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Empowering communities through citizen science and participatory action research: implementation of a schistosomiasis communication campaign in Uganda

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Schistosomiasis is a water-related disease strongly linked with high-risk water and sanitation practices perpetuating disease transmission. In Uganda, despite health education and sensitisation efforts through communication campaigns by the Ministry of Health to reduce schistosomiasis prevalence, common risky practices still pose a challenge, especially among endemic communities. Here, we steered away from the conventional top-down approach to communication campaigns and explored alternative methods. We employed citizen science (CS) and other participatory action research (PAR) techniques as a bottom-up approach to co-design and implement a communication campaign among communities of western Uganda, to achieve a more tangible outcome of behaviour change for preventing schistosomiasis. We collected qualitative data using data party, world café, prioritisation and ranking, focus group discussion, and key informant interviews from 378 purposively selected individuals and analysed it using a thematic analysis model. Community volunteers, community radios and local leaders were the most preferred channels for passing schistosomiasis information identified by participants. Lack of access to safe water and healthcare services, open defecation, and inadequate knowledge of schistosomiasis are some of the most pressing problems prioritised. Door-to-door visits by citizen scientists (CSs), community meetings, drama, and tournaments were the channels proposed by CSs and community groups during the co-design workshops. Over 1000 households and about 9000 community members were directly reached using the channels. Endemic communities prefer receiving schistosomiasis information using local channels instead of conventional ones. Combining citizen science with other PAR approaches empowers communities to interpret research findings in their contexts and take charge of the interventions. As such, clear and simple message coverage and a high audience turn-up can be achieved. A follow-up study is needed to evaluate the process and impact of the communication intervention on the citizen scientists and the community's knowledge, attitudes, and practices regarding preventive measures.

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Introduction

The World Health Organization (WHO) recommends preventive chemotherapy (through mass drug administration (MDA) of praziquantel (PZQ), behaviour change and snail control as the three main strategies for the control and prevention of schistosomiasis (WHO 2022). In the context of schistosomiasis prevention and control, interventions on behaviour change focus on improving water, sanitation, and hygiene (WASH) infrastructures, as well as health education and sensitisation through communication campaigns (Price et al. 2015). In Uganda, the MDA of PZQ was introduced in 2003 with support from the Schistosomiasis Control Initiative (SCI) (Adriko 2017). The program is accompanied by health education and sensitisations using a communication strategy as a form of social mobilisation. The program employs a top-down approach whereby Uganda's Ministry of Health designs messages with development partners' support and delivers them to the communities (Adriko 2017; Krauth et al. 2019). Since then, the MDA and health education and sensitisation interventions have registered tremendous success, such as increased praziquantel (PZQ) uptake and improved knowledge, attitude and practices regarding schistosomiasis (Adriko, Faust et al. 2018).

Despite the achievements, some limitations still make such interventions unsustainable (Adriko, Tinkitina, et al. 2018; Onasanya et al. 2021; Tuhebwe et al. 2015). As a result, some endemic communities continue to use contaminated water sources and practice common open defecation while linking the disease to certain myths and misconceptions (Muhumuza 2017; Anyolitho et al. 2022). Furthermore, a nationwide survey in Uganda reported a stronger link between schistosomiasis infection and water and sanitation (WASH), adding that the presence of WASH infrastructures alone does not necessarily translate to a reduction in infection (Exum et al. 2019). This finding corroborates the need to include communication campaign interventions to facilitate behaviour change in the WASH preventive strategies. In addition, the use of conventional channels for communicating schistosomiasis messages for behaviour change such as national television, radio, newspapers, billboards, magazines, and posters has been reported by several studies but with mixed results. Some studies have highlighted the importance of using mass media channels for better uptake of health information (Grilli et al. 2002). On the contrary, a study in Uganda reported that while conventional channels of communication significantly contribute to increased awareness about schistosomiasis and PZQ drug uptake, some rural communities do not receive such messages (Muhumuza 2017). The same study by Muhumuza also found that other community members find it challenging to understand some of the messages due to the use of the English language as opposed to local languages. These findings could suggest the need to contextualise the design of the communication campaign interventions by considering geographical, social and cultural variations as well as community involvement and participation (Kauppi 2015; Ngigi and Busolo 2018). A lack of community involvement and participation in the design and implementation of communication campaign interventions have been reported to hinder their acceptability, uptake and ownership, thereby inhibiting the achievement of the intended goals of the interventions (Andrade 2007). In contrast, active community involvement in communication campaign interventions could facilitate the development of the right message, packaged to the right audience, using the proper channels and taking into consideration social and cultural diversities thereby facilitating behaviour change (Estrada et al. 2018). It is also reported that interventions that aim at changing the behaviour of communities should be multi-dimensional and multifaceted, looking at health education, the social environment, physical infrastructures and other incentives (Torres-Vitolas et al. 2023). Other studies on interventions aimed at schistosomiasis control and prevention have also highlighted the need for community-co-design using approaches that are bottom-up, proactive and participatory in nature, to foster the sustainability of the programs (Person et al. 2016; Onasanya et al. 2021). One such form of community involvement is participatory action research.

