



Our River. Our Health. Our Future.

Inside Ghana's Kakum River basin, a science team and a community are reshaping how the world understands Female Genital Schistosomiasis — and what it means to heal together.

The River That Sustains Life... and Sustains a Hidden Disease

For generations, the Kakum River has functioned as the economic and social artery of Ghana's Central Region. It irrigates farmlands, enables connectivity, sustains livelihoods, and anchors childhood. Daily, children swim its currents, farmers traverse it to access fields, and women depend on it for domestic survival.

Yet beneath the surface operates an invisible adversary: schistosomiasis—a neglected tropical disease proliferating precisely where human life and freshwater intersect. The challenge transcends biology; it is structurally embedded in the social, cultural, and environmental systems that govern riverine existence.

This magazine documents a strategic departure from conventional control efforts. The Biomedical and Clinical Research Centre (BCRC), University of Cape Coast, is forging an integrated science-engagement-community partnership model that interrogates not only the parasite but the interconnected human, spatial, and systemic drivers of transmission. Lasting solutions are engineered at the intersection of rigorous evidence and lived reality.

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PARTNERS AND ACKNOWLEDGEMENTS



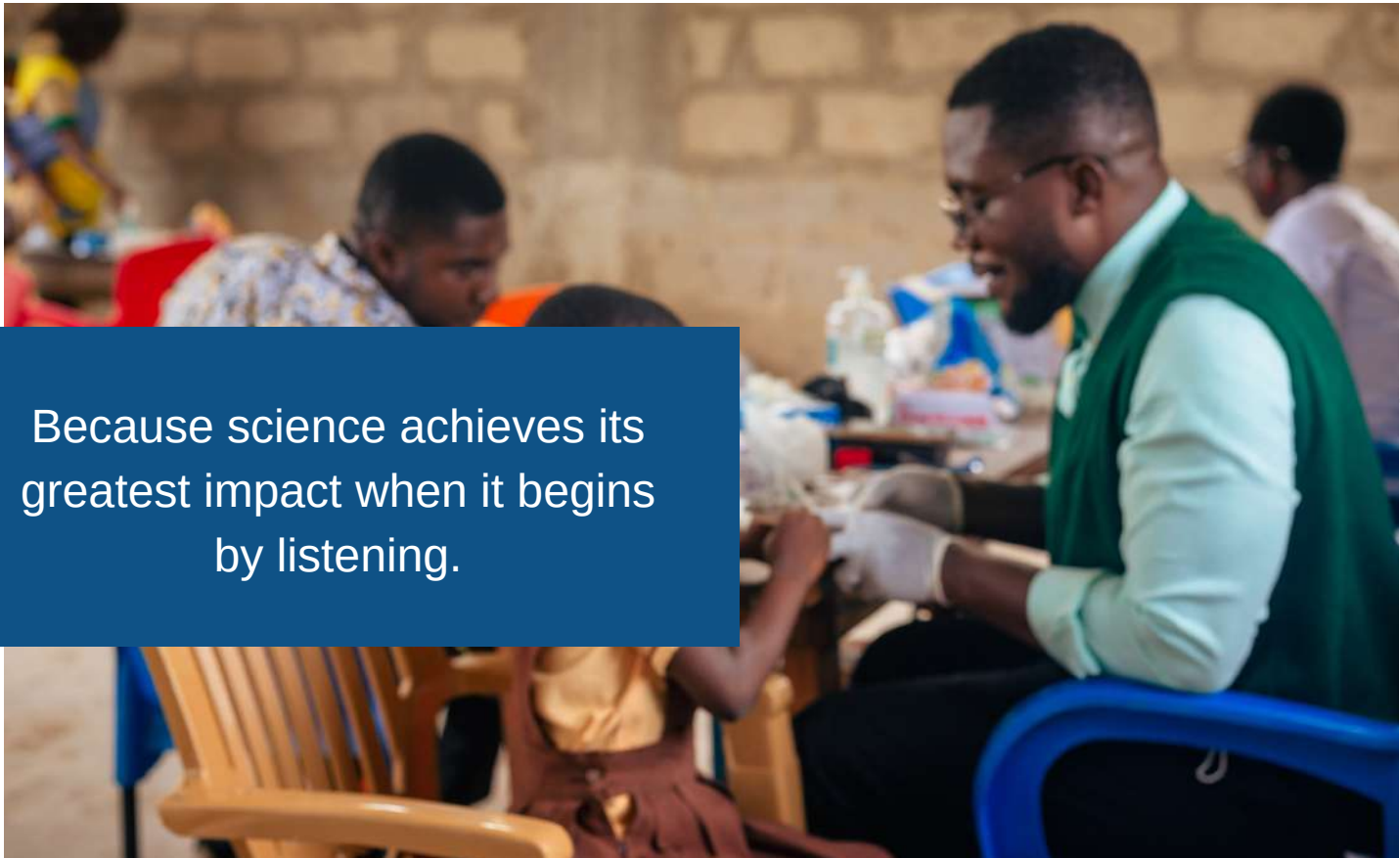
FOREWORD

Prof. Samuel Kyei, Director BCRC

SCIENCE BEGINS WITH LISTENING

Every river tells a story. Some have witnessed the rise of kingdoms. Others have carried commerce across continents. The Kakum River carries something equally profound. It carries the stories of communities whose lives are inseparable from its waters. For decades, efforts to eliminate neglected tropical diseases have focused largely on diagnosis, treatment and health education. These remain essential, but they are only part of the solution. The question we asked was different: What if communities were not simply recipients of scientific knowledge, but partners in creating it? At the BCRC, we recognised that the people living along the Kakum possess a sophisticated understanding of water-contact patterns, seasonal risks, and the subtle symptoms of female genital schistosomiasis—knowledge that rarely enters the epidemiological record.

