

I never knew that one day I would be called a doctor”: A participatory process evaluation of citizen scientists’ participation in behaviour change intervention regarding schistosomiasis among endemic communities of western Uganda

Maxson Kenneth Anyolitho

mangolitho@lirauni.ac.ug

Lira University

Karolien Poels

University of Antwerp

Caroline Masquillier

University of Antwerp

Viola Nilah Nyakato

Mbarara University of Science and Technology

Tine Huyse

Royal Museum for Central Africa

Research Article

Keywords: Participatory Evaluation, Citizen Science, Schistosomiasis, Most significant change, Uganda, Endemic

Posted Date: October 14th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10884845/v1>

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Additional Declarations: No competing interests reported.

Abstract

Introduction:

Schistosomiasis remains a major public health concern in sub-Saharan Africa, particularly in communities with limited access to clean water and sanitation. In western Uganda, frequent contact with infested water sources and poor hygiene practices drive transmission. Between August and November 2021, the ATRAP Uganda project implemented citizen science–led community awareness campaigns on schistosomiasis prevention in Kagadi and Ntoroko districts. This study explored changes experienced by citizen scientists (CSs), community perceptions of the approach, and key implementation challenges.

Materials and Methods

A qualitative participatory process evaluation was conducted using nine Most Significant Change (MSC) stories from CSs, 11 key informant interviews with community leaders, and 10 focus group discussions with 77 community members, all purposively selected. Data was analyzed thematically using NVivo 12.

Findings:

CSs gained knowledge, communication skills, and confidence, adopting safer water, sanitation, and hygiene practices while influencing community behaviour. Communities valued transparent selection, practical training, and culturally tailored, interactive engagement that enhanced message reach and trust. Challenges included long distances to sampling sites, harsh weather, community expectations for facilitation, unmet infrastructural needs, and occasional resistance due to cultural beliefs.

Recommendations emphasized managing expectations, strengthening local leadership involvement, addressing real community needs, and collaborating with NGOs.

Conclusions and recommendations:

Citizen science fostered empowerment, social recognition, and improved preventive practices, demonstrating that participatory, community-driven approaches are effective in schistosomiasis-endemic areas. For sustainability, future interventions should establish operational and monitoring structures, prioritize local ownership, and integrate broader WASH needs. Mixed-methods research is recommended to evaluate community-level changes in knowledge, attitudes, and practices.

1. Introduction

The World Health Organisation (WHO) recommends health education and sensitisation (HES) and community engagement as part of the behaviour change (BC) intervention strategies for the elimination

of schistosomiasis by 2030 (WHO, 2022). Behaviour change interventions are actions taken to ensure that individuals and communities behave in certain recommended ways that promote their health by minimizing exposure to disease and transmission (Alvarez, 2003; Kok et al., 2016; Ngigi & Busolo, 2018). In the context of schistosomiasis, behaviour change intervention activities involve ensuring that communities use clean and safe water, practice good sanitation and hygiene (WASH) and have good knowledge and awareness on how to protect themselves from infections (Sule et al., 2022). It also means changing communities' attitudes and beliefs towards preventive measures and the willingness to seek treatment (Spencer et al., 2022).

One way for effective behavior change is the classical participatory action research, and the more recent, but closely related citizen science concept, which is gaining a lot of attention in the Global North. Citizen Science (CS) is one of the participatory action research approaches that has gained prominence in many disciplines in the recent past (Elliott & Rosenberg, 2019). It is the voluntary and active participation of citizens as laypersons in the research process either wholly or partially and according to different levels of engagement (Den Broeder et al., 2017; Is et al., 2020).

This study was conducted in the context of a project named Action Towards Reducing Aquatic snail-borne Parasitic diseases (ATRAP). The project's goal was to contribute to the prevention of schistosomiasis (Bilharzia), which is a neglected tropical disease that is transmitted through freshwater snails. Chronic infection can lead to liver and bladder fibrosis, anemia, infertility and stunted growth and cognitive retardation in children (Dierickx et al., 2016), but also stigma and social exclusion (add reference). It is especially prevalent in poor regions in Sub Sahara Africa, where people depend on natural waterbodies for water access and sanitation practices, which expose them to the disease. Practices like open defecation and urination near these waterbodies will fuel the transmission of these diseases, as schistosome eggs are then released, which will develop further in freshwater snails. Therefore, the project engaged 25 citizens to monitor freshwater snails at fixed water contact sites to identify putative transmission hotspots, while they were also involved in setting up community-led awareness campaigns to induce behavior change.