Participatory Action Research (PAR) refers to collaborative research in which researchers and a group of community members actively identify and address particular problems that affect them (Pain et al. 2011). PAR facilitates a proper understanding of the problems and situates interventions in their social and cultural context (Jallad et al. 2021). PAR was very popular in South America in the 70 s, extending to all parts of the world, including the Global South (Gutiérrez 2016). It is associated with citizen science (CS), another collaborative form of science that also utilises participatory techniques (Schrögel and Kolleck 2019). Yuri Gordienk defines citizen science as "the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort, or surrounding knowledge, or with their tools and resources" (Socientize 2013). It is very popular in the Global North, especially in natural sciences such as biology, ecology, and conservation, ornithology, astronomy, meteorology, and microbiology, environment, history, technology, but not so much within the Global South (Ashepet et al. 2021; Campos et al. 2021; Crain et al. 2014; Law et al. 2017; Science Europe 2018; Thomas et al. 2021). There also exists an overlap between some forms of CS (especially within the social sciences) with PAR, hence the coining of the term, 'citizen social science (CSS)' (Fischer et al. 2021). Pudarm defines CSS as "volunteer participation in social science research alongside trained social scientists specifically to collect observation data as they go about their daily lives" (Purdam 2014). However, volunteer participation goes beyond data collection to include analysis, interpretation and dissemination of findings, and co-design as well as the evaluation of interventions (Albert 2018; Thomas et al. 2021). Some studies have reported that integrating CSS into social science research facilitates trust and acceptability in study findings and reduces barriers to stakeholder engagement (Crain et al. 2014; Schewe et al. 2020). Most of these studies have, however, focused on the Global North, with limited documented research on its application within the Global South.

In this study, we wanted to borrow from both CS and PAR in setting up a bottom-up communication campaign intervention to facilitate the behaviour change toward prevention and control of schistosomiasis along the Lake Albert region in Uganda. The study was situated within a project named Action Towards Reducing Aquatic Snail-borne Parasitic Diseases (ATRAP), which has been operating in Uganda and the Democratic Republic of Congo (DRC) since 2019. ATRAP combines classical CS (collecting scientific data) with contextualised outreach activities to accommodate the many ecological, social, cultural, and behavioural factors that challenge the elimination of this disease. The project has created a network of citizen scientists (CS), a group of volunteers selected and recruited with the help of community leaders and later trained to participate in the research process (Brees et al. 2021). The CSs conduct snail monitoring activities by collecting data on snail species that transmit schistosomiasis and liver fluke disease and participate in awareness raising regarding schistosomiasis. At the start of the study, a baseline survey on knowledge, attitude and practices (KAP) and that of health-seeking regarding schistosomiasis were conducted in the study area, which revealed risky water, sanitation and hygiene practices, misconceptions and taboos as some of the barriers to prevention and control (Anyolitho et al. 2022).

Table 1 Study Participants' Selection.

Category	Data collection method	Sub-counties					
		Kanara	Ndaiga	Kyaterekera	Mpeefu	Bwikara	Total
Participants for Current and preferred sources of information							
Adult community members	FGD	78	52	50	35	36	251
Health workers, village health teams & local council leaders	KII	4	4	2	0	2	12
Sub-total		82	56	52	35	38	263
Participants for Dissemination of baseline study findings and co-design of intervention							
Citizen scientists	Workshop	2	4	3	4	5	18
Participants for Dissemination of baseline study findings and co-design of intervention							
Local council one leader	Workshop	3	2	2	2	2	11
Local council three leaders	Workshop	1	1	1	1	1	5
Technical leaders	Workshop	3	4	3	5	3	18
Cultural and religious leaders and traditional health practitioners	Workshop	7	6	5	6	3	27
Village health teams	Workshop	2	2	2	3	2	11
Victims of schistosomiasis	Workshop	5	7	8	2	0	22
District Health Team	Workshop	0	0	0	0	0	3
Sub-total		21	22	21	19	11	97
Total		105	82	76	58	54	378

Generally, we wanted to explore whether and how CS (particularly CSS), can be integrated within the PAR bottom-up approach to design and implement effective communication campaign interventions to facilitate behaviour change regarding schistosomiasis. More specifically, we aimed to use a mix of both approaches to (1) disseminate our research findings on KAP and health-seeking behaviour regarding schistosomiasis, (2) assess the community's preferred channels of receiving schistosomiasis information, (3) co-design a communication campaign strategy based on the identified social and cultural problems identified during dissemination and lastly, (4) implement a contextualised communication campaign intervention adapted to the respective districts in southwestern Uganda to facilitate behaviour change regarding schistosomiasis prevention and control.

Material and methods

Study area and setting. The study was conducted in Kanara, Ndaiga, Kyaterekera, Mpeefu and Bwikara sub-counties of Kagadi and Ntoroko districts along Lake Albert in western Uganda. The sub-counties are part of the eight sub-counties included in the ATRAP study and are the ones in which baseline studies had been conducted. Also, the sub-counties were recommended by the district leaders as having a high prevalence of schistosomiasis. Ten parishes, two from each of the five sub-counties and 18 villages were included. The villages had also been randomly selected during the baseline studies. Two of the sub-counties-Kanara and Ndaiga, are found along the shores of the lake and are highly endemic for schistosomiasis. They are also hard to reach regarding health-service delivery, education, and road infrastructures, with Ndaiga having only a level II health facility. According to Uganda's healthcare service delivery system, a sub-county should have a Health Centre III serving between 15,000 to 20,000 people. In contrast, a health centre II at the parish level serves only about 2000 (Mukasa 2012). This is not the case for Ndaiga, which has an estimated population of over 15,000 as per the 2014 census (Statistics 2017). Besides, the area suffers from poor WASH facilities, such as a lack of access to safe water and low latrine coverage.

