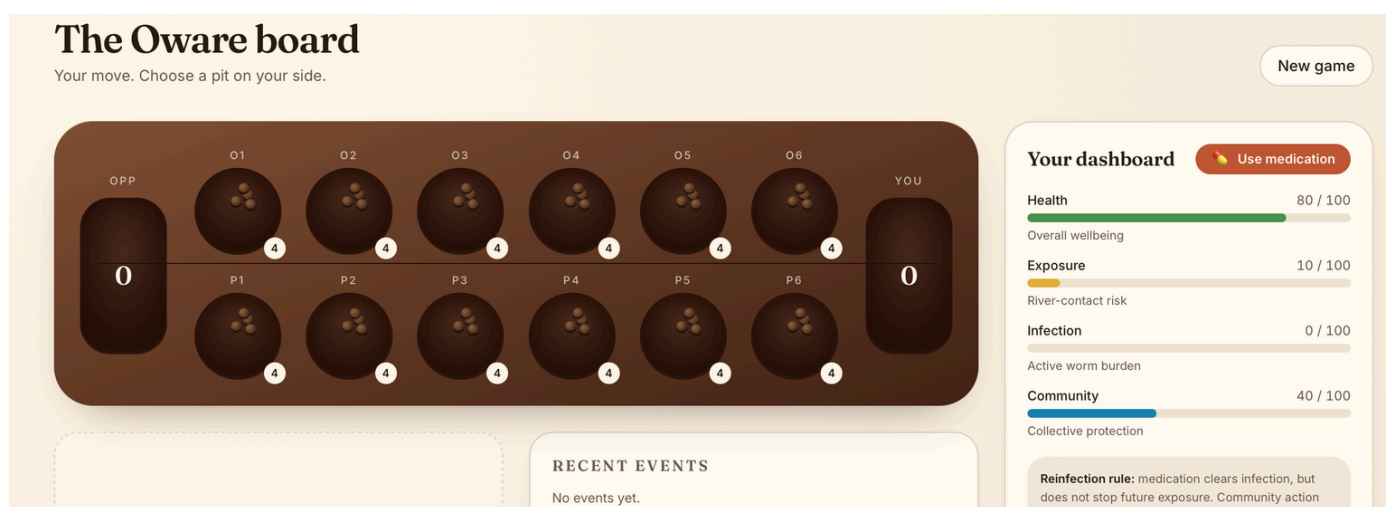
In the fight against schistosomiasis along the Kakum River, the project is betting on a familiar ally: play.

The Oware Avoid Re-Infection Game, inspired by the traditional Ghanaian strategy board game, transforms the schistosome lifecycle into an interactive learning experience. Players navigate transmission stages, confront exposure scenarios, and deploy a limited "super card" representing medication—forcing them to think critically about prevention rather than relying solely on treatment. The game is currently undergoing refinement, but early engagements in schools and community settings suggest it resonates. Children who might tune out a health lecture lean into the strategy, debating moves and learning transmission pathways in the process. Teachers report that the game opens conversations that traditional posters cannot.

"Meaningful learning often happens through participation rather than instruction," says Dr. Kwame Kumi-Asare, co-project lead. "Oware is already part of Ghanaian childhood. We are embedding scientific concepts within a familiar cultural framework, so the learning feels like belonging, not instruction."

The game is part of a broader suite of engagement tools, including Photovoice, Science Cafés, and participatory river mapping. Together, they represent a strategic departure from awareness campaigns that simply tell children to stay out of the river—a directive that collides with the developmental necessity of play.

The project's position is clear: children should not have to choose between health and childhood. The Oware game is one way of ensuring they don't have to.





Communities Map the River's Secrets — Participatory Mapping Reveals Hidden Transmission Hotspots

Conventional maps mark rivers, roads, and settlements. The maps emerging from the BCRC schistosomiasis project mark something different: the places where children swim, where farmers cross, where women collect water at dawn, and where stagnant pools create ideal snail habitat.