Since such interventions require a substantial amount of time, finance, labour, skills and commitment, it is important to evaluate their impacts to inform future interventions (Kobori et al., 2016). Evaluations take different forms and strategies including experimental (randomised controlled trials-RCT), quasi-experimental (case comparison designs & pre and post-interventional designs), most significant change, and case studies among others (Shae, 2021). Even though these evaluations provide valuable insights, some studies have highlighted the importance of evaluating the processes themselves. Process evaluation refers to "the evaluation of individual, collective or management perceptions and actions in implementing any intervention and their influence on the overall result of the intervention" (Nytrø et al., 2000). Process evaluations look at aspects of the causal mechanisms, that lead to an ultimate change in behaviour such as the context, fidelity and quality of intervention implementation, acceptability, appropriateness, reach and coverage, and experiences, perceptions, among others (Cissell, 2004; Moore et al., 2014; Lazo-Porras et al., 2023). For instance, a process evaluation of the communication for

healthy adolescents in Uganda revealed that the program activities were successfully implemented collaboratively, with the messages reaching the intended audience, and adolescents empowered to make informed decisions (Nalukwago et al., 2020). In Peru, findings from a process evaluation of an intervention revealed that the identification of intervention components like the context, mechanism of action, and implementation outcomes such as acceptability, fidelity and adoption, perceptions, and feedback, helped to guide successful implementations (Lazo-Porras et al., 2023). There is an increasing consensus that understanding the actors' perspectives of the processes involved in the intervention could equally be beneficial for its subsequent implementation (Albert et al., 2021). Participatory process evaluation is one of the techniques that allow for the involvement of citizens right at the start of the project in setting expectations, objectives and intended goals facilitating successful implementation (Kieslinger et al., 2020). Participatory process evaluation (PPE) is a technique that "uses methods that seek to get to grips with the life of an intervention as it is lived and perceived and experienced by different kinds of people, including programme or project personnel" (Cornwall, 2014). PPE has potential benefits such as citizens' involvement and active participation in addressing challenges that affect them, empowerment, changes in attitude, norms and values, improving coherence, community building, social capital, social learning and trust among others (Den Broeder et al., 2018).

Evaluation of citizen science projects has also received wide attention. For instance, a mixed methods study to evaluate the impact of a citizen science program for malaria prevention in Rwanda revealed increased knowledge and skills on preventive measures by both the citizen scientists and local communities (Asingizwe et al., 2020). An evaluation of the role of citizen science in human-wildlife conflict management in Colorado State of the United States of America also found that volunteer participation had positive effects on the way they related and thought about the project, enhanced knowledge, empowered the volunteers and communities to take action, changed their attitudes, beliefs and behaviours (Adams, 2014). However, these evaluations have predominantly emphasized quantifying impacts, while giving limited attention to processes, intrinsic aspects, and the perspectives of citizen scientists and other actors (Davies & Dart, 2005; Moji et al., 1998; Mulopo & Chimbari, 2021; Smith et al., 2013; Vohland et al., 2021a). In addition, except for the study in Rwanda, most evaluations of CS projects have concentrated in the Global North and few of them have involved citizen scientists in the evaluation. In this study, we demonstrate the relevance of the participatory process to the evaluation of the citizen science approach to the implementation of behaviour change intervention regarding schistosomiasis prevention and control to inform future similar interventions. Specifically, the study aimed to 1) explore the changes that have taken place to the citizen scientists as a result of their involvement and participation in communicating schistosomiasis information; 2) understand the communities' experience and perceptions of the citizen science approach in communicating schistosomiasis information; and finally, 3) document the challenges faced by citizen scientists while implementing behaviour change interventions and their recommendations for future improvement.

2. Materials and methods

2.1 Study area and setting

The study was conducted in Kagadi and Ntoroko districts in western Uganda in five sub-counties of Kanara, Ndaiga, Kyaterekera, Mpeefu, and Bwikara. According to the Uganda Ministry of Health, both districts are endemic to schistosomiasis (Adriko, 2017a, 2017b). Two of the sub-counties situated along Lake Albert, Kanara and Ndaiga, have schistosomiasis prevalence estimated to be over 90% (Exum et al., 2019). Recent studies have also reported risky practices related to water, sanitation and hygiene, like open defecation, contact with contaminated water as well as myths and misconceptions (Anyolitho, Poels, et al., 2022) and poor health-seeking behaviours due to the absence of praziquantel drugs as some of the hindrances to control and prevention (Anyolitho et al., 2023). The districts have poor road networks with some places being almost inaccessible. There are inadequate healthcare facilities and low levels of education in the area (NPHC, 2017; Statistics, 2017). The study took place between March and May 2022, about four months after carrying out the behaviour change interventions (Anyolitho et al., 2024).

2.2 Study design

Framed on the theory of change, the study adopted a qualitative participatory process evaluation design to examine the citizen scientists' involvement and participation in behaviour change intervention processes regarding schistosomiasis. In this study, the design was chosen because of the need to document the processes and changes from the actors' point of view, rather than on the outcomes of the intervention. Before fieldwork, a network of citizen scientists (CSs) was set up in collaboration with community leaders. The selection was based on criteria agreed together with the communities (Brees et al., 2021). A total of 75 volunteer candidates recommended by community leaders were interviewed out of whom 25 were successful. They were then trained on schistosomiasis signs and symptoms, transmission modes, diagnosis, treatment and preventive measures, different types of snails and their possible hot spots at the water sites. They were also trained in how to use smartphones for data collection and reporting. After the training, the volunteers were deployed to do snail sampling. Periodic training was provided every year to refresh the CSs' knowledge and skills and share feedback on the progress of their work.