Participants' selections. A total of 378 participants comprising citizen scientists, community leaders, health workers, religious and cultural leaders, traditional health practitioners and selected adult community members, including those who had ever suffered from schistosomiasis, were considered for the study (Table 1). The selection was made with the help of the citizen scientists and ATRAP focal persons in the five sub-counties. A purposive sampling technique was utilised to select the participants for the focus group discussion. Guided by the village local council chairperson and a member of the village health team of a particular village, the researcher identified adult men and women who had stayed in the village for at least over one year and whom the researcher felt would give relevant information regarding schistosomiasis. Criteria for selection of the FGD participants included geographical location, gender and age. Meanwhile living in the study area, occupying local leadership positions, being a citizen scientist, willingness to participate in communication campaigns, and possessing some information about schistosomiasis, among others were considered for selecting participants for the workshops.

Study design. We employed a qualitative participatory action research (PAR) design while integrating citizen social science as a bottom-up community engagement approach. In this study, and as seen in Fig. 1 below, we present a graphical illustration of citizen social science and PAR as a community-led approach in the co-design and implementation of communication campaign intervention aimed at attaining behaviour change regarding schistosomiasis. That is, the CSs work with community leaders and community groups to participate in the research process. We outline four key phases of the study, with the CSs and other members of the community getting involved from phases two to four. Phase I involved baseline studies to assess knowledge, attitude and practices (KAPs), health-seeking behaviours and lived experiences regarding schistosomiasis (Anyolitho et al. 2022, 2023), and the current and preferred channels of information regarding schistosomiasis. The second phase involved the participatory dissemination of findings of the baseline studies. In the third phase, the citizen scientists, community groups, and ATRAP researchers co-designed a contextualised communication strategy. Finally, in the fourth phase, citizen scientists implemented a communication campaign intervention in the community using the developed communication strategy.

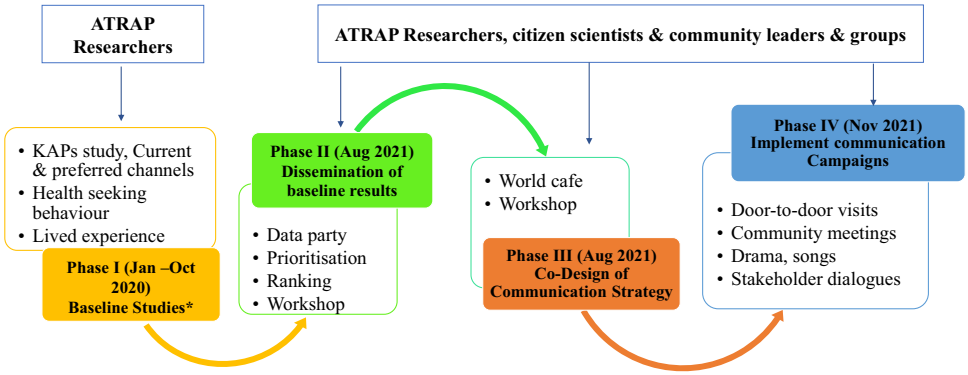

Fig. 1 Citizen science led schistosomiasis communication campaign facilitates effective awareness raising. Phase I demonstrates baseline studies conducted to identify social and cultural factors influencing schistosomiasis infection and control; phase II illustrates how participatory dissemination of findings from the baseline studies enables communities to appreciate the problems of the disease. Phase III demonstrates that communities guided by professional researchers can contribute to design of contextualised communication strategy; and lastly, phase IV demonstrates the citizen science led implementation of the communication campaigns using the designed strategy in phase III above.

The CSs played different roles at different study phases, except in phase I, when they had not been recruited. In phases II and III, the CSs worked together with local leaders and ATRAP researchers to identify and mobilise study participants, organise workshop venues, translate languages, lead discussions during workshops, and present group work. Meanwhile, in phase IV, the CSs identified and organised community groups in their respective sub-counties to participate in drama, songs, and football tournaments. They also mobilised community members and local leaders, organised venues for community meetings and eventually conducted awareness campaigns such as door-to-door, community meetings and dialogues, and organising football tournaments, dramas and songs. During these campaigns, the CSs explained to the communities the science of schistosomiasis, that is, what it is, its signs and symptoms, transmission modes, diagnosis, as well as treatment and prevention.

Data collection and analysis. Various data collection methods were employed during the different phases of the study. Information on data collection methods for the baseline studies on knowledge, attitude, practices, and health-seeking behaviour regarding schistosomiasis are found in published papers (Anyolitho et al. 2022, 2023). Also, in phase 1, we conducted 12 key informant interviews (KII) and held 28 (251 participants) focus group discussion (FGD) sessions. This was to obtain information on the preferred channels of receiving schistosomiasis information by the community.

In phase II, we used data party, prioritisation, and ranking techniques to disseminate the findings of the baseline studies in phase I above. We employed the data party, prioritisation and raking techniques to engage with the citizen scientists and community participants. Data party is a participatory technique in which participants are engaged in data analysis and interpretation of results (Bird and Lewis 2021; Franz and Franz 2013). The technique relies on a tool with five key guiding questions (Supplementary Text 1), to facilitate a proper understanding of data by participants. However, in this study, we adapted the technique by adding two more questions. The first question was on what participants thought were the problems related to schistosomiasis. The second one asked the participants to identify the three most pressing problems that needed attention. Five workshops were held, one in each of the five sub-counties, starting with Kanara, then Ndaiga, Kyaterekera, Mpeefu and Bwikara. ATRAP researchers presented the findings (data) to the participants in English, as the CSs translated into local languages. Also, copies of the presentations were printed and distributed to participants to follow during the sessions and to guide them during discussions. We divided the participants into groups according to different categorisations such as members of the village health team (VHTs), cultural and religious leaders, technical leaders, and local council chairpersons (Table 1). This was meant to encourage active participation among groups, stimulate discussion, generate differences of opinions and views and for easy communication among groups of similar social categories.