We asked how local ecological knowledge, cultural narratives, and gendered experiences of disease could reshape the very questions we pursue and the interventions we design. Our approach brought anthropologists, parasitologists, Strategic Science Communicators, Research Scientists, Health promotion experts, Focused groups, Opinion leaders and Community health workers into a shared space of inquiry, moving beyond extractive research toward co-creation. Through participatory mapping, storytelling, and joint analysis of transmission hotspots, we built a framework where scientific rigour and community insight are not in tension but in synergy. In doing so, we confronted the silence surrounding female genital schistosomiasis, a neglected condition compounded by stigma and misdiagnosis. By centering women's voices, we transformed clinical suspicion into community-led surveillance. The result is a dialogue—a reminder that rivers, like science, flow in two directions. This shift from extraction to co-creation redefines what counts as evidence. This publication documents that journey. It explores how science, culture, ecology and community knowledge can come together to build more inclusive and sustainable responses to schistosomiasis. Welcome to a project where communication is not an afterthought—it is part of the intervention itself, woven into every stage.



Because science achieves its greatest impact when it begins by listening.

FEATURE ARTICLE

Beyond Awareness Why Public Engagement is Transforming Schistosomiasis Research

"The greatest barrier to disease elimination is not always the parasite. Sometimes it is the distance between science and the people it seeks to serve."

For decades, schistosomiasis interventions followed a predictable script: disseminate information, distribute posters, encourage behaviour change, collect data, depart. These efforts have saved lives, yet endemic persistence demands a more unsettling inquiry. The critical question is no longer whether communities are aware, but why transmission endures despite years of awareness campaigns. For the BCRC project along the Kakum River, that question became the departure point. The answer lies not in refining messages but in reimagining the fundamental relationship between science and society. Meaningful impact requires moving decisively beyond didactic awareness toward genuine public engagement—where communities co-own the research, and knowledge flows bidirectionally. This is not a communications tactic; it is a methodological imperative. As the project's guiding principle articulates: "The greatest barrier to disease elimination is not always the parasite. Sometimes it is the distance between science and the people it seeks to serve." Closing that distance is the core intervention



Rather than asking, "How do we tell communities about schistosomiasis?", the project asked a more fundamental question: "How do communities experience the river, and what can science learn from those experiences?"

THAT SHIFTCHANGES EVERYTHING.