Between August and October of 2021, the citizen scientists participated in the dissemination of findings from the baseline study and in the co-design of behaviour change communication intervention. They were also trained in skills and knowledge on communication generally, and on how to communicate schistosomiasis information using the developed tools. Afterwards, the CSs conducted awareness about the disease for one week from November 5th to 10th of 2021. The exercise drew the participation of local leaders and community groups and youth. With the baseline studies that were already conducted before the intervention, there was a need to evaluate the CS project (Anyolitho et al., 2024).

2.3 Sample size determination and Participants' Selection

A total of 18 citizen scientists (9 for storytelling and another 9 for story selection) and 12 community leaders participated in the selection and development of the most significant change stories. A total of 10 community leaders comprising district vector control officer (1), sub-county health workers (1), community staff (1), VHTs (1), LCIII chairpersons (2), and local council leaders (4) participated in the study. Meanwhile, 77 community individuals comprising 43 males and 34 females and 11 community leaders provided information on their experiences and perceptions of the citizen science approach to behaviour change. Purposive sampling was employed for the selection of participants. For the citizen scientists, commitment/good track record in the project work, sub-county area of operation, gender and ability to read and speak English were some of the criteria considered. For the community leaders, participation in the project was key for selection. Criteria for selection of community participants were knowledge and participation in the project activities, attendance of awareness campaigns and or training, gender and place of residence where the project was implemented.

2.4 Data Collection Methods and Instruments

The study adopted three key qualitative data collection techniques that included: 1) the most significant change (MSC), 2) key informant interviews (KIIs), and 3) focus group discussions (FGDs). Data collected were entered into Nvivo version 12 and were analysed using a six-step thematic analytic model by Braun and Clarke. Key themes and subthemes generated include. In this section, we present the key findings from the data analysed. Three key techniques that are, the Most Significant Change (MSC), Key informant Interviews (KII), and Focus Group Discussion (FGD) techniques of data collection were employed. The MSC technique was used to obtain information from the citizen scientists regarding the most significant changes that had taken place as a result of their involvement and participation in the behaviour change intervention in the form of stories. This current study adapted the technique to suit the project implementation approach in two ways. First, only three levels of selection and ranking were employed, the first two levels by the CSs and community leaders ran parallel to each other, while in the third level, the corresponding author used a matrix of ranking and scores for each of the four selected stories (details in the analysis section). Secondly, we asked participants to propose recommendations for improving the citizen science approach. Facilitated by the corresponding author and a masters student and using the MSC story collection guide, citizen scientists verbally told their stories based on the domains mentioned above. Participants were free to use a language of their choice/interests. Where local language was used, the facilitators transcribed the stories after validating them. This was done by seeking comments and clarifications from the citizen scientists as to the correctness, clarity, and facts about their experiences. The facilitators probed and prompted participants to ensure all the aspects of the domains, levels and pathways were captured. Afterwards, the facilitators typed the stories and read them to the citizen scientists for proofing. Final versions of the stories were then saved ready for selection. Key domains of change identified and used in the study were: a) ability to sample and report on snails, b) ability to communicate schistosomiasis information c) knowledge, skills and attitude, d) increased respect, trust, social networks, and change in social status. Also, four key pathways of change were conceptualized in the study: 1) citizen scientists' selection and training, 2) snail sampling and reporting 3) community awareness and 4) community engagement. An adapted MSC story guide was

developed and employed for the collection of MSC stories from the citizen scientists. To triangulate the views of the citizen scientists regarding the changes that had taken place to them, we shared the stories gathered from the CSs and later, employed KII and FGD qualitative techniques with the local leaders and community members. KIIs helped to capture local leaders’ experiences in the intervention and their perceptions of the CS approach. The FGDs also enabled us to understand the community’s perspectives of the CSs’ approach to behaviour change interventions.

2.5 Data Analysis Methods and Instruments

Most Significant Change (MSC)

A total of nine stories were collected from the CSs and validated/cross-checked by nine other CSs and 11 local leaders that had participated in the interventions. Two phases of analysis, that is, primary and secondary were employed in the analysis of the MSC stories. The first phase involved three levels in the selection and ranking of MSC stories. In level one, nine citizen scientists that had participated in the project were given the nine stories picked from their colleagues. They were asked to go through and afterwards, select four stories that stood out according to their experiences and that of the community. The selected stories were later ranked using scores and the four best stories were picked. At level two, the same set of stories was given to the local leaders, and the same process was repeated. Likewise, the exercises concluded with four stories that stood out according to the local leaders being picked. Two of the four stories in each group selected by the two groups were the same, hence giving a total of six MSC stories at this level. In the third and last level, the corresponding author used a matrix of scores to select a story with the MSC (Table 1). A score of 4 was assigned to story number 1, followed by 3, 2 and 1 in that order for each of the two sets of stories. Combining scores from both groups, the story with the highest score was selected and considered to be the one with the MSC. Two stories (2 & 5) had the same scores of 5, followed by stories 1 & 4 with scores of 4 each and lastly, stories 3 & 8 had 1 score each. Hence stories 2 & 5 were selected and considered the ones with MSC.