Taking the facilitator roles and guided by the tool, the ATRAP researchers asked the groups to interpret the findings in their understanding and identify key socio-cultural factors associated with schistosomiasis. They were also asked to add any problems they felt were not captured in the findings. From the list of the problems, we asked participants to select at least three key problems they felt were most pressing. All the groups did this, after which we asked them to converge in a plenary. Each group presented their work showing the identified problems and the three most pressing problems selected. After all the presentations, participants went through all the issues and discussed and clarified them to generate consensus. This resulted in creating one single list of problems for the sub-county. Finally, participants prioritised, ranked, and scored the problems. Prioritisation was done through voting by show of hands (for the case of Kanara, Kyaterekera, Mpeefu and Bwikara) and by individuals tallying at least three pressing problems from the list (in the case of the Ndaiga sub-county). Finally, the participants selected and agreed upon three problems with the highest scores to be the most pressing social and cultural risk factors associated with schistosomiasis for that sub-county (Supplementary Table 1). This process was done for all five sub-counties. Using the thematic analysis method, the ATRAP researcher synthesised the data and created one aggregated list of social and cultural risk factors associated with schistosomiasis in the study area (Supplementary Table 2).

In phase III, the ATRAP researchers, the CSs and community groups co-designed a contextualised communication strategy to facilitate behaviour change regarding schistosomiasis (Fig. 1). As described in phase two above, five workshops were held in the same sub-counties with the same number and category of participants. World café participatory action research technique was used to guide the workshop. The technique has a tool that follows seven principles comprising of setting the context; creating a hospitable space; generating meaningful and important questions for discussion; encouraging everyone's contribution; connecting diverse perspectives

of participants; collective listening; and sharing (Terry et al. 2015). Conversations occur in a café environment where five to eight participants come together to brainstorm topics of interest (Brown 2002). In this study, the main aim was to generate data that would be utilised to develop a communication strategy to implement a communication campaign that would address the problems identified during dissemination in phase two above. As such, major themes for discussion included coming up with communication goals and objectives, generating the preferred messages, identifying the target audience, establishing key actors, and selecting appropriate and relevant channels and strategies.

The ATRAP researchers relied on the world café guiding tool to facilitate the workshop. Participants were divided into three to four groups, with every group comprising five to eight participants. Each group selected a secretary to act as a host for the session. The secretary steered the discussion, took notes, and explained to new participants what the previous participants had discussed. The new participants then discussed the same questions for about 20 to 30 min, after which they switched to the other groups leaving only the secretary as the host. This process continued until all participants switched to all groups, and the topics were thoroughly and exhaustively discussed. The groups gathered in the plenary, and the secretaries presented the groups' findings. With guidance from the ATRAP researchers, participants harmonised the findings to come up with a single communication strategy for that sub-county. This process was done for all the five sub-counties as presented in Supplementary Table 3. Participants also developed an action plan and selected an ad-hoc committee to implement it.

Finally, in phase IV, the 18 CSs led the communication campaign intervention with support from some community leaders and volunteer groups while being guided by a team of ATRAP researchers. It was aimed at raising awareness about the disease, debunking existing myths and misconceptions, as well as inciting WASH behaviour change based on problems identified during dissemination and translated into key messages during co-design. The activities occurred in the five sub-counties between November 5th to 10th, 2021. Door-to-door visits and community meetings took place between the 5th and 6th, while drama songs and dialogue meetings, including planting signposts in hot spot areas identified by the CS happened on the 7th and 8th, a football tournament and radio talk show on the 9th with stakeholder dialogue workshop as the last activity on 10th. Before the kick-off of the campaign, the CSs attended a two-day training organised by ATRAP researchers to equip them with general knowledge and skills on communication and how to contextually communicate schistosomiasis messages. The training also discussed the draft communication strategy developed with inputs generated during the co-design with the CSs. Finally, the training agreed on the appropriate channels of communication to use for intervention.

Results

Preferred channels of communicating schistosomiasis/health information. Based on the data analysed, the channels identified include community radios (and megaphones), community volunteers (VHTs) and local leaders, Local FM radios, and health workers. Some channels were being used during the study, while others were not.

Community radio and mobile radio/megaphones. Participants identified community radio (also known as mobile radio, megaphone) or *"mukalakasa"* in the local language, as the preferred means of receiving schistosomiasis information. Community radios are usually mounted on a tall pole and are mostly found at the trading centre. Meanwhile, mobile radios, megaphones or microphones are small, portable and hand-held. They are used for moving from door to door, mainly for mobilisation. Community radios are preferred for their effectiveness in passing information on health issues to many people within the same geographical area.

> "R1; the microphone because it is fast and quick. R4; the microphone because you can easily hear the person speaking even if you're in the distance far away. R9; the best way to spread information about bilharzia is our local radio, yes, megaphone" (Female FGD-5: Songarao village-Ndaiga Sub- County).

Community radios are most preferred, especially by participants along the lake shores, for passing schistosomiasis information second to VHTs and local leaders. The VHTs and local leaders themselves also confirmed this. Reasons for preference include ease of use, wider coverage of densely populated villages, ability to listen, and fast and quick to relay information.