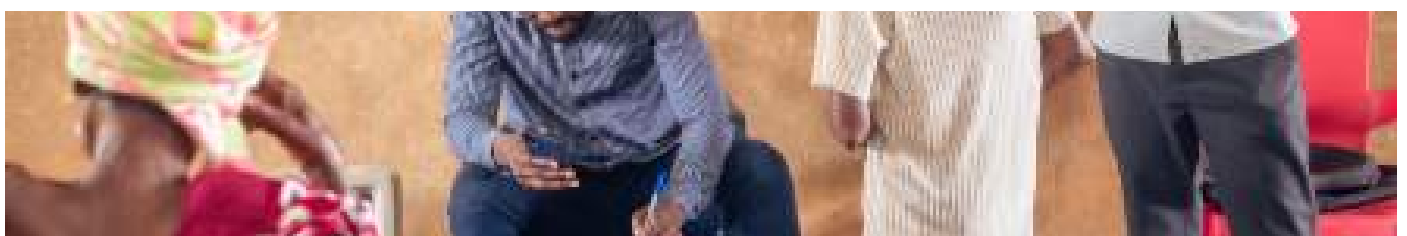
This is participatory river mapping—a method that positions community members as co-cartographers of their own disease risk. During facilitated sessions along the Kakum River, residents identified locations that formal surveys had missed: a shaded eddy where snail density spikes, a crossing used by farmers that matters more than the busy bank nearby, a water collection point used at dawn when alternative sources are inaccessible.

"We are layering community-generated spatial intelligence onto epidemiological data," explains Mustapha Amodu, public health and data manager. "The result is a sharper picture of transmission than either dataset could produce alone."

The maps are already informing intervention design. They identify priority locations for environmental modification, safer play zones for children, and alternative water access points at high-exposure crossings. Crucially, the process itself builds ownership. When communities map their own risk, they are more likely to act on the results.

Dr. Julia Quaiocoe, a geomorphologist, at the University of Cape Coast notes that the maps also capture environmental degradation—deforestation, sand mining, agricultural run-off—that creates the stagnant water where snails thrive. "The river is a living system," she says. "These maps help us see where human activity and ecological disruption converge to create disease risk."

The next phase will integrate these maps into a digital StoryMap platform, creating a visual, community-authored narrative of the Kakum River's health.



Building a legacy that outlasts the research

Sustainability Through Community Stewardship — 75 Volunteers Trained to Carry the Mission Forward



The long-term success of any public health intervention depends not on the permanence of the research team but on the capacity of the community to own and sustain the gains achieved. This principle is now being operationalised along the Kakum River through a deliberate succession strategy: the recruitment and training of 75 community volunteers across the five project communities who will assume responsibility for schistosomiasis surveillance, education, and advocacy after the project's formal lifespan. These volunteers are not randomly selected participants.

They are individuals already embedded in the structures of community authority and influence—pastors, chiefs, elders, imams, women's group leaders, such as market queens, youth leaders, assembly men and women, teachers—figures who command both respect and have the practical capacity to mobilise action. By anchoring the volunteer corps in existing leadership structures, the project ensures that health messaging does not arrive as an external directive but is reinforced through channels communities already trust.

"These are the people who open conversations when no researcher is present," explains Prof. Samuel Kyei, BCRC Director. "They are the ones who will notice when a child is missing school due to repeated infection, when a woman is too ashamed to seek care, when snail habitats are expanding near a new crossing. Our role is to equip them, then step back."

The training curriculum goes beyond basic health education. Volunteers are being prepared to serve as community watchdogs: monitoring water-contact sites, identifying emerging environmental risks, documenting suspected cases, and liaising directly with the research team and health authorities for follow-up. This creates a durable feedback loop that outlives any single funding cycle. Community-generated intelligence will continue to flow, and researchers will maintain a responsive channel for advice and support.

The selection of multiple leader categories—religious, traditional, gendered, and youth-focused—reflects a strategic understanding that influence in these communities is not monolithic. An imam reaches constituencies a women's group leader cannot; a youth leader commands attention where a chief may not. Together, they form a networked architecture of accountability.

Sustainability, the project insists, is not an afterthought. It is the endpoint. The 75 volunteers represent the first generation of what the team envisions as a permanent community health infrastructure—locally led, culturally embedded, and scientifically connected. The parasite persists where silence and fragmentation allow it to. These volunteers are the counterforce: organised, informed, and enduring.

The project's legacy will not be measured by what the researchers achieve while present, but by what the community sustains after they leave.