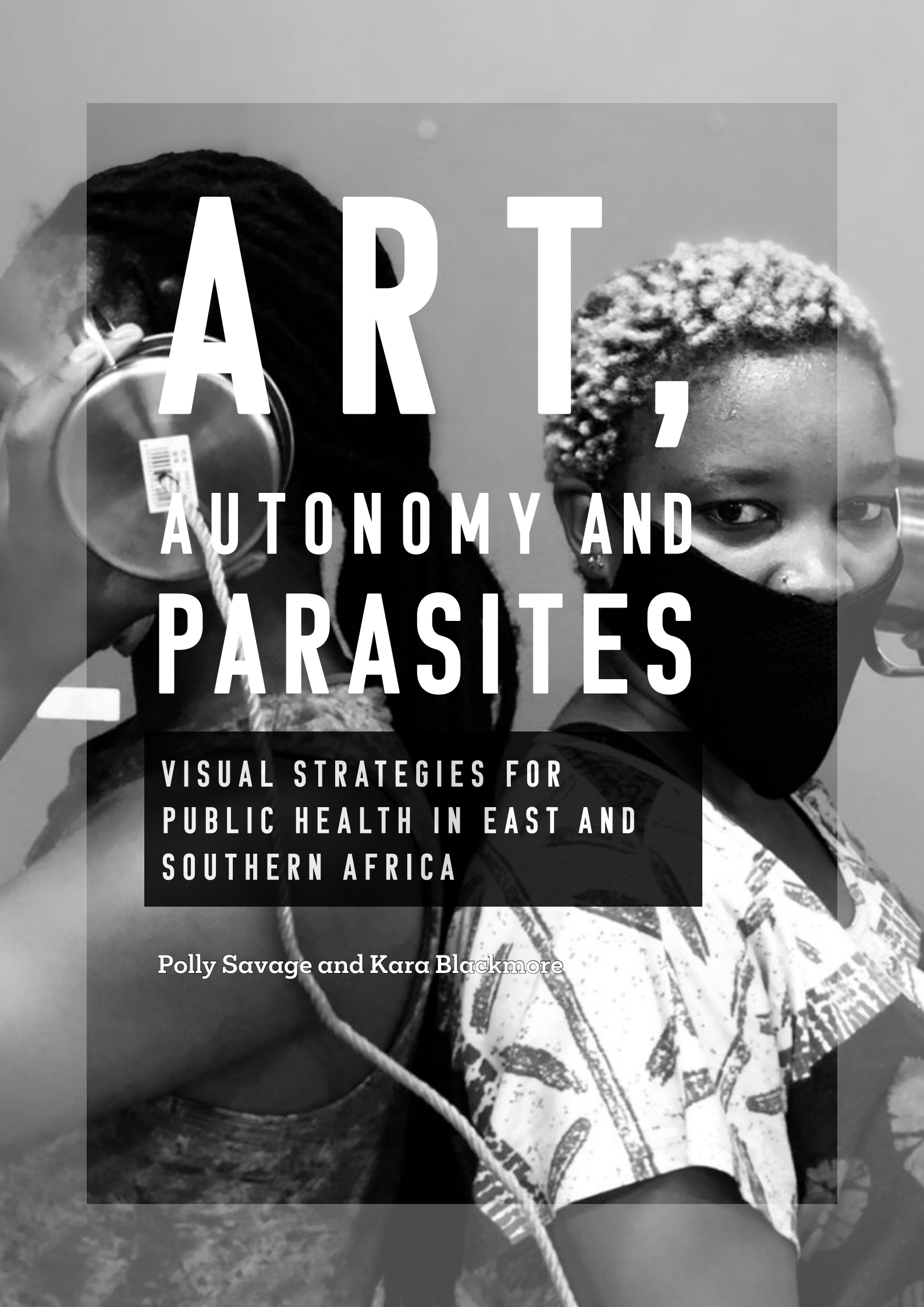




ART, AUTONOMY AND PARASITES

VISUAL STRATEGIES FOR
PUBLIC HEALTH IN EAST AND
SOUTHERN AFRICA

Polly Savage and Kara Blackmore

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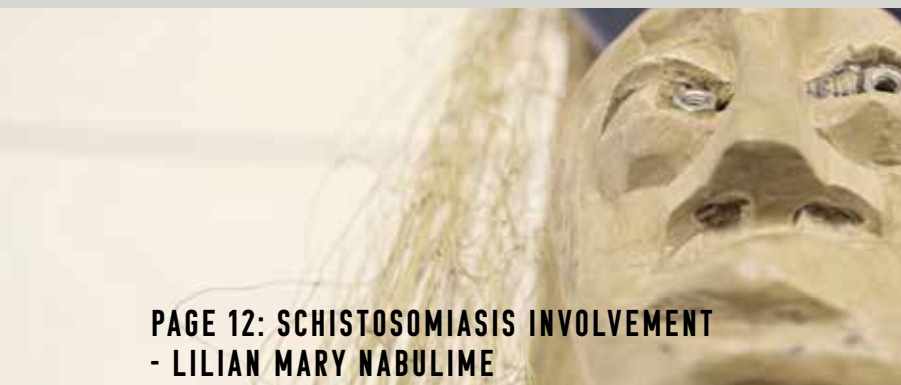
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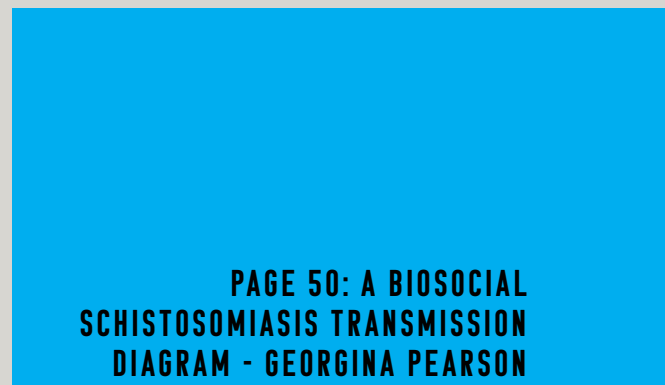


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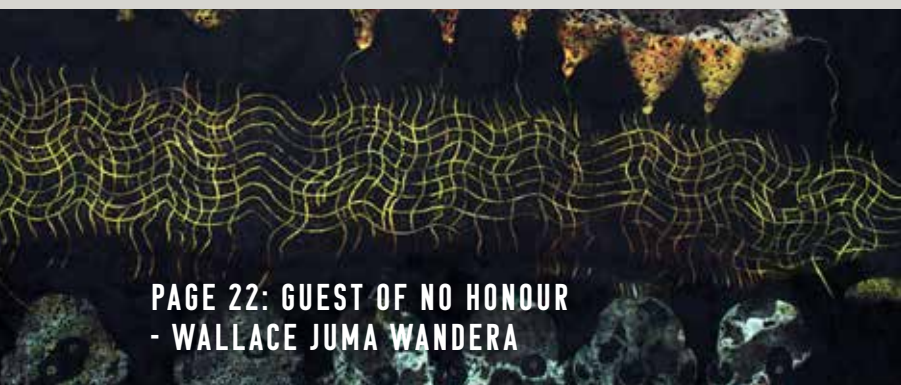
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Art, Autonomy and Parasites

Visual Strategies for Public Health in East and Southern Africa

Polly Savage and Kara Blackmore

Introduction

Who decides how we should medicate, heal and protect our own bodies? How is public health knowledge best communicated to populations, and in turn, how is people's knowledge of sickness and healing best communicated to those who make decisions about public health? How are global health programmes experienced at a local level? These are questions of particular urgency during a pandemic, as a global vaccination programme rolls unevenly out, and the human impact of policy and advice is laid bare in SARS-CoV-2 mortality rates, but they are also questions of long-running importance in the public health control of other, endemic infectious diseases.

This publication brings together the results of a project that sought to address these concerns through a range of visual arts approaches. A collaboration between art historians, medical anthropologists, designers and artists based in Uganda, Kenya, South Africa, Tanzania and the UK, the Visual Arts for Localised Evidence and Decision-Making (VALEAD) project aimed to explore alternative perspectives and strategies for health communications, to reinvigorate old ones with new relevance, and to foreground local creative practices in relation to questions of autonomy and medical knowledge.

VALEAD recognises that artists can potentially play a unique role in representing the social, political and embodied aspects of pandemics. Visual artists may enhance the work of social scientists by making public and accessible the lived experience of infection and survival in new ways. A range of strategies have been undertaken by South African creatives, often working in conversation with researchers, for example, to address the many facets of HIV and AIDS, ranging from art as activism, to art for community therapy (see Mills, 2019). Their work illustrates the possibilities of reframing perceptions of disease, drawing attention to lived realities of infection.

Localised Evidence and Decision - Making (LEAD)

So-called ‘Neglected Tropical Diseases’ have been highlighted as a global health priority since the early 2000s. With so much emphasis placed upon their control, calling them ‘neglected’ is something of a misnomer. They are the focus of one of the biggest global health interventions ever attempted - mass drug administration. Also commonly referred to as ‘preventative chemotherapy’, mass drug administration is the large-scale distribution of deworming tablets to populations or sub-populations in defined geographic areas without individual diagnosis. One of the most prominent targets of mass drug administration, also among the most prevalent of the neglected tropical diseases, is schistosomiasis (bilharzia). It is very common in many areas of sub-Saharan Africa, in communities making daily use of infected rivers and lakes. Schistosomiasis spreads when larval forms of the *Schistosoma* trematode worm are released by freshwater snails and then penetrate human skin during contact with contaminated water (see life cycle diagram on page 54). Whilst many people have minimal symptoms when initially infected, if left untreated, chronic infection can cause liver fibrosis, bladder cancer, and in rare cases, neurological disease, and can be fatal. In 2019, the WHO estimated that 236.6 million people globally were in need of preventive chemotherapy for schistosomiasis but, despite global mass drug administration programmes, for the same year they report that only 45.5% of those identified as requiring preventive chemotherapy received it. The disease continues to be highly endemic in many areas.¹

Why have mass drug administration campaigns failed? In 2005, a team of researchers based at the London School of Economics and Political Science and the London School of Hygiene and Tropical Medicine began examining this question in particular localities in Eastern Africa.² A common thread in their research is that this strategy does not take into account local perspectives, and this leads to the implementation of ‘one size fits all’, top-down approaches to transmission and control activities. In turn, these programmes are not achieving the successes promised and schistosomiasis persists in these areas, sometimes at higher levels than before implementation of mass drug administration began. In addition, the evidence used to support and evaluate these activities is developed outside of the locations of implementation, without any genuine feedback from individuals living and working in these areas. This feeds into the continued deployment of ineffective strategies.³

In 2019, a team led by Cristin Fergus and Professor Tim Allen began work on a two-year project to ask why, despite the evidence of its failures, mass drug administration programmes persisted, and how alternative approaches might be promoted. Titled Localised Evidence and Decision-making (LEAD), the project undertook a series of participatory workshops in Uganda and Malawi with health practitioners and those involved in schistosomiasis treatment and control at village, district and national levels. The aim was to create links between these practitioners and national level policy makers, with discussion focusing on the socio-political, economic and environmental complexities of

programme implementation and the specificities of local circumstances.

Interestingly, findings from previous anthropological research on the issue were echoed by public health practitioners participating in the LEAD workshops. They described a range of ways in which existing health information materials are failing, for example, by depicting people from different areas (leading to the perception that the materials are about ‘other people’), or by offering patronising narratives, incomprehensible artwork or incomplete storylines (such as by only explaining the effects of one species, *Schistosoma haematobium*, and ignoring *Schistosoma mansoni*). Public health practitioners described how failings in communication led to a lack of knowledge and, in-turn, undiagnosed conditions at critical junctures of disease onset. One of the conclusions of the research was that ‘trickle down’ approaches to disseminating health advice were rarely effective - the poor quality, or absence, of health communication materials was significantly reducing uptake of the public health control programmes on offer, and even prompting resistance to mass drug distributions.



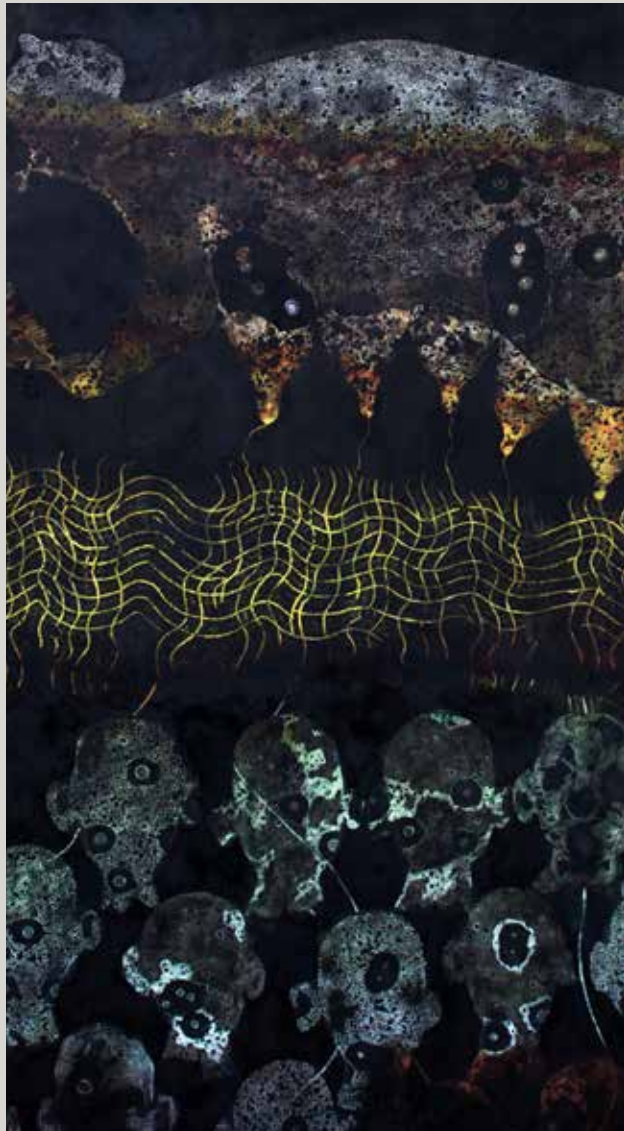
Lilian Mary, *Schistosomiasis Involvement*, 2021 (Installation detail)

1 World Health Organization Schistosomiasis <https://www.who.int/news-room/fact-sheets/detail/schistosomiasis> 18 May 2021

2 Parker, M., Allen, T., & Hastings, J. (2008). Resisting control of neglected tropical diseases: dilemmas in the mass treatment of schistosomiasis and soil-transmitted helminths in north-west Uganda. *Journal of biosocial science*, 40(2), 161-181.

3 Melissa Parker & Tim Allen (2014) De-Politicizing Parasites: Reflections on Attempts to Control the Control of Neglected Tropical Diseases, *Medical Anthropology*, 33:3, 223-239, DOI: 10.1080/01459740.2013.831414

To address these needs, the LEAD team approached us, as art historians and curators, to develop a project that would respond to, and extend, their findings through visual art approaches. Building on academic research conducted by anthropologists, political scientists and health workers, the VALEAD team collaborated with artists and designers



Wallace Juma Wandera, *Guest of No Honour*, 2021

based in Africa to develop new knowledge registers that might influence policy and change behaviour.

The project unfolded through two strands of work: visual art commissions which engaged in conceptual ways with the LEAD team's research, and didactic illustrations in the form of a graphic narrative and life cycle diagrams.

Together, the resulting collection of artworks become pedagogical tools to serve local populations, academic communities and public health professionals. Drawing on their own experience and research of health questions in these regions, the artists were not just interpreters of findings but also collaborators in developing new avenues for understanding and potentially controlling some of the neglected tropical diseases.

Strand One: Conceptual Arts

The conceptual strand of the project began in November 2020, with an open call for visual artists working in the affected regions to respond in creative and innovative ways to the challenges presented by schistosomiasis infections and treatments. This led to a six-month collaboration with Lilian Mary Nabulime (a sculptor and lecturer at Makerere University, Kampala), Wallace Juma Wandera (a painter based in Nairobi), and Wezile Harmans (a video and performance artist based in Johannesburg). Each artist undertook their own research with communities in lakeshore regions of Uganda and Kenya, and in rural parts of South Africa, documenting the journeys through photographs, sketches and writings. Sharing their work through weekly meetings, they highlighted issues such as water use, sharing of health knowledge, and the experiences of health workers at the village level where most vulnerable populations live - processes they discuss in detail in this catalogue. The resulting works speak to a broad range of issues relating to the body, and to disconnects in translating health related knowledge into action.

Lilian Mary Nabulime's sculpture ***Schistosomiasis Involvement*** provides a graphically unambiguous depiction of disease and its relationship to both the body and the environment. Using wood, terracotta, plastic, hammered metal, and fishing nets,

her sculpture depicts a figure carrying water through a tangled web of snails, acknowledging the natural dangers encountered by fishing communities in the soil or water. Her work demonstrates the bodily manifestation of disease in physical deformities, and the nature of livelihoods that require engagements with water. It references the communities she worked with in Uganda, as well as to other parts of the Great Lakes region of eastern and central Africa, who also rely on the lakes for drinking water and fishing. Nabulime demonstrates an everydayness in the sculpture whereby populations are shown, not in crisis, but in the somewhat banal habits of daily life.



Wezile Harmans, *The People*, 2021 (video still)

Wallace Juma Wandera's multimedia 2D work ***Guest of No Honour*** visualises the compounded social and medical aspects of disease affecting Kenyan communities in the lake areas where he grew up. The burnt relief triptych shows the interconnectedness between the people he interviewed and the diseases that affect them. At the base of the work, six portraits of silhouetted subjects are overlaid with spatters that reflect microscopic images of schistosomiasis and other helminth infections. An amorphous creature looms over the top

of the work, its skin blotted with rashes. The mottled skin references magnified images of parasites, as well as the psoriasis that results both from schistosomiasis and from conjoined diseases that are prevalent in these fishing communities such as diabetes, alcoholism or HIV. A fraying grid weaves across the centre of the work, alluding perhaps to pathways to infection, nets for fishing, or barriers to understanding. Wandera's act of burning and etching these scenes out of soot on a PVC base offers a metaphor for the tension between what is shown and what is hidden in public discussions of health.

Harmans's short film ***The People*** has a different take on the research. Layering sound, landscape and performance, the moving images raise questions around ways of knowing and being, asking how we can know our bodies and what knowledge is necessary to make sense of our health experiences. Through a series of juxtapositions between natural and studio settings, full colour and monochrome, masculine narration and feminine movements, Harmans makes reference to the tensions and disjuncture between formal and informal

knowledge systems. This power struggle takes embodied form through the interplay between two performers, whose movements suggest that the tension between who gets to speak and who listens remains perpetually unresolved.

Strand Two: Graphic Narrative

While the first strand of the art project fostered reflection on the critical and conceptual questions raised at the intersection of healthcare systems, knowledge, power and the body, the second strand of the project focused on communicating evidence-based research on schistosomiasis through the accessible format of graphic narratives. Storylines and life-cycles developed out of academic research have been illustrated for public health campaigns by artists Dianah Bwengye and Victor Ndula in booklet and poster form for district vector control offices across Uganda. The aims of these comics are firstly to disseminate contextually relevant knowledge about the transmission of schistosomiasis, and secondly to recount the experiences of health workers who are responsible for the delivery of health interventions within the communities.

Seeking to contextualise the issues raised by health workers through the LEAD workshops and to build upon LEAD's previous research in Uganda, Dianah Bwengye, in collaboration with researcher Gloria Kiconco, travelled to Jinja, on the northern shore of Lake Victoria, and Pakwach in the northwest of the country. They talked to district health officers and local communities about their experiences with schistosomiasis control and elimination activities. Drawing on their work, and the publications of the LEAD research team, the script of a 24-page cartoon booklet was developed in collaboration with Tim Allen, Melissa Parker, Cristin Fergus, Georgina Pearson and Benjamin Dix. It tells the story of a journalist who seeks to find out more about mass drug administration in Uganda. The character, Dembe, questions why mass drug distribution programmes have failed to eradicate or successfully treat schistosomiasis. Gaining perspectives from local leaders, health-workers and fisherfolk, the illustrated story explains that treatment without a deeper discussion on health or symptom-based diagnosis is ineffectual. It shows that the drivers of the programmes are not necessarily in touch with the lived realities of people who rely on water where the snail vectors that carry schistosomiasis live.