FROM INFORMING COMMUNITIES TO LEARNING WITH THEM

During the project's early community visits, researchers engaged chiefs, elders, schoolchildren, opinion leaders and community members through traditional durbars and discussions before administering the first round of treatment. The visits achieved more than introducing the project. They revealed realities that could never have emerged from laboratory data alone.

Researchers observed children swimming in the river after school, families crossing the water daily to reach farms and neighbouring settlements, and households depending on the river despite understanding some of the associated health risks. Sanitation conditions around sections of the riverbank were more challenging than anticipated, creating environments that could sustain disease transmission. Conversations also uncovered local beliefs surrounding blood in urine among boys, with some community members describing it as a natural sign of puberty rather than a possible symptom of schistosomiasis.

None of these insights could be fully understood through epidemiological surveys alone.

They required listening.

A Different Philosophy of Engagement

Historically, many health communication programmes have operated within what scholars describe as the deficit model—the assumption that public health challenges persist because communities lack knowledge.

The solution is therefore to provide more information. While information remains essential, experience has shown that knowledge alone rarely changes behaviour when people's daily realities remain unchanged.

For families living along the Kakum River, avoiding the river is rarely a realistic option. The river provides water for domestic activities, connects farms with homes, links neighbouring communities and serves as an important recreational space for children. Behaviour is therefore shaped not simply by awareness but by livelihoods, geography, infrastructure and culture. Recognising this complexity, the BCRC project adopted a public engagement approach that moves beyond information dissemination towards dialogue, participation and co-creation. Instead of asking communities to fit scientific recommendations into their lives, researchers began exploring how scientific interventions could be better aligned with community realities.

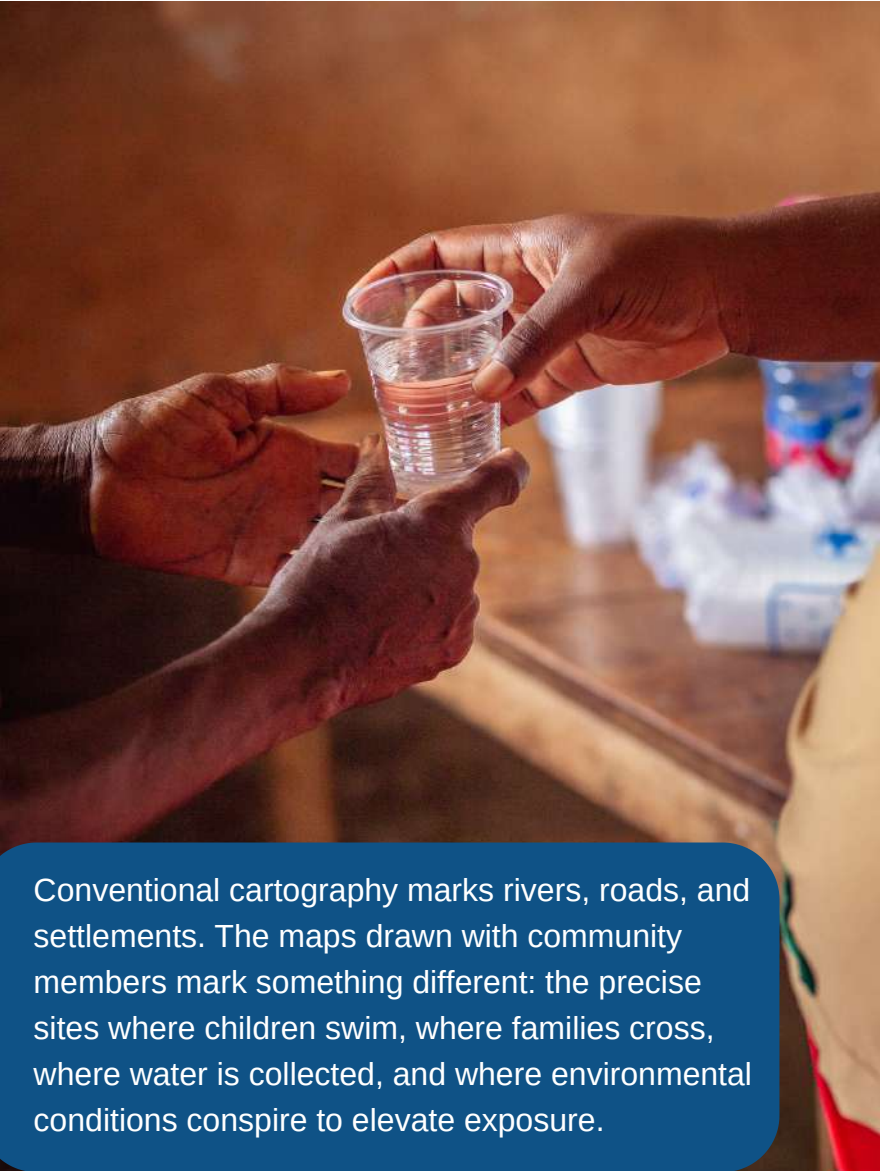
Story Circles: Listening Before Speaking