Table 1
Ranking of stories of Most Significant Change by the Citizen Scientists
and Community Leaders

MSC stories	Scores by CS	Scores by CL	Total Score	Rank
1	4	0	4	3rd
2	3	2	5	1st
3	1	0	1	5th
4	0	4	4	4th
5	2	3	5	2nd
8	0	1	1	6th
TOTAL	10	10	20	

Secondary analysis

In the second phase, all the MSC stories, together with transcripts from the KIIs and FGDs were uploaded onto Nvivo Version 12 software for further analysis. Data was analysed through thematic analytics using the seven steps model by Clarkes and Braun (2013). A coding frame was developed from both the MSC stories and the KIIs and FGDs. Codes were identified with the help of guides from the MSC story KII and FGD. Also, to enrich the coding frame, one transcript from each of the techniques ie the MSC story, KII and FGD, were used. Thereafter, coding proceeded by identifying texts in the transcripts that conformed to the codes. New codes identified in the process were created accordingly until all transcripts were coded. The corresponding author went through the coded data to identify themes and subthemes according to the study objectives. Themes and sub-themes that were similar were grouped, while those that were unique were put under separate headings. Themes and sub-themes identified regarding community experience with the intervention include awareness of the community-led approach to behaviour change before the project, citizen scientist selection and training, views on snail sampling and reporting, awareness-raising campaigns and participation in training and community engagement. Meanwhile, fidelity, acceptability, appropriateness, reach and coverage, recruitment, participation, and perceptions barriers/challenges were some of the themes and sub-themes under community experiences and perceptions of the CS approach. Afterwards, the corresponding author interpreted the data and wrote down the findings. Verbatims from the transcripts were extracted to support the main findings.

3 Results

This study evaluated the involvement and participation of citizen scientists in behaviour change interventions regarding schistosomiasis among endemic communities along Lake Albert, western Uganda. The findings presented below relate to 1) changes experienced by the CSs as a result of their involvement in the intervention, as well as 2) community experiences, perceptions and 3) challenges and 4) recommendations by both the CSs, local leaders and the community members. For improved interventions.

3.1 Changes Observed Among Citizen Scientists (CSs)

Increased Knowledge and Attitude Change Regarding Schistosomiasis

CSs reported significant improvement in their understanding of schistosomiasis and its prevention. Initially, many were unaware of the disease's severity and transmission routes. Participation in training, sampling, and awareness campaigns improved both their knowledge and attitude, which they observed spreading to the wider community.

"The change that has happened to me is that I never knew that the water we are using is harmful to our health. I learned that Bilharzia is a serious disease that if not treated can result in death... I used to think the

Bilharzia enters through the mouth, but I learned that they enter through the skin” (Citizen Scientist-2, Ndaiga Sub-county).

Improved Water, Sanitation, and Hygiene (WASH) Practices

CSs reported adopting safer practices, such as boiling drinking water, wearing gumboots, constructing latrines, and encouraging medicine uptake in the community.

“Before that, I always went to the lake to fish and drank unboiled water. But after the dissemination, I always carry my boiled water from home when I am going to fish” (Citizen Scientist-2, Ndaiga Sub-county).

“These days I wear my gumboots when I am going to dig or fetch water... nowadays I boil my drinking and bathing water” (Citizen Scientist-5, Bwikara Sub-county).

Communication and Community Engagement

CSs gained confidence and skills to communicate effectively with the community, including local leaders and stakeholders, enhancing their influence.

“I acquired communication skills... I am confident and no longer shy to talk to people now. I easily talk to my community about Bilharzia”(Citizen Scientist-5, Bwikara Sub-county).

“Being involved with different stakeholders and even having traditional healers was a big change... people started to respect me more. They even call me the ‘water doctor’”(Citizen Scientist-2, Ndaiga Sub-county).

Increased Trust, Respect, Discipline, and Social Status

Participation improved CSs’ social recognition and respect within families and communities. They were often referred to as “doctor,” “water doctor,” or “snail collector” due to their dual role in research and community sensitization.

“The changes that have happened to me is that my family respects me and the community also respects me... people respect me and trust me as a good person in the community”(Citizen Scientist-5, Bwikara Sub-county).

Unexpected and Unmet Changes

Unexpected benefits included access to equipment (gumboots, smartphones, scoop nets) and increased confidence in influencing community behavior.