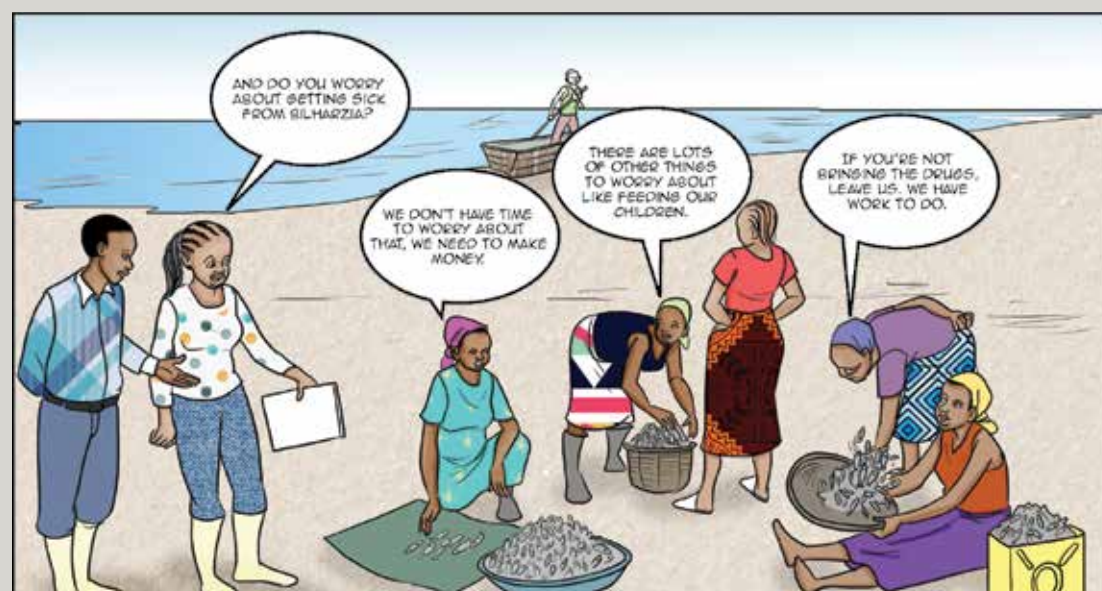


Image cutout: Dianah Bwengye, *Weak Links* 2021 (excerpt)

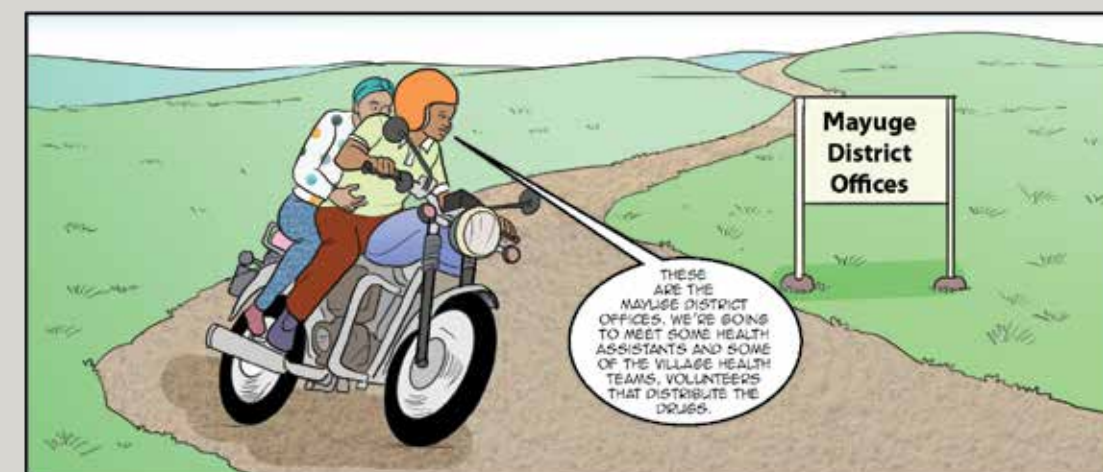


Image cutout: Dianah Bwengye, *Weak Links* 2021 (excerpt)

Following the project's aim to employ arts in support of health campaigns, the storybook includes up-to-date public health knowledge that is tailored to Ugandan contexts. To supplement this, Dr. Georgina Pearson and other members of the LEAD team worked with artist Victor Ndula to produce a transmission diagram with clear illustrations of the life cycle of the schistosome. The storybook and life-cycle are available to view or download online and in print form to be distributed by public health professionals in the region. They are a practical way in which research can be interpreted and disseminated outside of the academy.

Conclusion

Together, this collection of five works in film, sculpture, mixed media painting and graphic fiction offer a social portrait, making visible the everyday experiences of people foregrounded in the LEAD research. As new pedagogical resources, the artworks can inform scholars and health workers of the lived realities of people impacted by infections. At the same time, the didactic artworks are an informative tool for affected populations in communicating current, evidence-based public health information and telling stories that are context-specific. The socially engaged perspectives of these artists work to challenge preconceptions around health, and develop insightful narratives that produce new registers of knowledge.

As purposefully commissioned artworks, rather than historic works, these pieces also now form a unique part of the SOAS and LSE collections. To engage artists in research like this is not merely to represent findings, rather it is an invitation to collaborate in knowledge production. Through the collaboration, the artists have reframed the narratives of this disease by revealing a series of issues such as the everyday experience of infection, the complexities of mass drug distribution or the tensions in conjoined diseases. Their work creates inroads to new forms of inquiry and meaning around the dangers of an environment that is often depicted through a lens of nostalgic or fetishised African landscapes. The artworks are therefore part of a critical scholarship, often opening up intimate perspectives that can be accessible to diverse audiences.

In the pages that follow, you will find dynamic responses to helminth infections, curated in the ethos of caring for knowledge generated by researchers and artists that recognises those impacted by neglected tropical diseases.



Lilian Mary Nabulime
**Schistosomiasis
involvement**

157x200x200cm

MEDIUM : Wooden sculpture
(Markhamia lutea-omusambya),
plastic jerrycan, terracotta, fishnet,
aluminium plates, nails and gumboots

YEAR : 2021

Lilian Mary Nabulime
**Schistosomiasis
Involvement**

The LEAD research project's exploration of infectious diseases, which observes and uses different forms of evidence to make decisions around disease control, relates to my artistic practice concerned with health, risk and response in Uganda. Similarly, as a practicing artist, I also study the social effects of disease, finding a visual means through which to increase community knowledge and thus reduce infections.

My sculpture practice consists of artistic forms made of hard or plastic materials worked into three-dimensional objects. These sculptural forms may be embodied in freestanding objects, reliefs on surfaces, or environments ranging from the representational to contexts that envelop the spectator. Although the LEAD study bears similarities with my previous research on HIV/AIDS, responding to work on schistosomiasis brings different challenges which may lead to new direction in my sculptural practices.

I transcribed and analysed interviews with respondents in Panyimur, Pakwach in Uganda to refine my artistic ideas on the transmission, infection and control of schistosomiasis. I found similar concerns to HIV transmission and acquisition, of which schistosomiasis is noted to increase risk, and the effects of rising water levels.

Water hyacinth plants have taken over many Lake Albert shores, which has meant boats cannot land easily, and fishing communities are greatly struggling. Due to the increased water level, latrines have also become submerged, which has led to the contamination of shores with faeces and an increase in schistosomiasis infections. Furthermore, because 'snail mining' (gathering snails from the waters) is a more



Artwork in progress, Lilian Mary Nabulime



Artwork in progress, Lilian Mary Nabulime



Lilian Mary Nabulime, *Schistosomiasis Involvement*, 2021 (Terracotta)

lucrative livelihood than fishing, men and women have been pushed into infected waters. There is also a perception that medicine and medical facilities are inadequate and lacking, as people cannot afford to go to a major hospital in Kapchora for testing and treatment.

The artistic process happens in several stages. I first made sketches of the environmental and bodily things that relate to the disease. For example, the symptoms create deformed bodies with enlarged stomachs, and I wanted to show that when the disease is poorly or un-treated it disfigures body parts such as the, stomach, testicles, feet and liver. Other symptoms are harder to show like diarrhoea, bloody stools or vomiting.

To represent the snails that carry schistosomiasis in the waterways, I made them in modelling clay for the plaster of paris moulds and then completed them through a process known as 'biscuit firing'. I collected materials such as fishing nets as a metaphor for the lakes and rivers as well as toilet pans to represent symbolically the reduction of the defecation mode of transmission.

One of the most challenging issues is how to show the social issues of living with the disease, given sufferers of schistosomiasis are often isolated, in denial, stigmatised and discriminated against by their communities. To complete the sculpture, I blended the social, bodily and environmental factors.

I have created the sculpture to address health policymakers, practitioners, the Uganda Government, NGOs and researchers of schistosomiasis – people who can bring about positive change to the villages greatly affected by the disease. In particular, the work draws attention to the factors leading to increased numbers of infections, helping to create awareness and contribute towards preventative efforts. On a personal level, venturing into the field has taught me more about the risks and challenges affecting communities around the Great Lakes in Uganda than I expected.



Lilian Mary Nabulime, *Schistosomiasis Involvement*, 2021 (Installation)

Wallace Juma Wandera

Guest of No Honour

When I was developing this artwork, I was thinking about how small and invisible life forms such as bacteria, parasites, and viruses can affect and change the human body. It fascinates me that this small microorganism can pose so much danger to the human species physically, mentally, socially, and economically. I witnessed how the human body is vulnerable and how easily it can be preyed on and become deformed by diseases.

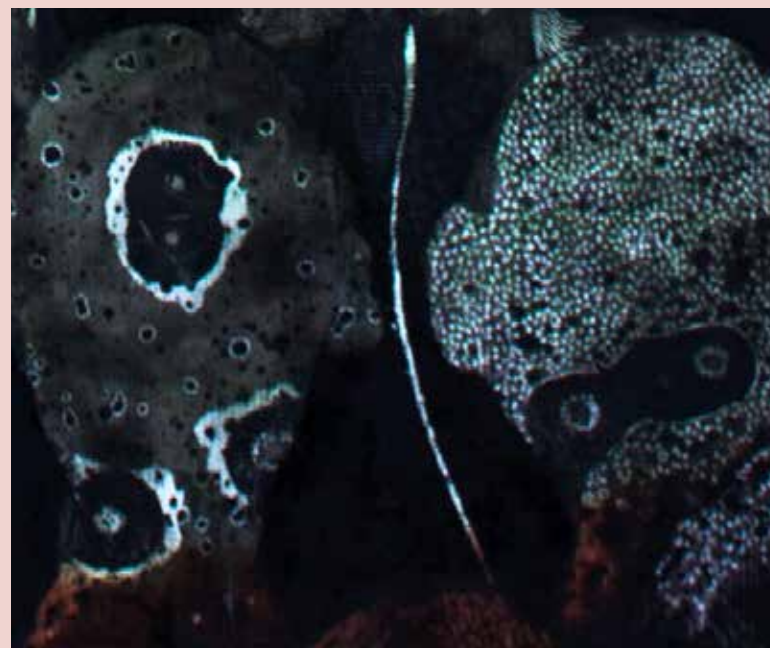
To create this work, I carried out research in the fishing villages and islands of Lake Victoria, specifically in Kenya's Busia county, where I made observations, took photographs, audio recordings, and sketches from fishermen, rice farmers, and river sand harvesters, all of whom spend a significant amount of time in direct contact with water and soil.

As in many fishing islands, at Sumba, there is a serious lack of sanitation, and most human waste is left on the shore to be flushed away by waves. I carried out a forum there, with about ten Sekeseke fishermen. Sekeseke is a fishing technique used by poorly resourced fishermen, in which they dive underwater to trap and catch tilapia fish by net or by hand near the rocky shores of the island. This fishing technique has always been associated with bilharzia infections, and in fact all ten fishermen were victims of the disease. Even though there are outreach mission hospitals that supply drugs on fishing islands, some victims gravitate towards traditional healing methods because they associate water related illness with spiritual forces.

Urination and defecation in the lake often seems unavoidable for many fishermen who spend hours on a single fishing trip in the waters. A single boat could carry between three and five fishermen, with hundreds of boats scattered in different fishing spots and nothing like a toilet.



Wallace Juma Wandera sketches microscopic life forms in water sampled from River Nzoia and Lake Victoria, at the community hospital in Budalangi, Kenya. Water from the lake and river supports thousands of households in the region.
Photograph: Wallace Juma Wandera, 2021.



Wallace Juma Wandera 'Guest of No Honour' 2021 (Detail).

The contaminated water is used on the shores for bathing, cooking, and even drinking, and so continues the transmission of schistosomiasis, cholera, typhoid and other infectious diseases.

There is a lack of adequate information on how these diseases are transmitted and spread. Myths and cultural beliefs mean that people with these infections are often misdiagnosed, and this prevents them from seeking urgent medical attention at an early stage of the illness. One informant, aged 77, told me that when her leg started swelling in the late 1970s from what appeared to be elephantiasis she was told by her family that it was a blessing because they thought she was pregnant and expecting twins. Another participant told me that when his leg started swelling, he was informed that it was because he had walked on the grave of someone who died from a snake bite. Misinformation about this disease not only deteriorates the health of its victims but also accelerates transmission.

Water and soil-based helminths have impoverished the lives of people in these communities to what would seem like the weakest human condition. When I met S, he



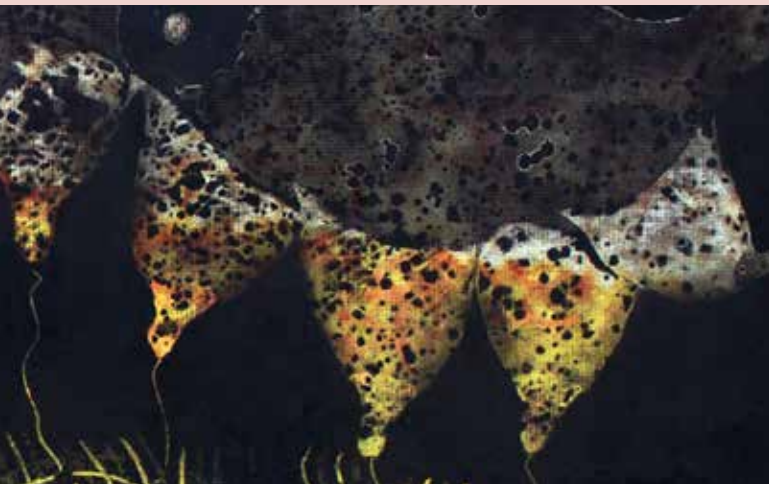
Two fishermen haul in their nets after an expedition on Lake Victoria.
Photograph: Wallace Juma Wandera, 2021.

was wearing a sandal on his most deteriorated foot, which was wrapped in bandages. The logo on the sandal read 'Paris', a symbol of fashion and lifestyle, but all S wished for was better health. In the past he had worked as a fisherman and a rice farmer, but his health condition had now separated him from his family. Another informant, M, covered her leg with a small towel to prevent infesting flies and smell from reaching people around her.



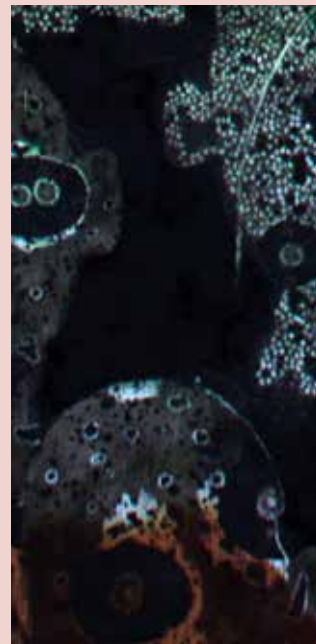
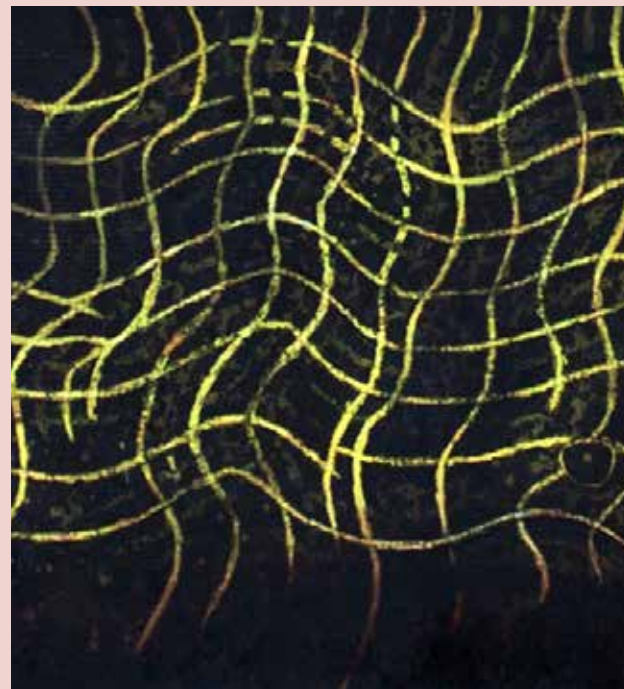
A man bathes while two girls fetch water for cooking and drinking from the shore of Lake Victoria, Igombe Village, Tanzania.
Photograph: Wallace Juma Wandera, 2021.

I brought together the experiences of these people, some of whom are current victims of bilharzia and elephantiasis, some of whom are survivors and medical practitioners, with sketches from the laboratory, photographs of wounds, scars, deformed bodies, facial expressions, moods and stories from the conversations I recorded. Through this amalgamation of information, I wanted to create a hybrid creature in a grandiose scale over the human body, exposing the vulnerability of human life with an aim to change how we see diseases often as small and invisible or non-existent and harmless. The large format of the artwork references the statistical scale of the problem. Using reverse drawing technique



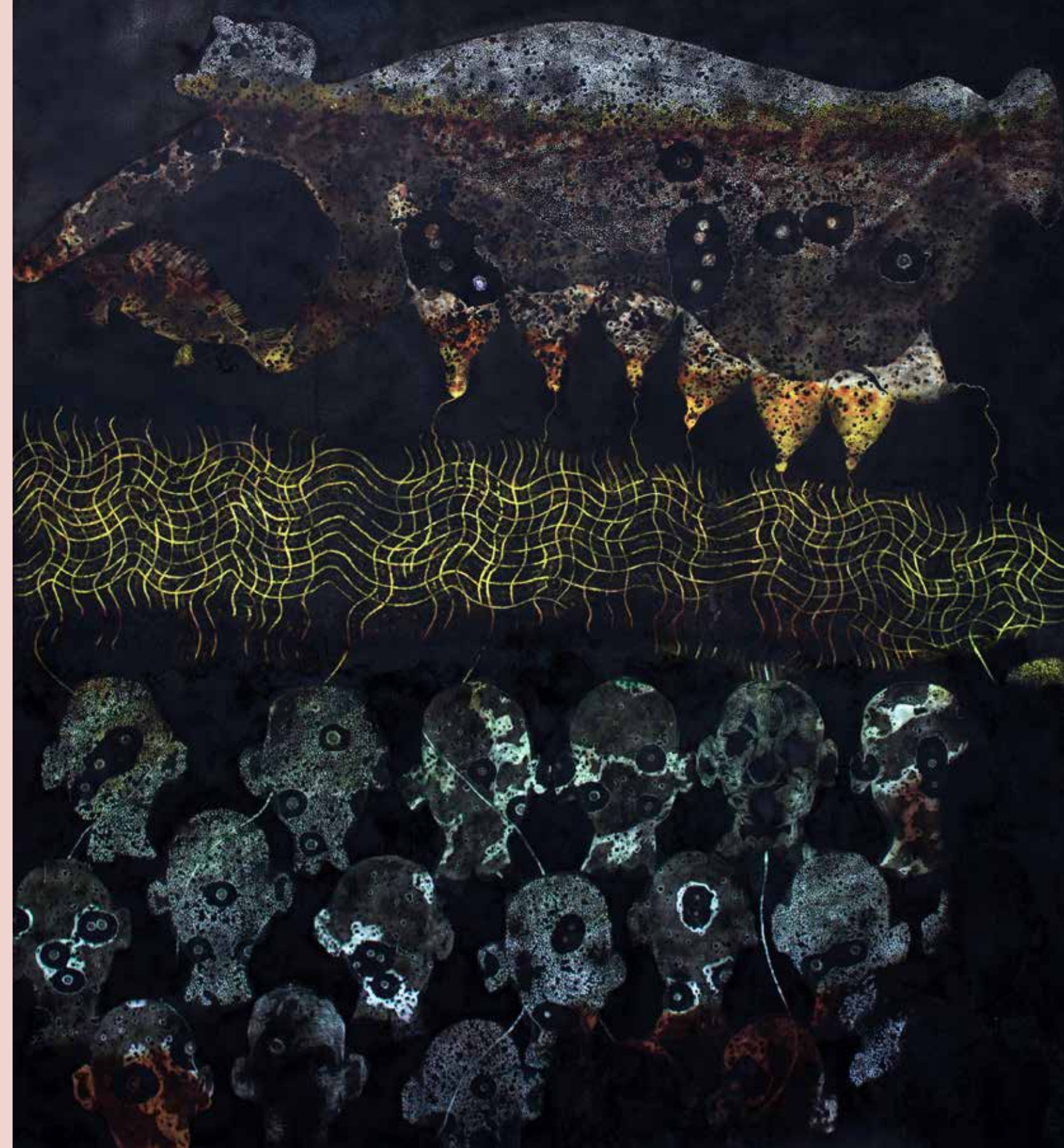
on PVC I used soot to blacken the surface and wipe away parts that I wanted to show. I drew the creature occupying the upper part of the canvas, with heads of people representing the community at the bottom, just as it is for them in reality, some of the heads scratched, scarred and some even disappearing in a dark corner of the canvas. Such was the case for S, who I heard had passed on, three months after we spoke.