One of the first public engagement methods introduced into the communication strategy was the Story Circle. Rather than beginning conversations with presentations about disease transmission, facilitators invited participants to answer a simple but powerful question: "What does the Kakum River mean to you?"

The responses revealed dimensions of the river that scientific surveys rarely capture. For some, the river represented childhood memories and recreation. For others, it symbolised family heritage, farming livelihoods or spiritual significance. These narratives transformed the river from a site of disease transmission into a living social and cultural landscape. Understanding these meanings is essential because people are unlikely to abandon places that define their identities simply because they are told they are dangerous.

MAKING COMMUNITIES

Visible Through Photovoice



Conventional cartography marks rivers, roads, and settlements. The maps drawn with community members mark something different: the precise sites where children swim, where families cross, where water is collected, and where environmental conditions conspire to elevate exposure.

Effective scientific research through the lens of public engagement demands that communities become co-producers of evidence, not merely subjects of its collection. Two methods deployed along the Kakum River—Photovoice and participatory risk mapping—operationalise this principle with striking clarity.

Photovoice hands the camera to those who live the reality under study. Rather than researchers deciding what merits documentation, residents capture the intimate choreography of daily life with the river: children swimming at well-worn banks, women balancing water buckets at collection points, farmers navigating the same crossings they have used for decades. They also photographed environmental conditions they themselves identified as health threats—stagnant pools, eroded sanitation infrastructure, overgrown pathways that force prolonged water contact. Each image constitutes more than illustration; it becomes evidence framed by community perspective, not external hypothesis. When placed into facilitated dialogue between residents and scientists, these photographs dissolve the hierarchy of whose knowledge counts. Scientific observation is no longer imposed but interpreted alongside lived experience, generating shared insight that neither party could reach alone.

Participatory river mapping extends this logic into spatial decision-making.

These are not geographical documents but behavioural atlases—visualising the intersection of human practice, ecology, and disease risk in a form that communities immediately recognise and researchers can operationalise. The resulting maps will directly inform future interventions by identifying priority locations for engagement, education, and environmental modification, ensuring that resources follow lived risk rather than administrative boundaries. Together, photovoice and participatory mapping reframe public engagement from a consultation exercise into an evidentiary partnership. They demonstrate that when communities document their own realities, the resulting intelligence is not softer than scientific data—it is sharper, more contextual, and essential for interventions that are both technically sound and socially durable.

SCIENCE CAFÉS:

From Lecture to Conversation

Equally critical to the architecture of this project are the deliberate communication spaces we designed—not as addenda, but as integral components of the intervention itself. The Community Science Café exemplifies this philosophy. Rejecting the unidirectional logic of the public lecture, the Café constitutes an informal, egalitarian forum where researchers and community members meet as co-investigators. Scientific evidence is not disseminated; it is laid alongside lived experience for mutual interrogation. Questions move in both directions: researchers explain what the data suggest, while communities articulate what the data may fail to capture—seasonal nuances, gendered exposures, the unspoken symptoms that escape clinical algorithms. The objective is never persuasion but collective learning, a process that simultaneously deepens trust and sharpens the relevance of subsequent research.

