PUBLIC AND COMMUNITY ENGAGEMENT IN HEALTH SCIENCE RESEARCH: OPENINGS AND OBSTACLES FOR LISTENING AND RESPONDING IN THE MAJORITY WORLD

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Editorial: Public and community engagement in health science research: Openings and obstacles for listening and responding in the majority world

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Editorial on the Research Topic
Public and community engagement in health science research: Openings and obstacles for listening and responding in the majority world

Community engagement is recognized as a valuable and ethical component of health science research and its inclusion is increasingly becoming a prerequisite for research funding and approvals (1–5). In general terms, community engagement aims to foster the interchange of perspectives, opinions, and ideas and promote the co-production of knowledge between researchers, research participants, and other stakeholders (6). Community engagement initiatives are often designed with the intention of enabling exchanges of this nature.

This Research Topic was designed to explore approaches taken by engagement practitioners, engagement scholars, social scientists, and researchers to promote listening and responding to community voices in research processes. It seeks to understand the challenges that obstruct meaningful integration of community voices in research design and responsiveness to expressions of needs and aspirations for change, in low-and-middle-income countries. The Research Topic draws experience from numerous majority world countries and explores multiple global health challenges and research approaches. The majority world is "where the vast majority of the world's people live yet they have access to a fraction of the world's wealth and power" (7). By discussing projects, programmes or guidelines, each article provides valuable experience and insight

FIGURE 1
A public exhibition held as part of an engagement project in water microbiology undertaken during a water crisis in Cape Town described by Black and Sykes.

into the effectiveness of efforts to promote listening and responsiveness in community engagement initiatives. The Research Topic comprises 10 articles including six original research papers, two community case studies, one methods article, and one perspective piece. Experiences are shared from Southeast Asia, Africa, and South America.

The first six articles discuss approaches and methods suggested or used to engage community members in pressing public health challenges and ethically complex fields of research.

The perspective article by Hickey et al. draws on data collected as part of an evaluation of community and public engagement (CPE) by National Institute of Health Research (NIHR) award holders to provide insights on CPE practice in global health research. The authors build on their analysis of this data and existing guidance to identify key components of "good" CPE.

Quoc et al. describe the methods and results of a situation analysis undertaken as part of community-based participatory research (CBPR) to engage southern Vietnamese communities in discussions about access to care for hepatitis C virus (HCV). The authors aimed to identify key groups and institutions working with underserved populations that are at high risk of HCV infection including people who inject drugs and those with limited resources (often migrant workers). The article emphasizes the value of using stakeholder information to build relationships, foster ownership, and ensure context specificity in CBPR.

In northern Vietnam, Cai et al. developed a participatory learning and action intervention that used community-led photography to address the problem of antimicrobial resistance (AMR) among both humans and animals. The intervention was implemented in preparation for a large-scale One Health trial. Through the thematic analysis of implementation documentation, the article shares important lessons learned in relation to optimizing participatory AMR engagement strategies that can add value to the conceptualization and design of community engagement activities.

Another participatory visual methods (PVM) approach to engagement in Southeast Asia is discussed by Delmas et al. The authors describe the development of a script for a film that was designed to engage thousands of community members living along the Thai-Myanmar border on the highly prevalent health challenge of tuberculosis. Their research shows that locally made films, which include patients and community members in script development and as leading actors, can have a significant impact on various aspects of disease awareness and knowledge.

Moving to an African context, Davies et al. also discuss the use of visual methods, in their case for the combined purpose of engagement and evaluation. This article focuses on the application of participatory video (PV) to explore the influence of a School Engagement Programme on the views and understandings of science and research among Kenyan state secondary school students. The authors draw on insights gained through facilitating the PV process to make recommendations for school engagement practice.

The case study published by Mumba et al. was also undertaken in Kenya. The authors discuss their experience of community and stakeholder engagement in human infection studies (HIS). They explain that HIS are complex because they involve infecting healthy individuals with disease-causing pathogens which can raise community concerns and jeopardize trust. The article describes how engagement activities were facilitated throughout a controlled human malaria infection study, highlighting the need for guidelines addressing specific considerations of HIS engagement.

The Research Topic also applies a critical lens to engagement frameworks and outcomes by discussing constraints in researcher, community, and government responsiveness.

Polidano et al. discuss their model of decolonial community engagement in a global health research program, focusing on cutaneous leishmaniasis. Their methodology implied that models for community engagement would be different in the culturally diverse contexts of Brazil, Ethiopia, and Sri Lanka. The authors evaluate their critical anthropological approach to engagement and in doing so reveal a gap between the exemplary community engagement frameworks available in the literature and the everyday reality of working in low-resourced communities.

Similar conclusions are drawn by Black and Sykes as they share insights from South Africa. The authors describe a case study of community engagement in water microbiology undertaken during a water crisis in Cape Town and the encroaching threat of a "Day Zero" when piped water supplies would be shut off (see Figure 1). They introduce the concept of engagement integrity to depict the gap between recommended standards of engagement formulated by global health organizations and what is achievable in marginalized contexts characterized by structural deficits and political exclusion.

The article by Nyirenda et al. raises questions about the opportunity for participatory community engagement to foster social justice in settings with pronounced social and structural inequalities. The authors report that digital story telling was an effective method for engaging community members in self-identified priority health challenges related to water, sanitation, and hygiene in urban Malawi. They go on to discuss how a lack of resources and power imbalances prevented participants from escalating their dissatisfaction through community activism.

Nouvet et al. examine responses to the question "*Is There Anything Else You Would Like to Add?*" in the context of a study that explored perceptions of Ebola research among West Africans. The authors raise important questions about what can and should be done when concerns and hopes expressed by research participants exceed the intended scope of a research project and ask what is at stake ethically in how researchers respond to such entreaties.

Collectively, the articles in this Research Topic share significant obstacles encountered, and valuable lessons learned through the design, implementation, and assessment of community engagement initiatives. By drawing on their learning the authors raise important questions and offer recommendations with the intention of strengthening and grounding community engagement practice in global health research in resource-limited contexts.

Author contributions

The authors of this article were co-guest editors of the Research Topic. GB wrote the first draft of the editorial. PYC, DN, and MC reviewed and provided feedback on the manuscript. All authors contributed to the article and approved the submitted version.

Conflict of interest

Author GB was employed by Sustainable Livelihoods Foundation.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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"Is There Anything Else You Would Like to Add?": The Ethics of (Not) Addressing Research Participants' Top Concerns in Public Health Emergency Health Research

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When conducting interviews or focus groups, researchers often end with a simple question; "Is there anything else you would like to add?" This article takes responses to this question provided by participants in a study of "West Africans' Perceptions of Ebola research" as its point of departure. A number of participants in that study accepted the invitation to add on to their interview at its end with details of suffering from the sequelae of Ebola in their communities, and criticisms of state social abandonment. Some explicitly asked the researcher to ensure the suffering of Ebola survivors would be recognized at the international level. These closing words exceeded the objectives of the study within which they emerged. This was a study focused on lived experiences and decision-making to participate in Ebola research during or after the 2013–16 West Africa Ebola outbreak. The study aimed to inform the ethical conduct of research in future public health emergencies. What to do, then, in the face of these participants' entreaties to the interviewer for action to address Ebola survivors' suffering and social abandonment? Can and should the public health emergency or qualitative researcher better anticipate such requests? Where participants' expressed concerns and hopes for the impact of a study exceed its intended scope and the researchers' original intentions, what is at stake ethically in how we respond to those entreaties as researchers? This paper offers reflections on these questions. In doing so, our intention is to open up a space for further consideration and debate on the ethics of how researchers respond to unanticipated requests made to them in the course of research projects, to leverage their power and privilege to advance local priorities.