“I never expected to educate the community, and I never expected that they would accept change... I think it is because they have been severely suffering from the disease” (Citizen Scientist-8, Ndaiga Sub- County).

Expected changes that did not occur included provision of umbrellas, bicycles/motorcycles, and clean water supply.

"I expected to be provided with an umbrella to help when it's raining and I have to go to my water contact points" (Citizen Scientist-5, Bwikara Sub-county).

"I expected that the project would give the community safe water or water tanks, but we haven't gotten them from this project" (Citizen Scientist-3, Kyaterekera Sub-county).

3.2 Community Experiences and Perceptions of Citizen Scientists (CSs)

Selection and Training of Citizen Scientists

Communities appreciated the participatory, transparent, and fair approach used to select CSs. The involvement of opinion leaders and the community in identifying committed individuals was seen as novel and effective.

"You know when dealing with communities, we use the element of social inclusion and active participation. That is the community must be involved in every step of the project. I can say the exercise was good because the community was actively involved. It was also transparent and fair enough" (KII-5, CDO Ndaiga Sub-County).

"Personally, I think this was a good method because the opinion leaders were used to giving names of people they know are hardworking and committed to the community" (KII-8, LCIII Chairperson Kyaterekera Sub-County).

FGD participants also valued the process, noting that selected CSs were experienced, trusted, and respected.

"The sub-county CDO came to this village, I knew about it and following the procedures he was successful. Because you cannot recruit someone who is not appropriate. Even the chairperson LC I was aware of it, and they were taken for training... there was not any form of partiality, and I wish other recruitment processes would be like that" (Male FGD-9, Ndaiga Sub-County).

Reach and Coverage of Messages

CSs were commended for extensive community engagement, going house-to-house and using interactive methods including drama. Their efforts were considered more thorough than other NGOs or government programs.

"You have really gone deep into the communities, you walked from house to house talking about Bilharzia, and other NGOs we just hear about them, and it stops there. Even using drama was good for those that don't know how to read and write; they went back with a message on Bilharzia. So, I must say it was good; everyone in the village knows the Bilharzia program" (KII-10, LCI Chairperson, Rugarama Village, Mpeefu Sub-County).

Community members confirmed learning about preventive measures through home visits, drama, and meetings:

“On that day we had a break, and a certain CS came on the microphone and started teaching about the disease and its preventive measures such as wearing protective gear and avoiding contact with contaminated water... we also learnt about how to prevent other diseases such as cholera” (Male FGD-12, Kyaterekera Sub-County).

“They taught us that we should always use latrines for defecation and wash our hands afterwards... some still go to the bush because the soil is bad for latrine construction” (Female FGD-11, Ndaiga Sub-County).

Mode of Delivery

CSs used interactive, simple, and clear messages, incorporating local language, demonstrations, and illustrations.

“You used the right approach because it was appropriate; the use of the local language made it easy for people to understand. The campaign was interesting because it attracted community support... the messages were ok and simple, and even children could understand. It was interactive using questions and answers, which facilitated better understanding” (Male FGD-7, Mpeefu Sub-County).

Citizen Science as a Resource and Preferred Approach

Participants valued the practical knowledge and skills CSs demonstrated, particularly linking disease prevention to snail control and water safety. CSs’ extensive training made them more effective than other volunteers.

“I appreciate the CSs’ work so much because here we are only two with my assistant. The CSs have been raising awareness about the disease... Unlike the CSs, who have received several pieces of training like communication skills, snail identification etc.” (KII-6, DVCO, Kagadi District).

CSs were preferred due to their practical approach, research involvement, and effective communication, though some noted both CSs and other volunteers complement each other.

“But generally, it would be good for both of them to work together, only that I am forced to choose, so I can choose the CSs” (KII-1, LCIII Chairperson Kanara Town Council).

3.3 Challenges of the Citizen Science Approach to Behaviour Change Intervention

Implementation and Operational Challenges

Citizen scientists (CSs) faced logistical challenges during snail sampling and reporting, including long distances to water contact points, transport difficulties, and environmental factors such as rain,

sunshine, and rising water levels.

“The major challenge is their walking from place to place while doing their work, especially on rainy days and sunny days as well yet this village is too big which makes it difficult for them to conduct the sensitization” (Male FGD-10, Ndaiga Sub-county).

“During the start of the project, there was a flood at the sub-county that affected the CRs’ work. Also, the area is hard to reach, in fact, one of the landing sites has been left out due to the transport problem” (KII-5, Ndaiga Sub-county).

Additionally, some water contact points were inaccessible due to religious restrictions, requiring rescheduling sampling.

“The religious challenge I also faced was that one of my water contact points is in the land of the Seventh Day Adventists, so the owner stopped me from going to that water contact point on Saturday, so I had to change the day of sampling to another day” (Citizen Scientist-6, Bwikara Sub-county).

Awareness and Community Engagement Challenges

CSs reported difficulties while interacting with the community due to long distances, lack of protective gear, and insufficient identification, which limited recognition and trust.