This participatory logic extends into cultural practice through the Oware Avoid Re-Infection Game. Grounded in the familiar strategic grammar of a traditional Ghanaian game, the prototype transforms the schistosome lifecycle into a playable system. Players navigate transmission stages, deploying a limited “super card” representing medication—a deliberate design constraint that displaces treatment dependency and foregrounds preventive reasoning. By embedding epidemiological concepts within an indigenous ludic framework, the game renders learning interactive, memorable, and communally owned, embodying the principle that lasting understanding emerges through participation, not instruction.

Beneath these tools lies a more fundamental reorientation. The Kakum River project refuses the framing of communities as passive beneficiaries or research subjects. It recognizes them as experts of their own environments—custodians of narratives that explain behaviours statistics cannot decode, observers of ecological shifts invisible to remote sensing, and co-authors of interventions that are culturally legible and practically durable. This shift from studying communities to working alongside them is not merely ethical posture; it is methodological necessity, and it represents the defining character of modern, impactful public engagement with science.

THE HIDDEN EPIDEMIC BENEATH THE WATER

- 01** The World Health Organization estimates that over 200 million people globally require preventive treatment for schistosomiasis, with more than 90% of cases concentrated in sub-Saharan Africa.
- 02** In Ghana, the disease is endemic across vast rural areas, where an estimated six million people remain at risk and infection prevalence among school-aged children in hotspot communities can surpass 50%.
- 03** For women and girls, these numbers conceal an additional, profoundly undercounted burden: female genital schistosomiasis, a complication that transforms a neglected tropical disease into a silent crisis of reproductive health, dignity, and social exclusion along the very riverbanks communities depend upon for daily life.



HER SILENT BURDEN

FEMALE GENITAL SCHISTOSOMIASIS:
THE NEGLECTED DISEASE HIDDEN IN PLAIN SIGHT

Auntie Afua was fifty-six when she learned that the blood she had been hiding for nearly a decade had a name, and that the name belonged to a disease the world has largely chosen to overlook. “I thought, whatever this is, it will take me one day, and then the silence will be over,” she said, seated beside the Kakum River, the same waters she had depended on since childhood. “I did not think I had the right to speak it aloud.”

What Afua could not name, and what the health system repeatedly failed to detect, was female genital schistosomiasis. The World Health Organization estimates that over 200 million people worldwide require treatment for schistosomiasis, ninety per cent of them in Africa. Buried within that figure lies an even starker statistic: between twenty and fifty-six million women and girls are believed to be living with the genital form of the disease. The numbers are imprecise because the condition itself is systematically unseen.

Its symptoms—vaginal bleeding, discharge, pelvic pain, pain during intercourse—mimic cervical cancer, sexually transmitted infections, and a dozen other gynaecological conditions. Misdiagnosis is not an exception; it is the clinical norm. 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.

The pathology, however, is only half the story. The deeper injury is social. In communities like Afua's, a woman's bleeding is rarely understood as a neutral biological event. It is read morally. “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 internalize 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. Praziquantel, the drug used in mass treatment campaigns, kills the worm but cannot reverse years of undiagnosed genital damage nor erase the psychosocial scars of having suffered in silence. 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.



During a community conversation about the river's hidden dangers, they described the blood, the pain during intimacy, the sensation of one's own body becoming a foreign country. “When they described those things, I started crying,” Afua said. “Not because I was sad—because someone finally saw me.” A subsequent examination confirmed what decades of clinical encounters had missed. For the first time, her invisible burden had a name, and a treatment pathway.

HER SILENT BURDEN

continue...



Her revelation points to a fundamental failure in how global health addresses neglected tropical diseases. “I suffered all those years, not because there was no medicine, but because no one thought to look for a woman’s story in a woman’s body,” she said. Her words articulate a truth that epidemiology alone cannot capture: that the gap between suffering and diagnosis is filled not only by a lack of resources but by a failure of imagination. Women’s own descriptions of water-contact patterns, symptom histories, and the social consequences of illness constitute an indispensable, largely untapped evidentiary resource. Integrating these narratives into surveillance, clinical training, and health communication transforms female genital schistosomiasis from a hidden burden into a visible, actionable priority.