I have struggled greatly with the ethics of making aesthetic objects about pain. I would say it's unethical to create aesthetics from people's pain when the sole goal is to gain recognition or profit. When I developed these artworks though, I did so with the clear intention of contributing knowledge on how to adapt better to our environment in relation



Wallace Juma **Guest of No Honour** 2021 (Detail).

to our bodies and diseases. The intention is to help break the cycle of pain by educating ourselves, while also archiving this information for the generation to come. I hope my pictures are going to evoke a sense of curiosity and steer information for the purposes of learning and exchanging knowledge across the globe.



Wallace Juma Wandera **Guest of No Honour**

MEDIUM: Mixed Media on Polyvinyl Chloride.
169cm x 183cm
YEAR: 2021



Wezile Harmans
The People

MEDIUM: VIDEO

DURATION: 3:38 SEC

YEAR: 2021

COLLABORATORS: Asanda Hanabe, Thandiwe Mqokeli.

Wezile Harmans **The People**

My journey in the arts began as a contemporary trained movement artist. While I was in that space, my curiosity led me to create work in site specifics. During the process of creating I will always ask myself questions regarding my practice, what I am doing and what are my intentions, because I am driven to use art mediums as tools for social change.

In my practice, I always produce peculiar, durational and abstract work. In this way, I aim to give room to further conversations, because this is something I believe we should have through art: a conversation.

I have been deliberate in highlighting voices and bodies. I am also very interested in the concept of distortion, memory, displacement and how historical events are presented in the modern day. I believe my motivations have emerged from my surroundings and experiences shared with others during my traveling. The story is much more powerful when you meet in person and allow one to project them in any way comfortable, to me it brings safety, kindness, and a room to welcoming spaces, to which I strongly relate.

I have developed an awareness that I am not unique, but that all people are on a journey of discovery; one that seeks social change, and one that requires us to face and perhaps forgive some very difficult realities. I envision my work as assisting humans to find their voices, despite their marginalisation and exclusion from public and social spaces, whether because of their economic status, background, gender, or sexual orientation.

I would wish my work to act as an inspiration to people to find hope, courage and healing, and to provide a platform to enable people to share deep feelings, without violating their sense of self or exposing them to further trauma.

My practice is informed by research that reveals human behaviour and the impact of knowledge in our society. I create artworks that engage with memory, displacement, love and knowledge. These somewhat universal themes are dealt with in my work by highlighting the peculiarity of experiences and developing ideas durationally as a way of creating deeper conversations.

This deliberate highlighting of voices and bodies relates to the LEAD project commission, by seeking and creating empowering conversations that forge new directions in the face of various forms of marginalisation and exclusion. Working on issues such as knowledge and vulnerability, the LEAD research sheds more light on angles that can be relatable and meaningful to communities using art.

In my practice, I discovered that conversations that relate to health issues in Africa are still seen as foreign due to the culture of communication and knowledge transmission we carry. The commission and my work both coexist in using visual art as a tool for social change and interrogating the dynamics of site, place and culture.

I have developed a script on voices of health and knowledge transmission. I focus on the ideas of African cultures and orality. I am trying to develop a playfulness with the metaphor of a children's game called 'whispers', where messages get passed from one person to the other, always changing. This signifies the LEAD project's many forms of knowledge: academic, scientific, lived experiences, etc. It shows how African peoples still rely on oral messaging and how some information, promoted by public health initiatives, can be misconstrued.

I worked with a team of actors, voice artists and filmmakers to make a short film that reflects the ideas I am trying to express. We used natural environments for the setting, and costumes that resonate with my own practice.

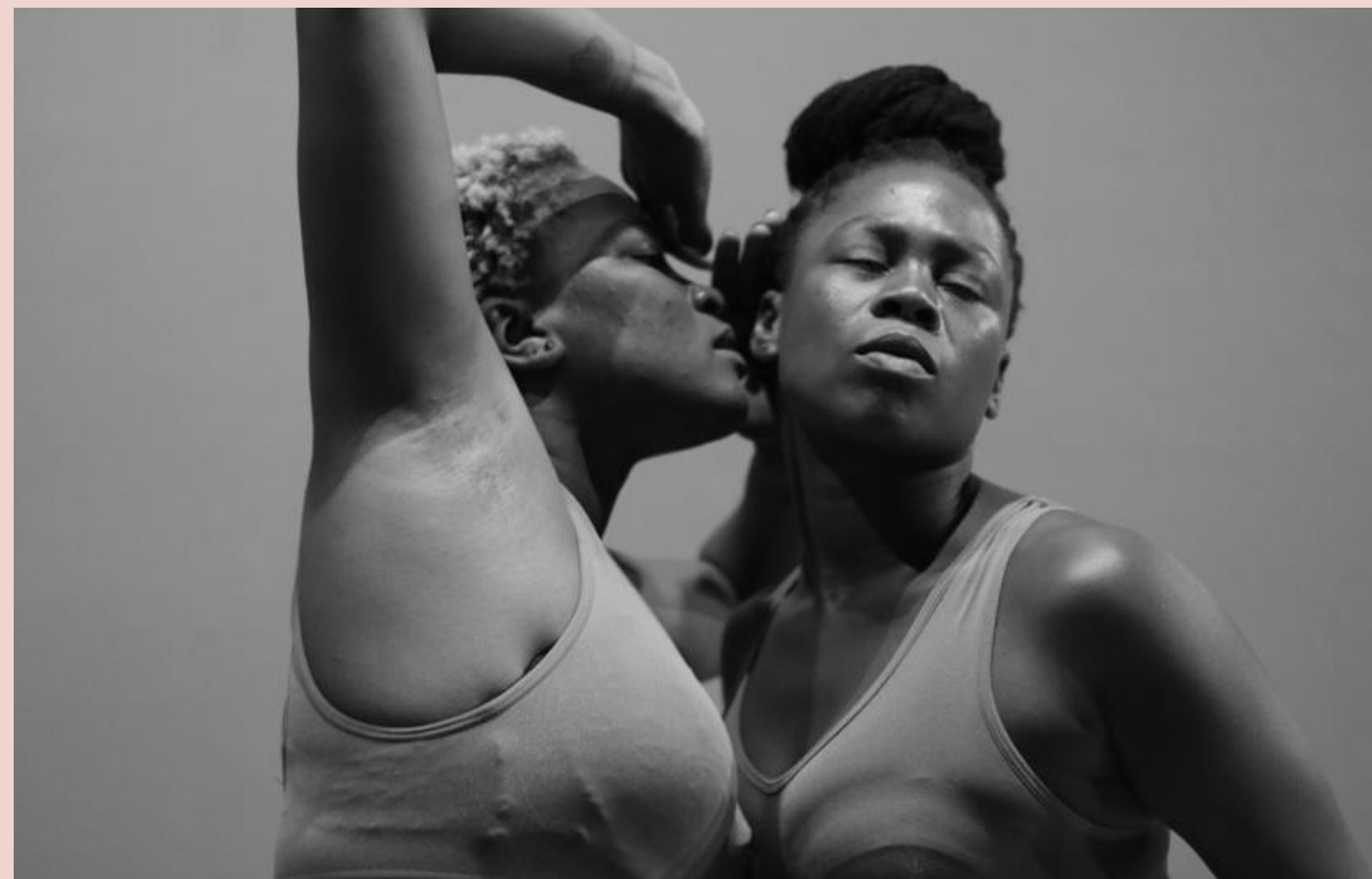


The film is a window into different ways of seeing the evidence, language and embodiment of knowledge on public health issues.

I want this work to reveal the impact and value of knowledge transmission and the responsibility of carrying such knowledge. The more socially-relevant the tradition and access to true information, the more likely this knowledge will be known and the longer it will be remembered. The more widely remembered the information, the further back in time it goes and the more mythical and non-specific it becomes.



Wezile Harmans, **The People**, 2021 , (Video Stills)



Wezile Harmans, **The People**, 2021 , (Video Still)

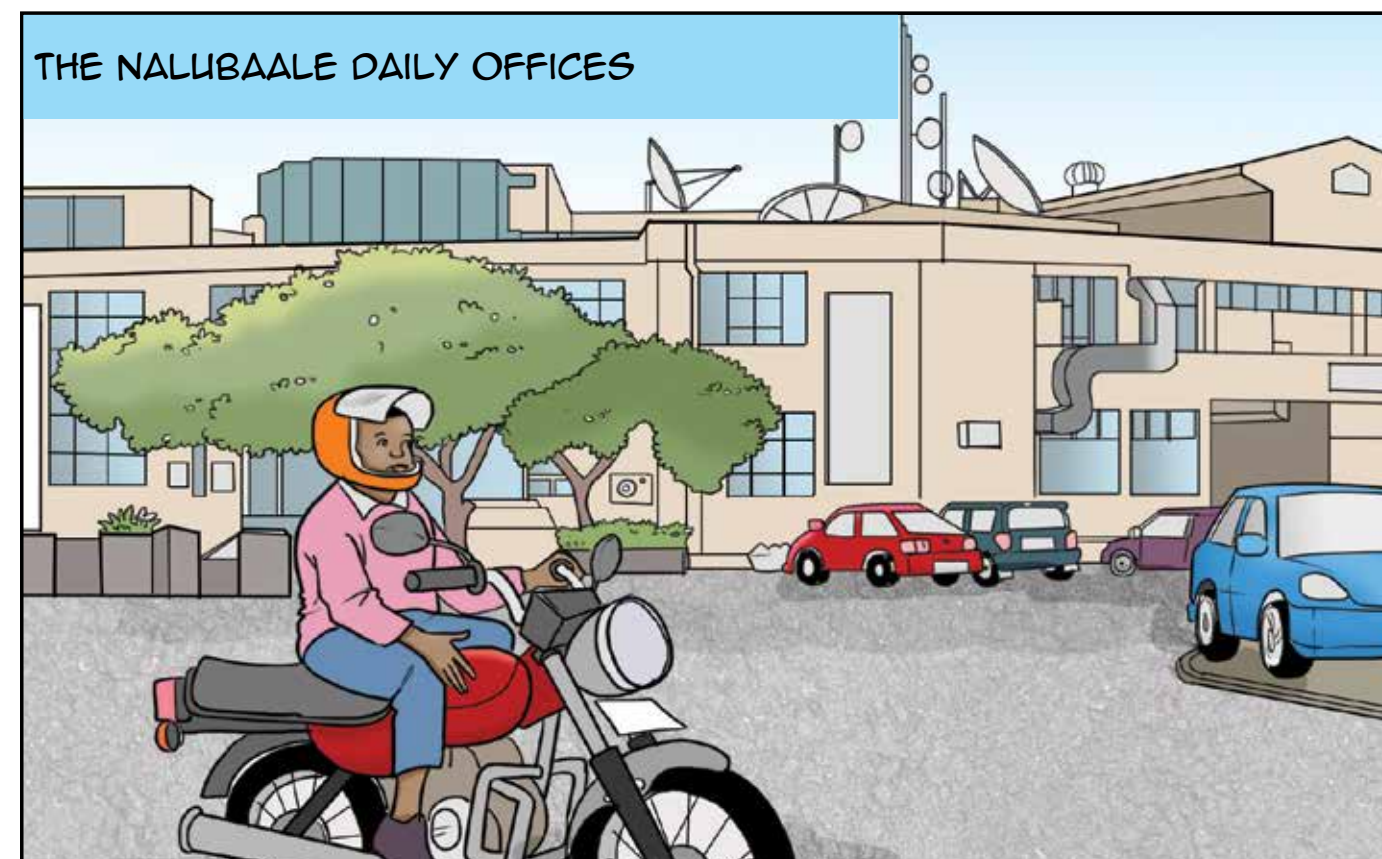


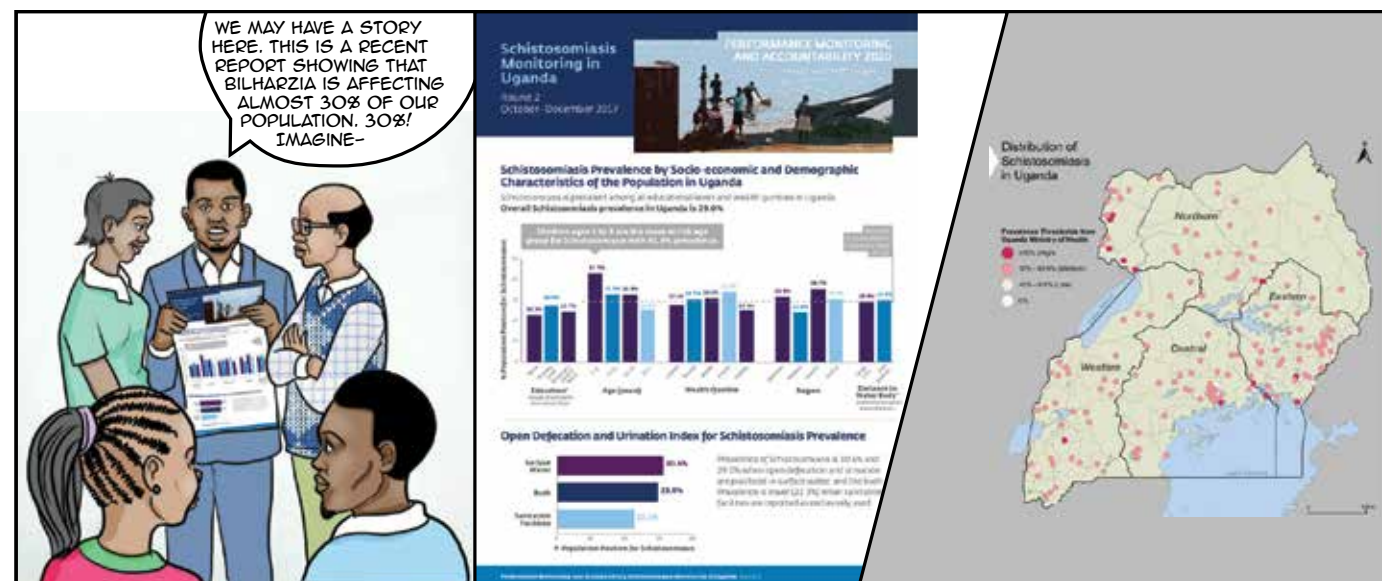
Weak Links:

The breakdown in Mass Drug Administration for Bilharzia



Artwork by Dianah Bwengye



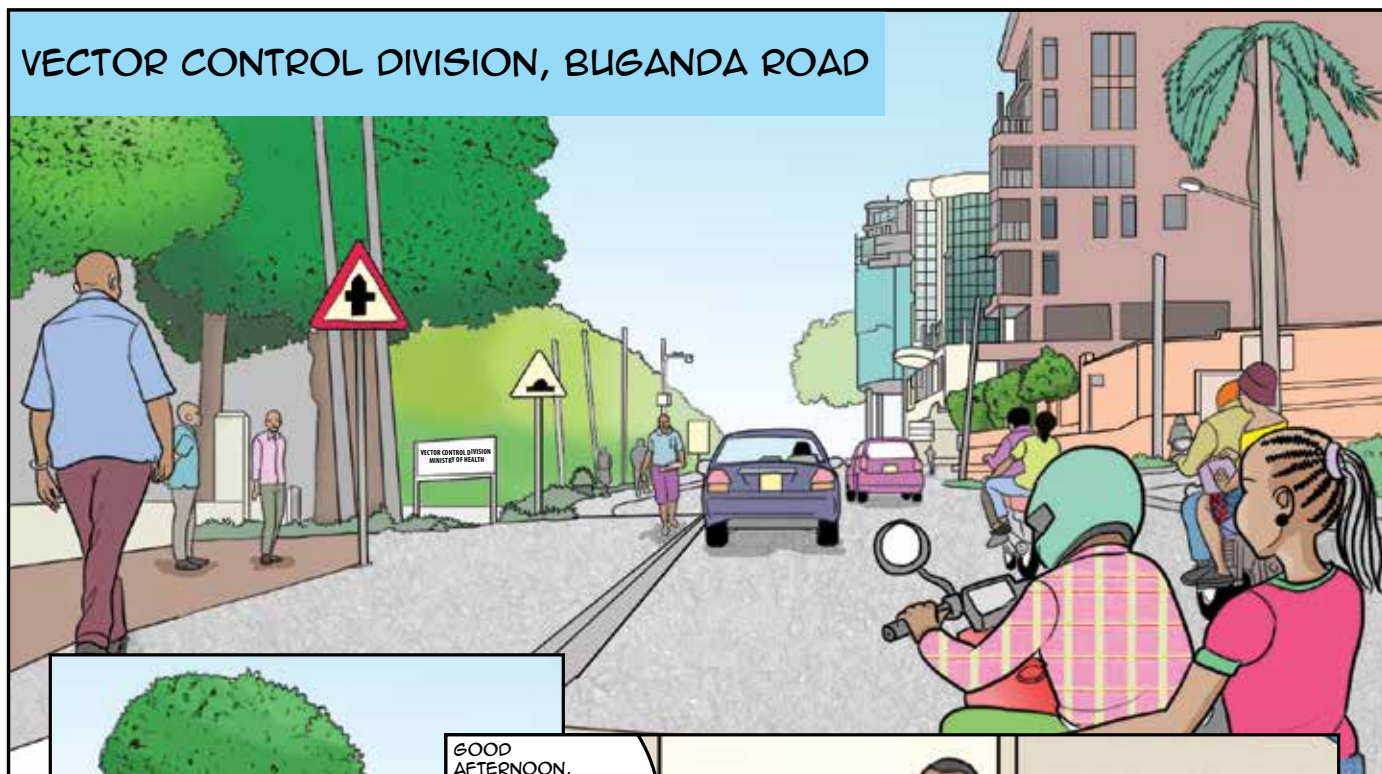


MY THOUGHTS EXACTLY. I DUG UP YOUR REPORT FROM 2003...

THERE WERE SEVERAL HIGH-PROFILE EVENTS AROUND THE ROLL OUT FOR MASS DRUG ADMINISTRATION IN DISTRICTS ACROSS UGANDA, ESPECIALLY THOSE WITH HIGH RATES OF INFECTION. SO WHY DIDN'T THE PROGRAMME WORK?



VECTOR CONTROL DIVISION, BUGANDA ROAD



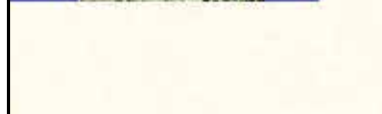
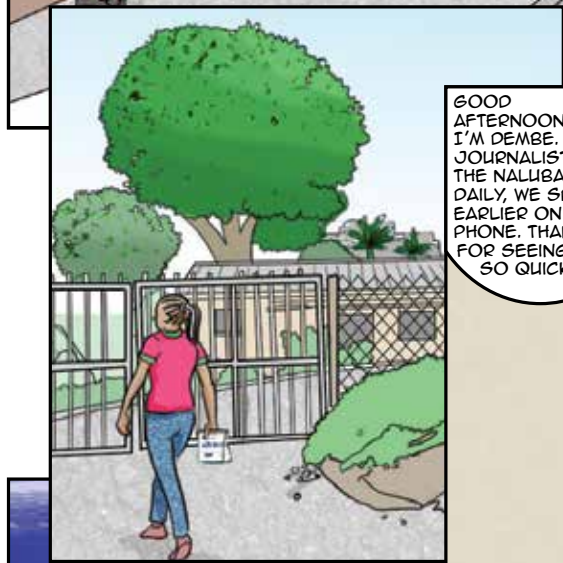
GOOD AFTERNOON, I'M DEMBE. I'M A JOURNALIST WITH THE NALUBAALE DAILY. WE SPOKE EARLIER ON THE PHONE. THANKS FOR SEEING ME SO QUICKLY.