“Walking on a hot sunny day without drinking water, umbrella, or bicycle, yet they are walking on their feet to different villages with no food to eat yet they have to carry out sensitisation the whole day” (KII-3, Ndaiga Sub-county).

“No clothes for them to be identified... their presence in the community is still not felt much, I don’t know why. But could be due to many factors” (Male FGD-5, Kanara Town Council).

Community expectations also created challenges, as many members expected facilitation or payments for participating in activities.

“The challenges I have faced are with the community members, some community members are biased and harsh especially when you try to tell them about Bilharzia. The other challenge is when I go to the community they ask me for money. They think I am making a lot of money so they ask me for money or sometimes soda” (Citizen Scientist-2, Ndaiga Sub-county).

Differences in priorities between the project and community needs—such as access to clean water, health facilities, and drugs—also limited engagement.

“I see they have a lot of challenges because the CSs have done adequate sensitization and we have got them but the biggest problem is the lack of access to clean and safe water. Because we cannot follow them if we don’t have water” (Female FGD-8, Ndaiga Sub-county).

“The challenge the CSs faced was that the people in the community were asking them to bring the facilities nearer to them so that if they are infected with Bilharzia they can go to that health centre. Also, they asked for good water, and the community also asked for roads which the CSs couldn’t provide these things” (KII-7, Ndaiga Sub-county).

Some CSs reported a disconnect with local leaders, whose limited knowledge of Bilharzia affected community uptake of messages.

“Some local leaders are reluctant and don’t want to be involved or even talk about Bilharzia, this has been a challenge because once a leader doesn’t think Bilharzia is a serious disease and does not talk about it, the people in the community will not think it’s serious too. You see, these leaders are trusted by the community members... if only they can wake up and work with us in fighting against Bilharzia I believe this disease will be kicked out of our community” (Citizen Scientist-2, Ndaiga Sub-county).

Limited awareness about the CSs’ role initially hindered recognition by the community.

“On the CSs, most people still don’t know what they are doing, they see the CSs always moving to water points to collect samples. Because when you go and ask the community about the CSs, but for us who are working with them we know when we are sensitizing. But the community doesn’t know” (KII-2, VHT Coordinator Kanara Town Council).

Finally, despite sensitisation efforts, some community members were slow to adopt recommended behaviours due to cultural beliefs and resistance to change.

“Some of the community members don’t want to change their habits, behaviours, and water practices. People still have their cultural beliefs about water practices. The human activities in places where I sample could hinder my sampling activity.” (Citizen Scientist-3, Kyaterekera Sub-county).

“Some community members are adamant and didn’t want to change when the citizen scientists talk to them about Bilharzia prevention; when the CSs go to their homes they are chased or even ignored” (KII-9, Mpeefu Sub-county).

3.4 Recommendations for Improving Citizen Science in Behaviour Change Interventions

Managing Community Expectations

Participants highlighted the need to manage community expectations regarding financial facilitation during meetings. CSs suggested that the project benefits should be clearly communicated from the outset, emphasizing that volunteers are not paid.

“The community shouldn’t be given any money, because when people get used to getting money, it becomes a habit. The community need to learn that these projects come to help them so they shouldn’t expect anything like money from the project” (Citizen Scientist-2, Ndaiga Sub-county).

Prior information and awareness by local leaders was also recommended to clarify the roles of CSs and prevent misconceptions about their earnings:

“The community should be informed that we are only volunteering and not earning a lot of money. There’s a way it affects your mindset especially when you’re volunteering and people think you’re earning a lot of money” (Citizen Scientist-1, Kanara Town Council).

Strengthening Community Involvement and Participation

To improve response and engagement, participants recommended involving local leaders from the beginning. Leaders are key bridges between the project and community, and their active cooperation ensures better acceptance of messages.

“The local leaders should be involved in sensitization and passing on Bilharzia messages in the community. There should be a way in which the leaders should cooperate and work hand in hand with the citizen scientists to communicate about Bilharzia in our community” (Citizen Scientist-2, Ndaiga Sub-county).

“We continue involving local leaders in this program since they are closer to people and people can listen to them. The local leaders are key people in the community and we can’t do anything in the community successfully without their involvement” (Citizen Scientist-3, Kyaterekera Sub-county).

Addressing Real Community Needs

Some participants emphasized addressing critical community needs—such as access to clean water—alongside awareness campaigns. Identifying and responding to real problems was seen as essential for community acceptance and sustainability of interventions.

“The project should provide clean and safe water to the communities and also continue with this sensitization program that has been started” (Citizen Scientist-3, Kyaterekera Sub-county).

Broadening Collaboration with NGOs

For sustainability, participants recommended collaboration with local NGOs and other organizations. This could help expand coverage, maintain continuity, and integrate additional activities to reinforce the citizen science approach.