Keywords: public health emergency research, ethics, advocacy, Ebola, West Africa

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INTRODUCTION

The interview is almost over. *Margaret* (a pseudonym), a nurse in a hospital in Freetown, Sierra Leone, has been talking about her participation in a vaccine trial held during the 2013–16 Ebola outbreak. In doing so, she has had to recall a painful period: healthcare workers were particularly hard-hit by the disease, and her decision to receive an experimental vaccine was fraught and contentious. Now that the interview guide has been exhausted, the interviewer has one last thing to ask. Is there anything else that *Margaret* would like to say, about any of the topics they have touched on, or otherwise?

There is, but it does not relate to her own experience of research participation:

> Well, because the most important thing [is] the survivors are here that Ebola virus hit, they are all over the country. Some of them, they are healthy. Some [have] problems with their eyes, their kidneys, they are having so many problems with their health. So we are asking some NGOs, some international organizations to come in their aid; so we are asking to help them.
>
> Because for me, I'm not sick with Ebola. Those people out there who are suffering from this Ebola outbreak after they are getting treated, up to this time they are facing a lot of health challenges, so if there are any organization out there, let them come and help them. Some of them are having eye problems, kidney problems, some of them are suffering a lot, but if some of them listen to this interview, let them come to their aid, let them come help them. Some of them they lost their parents, they are not able to go to school, some of them don't have houses to sleep. But if anybody hear this interview, let them come to their aid and help them, please. Thank you.

As a matter of course, and like the majority of social scientists and interviewers, we usually end the interviews we conduct with some version of: "Is there anything else you would like to add?" This is both polite and practical: a way of checking back in with the participant that may lead to some final details or insights or points of emphasis. Often, and we say this based on 20+ years of conducting semi-structured interviews in our capacity as social scientists and qualitative researchers, the question simply stands for the close of the interview, and is frequently interpreted by the participant as an invitation to feel released from any further obligation to share more, to thank the interviewer for listening to their story, or to ask the interviewer some personal questions.

Sometimes, however, this question is taken up by study participants as an opportunity to communicate information that matters deeply but does not fit neatly with study objectives. *Margaret*'s call for action is an example. Her calm yet arresting plea was not at all unusual in the context of the "Perceptions and moral experiences of research participation during the 2014–16 Ebola outbreak" study (hereafter, referred to as the Perceptions Study) in which *Margaret* had agreed to speak with the first author. This article reflects on what such entreaties produce within the context of research with public health emergency affected populations, and considers the ethical obligations and options of researchers in response to requests for advocacy that extend beyond the intended scope, and arguably beyond the resources, of a research project. We begin by presenting an overview of the Perceptions Study. We connect our team's lack of preparedness for Ebola study participants' requests that our team leverage its international networks and privilege to help them advance their priorities to the limited co-design of our study. We outline how greater collaboration with Ebola survivors might have avoided our team being unprepared for this stakeholder group's requests.

Following consideration of shortcomings within our study's design, we then move into reflection on the possibilities and ethical implications of researchers responding in different ways to unanticipated requests by participants, namely that the researcher extend their intended activities to help the participants achieve their priorities.

BACKGROUND: THIS STUDY AND ITS LIMITED CO-DESIGN

The "Perceptions and Moral Experiences of Research Conducted during the West Africa Ebola outbreak" study was funded by an ELRA R2HC grant. Co-led by an international interdisciplinary research team, including four anthropologists, as well as ethicists and healthcare professionals, this qualitative study had as its goal to deepen understandings of challenges and strategies for the ethical conduct of research during public health emergencies. The authors of the current paper include the two co-principal investigators of the study and one co-investigator. The first author conducted many of the interviews undertaken as part of the Perceptions Study. The impetus for this paper comes from her experiences and reflections about what to do with responses to the "anything else to add?" query. In reflecting on issues of researcher roles and responsibilities, she engaged in discussion with the two co-authors, both of whom have extensive experience conducting qualitative research studies in the domain of public health emergencies. All three are based at universities in Canada.

The study was designed in response to needs identified by partners and others engaged in the work of using, or overseeing and regulating the use of, unproven treatments and prophylactics—the only treatments and prophylactics then available for the disease—during the 2014–6 West African outbreak. Guinea's *Comité National d'Éthique pour la Recherche en Santé* (National Health Research Ethics Board, or CNERS) was a partner on the project, and a local anthropologist, Sekou Kouyate[1], played a key role in both data collection and analysis. The Ethics Research Board of Médecins Sans Frontières International (MSF or Doctors without Borders) also recognized the value of this study, as communicated in a letter of support for the project submitted with our application for funding. Our collectively developed plan was to use the study to develop the kinds of evidence that could be used to support decision-making by healthcare non-governmental organizations (NGOs), intergovernmental organizations, and research ethics boards. In our case, this meant trying to clarify and identify patterns within the experiences and perceptions of people who had engaged with research from different vantages, in different national and local contexts. We conducted

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[1] Sekou Kouyate died from sepsis complications on December 16, 2020.

108 semi-structured interviews with a wide range of Ebola research stakeholders: participants in clinical trials and other Ebola studies conducted between 2014 and 2016 in Liberia, Guinea, and Sierra Leone; researchers; and, key research decision makers (e.g., government representatives, scientific committee members; survivors' association representatives). Primary findings with further details on methods have been reported elsewhere (1).

The study was developed in dialogue with some but not all relevant stakeholder groups. Ethically, we failed: to ensure those potentially most affected by our research had a say in the focus of our research. We did not leverage the full potential of the project to enact respect and recognition for those in our study structurally and socially positioned to be routinely excluded from the setting of research agendas, as widely recommended (2, 3). We did not form a community advisory board for the study, a known strategy for more inclusive and equitable research in public health emergency research contexts (4). While working closely with members of the National Health Research Ethics Committee of Guinea in our study design, we did not involve Ebola trial participants on our study team. Collaboration with Ebola research participants likely would have drawn attention to the importance of this stakeholder groups' concerns early on. Perhaps this would have shifted our study objectives.