VECTOR CONTROL DIVISION
MINISTRY OF HEALTH

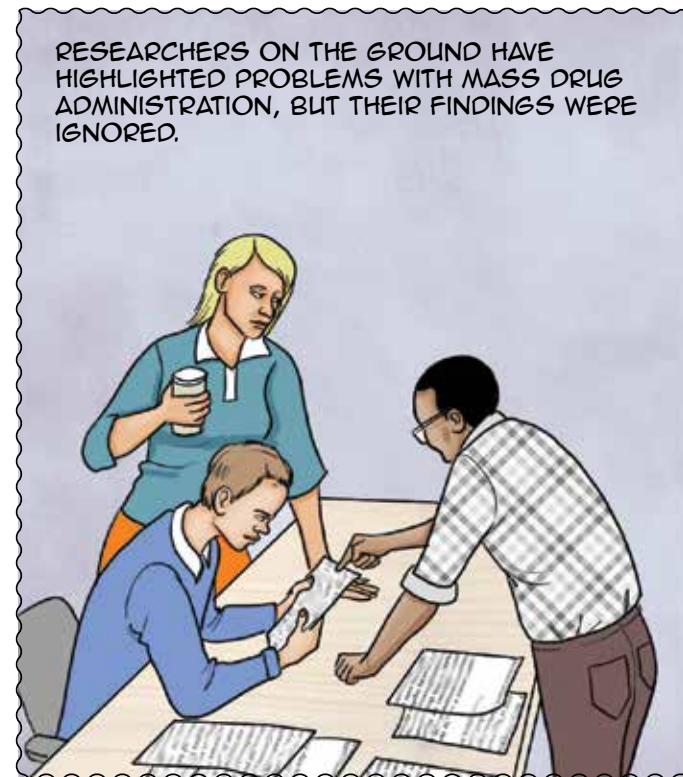
YES, YES, WELCOME. MY NAME IS KIBUKA MUTEBA, HEAD OF THE VECTOR CONTROL DIVISION WITH THE MINISTRY OF HEALTH.
NOW, HOW CAN I HELP YOU?

I'M WRITING A STORY ABOUT THE RISE OF BILHARZIA INFECTION RATES, BASED ON THIS REPORT. I UNDERSTAND YOU WERE HEAD OF THIS DIVISION WHEN THE NATIONAL PROGRAMME FOR BILHARZIA CONTROL STARTED. HOW IS IT THAT INFECTION RATES ARE NOW HIGHER? IT'S VERY TROUBLING.

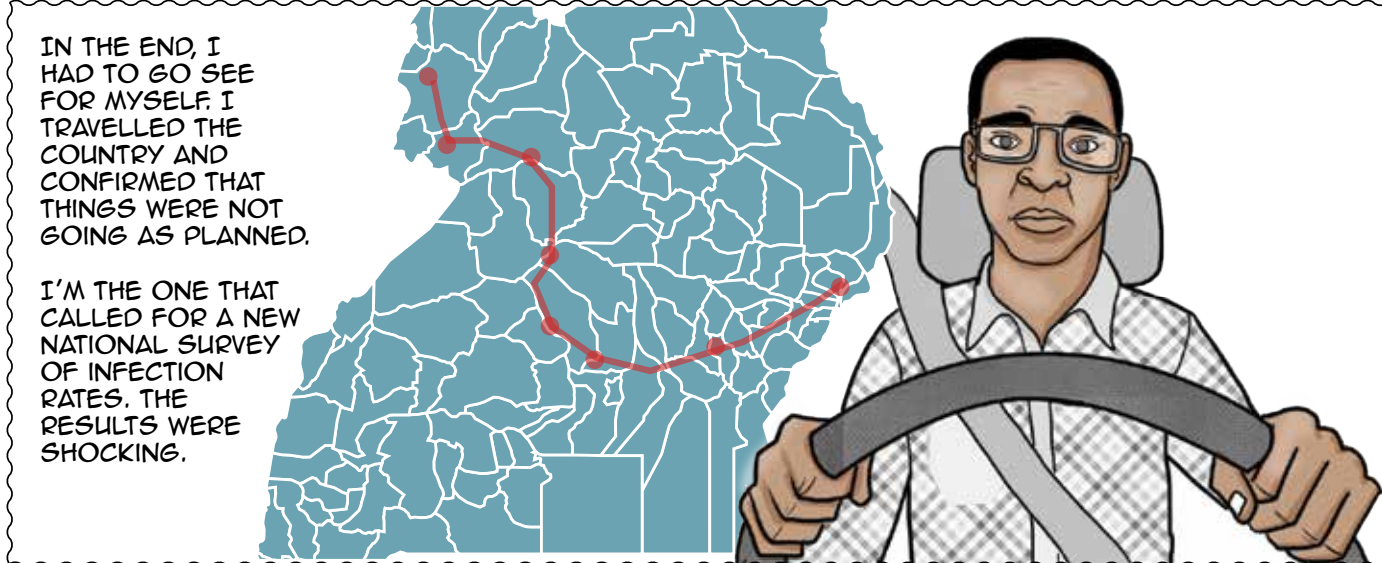
IT IS. YOU THINK MORE PEOPLE WOULD BE CONCERNED.



THE MINISTRY OF HEALTH PARTNERED WITH INTERNATIONAL DONORS TO DISTRIBUTE PRAZIQUANTEL, THE DRUG THAT TREATS SCHISTOSOMIASIS, COMMONLY CALLED BILHARZIA. PRAZIQUANTEL WAS DISTRIBUTED THROUGH UGANDAN AGENCIES TO PLACES WITH HIGH INFECTION RATES. THEY HAVE BEEN REPORTING THE PROGRAMME AS A SUCCESS, HOWEVER INFECTION RATES ARE STILL RISING

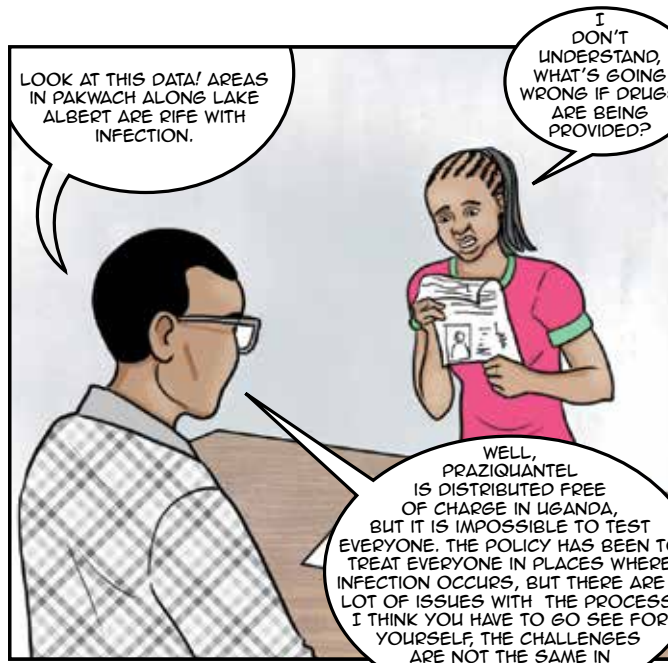
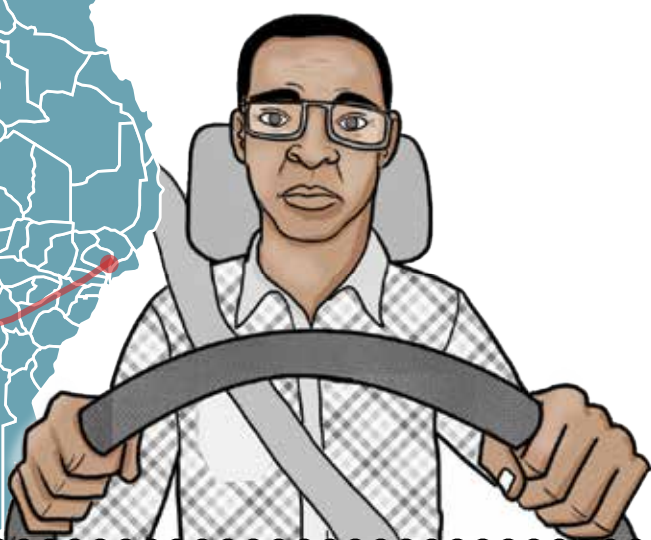
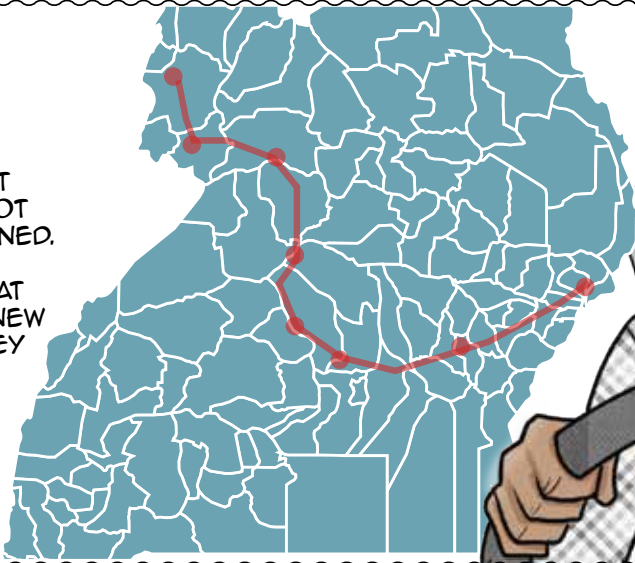


RESEARCHERS ON THE GROUND HAVE HIGHLIGHTED PROBLEMS WITH MASS DRUG ADMINISTRATION, BUT THEIR FINDINGS WERE IGNORED.



IN THE END, I HAD TO GO SEE FOR MYSELF. I TRAVELLED THE COUNTRY AND CONFIRMED THAT THINGS WERE NOT GOING AS PLANNED.

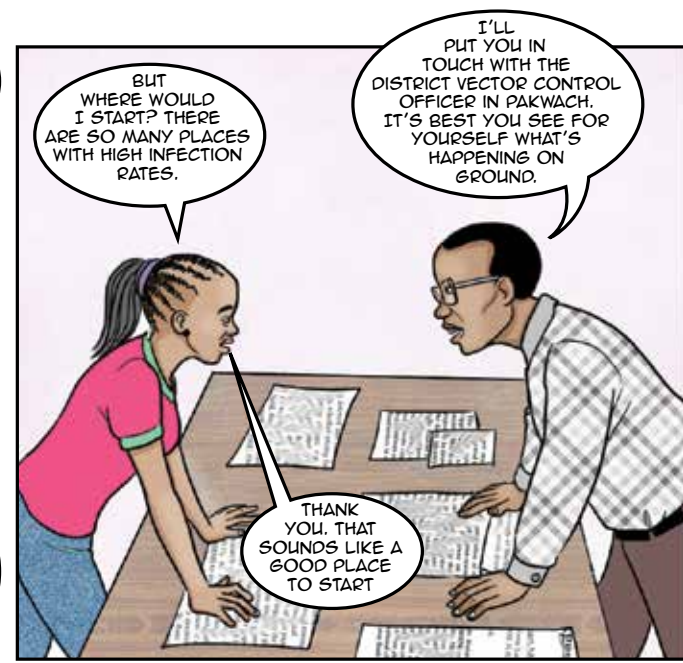
I'M THE ONE THAT CALLED FOR A NEW NATIONAL SURVEY OF INFECTION RATES. THE RESULTS WERE SHOCKING.



LOOK AT THIS DATA! AREAS IN PAKWACH ALONG LAKE ALBERT ARE RIFE WITH INFECTION.

I DON'T UNDERSTAND, WHAT'S GOING WRONG IF DRUGS ARE BEING PROVIDED?

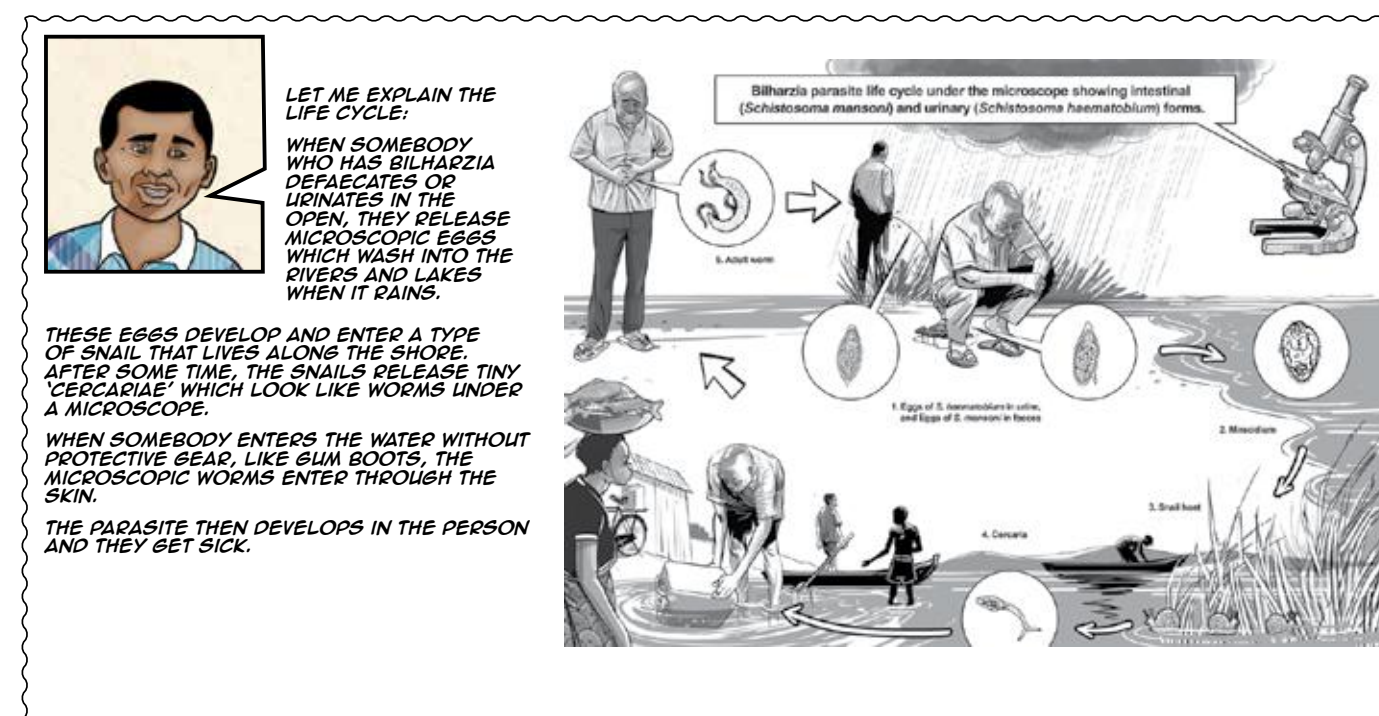
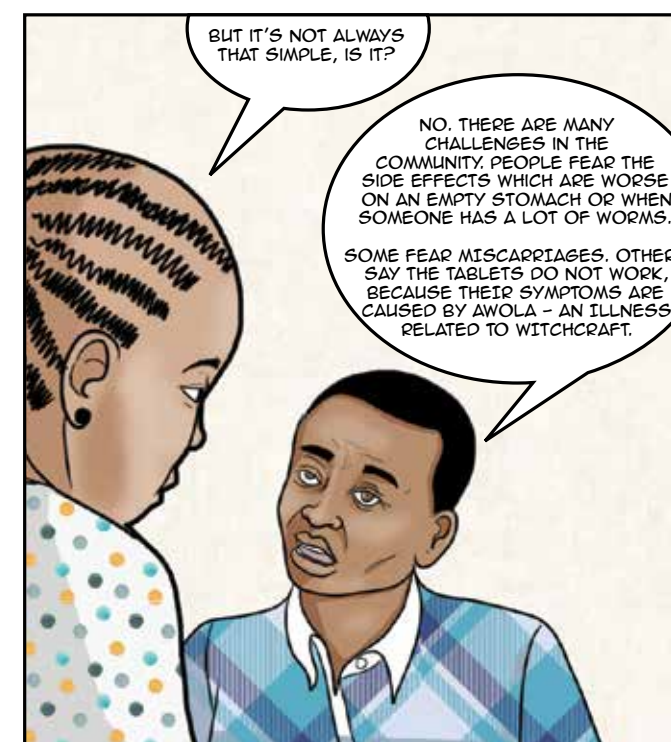
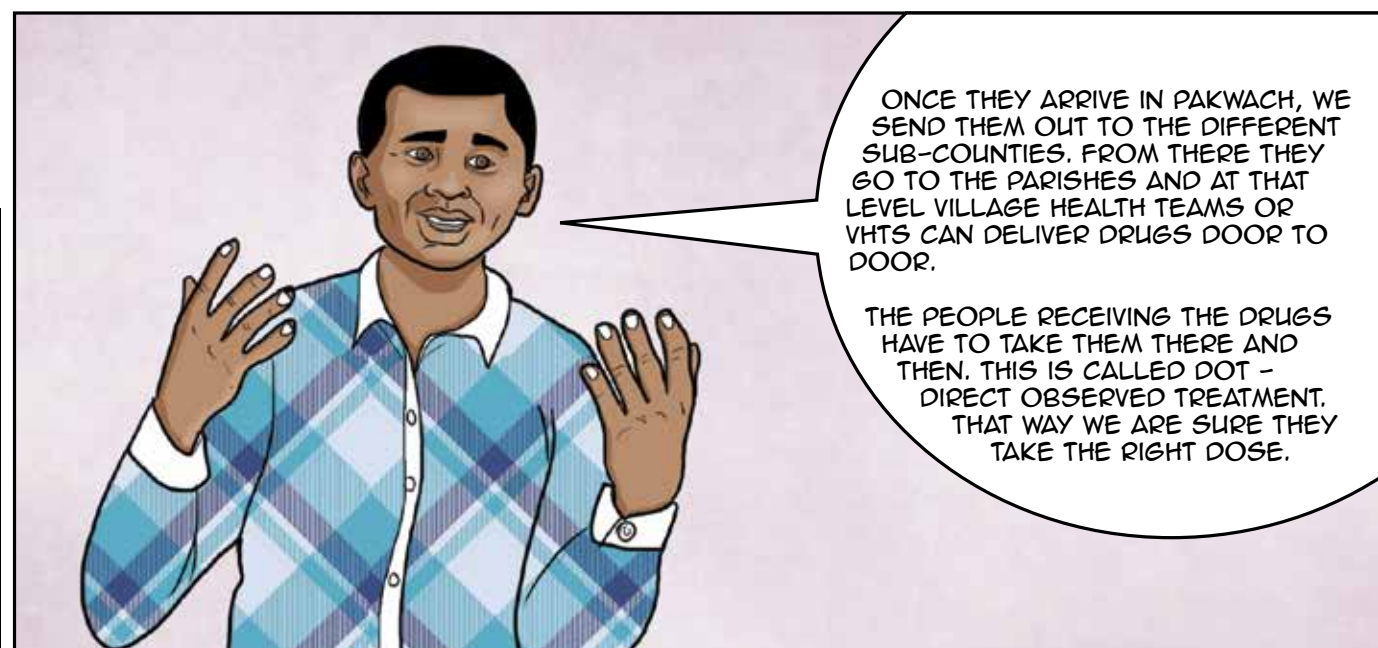
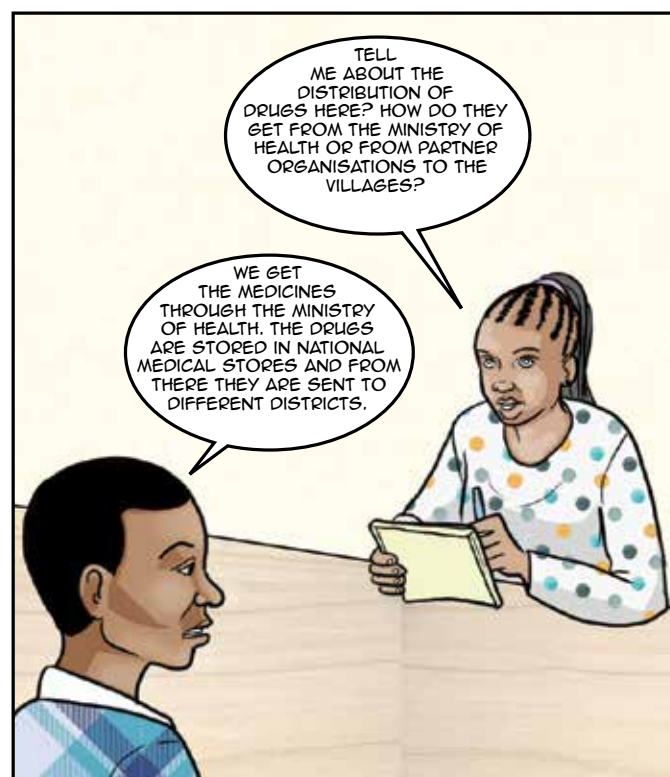
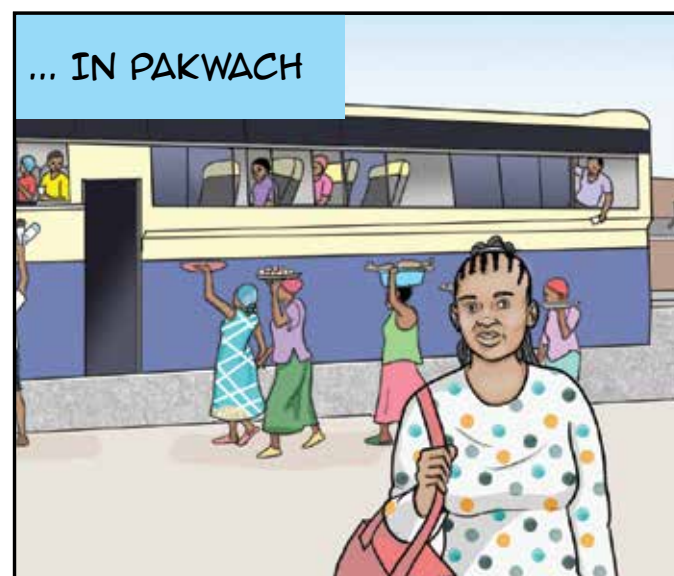
WELL, PRAZIQUANTEL IS DISTRIBUTED FREE OF CHARGE IN UGANDA, BUT IT IS IMPOSSIBLE TO TEST EVERYONE. THE POLICY HAS BEEN TO TREAT EVERYONE IN PLACES WHERE INFECTION OCCURS, BUT THERE ARE A LOT OF ISSUES WITH THE PROCESS. I THINK YOU HAVE TO GO SEE FOR YOURSELF, THE CHALLENGES ARE NOT THE SAME IN EVERY AREA.