Now on a care pathway and speaking openly—despite the risk—Afua offers no triumphant recovery narrative. She offers something more useful: a refusal to let her silence be inherited. “I speak so that the next girl who sees blood does not think she is already dead,” she said. The project underway along the Kakum River insists on the same principle. Listening to women is not a supplement to science; it is the precondition for it. To ignore the gendered face of schistosomiasis is to compromise the entire elimination agenda. The quiet water, after all, holds many stories; the question is whether we are prepared to hear them.

CHILDREN OF THE RIVER

Growing Up Between Play and Parasites—
Every Child Deserves a Healthy Childhood

For children along the Kakum River, the waterway is not a hazard to be managed—it is the irreplaceable landscape of childhood itself. It is where they gather to play after school, learn to swim, and navigate social bonds that shape their development. The river delivers joy, friendship, and physical mastery. Yet it also delivers exposure to schistosomiasis, a parasitic disease that thrives in these same waters.

Conventional health messaging often defaults to a simple directive: keep children out of the river. This instruction, however, collides with both developmental science and lived reality.

The American Academy of Pediatrics affirms that unstructured outdoor play is essential for cognitive, emotional, and social growth—building resilience, risk assessment, and collaboration. The World Health Organization recommends at least 60 minutes of daily physical activity for children; rivers naturally afford this. UNICEF frames play as a fundamental right, not a luxury. To bar children from the Kakum would be to deprive them of developmental experiences no classroom can replicate. A child cannot be asked to choose between health and childhood.

The BCRC project adopts a different strategic posture: honouring the developmental necessity of play while reducing infection risk through co-designed solutions. We do not begin with prohibitions; we begin with children's own knowledge of where, when, and why they play. This intelligence is gathered through participatory mapping, Photovoice, and facilitated dialogues in schools—positioning children as co-investigators, not passive recipients of warnings.

The goal is not to sever their connection to the river but to reconfigure it: identifying safer play zones, understanding seasonal transmission patterns, and embedding preventive practices into the rhythm of daily life.



Even the Oware Avoid Re-Infection Game transforms a familiar cultural play into a learning tool that fosters strategic thinking about prevention. Every conversation and every shared activity strengthens a dual outcome: healthier children who remain connected to the river that sustains their childhood. Protecting the next generation means protecting not only their bodies but also the developmental experiences that shape who they become.



WHERE FOREST MEETS RIVER

Ecology, People and the One Health Connection

Dr. Julia Quaicoe, a fluvial geomorphologist at the University of Cape Coast, describes the Kakum River in terms that transcend hydrology. "This river is not a simple channel," she explains. "It rises near Akyem Atendo, links the Prah and Birim systems, cuts through the Kakum Forest, and enters the sea at Elmina. Along that journey, it collects the consequences of every human and ecological decision made on its banks."

Those consequences, she argues, are written directly into disease transmission. Schistosomiasis persists not because the parasite exists, but because the river's physical behaviour creates the conditions for it to thrive. "When we extract sand, clear riparian vegetation, or allow agricultural run-off, we alter flow velocity," Dr. Quaicoe notes. "Slow, stagnant pools replace moving water. Those pools are precisely where snail intermediate hosts proliferate. The link between geomorphology and infection is direct, not theoretical."

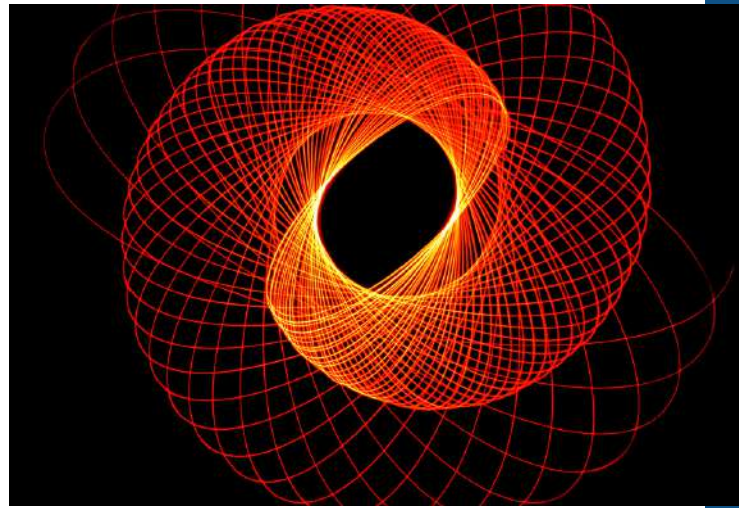
Her research maps these relationships spatially. Snail habitat distribution correlates with sediment grain size, water depth, and seasonal flooding patterns—variables that shift when land use changes. "Climate variability compresses or extends transmission seasons. The forest edge becomes an epidemiological frontier. Every cubic metre of water we slow down is a potential breeding ground."