Collaboration with Ebola survivors on the study's design might also have helped our team better prepare for interviewees requests that our team leverage its international networks and privilege to help this stakeholder group advance their priorities. Certainly, co-designing the study with input from Ebola research participants may have enabled us as a research team to anticipate and plan for requests for help and action beyond the conduct of research in public health emergencies. Such early conversation and collaboration with Ebola research participants might have also led to us explicitly ask those we interviewed to reflect on *our* study objectives, and the ethics of international researchers working to influence policy in one domain (in our case the domain of research ethics), when that domain is not the study participant's main concern. In retrospect, it is very clear to us that by not co-developing this study in dialogue with representatives from all the stakeholder groups we aimed to interview and serve through our study, we did lose an opportunity to explore additional questions relevant within a study on moral experiences of research. Moreover, in the absence of such co-design with Ebola trial/study participants, our team was caught somewhat off-guard by how much participants from this stakeholder group were adding at the end of their interviews, and by the consistent nature of the information added. So what can researchers do and what should researchers do in such instances? Do we have ethical obligations to respond with specific actions to entreaties for socio-political and material support when these have not been planned for at the time of a study's design? How do researchers' responsibilities depend on their position of power vis à vis those making such entreaties?

"YES, THERE IS SOMETHING I WOULD LIKE TO ADD"

Almost half of the 70 Ebola survivors with lived experiences of participation in Ebola research from whom we heard in this study ended their interview by describing the conditions faced by Ebola survivors or by others in Ebola-affected communities. A number of these descriptions involved, as did *Margaret*'s statement, decrying these conditions, and invoking or calling for international transformative action in response to local suffering.

Beyond the fact that all participants in the study had been touched by Ebola—as direct survivors of infection, as people whose families had suffered, or as members of heavily-hit communities and constituencies—and by Ebola research, the participants who made such statements harbored a range of social positions and experiences. A few were leaders and advocates from civil society organizations (Ebola survivors' associations). Some were healthcare professionals who may have been used to speaking for the communities they serve. Many were neither. This last group, the majority, included men and women with limited literacy working a range of jobs, most often in the informal sector. In the context of urban Guinea, Sierra Leone, and Liberia, as in many settings marked by social and economic class divisions, this last group has particularly limited resources—including limited social authority and opportunities based on connections—to shape understandings of the West Africa Ebola outbreak and its impacts on affected populations.

The statements made in the space created by the question "Is there anything you would like to add?" contained some differences as well as similarities. A few research participants called for specific measures. Participants already in positions of leadership or advocacy at the time of interview spoke, for instance, of wanting to see healthcare access guaranteed for all Ebola survivors throughout their lifetimes, or the introduction of capacity building programs to help survivors support themselves. Other participants, including healthcare professionals and limited literacy participants, spoke in fairly general terms, detailing what they framed as clear and pressing needs rather than on specific possible remedies. Many participants across all three categories simply described the situations that they had encountered: economic hardship following the loss of work while sick with Ebola, ongoing stigma in their families and communities as a result of their identity as an Ebola survivor, and their own or relatives' suffering from the physical sequelae of Ebola. These conditions were presented by participants as too hard to envision enduring long term, and for which solutions were needed. All categories of participants who spoke of suffering and needs at the end of their interviews described difficulties within their families, including economic or physical challenges not directly their own. The calls for aid were often simple and straightforward, but their anchoring in details and stories that the participants had faced or witnessed first-hand gave them additional power and made them especially compelling.

Justin (pseudonym) was interviewed as an Ebola survivor from Monrovia, Liberia. While acutely ill with Ebola, he had participated in a convalescent plasma study. Asked at the end of our interview if he had anything to add, his response was emphatic:

> *Yes! I would like to say many things because, what I want to say is (...) at least let them try and cure something to start our life for a re-settlement. (...) Because during the crisis, our mattresses, our things, our clothes, (...) everything, during Ebola, when Ebola catch you, yeah, they will take all your things and burn it. So your home is empty. So I appeal to (...) our leader then, I told him (...) the international community help, the NGO, they need to help out with something to start our life, to make business, to sit down, (...) to make our life, to start our life. Because Ebola came and spoiled all (...) so now there is no foundation for us.*

Justin continued to explain that survivors had difficulty accessing any care, that many had died as a result, and that for all of the investment in Ebola research, there has been "nothing for us" survivors. He spoke quickly, jumping between and entwining what did happen and should not have with what did not happen but should have in his view.

Bertrand (pseudonym), a nurse and Ebola survivor from a mid-sized city in Guinea, shared stories of his experiences as a healthcare provider, as an Ebola patient, and as a participant in a study that provided free healthcare for survivors following the West Africa outbreak's official end. *Bertrand* finished the interview by bringing up his concerns about what would happen after the study's conclusion:

> We have a child here today, if you tell him to walk over this way, he will walk over the other way. He is completely traumatized. His father and his mother are dead. So there are many. So there are children who cannot walk, who have no help from anyone, because everyone is dead. So there you have it: that is the problem that worries me a lot. And if there was to be help, it would really make me happy.

Justin's and Bertrand's responses to the question "Is there anything you would like to add?" spelled out specific hopes that exceeded the objectives of our study and the impact our team had envisioned for the project. These responses spoke to experiences of marginalization, suffering, and need that were at once continuous with but also extended beyond the conditions and perceptions of Ebola research participation our study had set out to document. These statements revealed feelings of invisibility and limited power, but also unmet and pressing needs for material (economic and health) supports for Ebola-affected individuals, families, and communities. Ethically, what *should* be done with this information and entreaties? Is attentive, respectful listening a sufficient response?

As noted, our project was developed in a way that did not anticipate contributing to change in West Africa beyond practices related to the conduct of public health emergency research. And yet these statements urge us to question our relationship to participants and their calls for help. What relationships to us as researchers are participants outlining when they share with us such information or requests? What exactly are our responsibilities as researchers once we have been entrusted with these expressions of concern that are evidently central to our participants? And, are these responsibilities inherent or optional where researchers have means beyond those the participants in their study to draw attention to such concerns within global or local (and usually both historically and socially entrenched) structures of power?

POSSIBLE RESPONSES WHEN PARTICIPANTS *DO* HAVE SOMETHING TO ADD

Statements such as those by *Margaret*, *Justin*, and *Bertrand* above could prompt us to reframe our understanding of the interviewee's agreement to an interview in important ways. They suggest that the decision to agree to an interview with our team might be intimately connected to a desire to speak about needs and hopes for action that lie beyond the goals of the project in which the interview is embedded. The positionality, perceived, and real relations of power between the interviewer and interviewee is important here. Interactions with researchers are shaped by structural and political factors (5). Two of the study's interviewers, including the first author, were white and Canadian. At the time of the interviews they held positions as assistant professors based at Canadian universities, and were responsible for overseeing data collection in Guinea, Sierra Leone, and Liberia. These white Canadian members of the team were assisted by three local social science trainees from the University of Sonfonia, in Guinea. The Canadian senior members of the team did conduct many of the interviews. When not directly conducting interviews, they remained close by: either sitting in on junior members' interviews, or conducting interviews at the same time as these local researchers in adjacent spaces. The very possibility of Canadians flying into West Africa to recruit participants and discuss with them their lived experiences of research communicated our team's connections to funding and networks extending beyond the localities participants inhabited. It is certainly possible, if not likely, that those agreeing to speak with our interview teams did so partially in the hopes that our team possessed, by virtue of connections to academic or other institutions or of their membership amongst a globally mobile "international community," the power to act on the wrongs that participants identified: the power to fund capacity development programs for survivors, or at least to advocate effectively for such programs to be developed or funded.