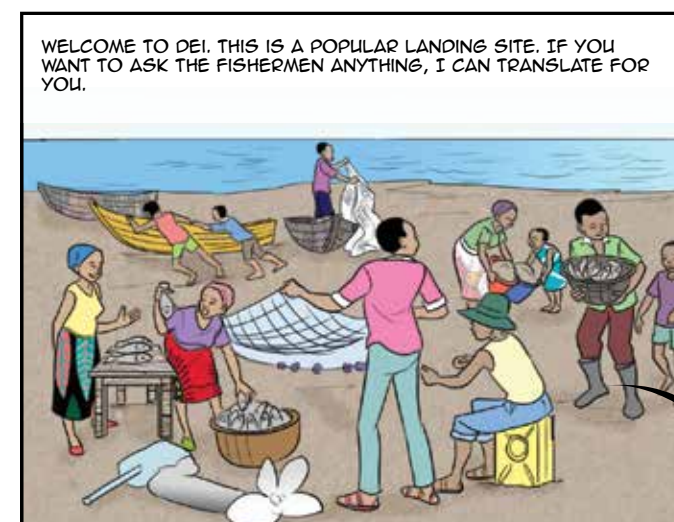
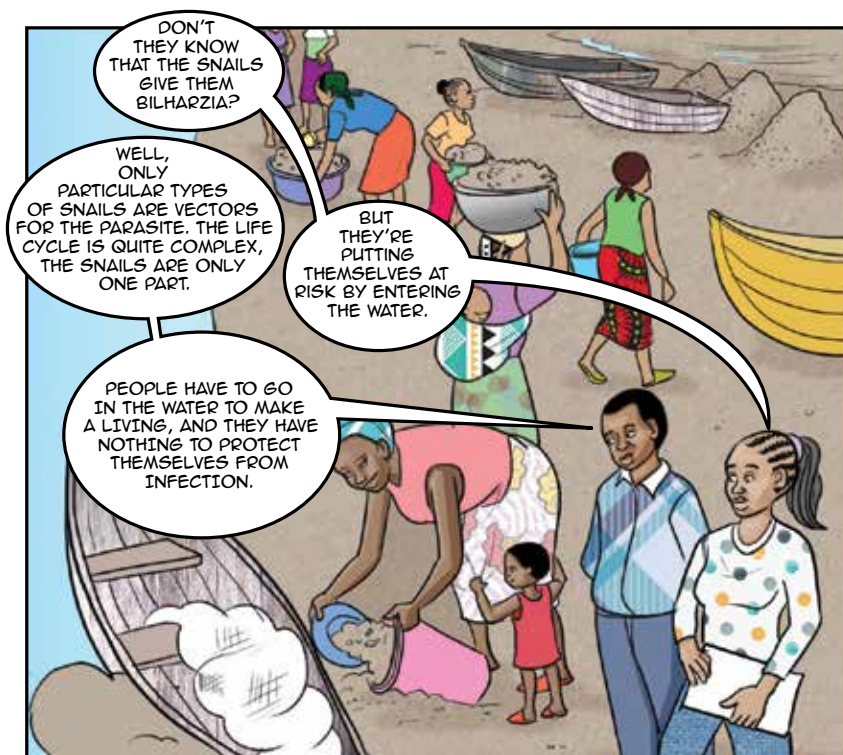
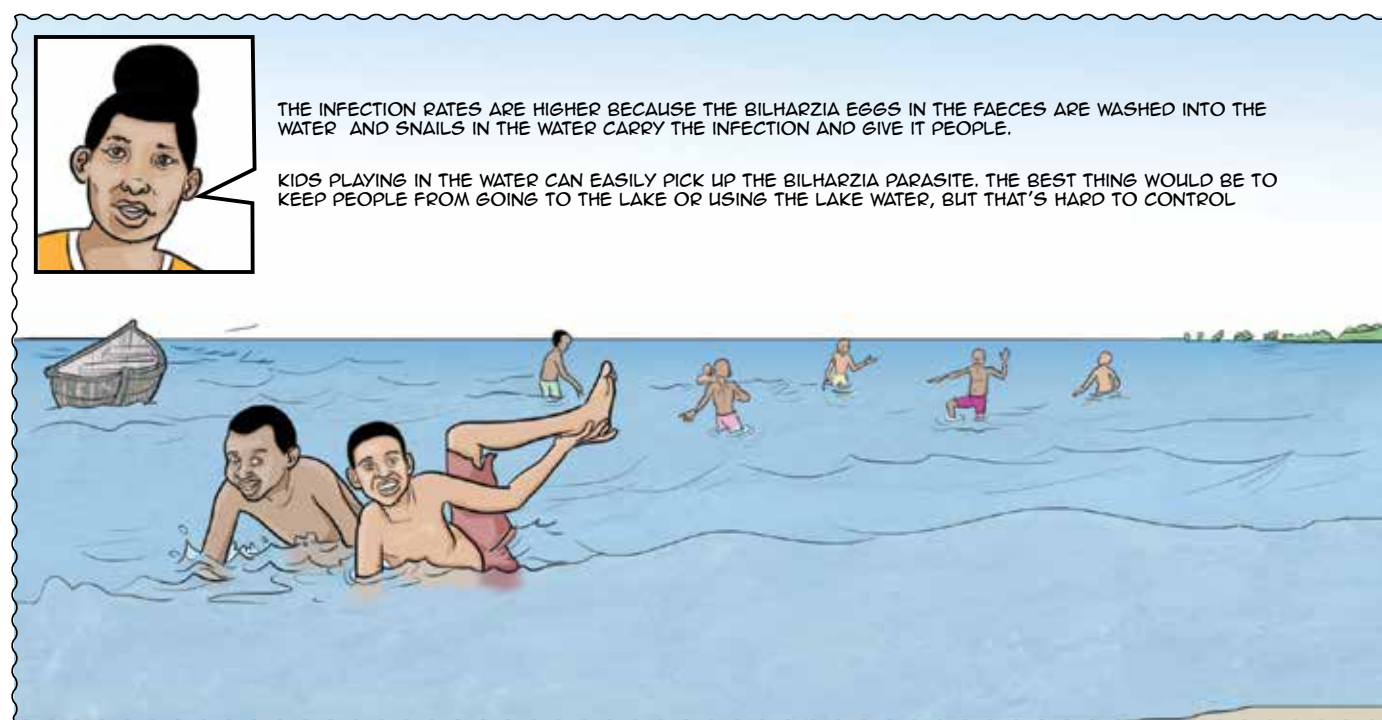


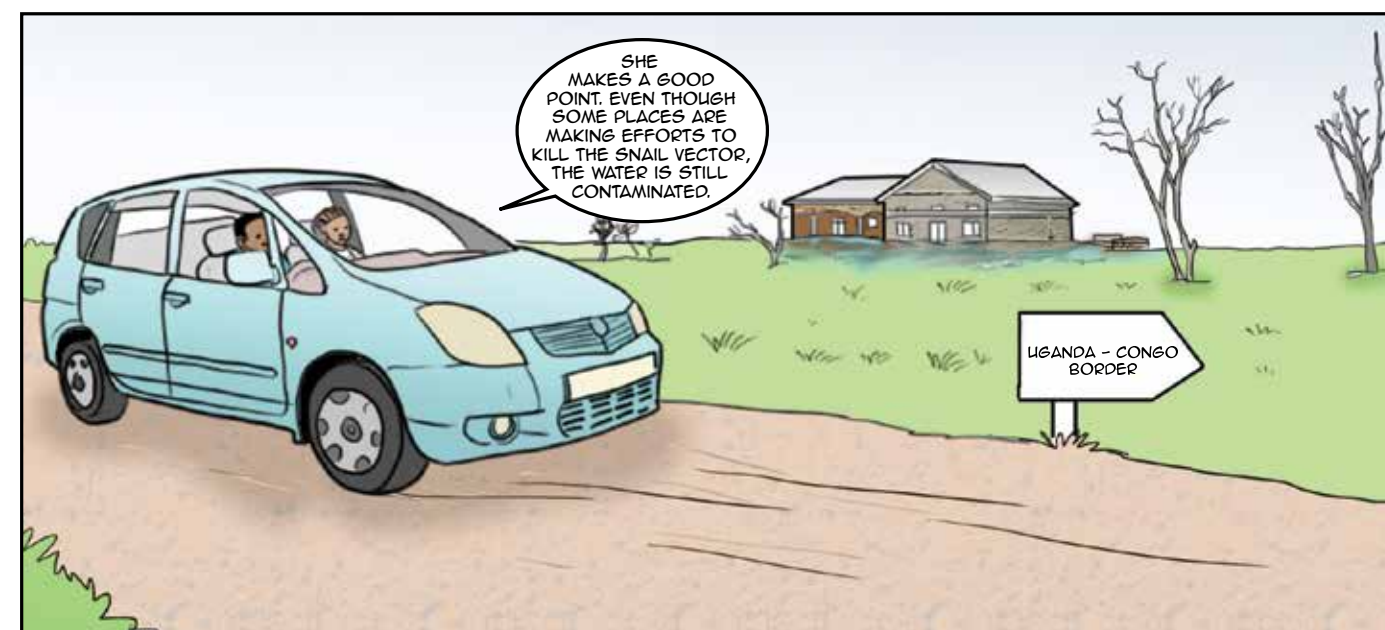
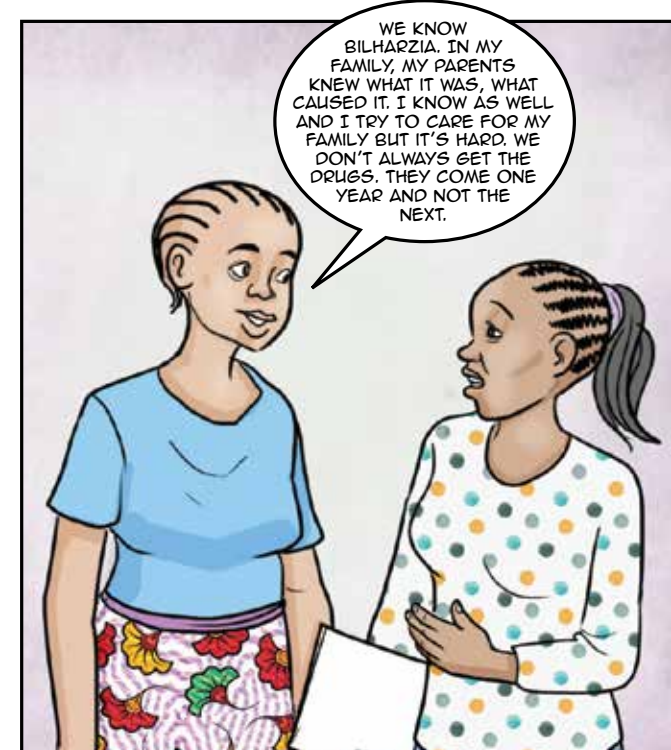
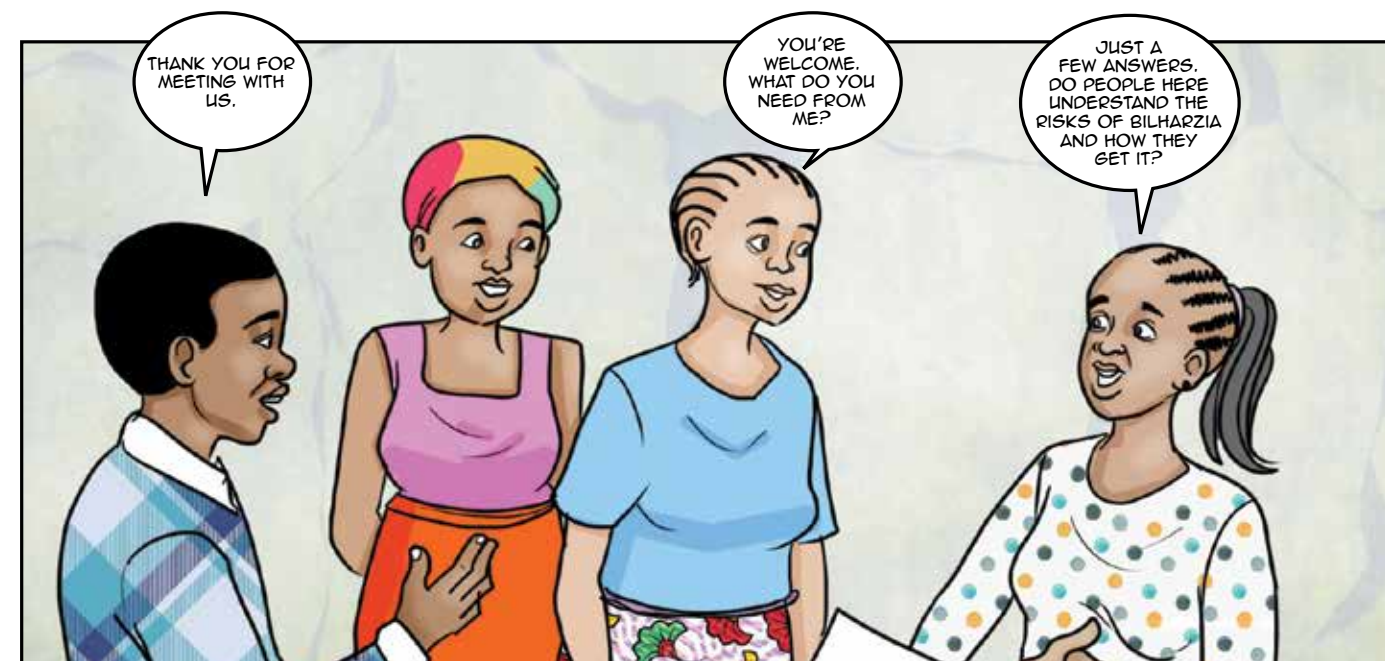
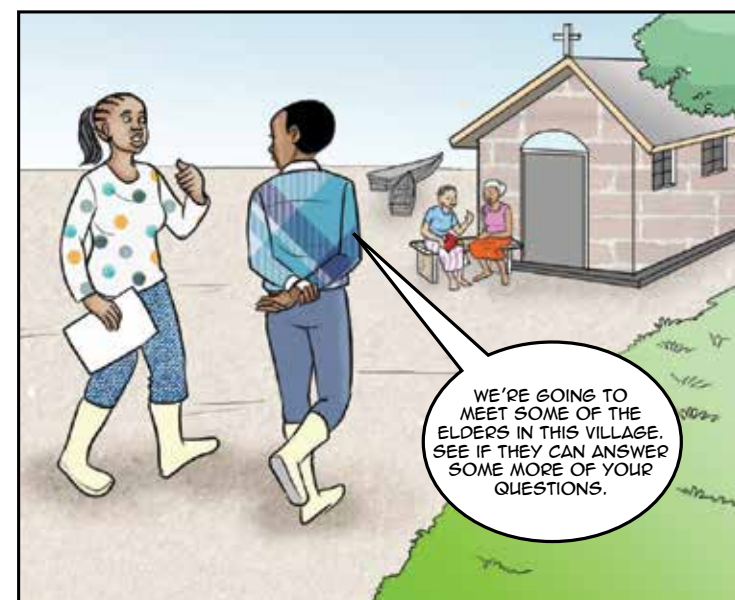
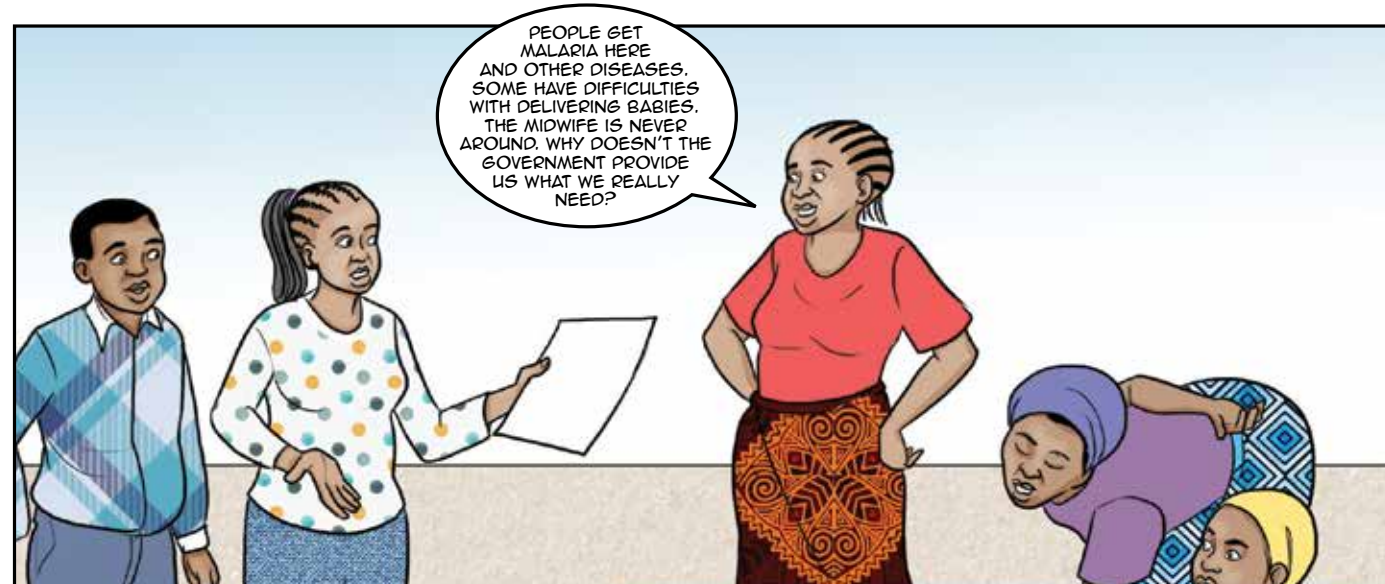
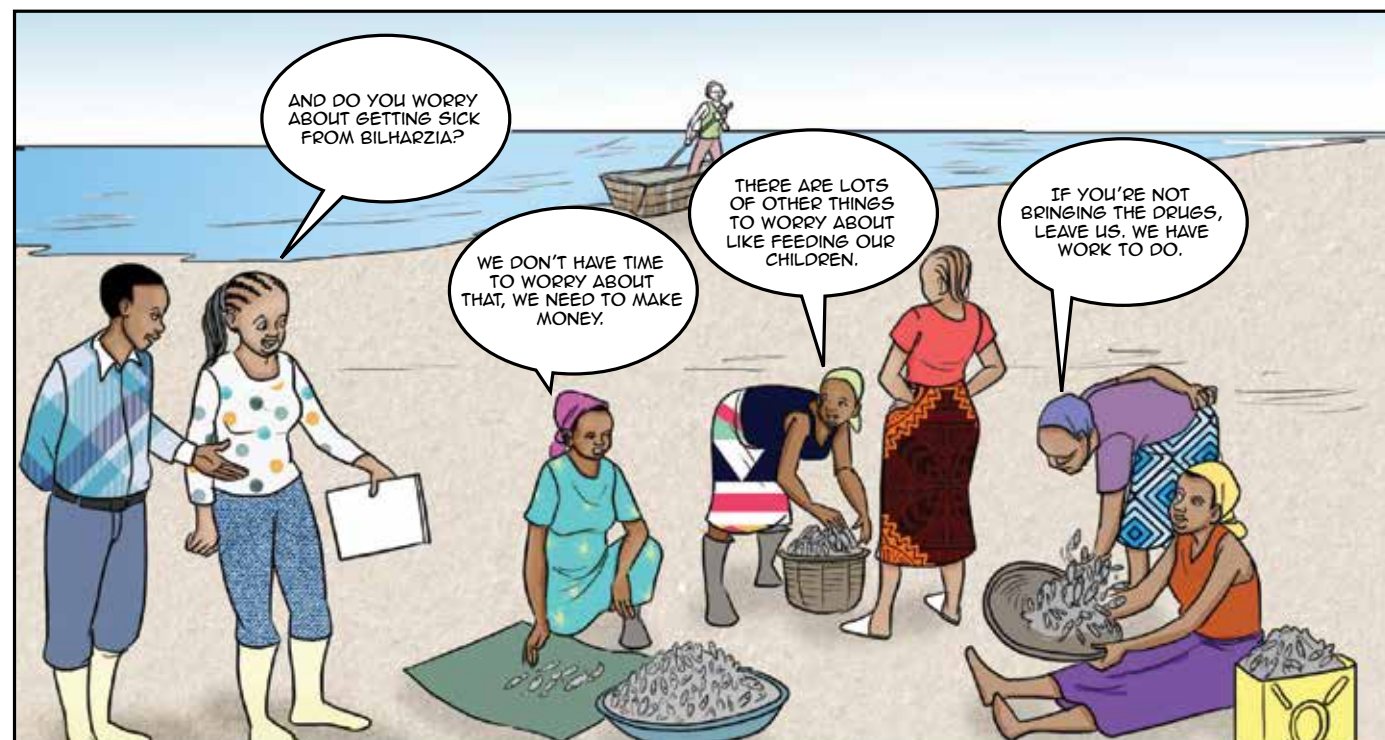
BUT WHERE WOULD I START? THERE ARE SO MANY PLACES WITH HIGH INFECTION RATES.