> "R3; the chairman walks around with the microphone informing people. R5; a person with a microphone walks around and reaches all the villages informing us about the new disease outbreak" (Female FGD-5 Songarao village-Ndaiga sub-county)

VHTs and local leaders. VHTs and local leaders were also mentioned by participants across all the five sub-counties, especially those from the lake shores. VHTs are people local leaders select to volunteer to provide basic health services at the village level. They are the first point of contact in Uganda's health care system. They carry out community mobilisation and sensitisation and participate in community health outreaches. The VHTs also provide basic health services such as malaria testing and treatments and family planning contraceptives. At times, some VHTs use community radios or microphones to pass health information to the community. Participants said they prefer the VHTs and local leaders because they are convenient and reliable in passing information. On the shores, the VHTs are said to do great jobs of community mobilisation and sensitisation, including drug distribution. Other participants prefer VHTs because they have experience passing information on other health-related conditions.

> "R1; now us here the VHTs have done a good job. For example, if a person has cholera, they take him/her to the hospital, and if it's true, they come back and inform us" (Male FGD-22, Ntoroko East B Village-Kanara Town Council)

Some participants, however, suggested that the VHTs need to be trained first on schistosomiasis information and how to communicate the information to the community if they were to be effective. "It *requires the use of VHTs to be trained to come and sensitise us*" (*Male FGD-19, Kisenyi A Village-Kanara Town Council)*

A significant number of male and female FGD participants, especially those from the lake shores, also said village council chairpersons would be resourceful in passing schistosomiasis information. Local leaders were reported to complement the VHTs in passing schistosomiasis-related information. Such participants argued that the local leaders have been working with the VHTs to mobilise and inform the communities. Local leaders are said to be involved in community sensitisation as well. They do this by moving from home to home or through the community radio.

> "The chairman usually calls for a meeting, then he informs us. We don't have radios here. It's either the chairman of

the "mukalakasa "(mobile radio) from Kitebere (neighbouring village)." (Female FGD-17, Nyamasoga village-Ndaiga sub-county)

Some community members, however, prefer to listen to the local leaders more than the VHTs due to their respect and trust in the leaders, their availability and easy accessibility, knowledge of community problems and challenges and being there for their people in case of any problems.

"Through the chairman, because he lives in this village and they always call him, and he reaches our households very fast" (Female FGD-27, Kayera village-Mpeefu sub-county).

Meanwhile, some male FGD participants complained about some local leaders for non-performing. Such participants said they prefer the VHTs, health workers, neighbours and friends as their primary source of health information.

"At times, the VHTs give us tablets but preferably to the women and the children only in this area of ours. Chairman does nothing and cannot even give us a piece of advice in the area" (Male FGD-4, Nyamasoga village-Ndaiga sub-county)

Healthcare workers. A few FGD participants also preferred health workers (HWs) in passing schistosomiasis-related information reasoning that the HWs know about the disease. Participants commended the HWs for sensitising communities about water, sanitation and hygiene (WASH) aspects, although the participants also suggested that the HWs should bring drugs to them.

"R11: through the health workers and bring us medicine, some for putting in water *(Female FGD-15, Kisenyi East B village-Kanara Town council)*

Local frequency modulation (FM) radio stations. FM radio stations were also mentioned by participants, mainly from the uphill side like Mpeefu, Kyaterekera and Bwikara, as a source of health-related information. Private individuals mostly own FM radio stations to broadcast information within certain geographical catchments for commercial purposes, although some are owned by faith-based organisations. They are spread throughout the country, although their signals tend to be weaker for communities in low-lying areas such as the Lakesides.

"We always listen to news and programs on the radio" (Female FGD-11, Nyamarembo village, Bwikara sub-county)

Similarly, a few participants said they prefer receiving schistosomiasis information through FM radio and TV. Big listenership was the main reason for preference. However, this was least mentioned compared to community radios and village health teams.

"Radio is good because it can be listened to by many, and those who have not listened to it will be informed by those who have" (KII-5, Kisuura village-Bwikara Sub-County).

Contextualised information communication. Some KII participants, argued that the choice of which channel to use for information largely depends on several factors. The information type, urgency, audience, and time are some factors considered when choosing a channel to use, as one of the key informants mentioned.

"It depends on the information we are giving out, if it's urgent and everyone should be aware of it; like Ebola, we use the mobile microphone because, with that one, people everywhere can hear the information. If it is the ministry of health with a sensitisation meeting, we mobilise people by word of mouth from house to house and tell them the venue and place where" (KII-3, Kanara Town Council)

As can be observed from the above, most local channels were being used for passing other health-related information at the community level, even though they were not being used for schistosomiasis specifically. Also, channels such as TVs, IEC materials and, in some cases, local FM radios were used for passing schistosomiasis, but the communities did not prefer them. Reasons provided for low preference include lack of affordability of TVs and radios, poor or no signals for the TVs and radios, and language problems for the case of IEC materials.

Citizen science and dissemination of findings of the baseline studies. From the phase II workshops on disseminating results, the CSs and community groups successfully identified the social and cultural risk factors influencing schistosomiasis infection and prevention (Supplementary Table 2). From the prioritisation and ranking, the most pressing problems identified by participants included lack of access to clean and safe water, lack of access to healthcare services, inadequate and irregular supply of praziquantel drugs in the facilities and open defecation. Also, poor health-seeking behaviour, inadequate knowledge of schistosomiasis, lack of testing for the disease and high level of poverty were prioritised. Furthermore, misconceptions identified by participants on top of the ones presented in disseminating the baseline studies included associating swollen bellies with poison and witchcraft. Some CSs and community groups said it was their first time to hear about some signs and symptoms, like blood in the stool. Other participants from the uphill side said they never thought the disease existed in their communities as they used to link it to only those at the lakeshores. Witchdoctors in some sessions also reported having treated some community members presenting with some of the identified signs and symptoms although they did not know that it was related to schistosomiasis.