As noted earlier, some of those interviewed in the study were not new to being invited to reflect or speak authoritatively on their own or others' experiences. As men and women with diverse positions of authority in families and communities, there is no reason to assume any of the study participants had not previously been asked to reflect on best practices or mediators of decision-making. Participation in an international study, however, represented for most a first opportunity to speak of their experiences in a public health emergency, and to individuals from outside their country positioned to circulate their statements internationally with potential impact on policy and practice.

Before Ebola and the attention this brought to survivors such as *Margaret*, *Bertrand*, and *Justin*, such opportunities were structurally unlikely. Systems of political and social exclusion predated and characterized access to knowledge and power in Ebola-affected countries (6). Participants such as those cited in this paper are excluded from the spaces of knowledge production reserved for the elite within such systems. For some of the participants in the Perceptions Study, prevalent gender, age, and other power dynamics and hierarchies may also further limit opportunities to be involved in the production of knowledge which has the potential to inform policy and debate at the international level, but even at national and local levels. Speaking with an international researcher could understandably be interpreted by participants as a rare opportunity to have their concerns recorded and, perhaps, acted upon. There is more than one possible ethical response in this situation.

Reiterating Study Goals

Where a participant indicates expectations of benefit or impact that exceed a study's objectives or what the interviewer regards as possible, the interviewer is generally understood to have an obligation to reiterate the goals of the study and its intended and expected scope of impact. Such scenarios remind us of the importance of clearly communicating a study's anticipated reach and limitations in terms of possible impact—something that is not clearly spelled out in many consent forms. Researchers have an obligation to be honest about the extent but also limits of their power, given the various strictures under which research is conducted, and when responding to questions participants may ask about the potential of the research to influence policy-makers and others. It is the researcher's responsibility to correct any misconceptions or misunderstandings they encounter on the participant's side, in terms of what their participation in research might achieve, when, for whom, on what bases. As interviewers, we did apply these normatively ethical responses to pleas for action we heard from participants at the end of interviews. We did so as part of respectful dialogue with our participants, and to avoid raising hopes and to avoid disappointments and disillusionments toward our team later. We did so also, because we did not feel it was within our capacity to achieve more than our study goals.

Under a strictly procedural understanding of what it means to engage in ethical research, requests from participants that exceed a project's scope do not ethically require a response beyond clarifying that such expectations fall outside the scope of the project. This is beyond consideration of legal obligations to report, which researchers do need to adhere to or negotiate. So, researchers who hear information about ongoing child abuse, for example, have legal obligations to report in many jurisdictions, including Canada. The above interpretation assumes that this sort of legal obligation is not present, and interviewees' statements are instead based on a misconception/misunderstanding of a study's scope of impact. If the problem is a misunderstanding, its remedy—information, communication—is relatively straightforward. Such rote normative research ethics "good practices" are simple enough to implement, if sometimes uncomfortable. But what if the source of participants' requests for further collaboration is not misunderstanding?

Participants Recognizing Space to Advocate

A second possibility is a bit more complicated and harder to address. A person being interviewed for research can understand the study goals, the reasons they have been invited to interview, and yet still feel able, and maybe even morally obligated, to draw the researchers' attention to other questions and realities that fall outside the scope of their study. Participants can and did in our experience "get" why they were being interviewed (in our case, to document experiences and understandings of Ebola research participation—a set of perspectives that has been under-considered globally). That did not stop many of them from asking us to consider, in light of hardships presented as post-Ebola hardship, how our work might become more directly beneficial to their communities. These participants called our attention to realities that did not connect directly to our study, but that mattered deeply to them, and which we as researchers were positioned to share with audiences different than the ones they could reach. Entreaties by participants to widen the scope of our attention and help secure tangible assistance are not, in this second interpretation, based on misconceptions of our study goals at all. Indeed, that which participants choose to "add" at the end of interviews within this second perspective, could be seen as participants taking up what they regard as an opportunity to carve out greater benefit for their community, than a reflection of participants' misunderstandings. In this interpretation, what is at stake in responding or not responding to participants' requests that we as a research team extend our work to collaborate with them on their advocacy efforts?

POWER, ADVOCACY, KNOWLEDGE, RESPONSIBILITY

Public health researchers with positions in universities are empowered, through normative understandings of expertise contingent on educational attainment, track records of publication, and positions as paid "experts" in socially sanctioned institutions of knowledge production (primarily universities), to be heard when they speak. There are definite hierarchies of epistemic authority within academia and societies. While such hierarchies emerge through uneven access to opportunities for developing such expertise, and attribution of authority can vary greatly across and within disciplines, universities, and countries, academics *in general* are particularly well-positioned to secure attention and authoritativeness for their utterances. We may lament our limited readership, or get frustrated by the limited impact of our work on policy, practice, and thinking, but we are nevertheless socially anointed as experts to produce what is culturally sanctioned as "evidence." In an era where "evidence-based" is an expected justification for change and action, academics' power to gather, and vet evidence, whether deserved or not, is meaningful. And yet, transforming the information participants such as *Justin* and others shared in the space of "anything to add" to produce the results he and other Ebola survivors seek is not a straightforward possibility here.

First, because the "things added" emerged at the tail end of interviews, and were not explored in depth with participants. Matters discussed at this point in the interview were not explored in depth. Considering these statements after data collection ended, we are concerned about the limits of what we know with respect to the preoccupations and recommendations for action outlined. We know that many Ebola-affected people and communities lack and need support, but we do not feel we know this in a way that would allow us to meaningfully inform, guide, or suggest action—at least not within the context of academic and applied academic scholarship.

Then, there is the question of how to frame integration of participants' entreatie. Merely transmitting or re-presenting participants' important claims and hopes by repeating them to academic audiences, as addenda to the more traditional research findings we may share, is one possibility. But it comes with risks: engaging in advocacy for social recognition and resources participants outlined wanting and needing could erode funders' or fellow academics' trust in our abilities to stay focused within our study goals and skill set as researchers.

Explicit advocacy within social science research arguably harbors risks. Within anthropology, 25 years ago, Scheper-Hughes (7) called for but also recognized the marginal status of social scientists unapologetically standing alongside research participants. Calling for action as a social scientist goes against a long history of equating the scientist's supposed detachment and neutrality with doing good research (7). Critics of Scheper-Hughes' push for the researcher/advocate have argued that taking clear stances on politically sensitive issues may do more harm than good: eroding the anthropologist's/researcher's trustworthiness in the eyes of decision-makers, given entrenched norms of equating sound research with neutrality (8). If calls for action are interpreted as biased, would this interpretation result in our overall analysis of West African Ebola research experiences being discounted as biased?