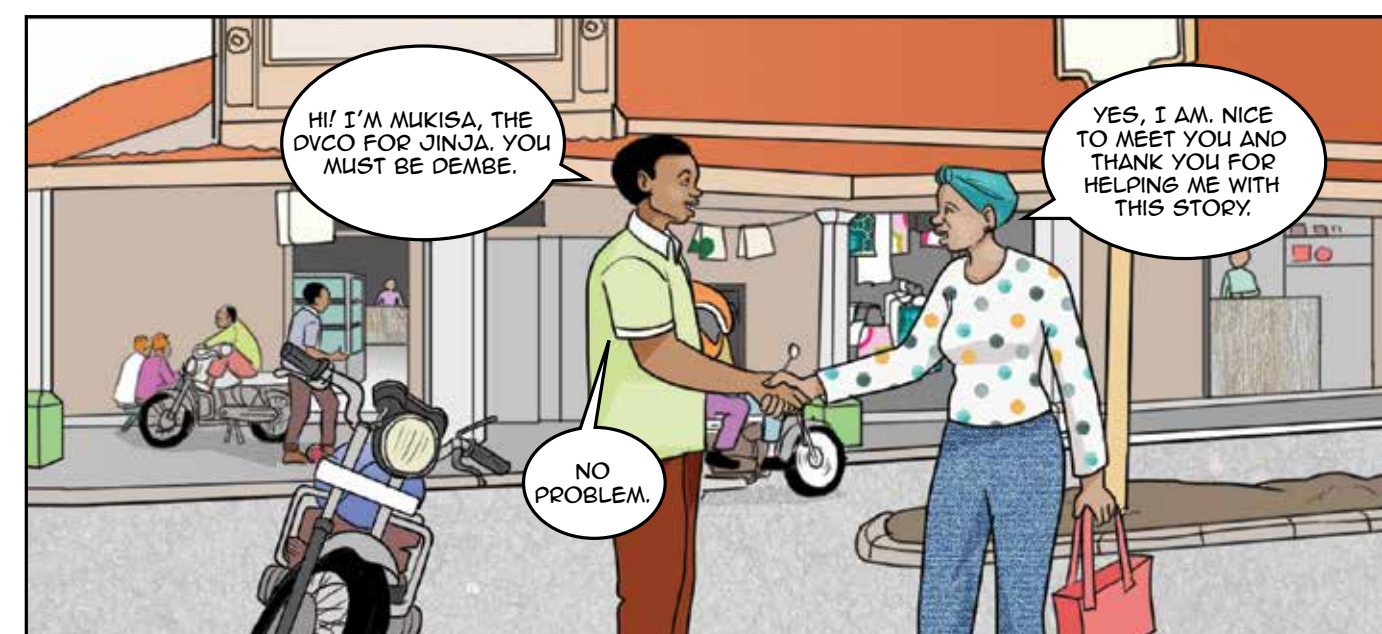
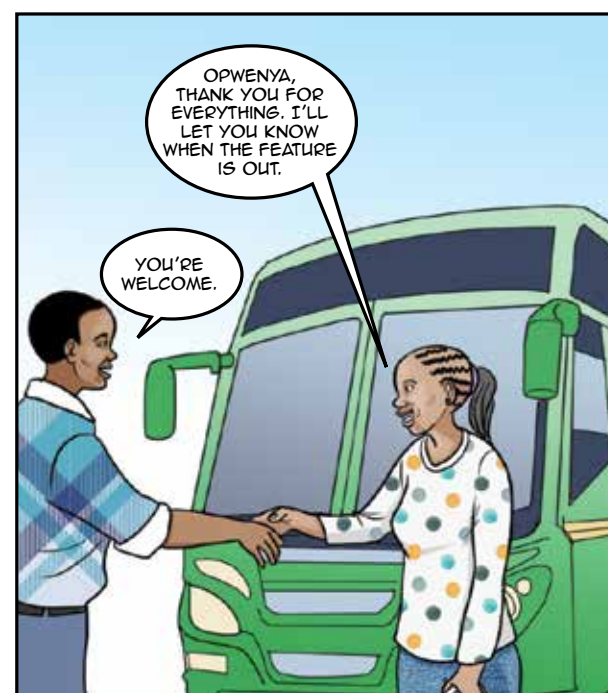
I'LL PUT YOU IN TOUCH WITH THE DISTRICT VECTOR CONTROL OFFICER IN PAKWACH. IT'S BEST YOU SEE FOR YOURSELF WHAT'S HAPPENING ON GROUND.

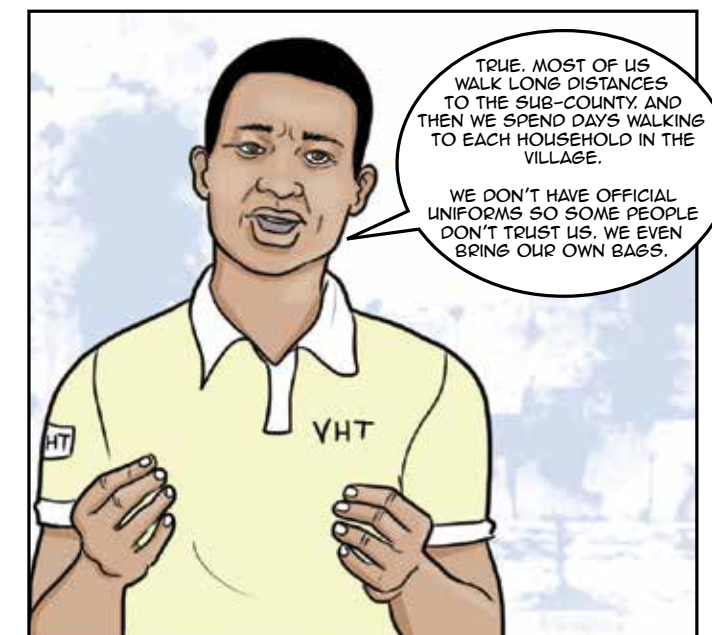
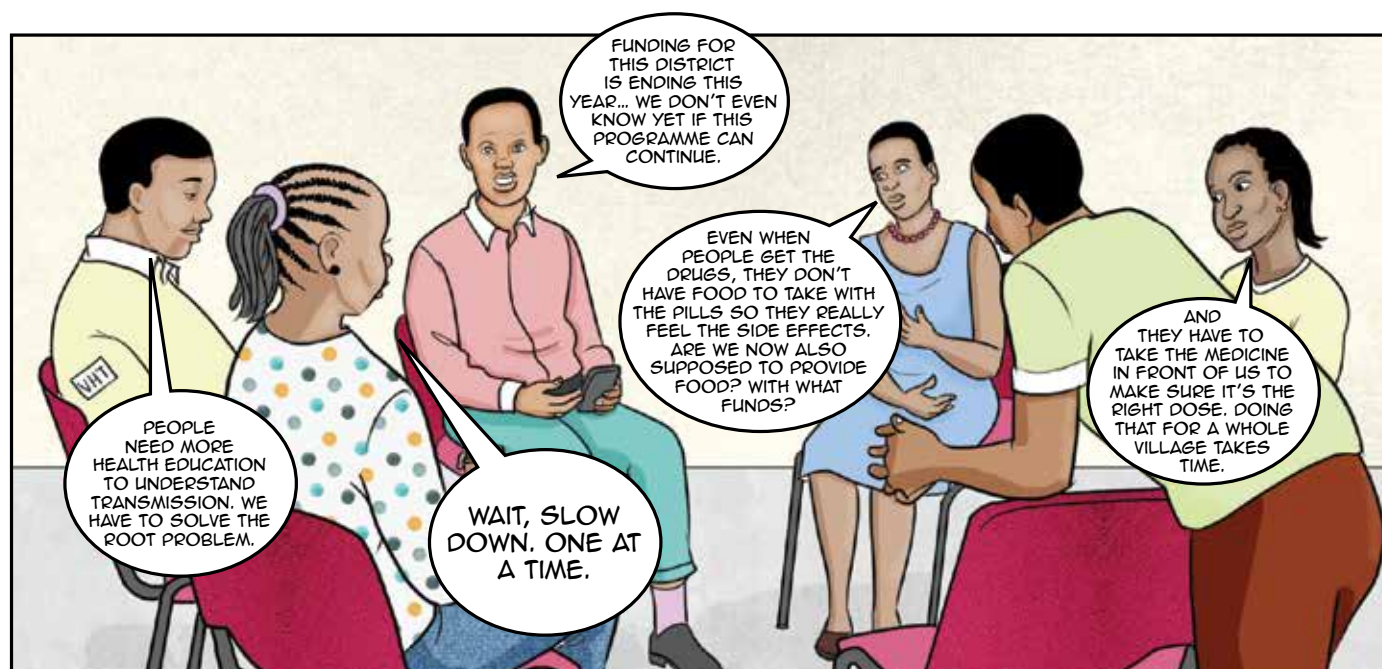
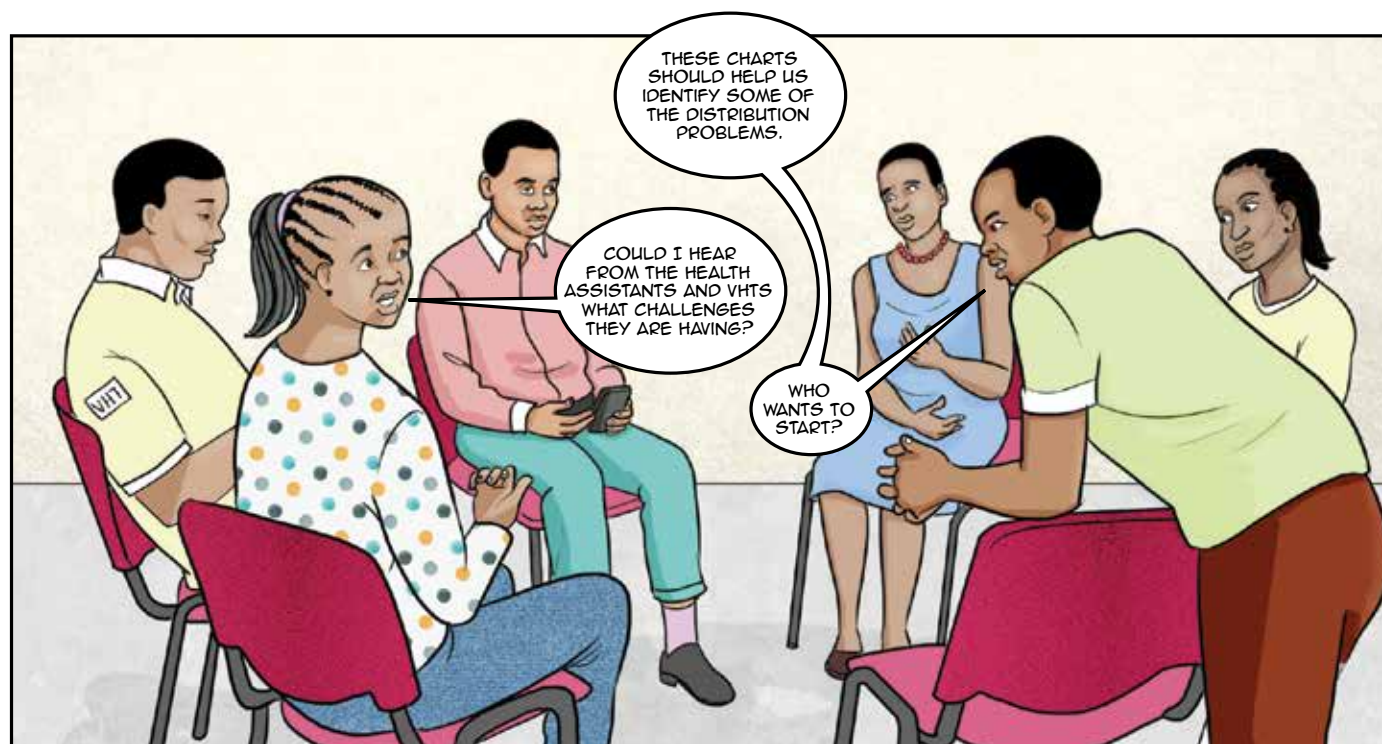
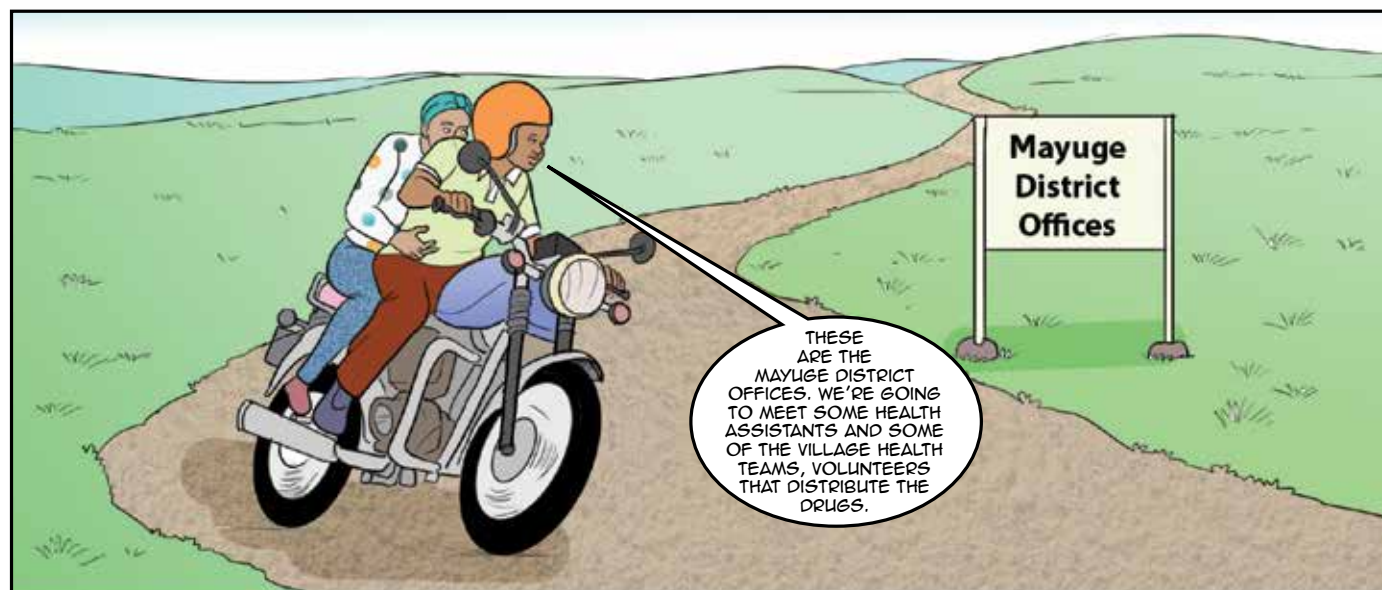
THANK YOU. THAT SOUNDS LIKE A GOOD PLACE TO START

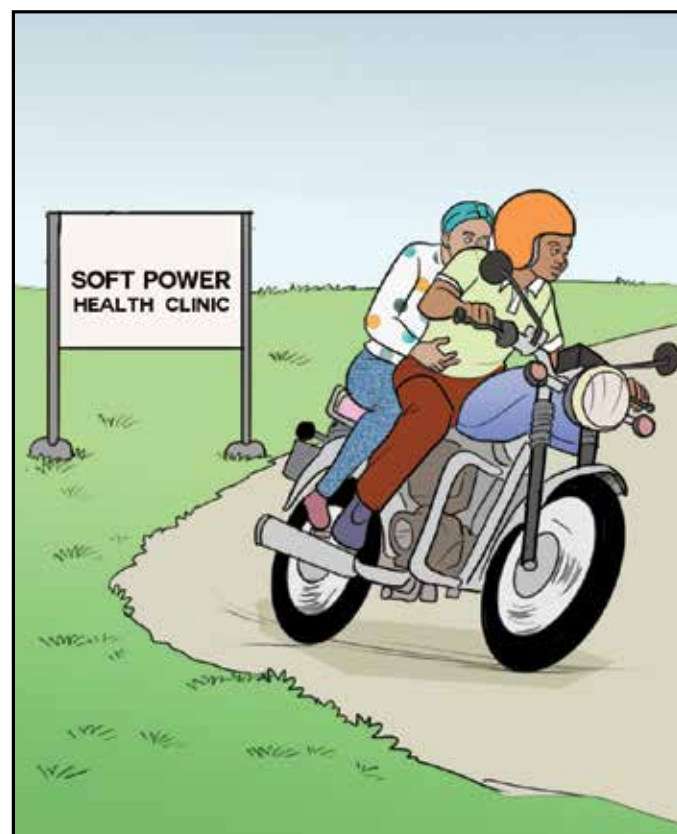
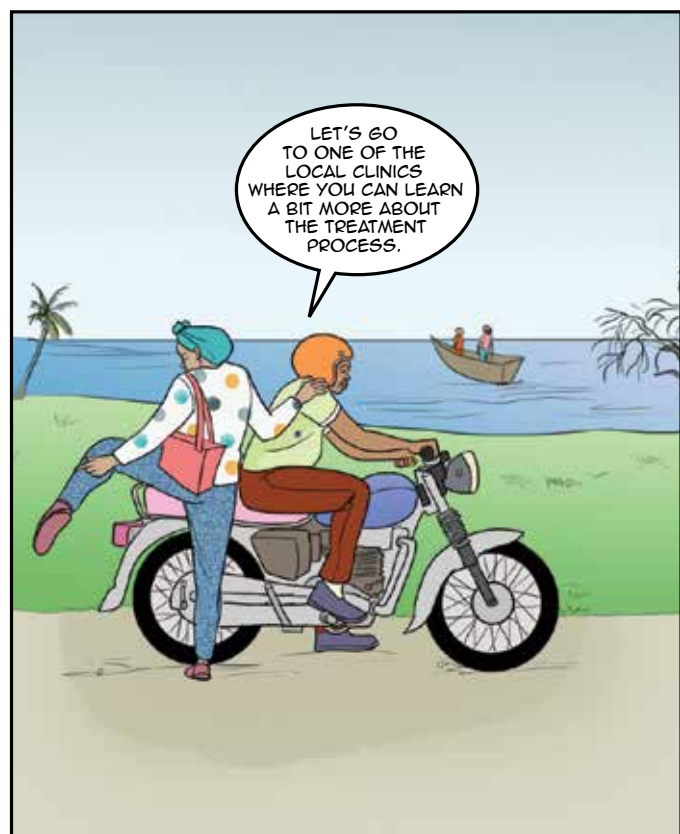
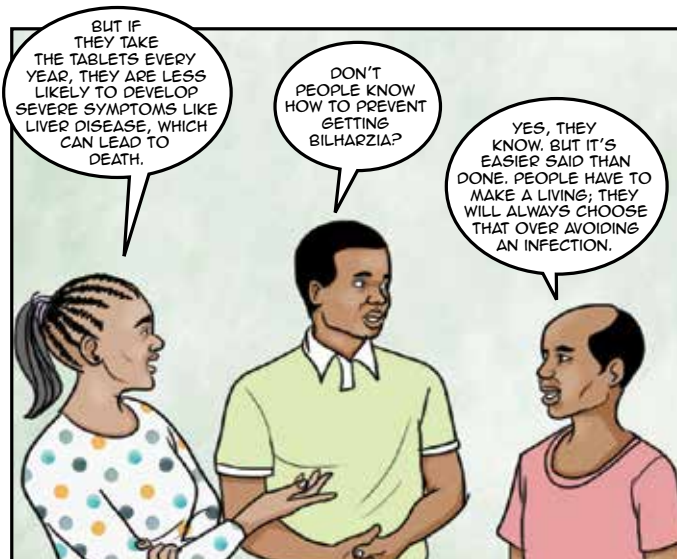
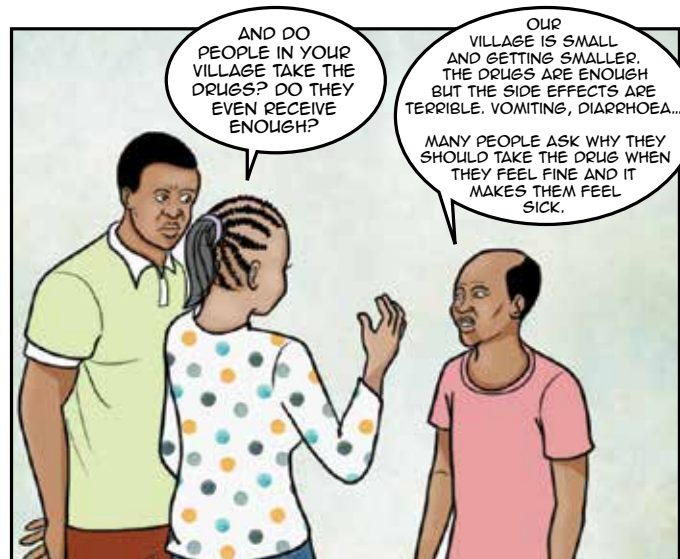
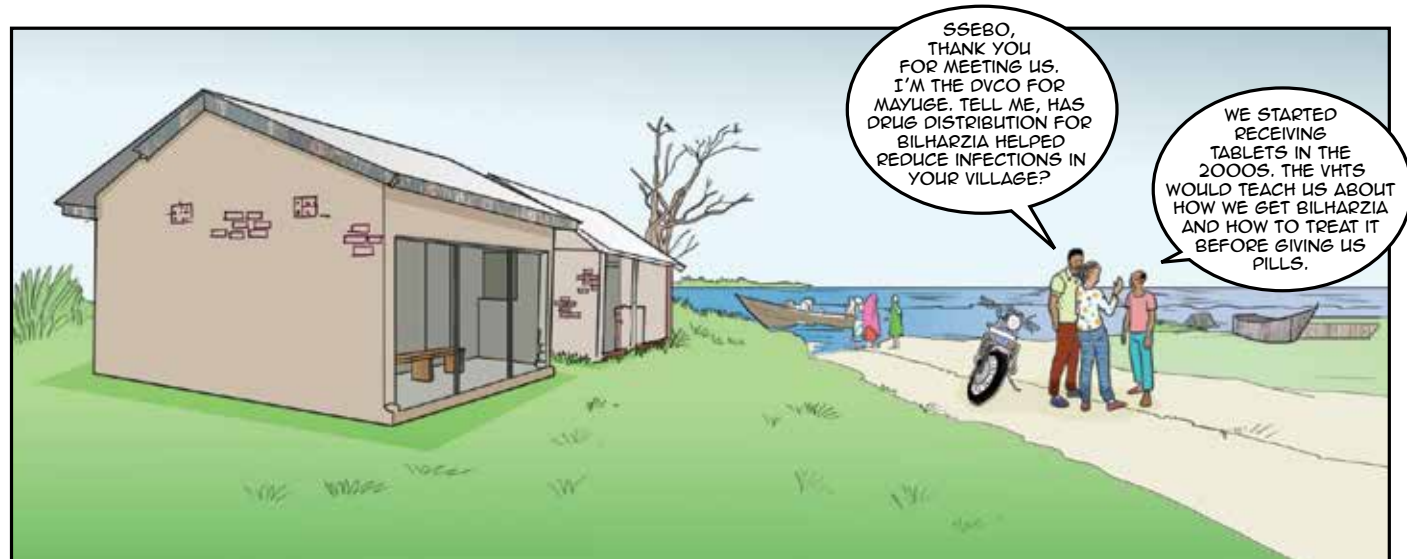