This perspective anchors the BCRC project's One Health framework. "You cannot understand transmission by studying the parasite alone, or the snail alone, or the human alone," she insists. "We integrate snail ecology, water quality, land-use change, and community behaviour because the river connects them all in a single system. Upstream sand mining in one location alters infection risk for communities twenty kilometres downstream. No single sector owns this problem."

For Dr. Quaicoe, sustainable intervention demands ecological literacy. "Solutions must be engineered where environmental stewardship and public health converge. The river does not distinguish between them—and neither should we."

ONE DISEASE. MANY SYSTEMS

Why Schistosomiasis Cannot Be Solved by the Health Sector Alone



Schistosomiasis is routinely classified as a neglected tropical disease, a designation that suggests a biomedical problem awaiting a pharmaceutical solution. The reality is considerably more complex. The persistence of transmission along the Kakum River reveals a condition sustained not by a single vector but by an entire system: water infrastructure that guarantees daily exposure, sanitation deficits that perpetuate contamination, agricultural practices that demand river contact, and cultural patterns that normalise risk. No health ministry, however well-resourced, can unravel this entanglement alone.

Elimination demands a deliberately assembled, multisectoral architecture. The BCRC project convenes fluvial geomorphologists who analyse how sediment dynamics shape snail habitats, alongside engineers capable of designing alternative water access points that reduce exposure. Anthropologists decode the social meaning of river practices that epidemiology alone cannot interpret. Public health experts align intervention design with clinical reality, while strategic science communication analysts ensure that community engagement is evidence-based, not merely aspirational. Government institutions responsible for water and sanitation bring regulatory authority and infrastructure mandate; school teachers and children contribute behavioural intelligence and peer influence networks. Community opinion leaders broker trust where institutional presence is thin.

This is not coalition-building as rhetoric. It is operational necessity. A strategic focus group structure ensures that each sector contributes its specialised intelligence to a shared analytical framework. The parasite exploits fragmentation; an effective response demands integration. The Kakum River project models what this looks like in practice: research scientists, community members, and institutional partners working from a common evidence base toward interventions that are medically sound, environmentally informed, socially embedded, and institutionally sustainable. One disease, many systems—and finally, one coordinated response.



SCIENCE IN PICTURES

Kakum-the river that gives life

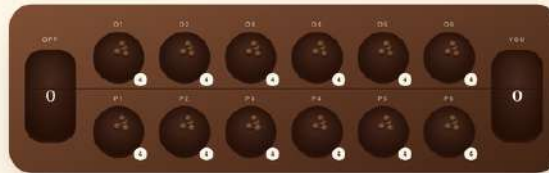
Schistosomiasis control needs more than medicine?

Jessica Ahedor
July 3, 2026



ROUND 0 - YOUR TURN The Oware board

Your move. Choose a pit on your side.



Your dashboard Use medication

Health	80 / 100
Overall wellbeing	50 / 100
Exposure	30 / 100
River contact risk	9 / 100
Infection	40 / 100
Active worm burden	40 / 100
Community	40 / 100
Collective protection	

Reinfection rule: medication clears infection, but does not stop future exposure. Community action stops.



TEAMS IN PICTURES



Funded by



Partners and Acknowledgements

Ghana Health Service
Central Region

Ghana Education Service
Central Region

Chiefs and opinion leaders
of the five communities

Residents of the five
communities

Volunteers and other
support groups

Project communications by
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