“If there is a way, there could be advocates for NGOs and other organizations to help because the catchment area is too big. And if possible other CSs could team up in one sub-county then others are recruited. I think looking for the sustainability of the project is also important like continuing with sensitization through saying football, forming SACCO, and integrating other projects into the ATRAP for it to continue” (KII-9, Mpeefu Sub-county).

4 Discussion

Evaluating behaviour change interventions is essential to inform future actions. Using a qualitative participatory design, this study evaluated the citizen science (CS) approach to schistosomiasis behaviour change interventions among endemic communities in Lake Albert, western Uganda. The findings show that citizen scientists acquired new technical and communication skills, engaged stakeholders effectively, and enhanced knowledge, attitudes, and preventive practices within their communities. The CS approach was preferred for its practicality, contextual relevance, participatory nature, and ability to drive meaningful change.

4.1 Skill Development and Knowledge Acquisition

Snail Sampling and Reporting

Citizen scientists gained significant technical capacity in snail sampling and reporting using smartphones. Training by ATRAP researchers equipped them to collect and transmit field data—realising the project’s goal of empowering local citizens to “put science into practice.” This finding aligns with studies in the USA where training made participants more practical and skilled (Henry et al., 2022) and similar outcomes in other professional development programs (Limato et al., 2018). The ability to explain their work to community members enhanced transparency and trust, while the MSC approach effectively captured participants’ lived experiences and contextual learning.

Effective Communication about Schistosomiasis

Citizen scientists also developed strong verbal and non-verbal communication skills through ATRAP training, helping them confidently educate communities about schistosomiasis, something they previously struggled with. Effective communication has been associated with building advocacy and coalitions for service improvement (Henry et al., 2022). Similarly, interventions focusing on citizen science could emulate this model to strengthen communicators’ capacity. However, caregivers in another study were only willing to discuss comfortable topics in sexual and reproductive health communication (Akaturukwasa et al., 2023), showing that communication training must address sensitive subjects comprehensively.

4.2 Community and Stakeholder Engagement

The CS approach strengthened relationships with communities and local leaders. Similar to findings in the US, leadership training helped participants engage stakeholders to influence policy and behaviour change (Henry et al., 2022). Community engagement also improved uptake of praziquantel due to deeper understanding of the problem (Al, 2022). While other interventions, such as a school-based program in China, limited engagement to specific groups (Wang et al., 2022), this study targeted all demographic categories since schistosomiasis affects everyone. Effective community engagement remains a critical factor for successful health interventions (Martin et al., 2021).

4.3 Knowledge, Attitude, and Behaviour Change

Citizen scientists and their communities reported increased knowledge and more positive attitudes towards schistosomiasis. They identified symptoms, transmission modes, and prevention measures previously unknown to them. Earlier risky behaviours stemmed from limited understanding (Anyolitho et al., 2022). These findings echo prior evidence that interventions enhance knowledge and attitudes (Akutukwasa et al., 2023; Dahmen-Adkins & Peterson, 2019; Gommerman & Monroe, 2012; Helinski et al., 2015). In contrast, the Obulamu program in Uganda found no significant knowledge increase among participants (Burke et al., 2021). Nonetheless, knowledge, attitude, and practice (KAP) indicators remain standard measures of intervention success (Somerwill & Wehn, 2022).

4.4 Improved Preventive Practices

Improved hygiene and sanitation practices, such as using boiled water and latrine construction, were notable outcomes. These behavioural shifts occurred at individual, household, and community levels. Similar results were reported elsewhere, including improved maternal health service use (Limato et al., 2018), parenting practices (Shah, 2014), healthcare provider behaviour (Ho et al., 2015), organisational participation (Dahmen-Adkins & Peterson, 2019), family planning uptake (Aisiri et al., 2020), and SRH outcomes (Akutukwasa et al., 2023). Such results affirm that well-implemented behaviour change interventions can yield lasting community impact.

4.5 Trust, Social Recognition, and Status Change.

Community trust and respect for CSs increased significantly as their knowledge and communication improved. This mirrors findings that community engagement fosters mutual confidence and dialogue (Shah, 2014). Moreover, CSs were locally referred to as “snail doctors” or “water researchers,” symbolising elevated social status. Comparable recognition occurred in Japan, where community–university collaborations led to public acknowledgment of participants’ expertise (Kitamura et al., 2020). Though ATRAP did not issue certificates, communities still perceived CSs as experts. Future interventions could formalise training for community volunteers, integrating such programs into education or certification systems to sustain motivation and professional growth.

4.6 Implementation Experience and Perceptions

Selection and Recruitment: The community valued ATRAP’s transparent and participatory recruitment process. Local involvement—from defining criteria to interviewing candidates—enhanced ownership and trust. Similar participatory recruitment models have proven more effective than impersonal methods such as newsletters or flyers (Van Eerd et al., 2018). Conversely, projects in Mozambique struggled with recruitment due to limited community engagement (Martin et al., 2021). Likewise, Uganda’s Communication for Healthy Communities program revealed disconnects when educators lacked relevant communication skills, underscoring the need for participatory recruitment sensitive to local contexts.