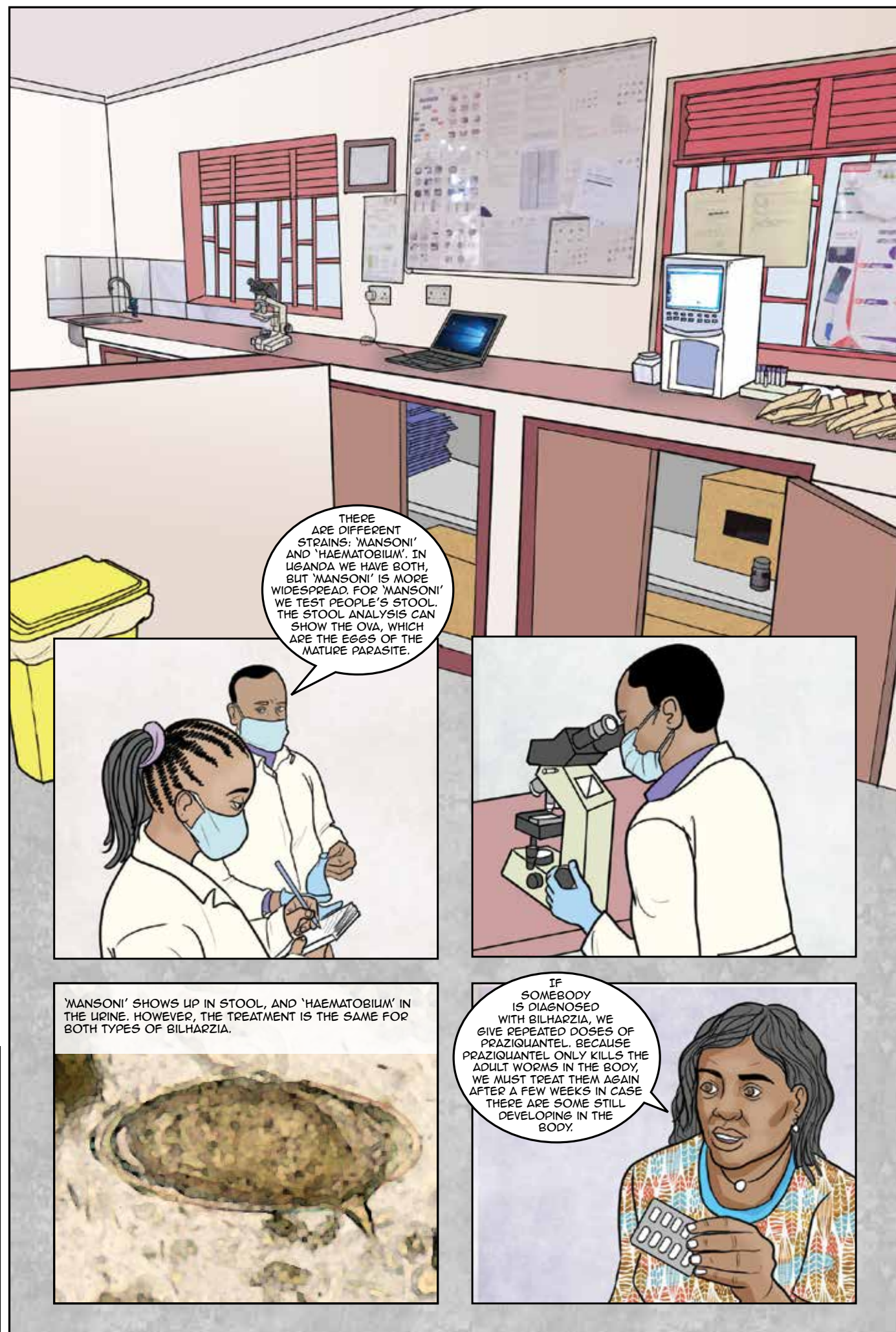


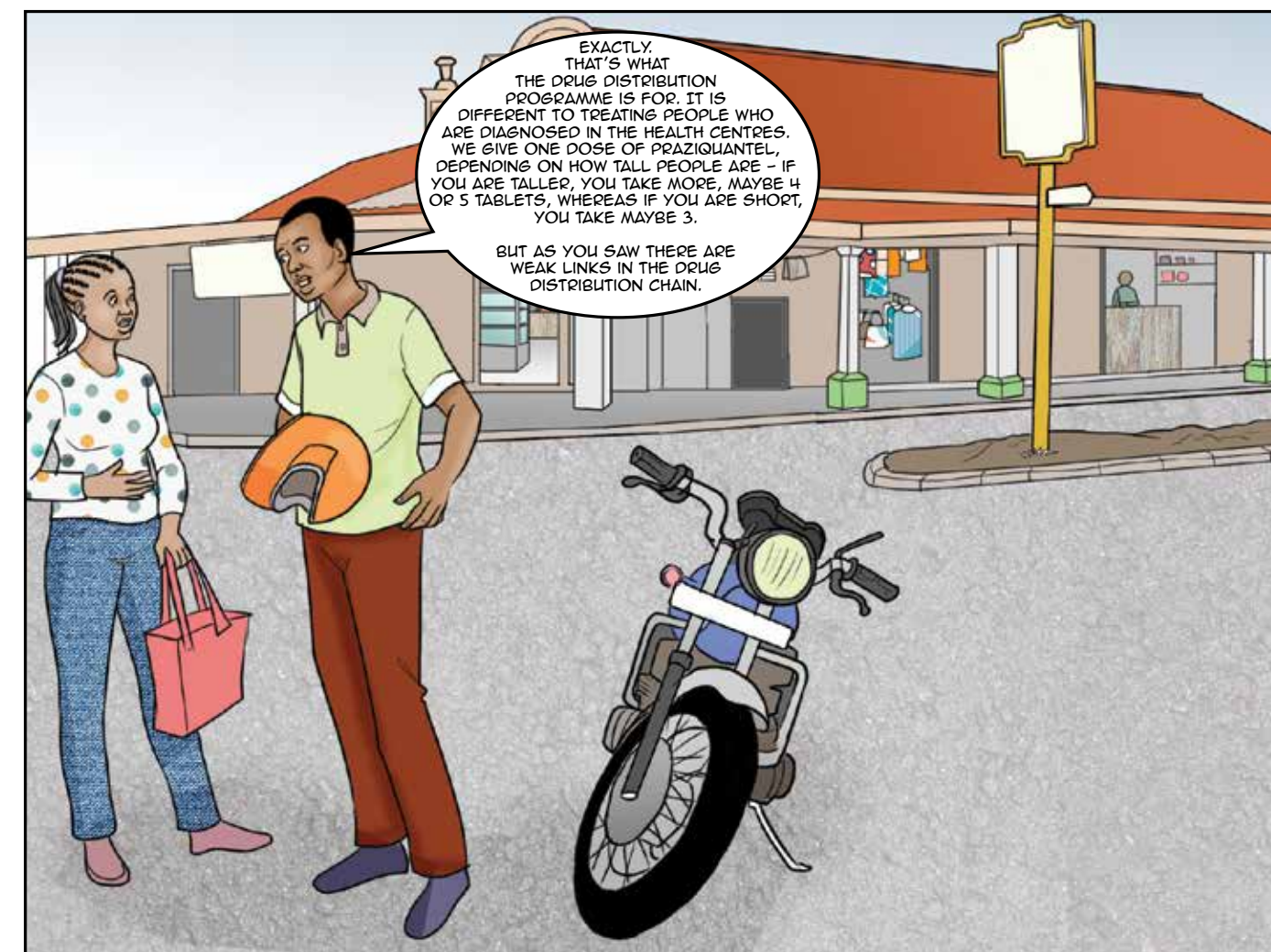














THANK YOU, I'LL BE THERE IN AN HOUR.



AFTER MY TRIPS TO JINJA AND PAKWACH IT BECAME CLEAR WHY THE NATIONAL PROGRAMME FAILED.

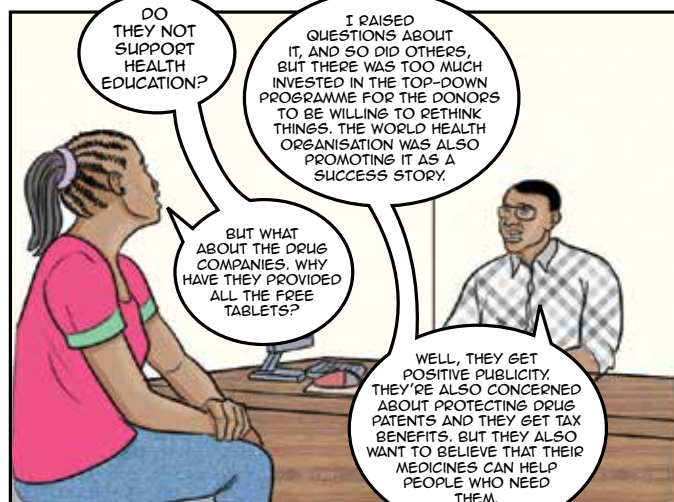
I ALSO FOUND AN INTERVIEW WITH YOU FROM 2009 WHERE YOU EXPLAINED THE PROBLEMS. WHY DID NOTHING CHANGE THEN?

I GOT INTO LOTS OF TROUBLE WITH THE BIG INTERNATIONAL DONORS FOR GIVING THAT INTERVIEW.



YOU SEE, THE INTERNATIONAL DONORS WERE OFFERING FUNDING AND MEDICINE, AND THEY WANTED QUICK RESULTS. THEY WERE NOT VERY INTERESTED IN THINGS LIKE HEALTH EDUCATION, AND EXPECTED PEOPLE WOULD BE EAGER TO SWALLOW TABLETS.

MONITORING WAS ALL ABOUT TABLETS ARRIVING IN THE COUNTRY AND BEING SENT TO DISTRICTS. THERE WAS LITTLE ASSESSMENT OF ACTUAL DRUG CONSUMPTION.



DO THEY NOT SUPPORT HEALTH EDUCATION?

I RAISED QUESTIONS ABOUT IT, AND SO DID OTHERS, BUT THERE WAS TOO MUCH INVESTED IN THE TOP-DOWN PROGRAMME FOR THE DONORS TO BE WILLING TO RETHINK THINGS. THE WORLD HEALTH ORGANISATION WAS ALSO PROMOTING IT AS A SUCCESS STORY.

BUT WHAT ABOUT THE DRUG COMPANIES. WHY HAVE THEY PROVIDED ALL THE FREE TABLETS?

WELL, THEY GET POSITIVE PUBLICITY. THEY'RE ALSO CONCERNED ABOUT PROTECTING DRUG PATENTS AND THEY GET TAX BENEFITS. BUT THEY ALSO WANT TO BELIEVE THAT THEIR MEDICINES CAN HELP PEOPLE WHO NEED THEM.



WHAT DO YOU THINK NEEDS TO CHANGE?

WE NEED BASIC PRIMARY HEALTH CARE - WHERE WE HAVE THE EQUIPMENT TO DIAGNOSE THE DISEASE AND MEDICINE IN STOCK TO TREAT INFECTED PEOPLE - WITH A REFERRAL SYSTEM FOR THOSE WITH COMPLICATIONS. THEN WE COULD TEST PEOPLE BEFORE TREATING THEM.

WE ALSO NEED TO FOCUS ON CHILDREN UNDER FIVE YEARS. UP TO NOW, THEY HAVE NOT BEEN INCLUDED IN THE DRUG DISTRIBUTION PROGRAMME BECAUSE WE HAVE NOT HAD THE KIND OF TABLETS NEEDED FOR INFANTS. IF WE GET THEM IN THE FUTURE, WE CAN AIM TO PROTECT ALL CHILDREN, AND THAT SHOULD STOP MOST OF THEM HAVING SERIOUS SYMPTOMS IN LATER LIFE.



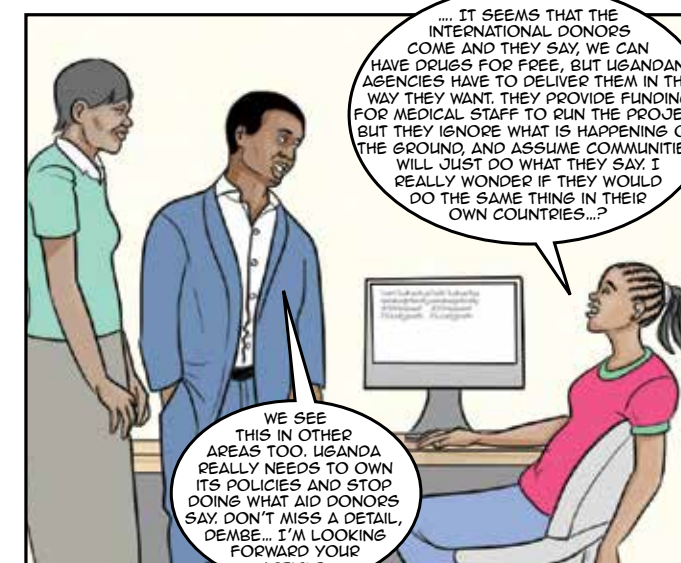
THAT IS WHAT THE GOVERNMENT IS NOW COMMITTED TO - UNIVERSAL HEALTH COVERAGE. WE HAVE TO MAKE OUR INTERNATIONAL COLLEAGUES UNDERSTAND THAT PROVIDING FREE DRUGS IN A WAY THAT CRIPPLES OUR SYSTEM DOESN'T WORK.

AND WILL USANDA'S AID DONORS ACCEPT THAT?



HOPEFULLY. SOMETIMES IT IS HARD TO CHANGE THINGS FROM INSIDE. THAT IS WHERE JOURNALISTS LIKE YOU CAN HELP US.

I SUPPOSE WE CAN AT LEAST TRY TO TELL THE FACTS AS THEY ARE, AND HOPE SOMEONE LISTENS.



... IT SEEMS THAT THE INTERNATIONAL DONORS COME AND THEY SAY, WE CAN HAVE DRUGS FOR FREE, BUT USANDAN AGENCIES HAVE TO DELIVER THEM IN THE WAY THEY WANT. THEY PROVIDE FUNDING FOR MEDICAL STAFF TO RUN THE PROJECT, BUT THEY IGNORE WHAT IS HAPPENING ON THE GROUND, AND ASSUME COMMUNITIES WILL JUST DO WHAT THEY SAY. I REALLY WONDER IF THEY WOULD DO THE SAME THING IN THEIR OWN COUNTRIES...

WE SEE THIS IN OTHER AREAS TOO. USANDA REALLY NEEDS TO OWN ITS POLICIES AND STOP DOING WHAT AID DONORS SAY. DON'T MISS A DETAIL, DEMBE... I'M LOOKING FORWARD YOUR ARTICLE.



A biosocial schistosomiasis transmission diagram

-Georgina Pearson

As a neglected tropical disease, schistosomiasis (or Bilharzia as it is commonly known) is associated with poverty, predominantly affecting rural populations living in tropical and sub-tropical environments. Accurate prevalence data is hard to come by, however recent estimates from the World Health Organization suggest that over 290 million people worldwide required preventive chemotherapy in 2018 (WHO 2020). While preventive chemotherapy, the mass drug administration of praziquantel to populations living in high endemic areas, has been the predominant public health control strategy since the early 2000s, consensus is that sustained control, and potential elimination, of schistosomiasis cannot be achieved solely through the mass distribution of praziquantel (Tchuenté et al. 2017; Grimes et al. 2015). Transmission is influenced by factors beyond the biological, with disease patterns showing micro-geographical variations. Scholars have thus called for biosocial approaches to controlling the disease (Parker, Polman and Allen 2016), and the need to understand transmission within a broader biological and social context in the localities where the parasites and people co-exist (Pearson 2016).

Schistosomiasis transmission cycle diagrams used for public health education and promotion tend to focus on the biology of transmission, overlooking the social and structural aspects that enable and constrain transmission and control. Our previous and extensive research in Uganda since the early 2000s has clearly documented the implications – for both understanding transmission and seeking

control – of focusing narrowly on the vertical public health programme, without taking into account the broader context (Parker, Polman and Allen 2016; Pearson 2016). Furthermore, in 2019, as part of the Localised Evidence and Decision-making project (LEAD), we conducted a series of participatory systems mapping exercises with national and district staff involved in public health control of schistosomiasis in Uganda and Malawi to elicit local perspectives on schistosomiasis transmission. The maps produced clearly brought out broader and various factors relating to schistosomiasis transmission, with mass drug administration and access to praziquantel being one component, among many other interlinked components. Drawing on this work, we thus developed two interlinked diagrams that depict the biological and social dimensions of schistosomiasis transmission in a localised environment that would be useful as a public health tool for practitioners involved in the control of schistosomiasis at district level or equivalent.