Citizen science and co-design of communication campaign strategy. Regarding co-design, the CSs and community groups generally agreed on the goal of improving the community's health and reducing schistosomiasis prevalence by a specific timeframe. Different sub-countries projected different timeframes ranging from one to five years. Participants also agreed that to achieve this, there was a need to increase awareness regarding the disease to change the behaviour of the community. Also, improving access to and utilisation of clean and safe water and latrines, and debunking myths and misconceptions were discussed. Another objective was to increase the PZQ drug supply and make it accessible to the community. However, due to resource constraints such as time and funding, both the researcher and the community unanimously agreed to implement a communication campaign to raise awareness regarding the disease. The other objectives raised by the community were left out to be presented to the district and other stakeholders through lobbying and advocacy. The key messages suggested by participants included, using clean and safe water, avoiding contact with contaminated water, emphasising constructing and using latrines, debunking myths, and misconceptions like defecating in the lake does not bring good fish catch, encouraging people to seek medication from hospitals and facilities, reminding people about signs and transmissions and how to prevent schistosomiasis. These messages were generated from a list of the most pressing problems of schistosomiasis identified during the participatory dissemination of baseline findings in phase II above.

To ensure the messages effectively reach the communities, the participants recommended key channels such as door-to-door visits, community radios and community meetings, drama and songs, and informal gatherings such as churches, funerals, wedding parties, posters and radio talk shows. Community volunteers such as the CSs and VHTs, local leaders like the local chairperson council, religious and cultural leaders, and health workers were proposed as the main actors in passing the messages (Supplementary Table 3). It should be observed that the channels were contextualised, with door-to-door community meetings and community radios being preferred by participants along the lakeshores. Meanwhile, drama, dance, songs, and community radio were suggested by those CSs and community groups from the uphill, even though the CSs received training on all the different channels and applied them as and when they deemed appropriate with guidance from the ATRAP researchers.

Citizen science and implementation of a communication campaign. Implementing the communication campaign was the last phase in the intervention. The CSs, selected local leaders and community groups carried out the communication campaigns using the key channels proposed above. Key messages passed were about schistosomiasis signs and symptoms, transmission modes, diagnosis, treatment and preventive ways. Also emphasised was practising preventive measures such as constructing and using latrines, avoiding contact with contaminated water sources or acquiring and using protective gear for those who cannot avoid it. Furthermore, myths and misconceptions were debunked mainly using drama and songs. Lastly, the CSs encouraged the communities to always seek medication from hospitals and facilities instead of going to witch doctors or herbalists and to respond positively to the MDA program whenever it comes. Using the above channels, the CSs reached over 1000 households and about 9000 individuals during the one-week awareness intervention (Supplementary Table 4). The channels are explained below.

Door-to-door visits. The CSs moved from house to house in the identified villages sensitising the members of the households about schistosomiasis. Household members asked the CSs about areas they did not understand, and the questions were responded to accordingly. Where the CSs did not understand or never appropriately explained, the ATRAP researchers supported them by providing more explanation and clarification.

Drama and songs and community dialogue meetings. The CSs also organised drama and songs performed by different groups in the sub-counties with the support of the local leaders. Furthermore, the CSs consulted with local leaders to identify central venues for the drama and mobilised the community members. The CSs also held community dialogue meetings, especially at public places such as trading centres, markets, and health facilities. Additionally, the CSs used drama and meeting sessions to dialogue with community members about the disease. Also, during the same sessions, over 80 signposts were planted in the highly endemic sub-counties of Ndaiga and Kanara along the lake. The signposts were planted in specific hotspots where open defecation and risky water practices were common. The signposts contained key messages in local languages encouraging communities to always defecate in the latrine while avoiding open defecation. Other messages encouraged the use of clean and safe water while discouraging the use of unclean water sources.

Football infotainment tournament. The CSs organised a one-day tournament in which six clubs, one from each of the five sub-counties, and the sixth club, the CSs themselves, participated. During the tournament, CSs alternately went on the public address system and passed messages regarding schistosomiasis. Also, they distributed fliers and posters containing schistosomiasis information, while a huge banner containing schistosomiasis information was hung at the roadside for passers-by to read.

Stakeholder dialogue workshop. ATRAP researchers also organised a stakeholder dialogue workshop attended by CSs, sub-county technical and political leaders, district technical and political leaders, officials from the ministries of health and of water and environment, and representatives of NGOs. During the dialogue, the CSs captioned the community perspectives of the key issues identified from the study findings during the community workshops. In a participatory manner, the attendees discussed the key issues in separate teams to formulate key recommendations for better schistosomiasis prevention and follow-up.

Discussions

In this study, we wanted to borrow from participatory action research (PAR) and citizen science as a bottom-up community-based strategy to implement a communication campaign regarding schistosomiasis. Specifically, the study assessed the preferred sources of schistosomiasis information received by the community, employed participatory techniques to disseminate baseline study findings and to co-design a bottom-up communication campaign intervention. Finally, the citizen scientists together with community groups implemented the intervention. This section discusses the main findings presented in the sections below.