Practical Knowledge and Communication Skills

Communities valued CSs’ practical knowledge, confidence, and clear communication. Such skills facilitated message comprehension and task execution, consistent with findings that communication

abilities enhance public engagement (Asadullah & Muniz, 2015; Vohland et al., 2021b). The Obulamu program's success also hinged on communicators' delivery rather than message content (Burke et al., 2021), highlighting the importance of training community volunteers in communication for effective behaviour change.

Approaches Used: CSs employed context-specific and simple methods—such as drama, door-to-door visits, and community meetings—tailored to different audiences. Using local languages and culturally familiar formats enhanced understanding and participation. Similar findings from Uganda show that communities often struggle to interpret messages from health workers and lack adequate IEC materials (Muhumuza, 2017). Locally led and culturally appropriate communication approaches, therefore, enhance message reach, inclusivity, and cost-effectiveness.

4.7 Reach and Coverage.

The intervention achieved broad reach and message diversity, covering snail types, transmission, symptoms, and preventive practices. Using local volunteers who traversed multiple villages ensured deep community penetration. Comparable studies also reported improved outcomes from wide-reaching community initiatives (Pramanik et al., 2012). In contrast, top-down programs such as Obulamu had limited coverage due to generic strategies and reliance on mass media (Burke et al., 2021; Nalukwago et al., 2020). The current study's bottom-up approach offers an effective alternative for rural settings, emphasising the value of community-driven delivery systems.

4.8 Study Limitations

This study provides valuable insights into the role of citizen science in schistosomiasis control but had limitations. Geographical coverage was narrow, and no formal structure or monitoring and evaluation (M&E) framework existed initially, constraining impact measurement. The intervention focused mainly on awareness-raising rather than addressing broader issues like WASH. Methodologically, the study's qualitative design limits generalisability, though it offers rich context on perceptions and experiences.

Conclusions and Recommendations

A well-planned citizen science initiative, implemented jointly with communities from inception, can foster empowerment, inclusivity, accountability, and participation. It enhances knowledge, skills, and attitudes, while strengthening social networks and community leadership. For sustainability, future interventions should establish clear operational and M&E structures, prioritise local ownership, and address broader needs such as access to clean water and sanitation. A mixed-methods design is recommended for future research to assess community-level changes in knowledge, attitudes, and practices regarding schistosomiasis.

Declarations

Ethical approval and consent to participate

This study was not a clinical trial; it employed an observational/descriptive research design. A clinical trial number is not applicable. Furthermore, this study did not involve clinical interventions or collection of personal health data requiring formal ethics approval. However, all standard ethical considerations such as voluntary participation, informed consent, and confidentiality were duly observed. The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki (World Medical Association, 2013). The study was approved by the Mbarara University of Science and Technology (MUST) Research Ethics Committee (MUST-REC) reference No. MUREC 1/7 and was registered with the Uganda National Council for Science and Technology (UNCST) reference No. SS836ES. It was also cleared by the district health officers of the two districts. Finally, we introduced the study to the local leaders at the community level before data collection. All participants provided their informed consent to participate in the study, both in writing and verbally. Participation was voluntary, and confidentiality was ensured throughout the study process. Participants were also assured of data confidentiality, and all sessions were conducted in private places where it was quiet and separate from the public.

Acknowledgements

We would like to thank the district officials of Kagadi and Ntoroko district, for permitting us to collect data from their communities, the community members from the two districts, health workers, local government staff, and VHTs who participated in the study. Our gratitude also goes out to research all the citizen scientists, especially those who participated in providing their stories of the most significant changes since their involvement and participation in the ATRAP Project. Lastly, we convey our appreciation to Ms Faith Mugabi for her active participation and support with the data collection, and all the ATRAP project Team for their teamwork exhibited.

Declaration of competing interests

The authors declare that they have no competing interests.

Availability of data and materials

Transcripts and other field data content for this study are available, up on request from the corresponding author.

Funding

This study was supported by the Action Towards Reducing Aquatic Snail-Borne Parasitic Diseases (ATRAP) project of the Belgian Development Cooperation program dd. 01.04.2014 of the Royal Museum for Central Africa (RMCA) with the support of the directorate-general of Development Cooperation and Humanitarian Aid. ATRAP is a collaboration between the Mbarara University of Science and Technology (MUST) in Uganda and the RMCA in Belgium. The contents and all page materials therein are the sole responsibility of the authors and do not in any way represent the views of the funders. The funders had no role in the study design, data collection and analysis, publication decision, or manuscript preparation.

Authors' contributions

MKA, KP, MC and VNN conceptualized the work. MKA collected, analysed and interpreted the data. MKA interpreted the analysed data. MKA drafted the first manuscript copy, which was reviewed and edited by KP, MC, TH, and VNN. All authors read and approved of the final manuscript.

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