The study we set out to conduct to foreground lived experiences of Ebola research in West Africa was designed to produce the kinds of knowledge that would be "useable," and recognizable as such, by researchers, policy-makers, and research ethics committees and regulators, in relation to research conducted during public health emergencies. Recruitment strategies, interview guides, and inter-disciplinary team-based analysis were developed to ensure that the conclusions we shared would be aligned with this objective.

Action for the sake of action also risks producing hollow gestures, whose value is purely symbolic and whose purpose is disconnected from the issues that participants sought to bring to our attention. Using our access to academic and other networks to pass on participants' words, without connecting participants to those networks, and without ensuring that what we say will be heard as meaningful, could become such a gesture, whose only real purpose/effect would be to act on and/or enact our power and status as public health emergency researchers. Doing so could be seen to reiterate an old Western hero framing that reproduces its own hegemony [e.g., (9), p. 430, response to (7)]. There is also—and this is a concern we had in writing the present piece—a risk that focusing on researchers' emotions (guilt, sense of responsibility), in a way that makes these objects of analysis themselves, draws attention away from the participants and their moral engagements.

If knowledge/engagement debates say something about why doing something feels risky, they also speak about why doing nothing feels wrong. In his call for an anthropological study of morals, [(10), p. 341–4] argues for the necessity of attending to interactions between researchers and research participants, as interactions between culturally/socially situated moral actors. In this logic, our own feelings of inadequacy and perplexity as researchers are telling and should be heeded and explored. They can serve as "a genuine research tool, which enables us to understand how our particular system of morals helps us to grasp or, sometimes, *prevents us from grasping*, moralities governing the life of the social groups we are observing." [(10), p. 352, emphasis ours]. What kind of moralities are at play when participants speak to us, and what dimensions of our system of morals [and more broadly, of the academic and ethical apparatuses within which we are acting, cf. (11)] make it difficult for us to respond in kind?

We take seriously Scheper-Hughes' (7) argument that researchers have a responsibility to try to understand and engage with the struggles those participating in research face. We are familiar with concerns raised by others who have responded to her work, who argue that such engagement might undermine researchers' ability to perform a role as unbiased analyst. But it seems worth asking if the researcher's performance of neutrality is (always) ethical and appropriate, or merely conventional. As Fassin (12) and Stoczkowski (10) model, it would be best to unpack rather than frame in false dichotomies tensions between ethics and epistemology, engagement and knowledge. Doing so seems especially appropriate where these tensions pertain to researchers' attempts to understand, engage with, and become actors in, moral and political struggles that they are brought into contact with through their research.

To what extent does the context of participants' request to researchers matter to the researchers' obligations to respond? One of the things that the "Perceptions" study *did* set out to explore were participants' motivations for joining (or refusing to join) research studies (1). Many explained that they had joined studies in order to serve others, be it by donating plasma that might save the life of an Ebola patient, or by helping to test a vaccine that could potentially protect communities hit by future outbreaks. Participation in Ebola research was, as such, a moral act for many people (13, 14). Deciding to join or not to join a study enacted membership in a moral community [(15), p. 44]. As a reflection and affirmation of ties to other persons, it was an act discussed with, and sometimes advocated for amongst, other members of a moral community. Many participants explained how ethical concerns had informed the way they discussed research with their families and communities.

Often—very often—motivation to support clinical Ebola research as a participant was anchored in the participant's personal experience with, and firsthand knowledge of, Ebola. One man explained what motivated him to donate plasma, a gesture that he understood as potentially risky, but *necessary*, because:

> Well, since I already knew the consequences of this disease, I knew how many people had died in front of me, so I wouldn't even wish this disease on an enemy. So I saw this. Since [plasma] was the first proposed treatment, that is why I had to participate.

(*Aboubacar*)

He also felt called on to act as an advocate, by "mobilizing" his family "to make sure that they would be vaccinated."

This sense of responsibility borne from knowledge was characteristic of many participants in the "Perceptions" study. Often as a result of tragic events and great losses, but also of courageous and generous actions taken during the outbreak, many knew Ebola well. This deep knowledge stood in contrast to the Ebola denial that was widespread in many communities, especially during the early days of the outbreak, and to the slow international response to the outbreak. In other words: this deep knowledge stood in contrast to both ignorance about and/or indifference to the disease and its effects, or the people and communities it might (did) affect and the ways it might affect them. It became clear in our interviews as we asked about decision-making related to participation in clinical trials, that many felt that their hard-earned "expertise" had a moral weight as individuals who had lived Ebola infection and survived. Knowing Ebola implied a certain responsibility toward others. Agreeing to participate in a clinical trial related to Ebola, though sometimes terrifying and difficult, was a decision anchored in that sense of responsibility. As one participant explained: having survived, and having seen others die, meant that he could never "just stand there, with crossed arms" while others were still falling ill.

The ethical impetus to action implied by first-hand knowledge of suffering that emerged in the "Perceptions" interviews may provide a key to understanding why so many participants did respond in the way they did to the final interview question, "Is there anything you'd like to add?" Taking this question as an opportunity to speak of needs and identify means to mitigate further suffering beyond the scope of our project is consistent with a knowledge of suffering/action to try to mitigate suffering nexus found in many participants' explanations of why they had volunteered for Ebola research.

In this understanding, *Margaret*, *Justin, Bertrand,* and others can be understood to be engaging with our research project, to enact a moral sentiment that knowing about some suffering impels, ethically, trying to alleviate that suffering. In this emic perspective, for us as researchers to cast aside descriptions of need and entreaties to action as data "out of place," and with no place in a presentation of findings, may feels particularly problematic.

METHODOLOGICAL EXIGENCIES—ETHICAL CONDUCT OR MORAL FOLLY?

There is an extent to which part of the problem falls within the requirements of the methods of academic research. The rigors of what is expected in the methodological process, data collection, and analysis help contain the research and give it some consistency within academic expectations, and help maintain focus and attention to an inquiry's established objectives, increasing the likelihood these will be achieved. This confers authoritativeness based on rigor, consistency and other desirable features. However, adherence to rigor can also erect borders affirming which interview content counts, and which does not. These borders may be acceptable and normative in some research, but they can also be regarded—and perhaps merit being rejected—as problematic.

Certainly, these feel artificial and morally distant from the person-to-person connection formed, if only temporarily, in the exchange that occurred in the context of the Perceptions study. This in turn raises questions about method and draws attention to the moral posture of the researcher, the obligations it create, and interpersonal responsibilities connected to unequal power between researchers and research participants.

In the face of this web of relationships, we might ask whether strict adherence to study objectives is appropriate in the context of this study, but even for qualitative research in general? Qualitative interviews are the best way to explore complex, often unexplored ideas, so it naturally opens unanticipated territory. The researcher can chose to "manage" moments that exceed a study's intended objectives, by politely acknowledging and then steering the interview "back on track" with further questions about the phenomenon of interest. But in the case being explored here, and given the exchange and relationships involved, it seems hard to call the comments made by *Margaret*, *Justin*, and *Bertrand* irrelevant. It is more the exigencies of academic limits that seem "irrelevant" in this moral context.