Preferred channels of health/schistosomiasis information. This study found that endemic communities prefer to receive schistosomiasis information using local channels such as community radios and door-to-door visits by volunteers and local leaders. The channels were preferred for their simplicity, ease of use, and effectiveness in delivering information to remote rural communities such as those along the lake shores. In addition, the channels were appreciated for being interactive, allowing questions and answers for quick feedback. On the contrary, most participants did not prefer channels like television (TV), FM radio and magazines, even though some acknowledged that such channels were being used for passing information on other diseases. This difference in preference is probably because the conventional channels use languages that make it difficult for the rural communities to understand, and also, they do not reach the rural settings, as reported by some studies (Muhumuza 2017; Natifu 2006). The findings from our current study are important in guiding the design of contextualised communication strategies instead of the one-size-fits-all conventional approaches.

The current study also found that some community members prefer health workers for passing schistosomiasis-related information, even though they face challenges with financial and logistical constraints. This could explain why most community members do not think the health workers are appropriate to pass out schistosomiasis-related information. Other studies have also reported challenges faced by health workers in delivering outreach services to the communities, such as limited facilitation, bigger areas to cover, transport problems and lack of motivation (Kabatereine et al. 2014; Tuhebwe et al. 2015). Supporting the health workers to train and equip local VHTs with the necessary skills, knowledge, and materials for creating awareness regarding

community health problems could help meet some of these challenges.

Finally, our study revealed some notable findings whereby, participants recommended contextualising schistosomiasis communication channels depending on geographical, social, and cultural factors. For instance, the use of local FM stations instead of community radios and megaphones for areas with good coverage and usability to complement the community volunteers and local leaders. This is crucial since it helps to address limitations of reach, coverage, accessibility, acceptability and affordability. This idea of contextualising communication strategy is an added value to how interventions have previously been done. It is a necessary basis for co-designing a bottom-up communication campaign strategy that could be adopted or adapted for other future interventions. Previous studies have also highlighted the importance of considering social and cultural sensitivity in selecting channels to use for improved understanding, acceptability and uptake of the messages (Person et al. 2016).

Citizen science and the dissemination of study findings. Findings from our current reveal the engaging nature of citizen social science in the data party participatory approach that enables the interpretation of study findings. We observed that the modified data party technique using the seven guiding questions, (Supplementary Text 1) enabled the CSs and the community groups to interpret the baseline KAPS findings. We also noticed that the participatory technique aided them in identifying the social and cultural risk factors associated with schistosomiasis infection in their communities and prioritised and ranked the most pressing problems. Furthermore, they could identify other myths and misconceptions not highlighted in the KAPs baseline study. This process allowed participants to appreciate and acknowledge the problem of schistosomiasis in their contexts. This would not have been achieved if the findings had been "imposed" on them. Our findings are in agreement with other studies that also reported that citizen science fosters a better understanding of human behaviour, enhances lay persons' knowledge, and facilitates community empowerment through the involvement of lay persons in the research process (Albert 2018; Bisung et al. 2015; Ciasullo et al. 2021). Our current study also provides interesting insights into how expert researchers can collaborate with local communities in this crucial phase of the research process. This was demonstrated by the way the ATRAP researchers, together with citizen scientists and the community representatives collaboratively discussed the study findings allowing them to trust the findings of the study. Other studies had, instead, mainly looked at the involvement of citizens as lay persons in data collection and interpreting study findings (Senabre et al. 2018). Future research could adopt our strategy of citizens' involvement and participation in the research process to build trust, honesty, transparency, and accountability in study findings.

Citizen science and the co-design of communication campaign strategy. Our current study shows that the world café technique enabled the CSs and community representatives to provide qualitative data that was used to generate critical messages to be passed to the community. Also, through the workshop, we noticed that the participants were able to suggest appropriate audiences, actors, and channels for use during implementation.

The current study also found that participants easily dialogued in a meaningful engagement that generated consensus around the topics, which fostered mutual learning. This way, the CSs and community representatives could generate ideas and suggestions about the communication tools used during the intervention. Whereas the World café allowed contextualising the messages, citizen science allowed the participants to own the processes and outcomes. Research ownership is an important element since it empowers communities to have a voice in coming up with solutions to problems that affect them. Our findings are supported by another study which also revealed that World café, as a participatory technique, facilitates dialogue and mutual learning, thus motivating their participation and responses (Löhr et al. 2020). The world café, as a PAR technique, is also a powerful tool that facilitates smooth knowledge generation by local communities (Broom et al. 2013). Also, a study in Zanzibar demonstrated that the co-design of schistosomiasis interventions together with communities enables them to contribute to the development of contextualised education campaigns (Person et al. 2016). Therefore, future interventions could consider employing local citizens in co-designing interventions for easy acceptability by the community.

Citizen science and implementation of communication campaign intervention. Firstly, from our current study, we found that the citizen scientists were able to mobilise and organise the communities to participate in the awareness intervention. This could probably be attributed to previous engagement by the CSs with the community leaders and, the fact that the CSs are known and trusted by the community. This is critical as the first step in successfully implementing any community-based intervention requires effective community mobilization and organisation (McCloskey et al. 2013; Kyaw 2018). Our finding is in agreement with many other studies that have also underscored the importance of community mobilisation and organisation towards concrete action (Albert et al. 2021), fostering a supportive environment (Torres-Vitolas et al. 2023), adding voices to community members and awareness raising for informed action (MercyCorps 2020). On the contrary, inadequate community mobilisation creates a knowledge gap in the community regarding existing health problems, as reported by a study on schistosomiasis in Mozambique, with a recommendation to broaden its scope (Rassi et al. 2016).