Schistosomiasis transmission and the parasite life cycle

A number of species of schistosome cause disease in humans (*S. mansoni*, *S. haematobium*, *S. japonicum*, *S. mekongi* and *S. intercalatum*). Our diagram depicts *S. mansoni* and *S. haematobium*, the species that are endemic in Uganda and other sub-Saharan African countries. As depicted in the life cycle diagram, biologically, the transmission of *S. mansoni* and *S. haematobium* occurs when faeces and urine, respectively, containing the parasite eggs contaminate rivers and lakes [1] that contain the snail intermediate hosts (of the genera *Biomphalaria* for *S. mansoni* and *Bulinus* for *S. haematobium*). The eggs produce miracidia [2] that enter and develop inside the snails [3]. Subsequently, microscopic cercariae [4] are released into the water which enter the human body through the skin when a person

comes in contact with infested water. Within the human body, the cercariae migrate and develop into male and female adult worms [5], which reside in the intestinal and urinary venous systems and continue to release eggs into the intestinal and urinary tracts. Thus, the cycle continues when somebody with the parasite defecates or urinates in the open.

Transmission cycles focused on the microscopic components of the parasite life cycle have a tendency to present unrealistic depictions of the human interactions with the unseen parasite life cycle (Centers for Disease Control and Prevention n.d.; Downs et al. 2017, Figure 1). Two aspects were of particular concern that we aimed to address in developing the life cycle diagram. First, the depiction of enlarged cercariae entering people's legs in the water presents an image of a visible worm-like creature, despite cercariae being unseen to the naked eye. Second, the depiction of people defaecating and urinating outside and in the open is an unfavourable presentation of what is 'hidden' from view and shaped by necessity – people working where there is no access to safe water and sanitation in the vicinity of the shoreline. We present the scaled-up microscopic stages of the parasite's life cycle within a scene of life and living along the lake and river shores in northwest Uganda.

The Bilharzia parasite life cycle diagram was developed to show the parasite life cycle alongside broader aspects of schistosomiasis transmission, encompassing aspects of everyday life and livelihoods at river and lakeshores, depicting water contact and activities relating to water, sanitation and hygiene. The Schistosomiasis transmission illustration depicts life near the water and the various activities that occur in proximity to the shoreline that enable transmission. In doing so, it highlights water contact and open defecation/urination alongside the need for diagnosis and treatment (including, but beyond mass drug administration) through the primary health care system. These various

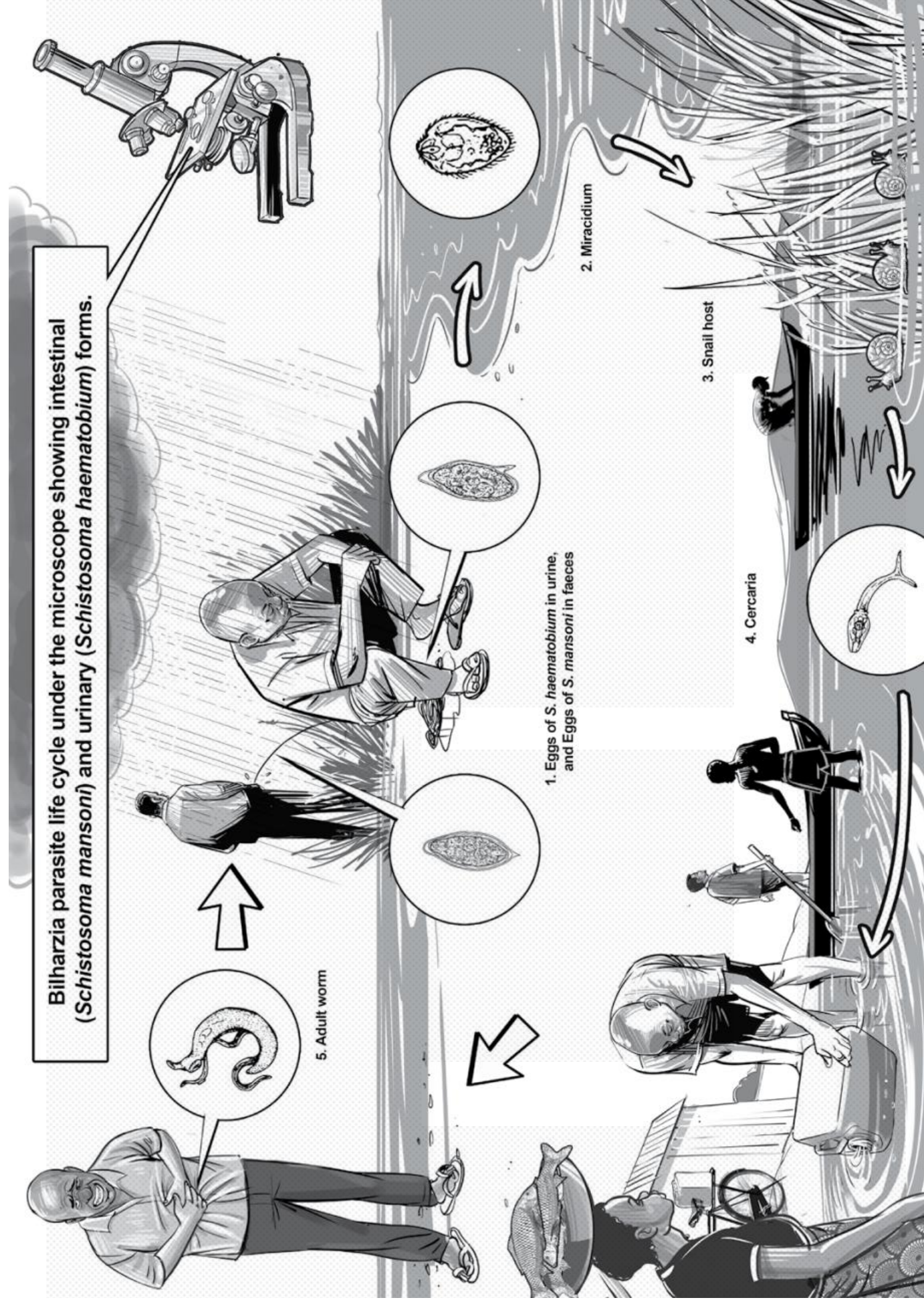
preventive structures (access to safe water, sanitation facilities and primary healthcare) tend to be at a distance to shoreline locations where daily activities take place – a distancing which thus impacts on transmission and limits control.

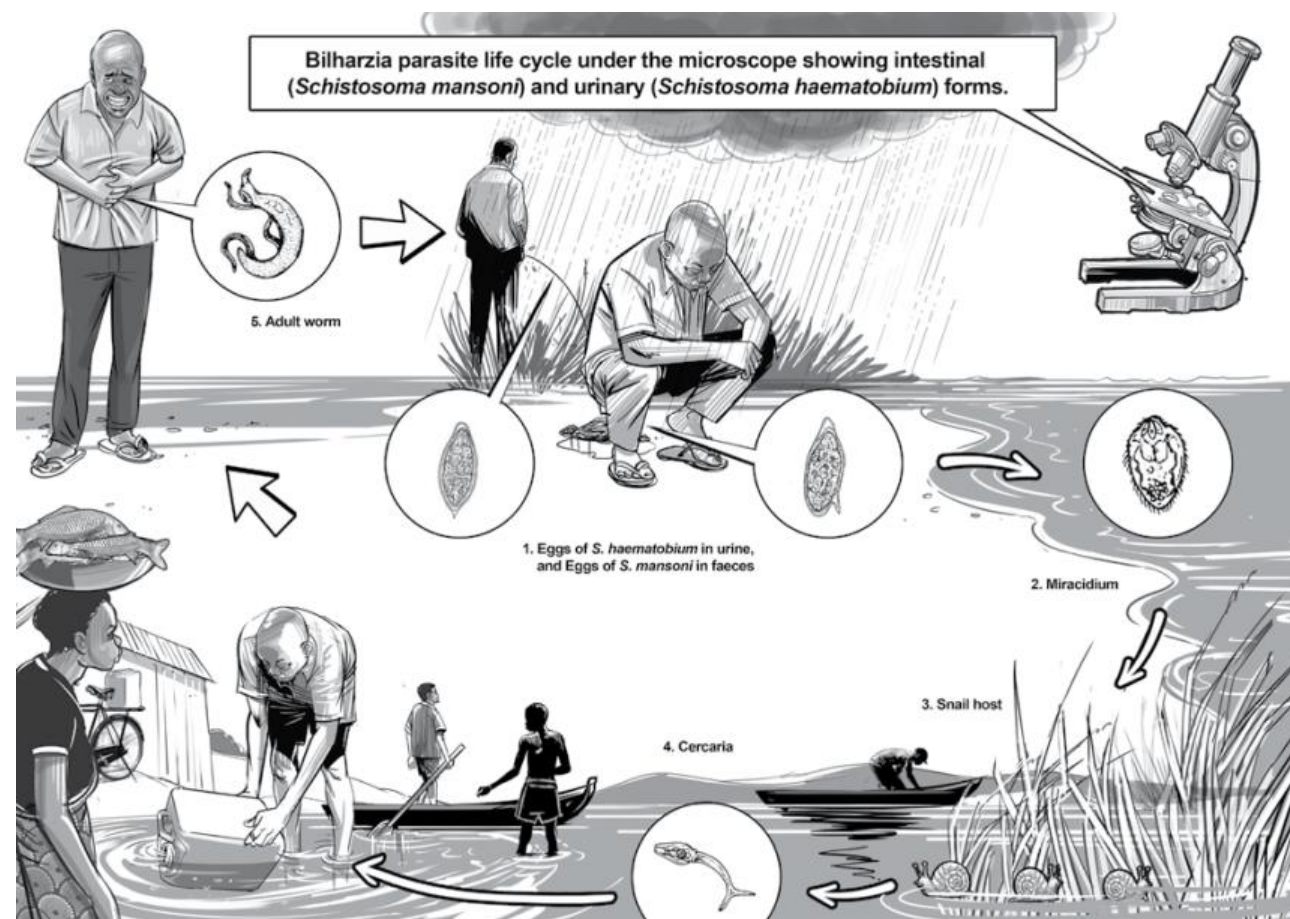
The diagrams as a public health tool

Presenting a localised transmission scene, it is intended that the diagrams will be useful as a public health tool at district and community levels, and used by healthcare providers and local actors involved in public health messaging and education around schistosomiasis control (District Vector Control Officers, Health Educators, Health Inspectors, Health Assistants and Village Health Teams), as part of ongoing activities including Social and Behaviour Change Communication (SBCC). The scene can be used to facilitate discussion on issues of water use, access to safe water, sanitation and primary healthcare, alongside measures that people may take to mitigate transmission of water-borne disease such as schistosomiasis. The scene can be adapted to reflect the local environment in other areas of Uganda and elsewhere where schistosomiasis is present, to facilitate discussions on the complexities of transmission in different localities.

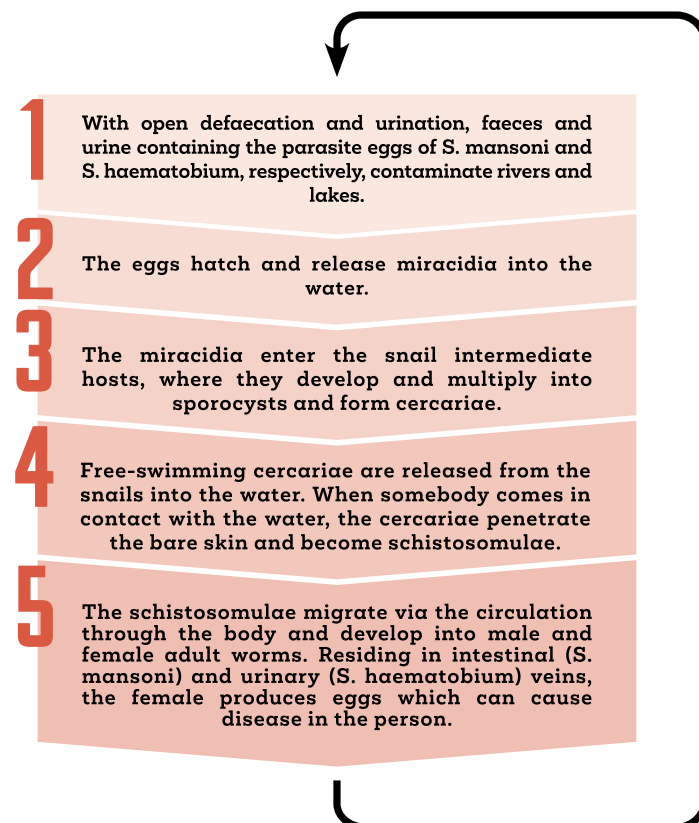
Contributions

Georgina Pearson led the development of the diagrams and written commentary. Mirembe Musisi developed initial drafts for the diagrams and Victor Ndula completed the artwork. Tim Allen, Melissa Parker and Cristin Fergus (LEAD research team) provided comments on the diagrams. Isaac Leku and Michael Nyaraga (District Vector Control Officers, Uganda) provided comments on the diagrams and input on the written commentary.





Key for the Bilharzia parasite life cycle diagram



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World Health Organisation (2020), Schistosomiasis Fact Sheet, available at <https://www.who.int/news-room/fact-sheets/detail/schistosomiasis>; Accessed 21.04.21.



Lilian Mary Nabulime

Dr Lilian Mary Nabulime is a Senior Lecturer and former Head of the Sculpture Department in the School of Fine Arts (CEDAT) at Makerere University, Kampala. She holds a PhD in Fine Art from Newcastle University (2007). Her research interests include art as a social practice, and bringing together art practice and HIV/AIDS research. Using everyday objects such as soap, bowls, mortar and pestle, found objects, and through modelling, wood carving and installations, she seeks to embody a specific social agenda that raises awareness, fights taboos and promotes discussion, as well as moving the meaning of art beyond the visual. She has exhibited worldwide, and received numerous awards and residencies including: Bezalel Academy of Arts and Design, Jerusalem 2019-2020; MICA, USA 2015; Commonwealth Fellowship Award 2012; Robert Sterling Fellowship, Vermont Studio Center, USA 2011; African Stones Talk Sculpture Symposium, Kenya 2011; British Academy International Visiting Fellowship, Department of Geography, Durham University and the Developing Areas Research Network Newcastle University 2009; ROLS UK and Commonwealth Fellowship UK 1997.



Wezile Harmans

Wezile Harmans is an art practitioner whose interdisciplinary practice encompasses performance, film and installation as a tool for social change. His work confronts prejudices and advocates against social inequality and creates a platform for critical self-reflexivity within unwelcoming spaces. Harmans' work is influenced by how things have come into existence, as well as motivations behind certain movements, reactions, examining human behaviour and mostly how these become symbols.

Harmans' awards and commissioned projects includes **M1/M2 Highway Billboard Feature** by Centre for Less good ideas, A Film by Human Rights Defender Hub Activism and University of York (CAHR), ANT Mobility Fund recipient, David Koloane Award 2019, Fruits of Democracy in Arts 2019 and the Arts & Culture Trust Impact Finalist award 2020. Harmans' work has been exhibited at Iziko National Gallery, Norval Foundation, South African State Theatre, Hangar and Vrystaat Arts Festival and Spier Light Art. He has taken part in an ICA Fellowship, Infecting the City and Thupelo workshops and an OpenLab residency.

Wallace Juma Wandera

Wallace Juma Wandera was born in 1987 on the shores of Lake Victoria in western Kenya, where he spent his early years before relocating to Nairobi city. After gaining his O'Levels, he joined Buruburu Institute of Fine Art in 2010, where he studied art and design. Two years later he began a full time career as a visual artist working closely with both his Nairobi and rural communities.

In his art Wandera uses an array of materials and techniques to visualise his message and thoughts. His work has been exhibited in East Africa, Nigeria, Germany, Belgium, USA and Australia, and features in numerous private collections and art publications. He attended the Art Kathatica artist residency in Rusinga island Kenya in 2018, and received first prize in the Manjano art contest in Nairobi, and second prize in the Artist View Schramberg in Germany for a collaboration with his artistic mentor in 2015. Most recently he won an artist grant and stay-at-home creative residency from Africalia Belgium in 2020.



Victor Ndula

Victor Ndula is an editorial cartoonist who lives and works in Nairobi, Kenya. His work is published daily in **The Star** under the caption "Victor's View". Drawing cartoons for roughly a decade, Victor is a member of the global organization Cartoon Movement. He has exhibited his work at cartooning festivals in Switzerland, France, Germany, Peru, Qatar, The Netherlands and at the London School of Economics (LSE). Victor has won the first prize of the United Nations / Ranan Lurie Political Cartoon contest.



Gloria Kiconco

Gloria Kiconco is a poet, essayist, and zine-maker based in Kampala, Uganda. Her poetry has been published on various online platforms and anthologies. Gloria shares her poetry through spoken word performances, readings, and audio compilations in collaboration with music producers. Her poetry practice inspired the use of zines as a way of self-publishing and exploring alternative forms. She has created various zines including **SOLD OUT** (2016), **RETURN TO SENDER** (2018) in collaboration with illustrator Liz Kobusinge, and **You Are Lost, You Are Here X** (2020) through a residency with Crater Invertido in Mexico City, Mexico.

As an arts journalist, Gloria's work on African and afro-diasporan artists has appeared in various publications including **People Stories Project**, **Dazed magazine**, **The Wire**, and **Perform!** Her personal essays can be found on **Adda** and on **undermyoureskin**, a collection of interactive essays, created in collaboration with writer Raksha Vasudevan. Gloria is also an independent consultant for art writing, editing, and workshop design/facilitation.



Georgina Pearson

Georgina Pearson is a Lecturer in the Institute for Global Health and Development at Queen Margaret University, Edinburgh, and a Visiting Research Fellow at the Firoz Lalji Institute for Africa, London School of Economics. A medical doctor and medical anthropologist by training, her research investigates global health priorities from an interdisciplinary, biosocial perspective, and local understandings of health, illness, disease and public health interventions, particularly among fishing populations. Georgina's PhD was based on long-term ethnographic fieldwork and epidemiological study exploring everyday realities of neglected diseases (schistosomiasis, Buruli ulcer and hepatitis) and their control among fishermen and women in northwestern Uganda.

Dianah Bwengye

Dianah Bwengye is an illustrator and graphic designer based in Uganda. She has eleven years experience working with several organisations and institutions. She enjoys using her skills to contribute to the exciting developments that happen every day in Uganda's creative industry. She graduated from the Kyambogo University in Uganda with a Bachelor's degree in Art and Industrial Design in 2011.



Cristin Fergus

Cristin Fergus is Lead Investigator for the LEAD Project, based at the Firoz Lalji Institute for Africa, and PhD researcher in the London School of Economics Department of International Development, where she examines aspects of evidence for decision-making within global health. Prior to joining LSE, Cristin trained in public health measurement and evaluation, and worked for international organisations and NGOs on the development of disease metrics and evidence to support health policy and practice.



Tim Allen

Tim Allen is inaugural Director of the Firoz Lalji Institute for Africa and Professor in Development Anthropology in the Department of International Development at the London School of Economics and Political Science. His research has focused on international criminal justice, non-formal accountability mechanisms, forced migration, reintegration following displacements, war and conflict, aid programs, witchcraft and social healing, tropical diseases, HIV/AIDS and health programmes, including the control of neglected tropical diseases. He has carried out long-term field research in several African countries, mostly in East Africa. Amongst his publications is the widely used textbook, **Poverty and Development**, which is now in its third edition.



Kara Blackmore

Dr Kara Blackmore is a curator and anthropologist who works at the intersection of arts, heritage and social repair. She has curated exhibitions in Uganda, South Africa, the UK and the Netherlands. Her most recent exhibition *When We Return: Art Exile and the Remaking of Home*, invited artists to reflect on research and forced migration between east and central African countries. She has authored academic and arts journalism texts in outlets such as *Critical Arts*, the *Journal of Refugee Studies*, *C&*, *Something We Africans Got*, and *Art Africa*. Kara is currently a Policy Fellow at the Firoz Lalji Institute for Africa.

Melissa Parker

Melissa Parker is a Professor of Medical Anthropology at the London School of Hygiene and Tropical Medicine. She carried out research on the social and behavioural dimensions of schistosomiasis in Sudan in the 1980s. Since 2005, she has worked on schistosomiasis and other neglected tropical diseases in Uganda and Tanzania and worked with colleagues at WHO to revise guidelines on effective ways to prevent and control some of these diseases. Parker also works on the relationship between politics and evidence for emerging infectious diseases such as Ebola and COVID-19. In 2020 and 2021, she contributed to the Scientific Pandemic Influenza Group on Behaviours and the ethnicity subgroup of SAGE; and joined Independent SAGE in 2021.



Polly Savage

Dr Polly Savage is Lecturer in the Art History of Africa at SOAS, University of London, and Principal Investigator for the VALEAD project. Her research focuses on the arts of 20th and 21st century Africa and the Caribbean, with particular concern for the visual cultures of socialism and liberation movements in Lusophone Africa. Her writing has appeared in journals including **Third Text**, **African Arts** and **ArtNews**, and her edited volume **Making Art in Africa 1960-2010** was published by Lund Humphries in 2014. She has curated a number of exhibitions, including most recently with Richard Gray, **Our Sophisticated Weapon: Posters of the Mozambican Revolution** for London's Brunei Gallery, 2021.

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