It feels wrong to do nothing with participants' entreaties to make survivors' suffering and needs heard, given in such entreaties participants such as *Margaret* are approaching us as fellow moral agents. They are inviting us into their moral community by sharing their knowledge. In the context of these participants affirming that for them knowledge and action are ethically inseparable, once the researcher as moral being holds the information, this information carries, at least for us, a weight of responsibility: an obligation to act rather than ignore. The appropriate thing to do is not to say—"this is out of the project requirements"—but instead to acknowledge that this is a finding that requires some form of response. At the very least, it seems fitting to include the information among the findings of the study either as an associated theme or as recommendations for further research or action.

We may not be able or willing to devote the time Ebola survivors' healthcare and social needs merit. As humans, however, we feel obligated to recognize these participants' moral sentiments by writing about them. The alternative seems ethically untenable. As Schepper-Hughes [(7), p. 418] argues, for anthropologists:

> "Seeing, listening, touching, recording can be, if done with care and sensitivity, acts of solidarity. Not to look, not to touch, *not to record can be the hostile act, an act of indifference and turning away.*" [(7), p. 418].

Finding a place to share what participants in our study consider crucial to have us hear is ethically important beyond choosing concern over indifference. Thinking hard about these words spoken in the space of "Is there anything you would like to add?" feels crucial to defining our research endeavor as genuinely respectful of other ways of being in the world. Words spoken in that small space of the interview outline a moral logic: a shared understanding of the world as a place where when one knows about something that has caused or is causing suffering, one will do something toward its alleviation. To demonstrate respect for participants, it is necessary that we consider how we can document and disseminate such utterances, especially given we conducted these interviews to clarify what (un)ethical research means to those we interviewed. Ensuring participants' hopes for their engagements with research to result in change for their lives beyond the ethical conduct of research in emergencies gets recorded and shared in our study reports is something we can do.

The issue of power is key to thinking about what is produced in the space of "anything to add," and about the ethics of how a research team respond to unanticipated entreaties for collaboration or advocacy. Ignoring matters of importance to participants strike us as particularly problematic in the context of a study designed with limited stakeholder input. Our team had already at the point of data collection failed to appropriately engage Ebola trial/study survivors in the co-design of the study. To only report on answers from Ebola survivors/study participants that mapped back to questions developed without input from this stakeholder group would further silence this group. Such silencing of under-heard groups lies at the heart of extractive research practices that are increasingly denounced in research with historically marginalized groups. As defined by Tilley, "[a]n extractive empiricist approach is, in part, one which assumes the right theory-guided questions are being asked, based on a prior assumption of sufficient knowledge about the field." [(16), p. 38]. If we aim to distinguish ourselves from unethical extractive research, we need to practice being "guided at least partly by questions formulated by the participating community." [(16), p. 38].

It is today widely recognized that being responsive to affected populations' priorities is key to good/ethical research in public health emergency research and indeed in all global health research, but arguably this is not in itself sufficient. It strikes us as equally important to be transparent and reflexive about that process of acknowledgment and its politics and ethics. Moving away from extractive research involves reflexive practice (16, 17). Practicing reflexivity is taken here to imply, "that the researcher should constantly take stock of their actions and their role in the research process and subject these to the same critical scrutiny as the rest of their "data." [Mason in Guillemin and Guillan (18), p. 274]. As others before us have noted, the crux of ethical practice in qualitative research is not limited to ensuring international and general guidance are respected in protocols: ethical practice emerges in specific study contexts, through specific research events, in relationships, and in the decisions we make as researchers when faced with unanticipated situations or information in the course of conducting research (17–19). Unpacking the ethics of what to do in the face of unanticipated requests or findings that emerge as research unfolds means critically interrogating how and on what bases we feel compelled to respond in a particular way becomes part of that process. We do not just choose or not choose to report on particular concerns in relation to research objectives: inseparable from these scientific decisions is the power we have as researchers to make those decisions (17).

In ensuring participants' central concerns are reported, we do what many researchers working with marginalized populations do: we instrumentalize our authority and privileged positions in systems of knowledge, to act as agents of echolocation for research participants who do not have the same access to rendering their voices public (17, 20, 21). We acknowledge this remains an imperfect way forward. In this process, we reproduce the very systems of knowledge and exclusion that are part of Ebola survivors' limited access to being heard: colonial, historically entrenched, class, race-based, and linguistic systems of knowledge production that require so many in the world to rely on researchers as instruments through which they might increase their chances of being heard (17, 22).

A key take-away for our team from this experience relates to the crucial importance of engaging representatives from all—and not only some -stakeholder groups, when aiming for a co-created, context-relevant study. Such engagement seems especially important where qualitative research is undertaken on uneven geographies of knowledge production that make it difficult, if not impossible, for researchers to anticipate what will matter most to study participants based on published literature, or in conversation with colleagues who, while local, may also be disconnected from the realities of more marginalized stakeholders in a given research context.

CONCLUSION

Knowledge can be generative of moral commitments, and shared knowledge of moral communities. When participants told us about the things that they needed to add, we *felt* obligated as researchers, as humans, and in reciprocity for their participation in the study, to listen. And yet we have struggled to clarify our obligations vis à vis responses to our question "Is there anything you would like to add?" Reflecting on our participants' responses to these questions has left us wondering about researcher obligations and relationships to participants' more generally. We could have ignored these responses: left them uncoded in our NVivo and parked them for oblivion. But to do so would reproduce the very exclusion of knowledges of people who had participated in Ebola research that our study had set out to address.

There may or may not be important differences in the ethics of taking a stand in one's research, dependent on whether one's work engages political conflicts that have already been defined as such. In the case of Scheper-Hughes, her consideration of what it meant to become or refuse a position of advocate occurred in a context of explicit political sides and agendas. We did not enter a world of clear political sides and agendas. Our research study was not at any point presented to potential participants as a project that would embark in advocacy efforts to transform existing conditions of economic, social, or healthcare need for survivors. But, not engaging with our participants' descriptions of daily hardships and need, feels wrong. It alerts us to the practical and ethical limits of defining our obligations to research participants based on a procedural understanding of researchers' obligations focused on ensuring voluntary and informed consent. Such an understanding protects us as researchers from any requests for relationships or benefits beyond those defined by the researcher and explained to potential participants in advance. Such a definition of our obligations as researchers normalizes extractive research: research that aims to pull out data based on the researcher's conceptualization of a problem, and which favors the flow of benefits from the knowledge it produces toward the researcher, rather than toward participants and their communities (11, 16). Working as anthropologists and qualitative researchers in global health, a field dedicated to foregrounding the uneven distribution of life and suffering, and global inequities in control over and access to resources, reproducing such extractive research does not feel ethical. As noted by Wright, "ethics also needs to take account of the political and structural factors that shape people's lives and their interactions with the research process" [(5), 516].