Furthermore, we observed that the citizen scientists were able to carry out the awareness campaign using the local channels of communication recommended by participants during the co-design phase. For instance, using door-to-door visits and community meetings held by the CS facilitated two-way interaction with the community members. Meanwhile, drama and dance enabled the delivery of messages to the communities by illustration, aiding easy understanding of messages. Our current finding is supported by a previous study that revealed that the use of conventional TVs, radios and print media approaches faces challenges in reaching out to marginalised and endemic communities (Muhumuza et al. 2015). Also, the fact that CSs were from the communities could explain why people positively responded to the campaigns. Public participation of citizens in research is said to allow for the democratisation of knowledge acquisition (Strasser et al. 2019). Therefore, the active involvement of communities in the implementation of contextualised communication campaign interventions is highly recommended.

The implementation of the above interventions could be attributed to several factors such as the participatory selection of the CSs, the use of social media platforms for communication and feedback, as well as community engagement and regular encounters with the ATRAP researchers. Also, knowledge and skills on schistosomiasis, snail sampling and communication provided during different refresher training sessions and workshops conducted by the project could have contributed to the successful conduct of the intervention. In addition, financial

compensations provided to the CSs by the project during snail sampling (Ugx. 75,000/ = only per month) and during the one-week awareness campaigns (Ugx. 20,000/ = only each day) could have motivated them. Our study is supported by other studies that also revealed that proper training and other supports enable citizens to collect quality data (Gommerman and Monroe 2012), provide opportunities to learn new ideas (Kitamura et al. 2020), increase volunteers' perception of their capacity to overcome challenges and achieve desired objectives (Torres-Vitolas et al. 2023).

Finally, this research encountered certain limitations that merit consideration. The initial phase of the study suffered from a gap in comprehensive community engagement. That is, engagement efforts were primarily focused on only a select group of community leaders during the initial meetings and the endorsement of the study, which was instrumental in gaining initial support, but might have hindered broader understanding and engagement amongst the general community. Consequently, this restricted engagement could have influenced the extent of some community leaders and community members' participation and potentially slowed the process. Additionally, the researchers missed out on opportunities by not including the citizen scientists when the baseline study was conducted. This would have increased their understanding of the study's aims and findings right from the start. This could be improved in follow-up studies. Lastly, the focus of this study was on documenting the participatory dissemination of findings, the co-design of the communication campaign, and its implementation. However, it did not encompass a comprehensive assessment of whether the intervention reached its initial goals as well as an understanding of how the intervention was implemented. Concretely, the study did not test the intervention's impact on modifying the community's knowledge, attitudes, and practices concerning the disease. Although this limitation was due to constraints in terms of time and money, it points to potential areas for future research to comprehensively evaluate the efficacy and outcomes of similar types of health interventions.

Conclusions

Integrating citizen science within other participatory approaches, especially in the global south has hardly been documented before. Firstly, our study has revealed that endemic communities prefer receiving schistosomiasis information using local approaches instead of conventional channels. Furthermore, citizen science and PAR provide a highly valuable and recommendable approach for communities to understand and appreciate study findings and, to co-design and implement contextualised schistosomiasis communication campaigns that could facilitate effective and inclusive behaviour change. Therefore, future studies should consider involving citizen scientists right from the beginning of the research process, including identifying the research questions and implementing and evaluating interventions. Finally, there is a need for a follow-up study to evaluate the intervention process and the impact to ascertain possible changes in knowledge, attitudes and practices of both citizen scientists and communities regarding schistosomiasis prevention and control and to guide future interventions.

Data availability

The data generated or analysed during this study are included in this published article and its supplementary information files. Transcripts of the qualitative data collection are not publicly available, but accessible from the corresponding author upon reasonable request.

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Author contributions

MKA, TH and VNN conceptualised the study. MKA investigated the study. MKA collected and analysed the data., TH, mobilised funding. MKA, KP and TH wrote the original draft. MKA, KP, TH, CM and VNN reviewed and edited the manuscript.

Ethical approvals

This study was performed in line with the principles of the Declaration of Helsinki. The study received ethical approvals from the Mbarara University of Science and Technology Research and Ethics Committee (MUST-REC) with reference no. MUREC 1/7 and the Uganda National Council of Science and Technology (UNCST) with approval no. SS836ES. Clearances were also obtained from the district health officers of the two districts of Kagadi and Ntoroko. Before the start of the study, the project was introduced to the sub-county and village leaders in the respective sub-counties and villages, who later introduced the project team and the researchers to the community members.

Informed consent

Informed consent to participate in the study and to publish was obtained from the individual participants and the community by both the corresponding author and the CSs. Two informed consent forms were prepared. The first one, for collecting data on the preferred sources of schistosomiasis information was obtained from adult individuals. Meanwhile, the second one for participation in the awareness campaigns was obtained from the community members through their local leaders. For the dissemination of findings and co-design of interventions, it was not necessary to obtain written informed consent since the participants willingly responded to workshop invitations. The corresponding author prepared an informed consent form, which stipulated the study title and purpose, the procedures for selection and participation and what was required by participants. Furthermore, participants were assured of voluntary participation, confidentiality, and privacy. After going through the documents, participants were asked to state whether they agreed to participate in the study or not. Acceptance was by use of signing acknowledgement.

Competing interests

We declare that no conflicting interests exist. This study was supported by the ATRAP project (Action Towards Reducing Aquatic Snail-borne Parasitic Diseases) of the Belgian Development Cooperation program. The contents and all the 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 study design, data collection and analysis, the decision to publish, or the preparation of the manuscript.

Additional information

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