The spheres in which we have power and ability to act (academic scholarship, including engaged anthropology) do not readily recognize the kinds of knowledge imparted to us as ethically requiring a response. But knowledge is also circulated, assessed, and made meaningful within relationships and moral communities. As academics, we found ourselves struggling with how to meaningfully share and act on the knowledge we were given, and the obligations we were drawn into. It seems like even if we cannot change the social, economic, political conditions indicated by the participants, perhaps we can and should engage with these requests as a matter of respect and moral concern. Not necessarily as researcher to participant, but person to person. We hope our reflections here render available for further discussion and debate how academic norms (both evidentiary and ethical) shape the possibilities for developing the extended moral communities some participants might be aspiring to establish as they engage in research, and to considering how researchers might respond when participants do indeed have "something else to add."

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: We did not obtain permission to render datasets publicly available from the Ethics Review Boards that approved the study. The corresponding author can be contacted to discuss access to data options. Requests to access these datasets should be directed to enouvet@uwo.ca.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Hamilton Integrated Research Ethics Board (Canada); Comité National d'Ethique en Recherche de la Santé (Guinea); Sierra Leone Ethics and Scientific Review Committee; University of Liberia Ethics Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

EN prepared the initial draft of this article. MH and LS provided critical feedback to refine its arguments. All authors contributed to revisions and approved the final manuscript.

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What Does "Good" Community and Public Engagement Look Like? Developing Relationships With Community Members in Global Health Research

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Community and public engagement (CPE) is increasingly becoming a key component in global health research. The National Institute for Health Research (NIHR) is one of the leading funders in the UK of global health research and requires a robust CPE element in the research it funds, along with CPE monitoring and evaluation. But what does "good" CPE look like? And what factors facilitate or inhibit good CPE? Addressing these questions would help ensure clarity of expectations of award holders, and inform effective monitoring frameworks and the development of guidance. The work reported upon here builds on existing guidance and is a first step in trying to identify the key components of what "good" CPE looks like, which can be used for all approaches to global health research and in a range of different settings and contexts. This article draws on data collected as part of an evaluation of CPE by 53 NIHR-funded award holders to provide insights on CPE practice in global health research. This data was then debated, developed and refined by a group of researchers, CPE specialists and public contributors to explore what "good" CPE looks like, and the barriers and facilitators to good CPE.

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A key finding was the importance, for some research, of investing in and developing long term relationships with communities, perhaps beyond the life cycle of a project; this was regarded as crucial to the development of trust, addressing power differentials and ensuring the legacy of the research was of benefit to the community.

Keywords: patient and public involvement, research relationships, power dynamics, research stakeholders, respecting community

INTRODUCTION

Community and public engagement (CPE) in the development, undertaking and delivery of global health research, interventions and policy is increasingly regarded as essential by funding bodies (1–3). We use CPE for the purposes of this paper, but the term officially used and referenced by NIHR is community engagement and involvement (CEI). The National Institute of Research (NIHR) is committed to CPE and to involving the most marginalized communities in the global health research it funds, arguing that it is vital to improving the reach, quality and impact of the research. The recognition of the importance of CPE has led to the development of various guidelines and standards for CPE generally (3, 4), techniques and approaches for CPE, such as approaches guided by participatory action research techniques (5), and CPE criteria being included in ethical guidelines that apply to global health research specifically (6–13).

The UK equivalent of CPE is patient and public involvement (PPI). The UK Public Involvement Standards Development Partnership guidance on “what good looks like” in PPI has been encapsulated in the six standards for public involvement (14). These standards are not a prescriptive “how to” manual; they can find expression in a variety of ways and can be used to guide and evaluate PPI in research. Furthermore, they are flexible enough to be applied to all research topic areas and in conjunction with any research methods.

As the NIHR further develops a portfolio of work in global health, what can its past experience championing PPI contribute to current debates on what constitutes “good” CPE? And can we develop something that involves a partnership of actors from both high income countries (HICs) and low and middle income countries (LMICs)? The CPE guidelines that are currently available are useful, but many are either non-health research focused (3), focused on a specific region/condition or research approach (4, 15, 16), or focused on the ethics of engagement (17). Clear guidance on CPE, which builds on existing guidelines and frameworks, would be useful in ensuring clarity of expectations of award holders, and the design of monitoring and evaluation frameworks. Of course, it must take account of the reality that CPE is not free-standing and is likely to be affected by the nature of politics and policy drivers in any particular setting (18).

The NIHR, in collaboration with the UK’s Institute of Development Studies, has recently produced a series of learning resources to support applicants and researchers in planning and delivering meaningful CPE (1). With this paper, we hope to add to and build on this resource. This paper is our first step in trying to identify the key components of what makes for “good” CPE, which can be applied across all approaches to global health research as well as different countries and contexts.

METHODS

Thematic data analysis (19) of 139 progress reports submitted between 2017 and 2019 by all 53 NIHR Global Health Research Units and Groups was undertaken by two members of the study team (**Table 1**). The UK-led Units and Groups deliver world-class applied global health research and work in partnership with researchers in LMICs, who are eligible to receive UK funding, to address under-funded or under-researched topics specific to those countries (20). At the time of writing, the Units and Groups involved in this analysis have either completed or are nearing completion of their funded research. Inductive coding was used to identify common themes (19) highlighting potential enablers for and barriers to good CPE. Qualitative data analysis was supported by NVivo software.

TABLE 1 | Further information on the sample used in the content analysis and the participants involved in the workshop.

Method	Sample
Content analysis	No Units or Groups (that were funded at the time of analysis) were excluded. No available progress reports were excluded. The Units and Groups that were included in the content analysis were collectively undertaking research in 61 LMICs, as follows: - 12 LMICs in Latin America and the Caribbean - 2 LMICs in Northern Africa - 23 LMICs in Sub-Saharan Africa - 4 LMICs in Middle East - 1 LMIC in East Asia - 5 LMICs in South Asia - 10 LMICs in Southeast Asia - 4 LMICs in Europe
Workshop	Purposive sampling was used to identify a group of CPE/PPI specialists and public contributors located in diverse country contexts that could bring a range of experience to the workshop. Out of the 18 people who were invited to participate, 11 were able to attend. The 11 workshop participants are authors on the paper along with the 7 people who could not attend but were involved in other aspects of the research. The global regions represented in the workshop, and the number of participants from each of these contexts were: - UK (7) - Sub-Saharan Africa (2) - Southeast Asia (1) - South Asia (1) Workshop attendees included seven people who would be considered CPE and/or PPI specialists and four public contributors with lived experience.

TABLE 2 | Potential enablers of good community and public engagement (CPE) as identified through the content analysis, workshop discussions and the merged findings of these two processes.

Enablers from the content analysis	Enablers from the workshop discussion	Merged potential enablers of good CPE
Knowledge of community dynamics and structure	Respond and adjust to cultural norms, and increase cultural competence of researchers	Adaptation to local cultural norms and customs
Awareness and knowledge of the research amongst the community members involved		
Create opportunities for open communication and feedback	Avoid transactional relationships and encourage open and honest communication	Treat community members with respect
Respond and adjust to the barriers to involving marginalised communities in research	Actively reach out to the community	
	Respect the diversity of local knowledge and reflect on hierarchies of knowledge at the local level	
Awareness of local gatekeepers and when they might restrict access to community members	Understand how to work with gatekeepers and why they might restrict access to community members	Acquire permission from and work with local gatekeepers
Awareness of power inequities between HIC researchers and the LMIC community members (as well as between community members)	Identify and address power inequities within and between local communities	
Community involvement from the outset to ensure relevance of research to the local context	Undertake research that is relevant to the community and involve them in developing research priorities	Seek community involvement in, and ownership of, the research
Undertake locally led activities in the health intervention with the community		
Involve multiple local stakeholders to ensure the intervention is beneficial to all		
Encourage development of community members and their engagement with issues (aka a "virtuous circle")		
Utilization of strong existing relationships when available to quickly get CPE activities started	Avoid overburdening communities (i.e., different research teams involving the same community members over an extended period of time)	Avoid overburdening communities
Address competing research priorities e.g., policy makers vs. local communities vs. HIC researchers Understand how CPE activities are restricted by finite resourcing and funding	Investment in long term relationships (or the legacy of the research) to enable partnerships which address research and community needs around social justice and long term health outcomes	Investment in long term relationships and research goals

The findings from the content analysis informed the discussion at a workshop where participants explored what good CPE looks like and identified factors that facilitate and inhibit CPE. The workshop was attended by 11 participants and facilitated by two representatives of NIHR (**Table 1**). Participants broke up into two groups, and each group addressed questions relating to enablers and barriers of CPE. Discussions were transcribed after the workshop via an online transcription service, and quality checked by two members of the research team by listening to the recordings. Common themes were identified from the workshop transcript through use of inductive coding (19) by two members of the research team.

EMERGENT FINDINGS

The potential enablers of good CPE that emerged from the content analysis and subsequent workshop discussion are presented in **Table 2**. These were merged to form broad potential enablers which are outlined in the next section and interpreted in light of the literature in this area. In practice, these enablers are not exclusive, but rather they overlap and intertwine to make up what "good" looks like in CPE.

DISCUSSION

Adaptation to Local Cultural Norms and Customs

The importance of being aware of and sensitive to cultural and social differences is a key principle of ethical CPE (10, 11). This is underpinned by the notion of respecting cultural differences—which is addressed in the next section. The example below shows how awareness of, and adjusting CPE activities to fit, local culture and community dynamics can lead to the inclusion of people who otherwise would not be part of research.

> *"In Pakistan and Bangladesh, engagement of women in the research can be challenging, but is overcome by having dedicated facilities (or sessions) for women, where they are seen by female only staff. In contrast, in Sri Lanka, engagement of men is harder, as they place their main focus on their employment. We overcome this by adopting approaches that more actively engage with men, approaching employers to release their workers for health assessments / interventions and by making sessions outside the working day (evenings and weekends)." (Unit #6 - from content analysis)*

Respecting and adapting to local cultural norms and customs also finds expression in researchers traveling to reach the community. Expecting community members to travel to academic institutions can exacerbate the perceived power imbalances between the researchers and the community (6, 21), and so engaging people within their community context can make them feel more comfortable in conversations.

When explored further in the workshop, researchers dressing in a certain way was given as a further example of adaptation.

> *"...we need to accept certain cultural norms, for example, I'll share from my experience, I don't (usually) cover my hair, I don't wear a headscarf.... If I go into a suburb or rural area, I have to change the way I dress up" (Workshop participant #5)*

The excerpt below demonstrates that adapting also applies to incentives to participate in research. Researchers should be conscious that what is considered morally and ethically acceptable may differ across cultures and countries (22).

> *"But I was so surprised when for the first time I went to the Philippines, … the degrees on the wall, … you know, like mayors and, and government officials. But they were not degrees, they were kind of tokens and certificates of participation in a project. So then I started realising 'Oh, I didn't bring anything'... The next time we went, we made sure that we did." (Workshop participant #3)*

Treat Community Members With Respect

The development of respect toward communities is another issue that is articulated in various ethics criteria (7, 11, 23). This was an issue that was implied in the progress reports and addressed in detail in the workshop.

Respect found expression in terms of valuing local skills and knowledge. Gautier et al. (24) stress the importance of moving away from paternalistic, top-down CPE methods and encouraging listening and response methods between the researchers and the community. This sense of a two-way interaction, and valuing and respecting different types of knowledge, was discussed in our workshop.

> *"...It's not bi-directional. It's just like one direction, assuming that someone knows more, and someone knows less. So someone has skills, all of these research competencies, you know, all of these degrees, and then someone has less, but how do we elevate the knowledge, the competencies, the skills of these people, and recognise them as valuable as what other people know and have? And I guess that's where the respect comes in as well and not having that kind of paternalistic approach..." (Workshop participant #9)*

Respect also includes appreciating and listening to local knowledge about the relationships and power dynamics within the community and relations with other communities in the area. Talking and listening to community members or local researchers can help non-local researchers to avoid tense situations.

> *"...if somebody from the community goes into the community or understands the politics, the social economic dynamics, then that person would be able to understand not to bring these two tribes together, because that would be an all out war in that community engagement programme." (Workshop participant #5)*

Acquire Permission From, and Work With, Local Gatekeepers

The importance of engaging with local, regional and national health authorities (8) and gaining the necessary legitimacy via the permission and approval of local actors (22, 23, 25) was evident in the literature.

The content analysis and workshop discussions demonstrated that when engaging a community, researchers may have to work with local community leaders (i.e., gatekeepers) to gain access to a community or to get approval to carry out research in their area and give the research legitimacy.

> *"trying to engage the community without engaging the local health ministry was a non-starter completely… there was a lot of inducements that needed to be applied to the local policymakers, and involved numerous meetings, numerous visits to the health ministry, basically tried to convince them, this is a good idea." (Workshop participant #1)*

The workshop discussion also showed that community leaders were sometimes instrumental in creating barriers to working with the most marginalized communities. There are multiple reasons that gatekeepers might block entry to researchers, which can be predicated on past experiences with international or other forms of health research where they live.

> *"...gatekeepers of or leaders of communities may restrict access to the most marginalised members of the community. And I think that's absolutely true (...) But a lot of it is not being paternalistic, but they are sometimes advocating for those members and keeping them safe." (Workshop participant #2)*

There can also be a less benign side to some of those actors—political actors—whom researchers depend on for permission to do their research in the community. So, gatekeepers can be barriers as well as people who can facilitate access.

> *"I had to cancel one of my events, because I was working with one member of parliament coming from an opposition political party. And when the government noted that, they withdrew the police services to cover my event." (Workshop participant #7).*

Seek Community Involvement in, and Ownership of, the Research

The importance of the community having ownership of the research and its outcomes emerged from analysis of the progress reports.

> *"To ensure long-term, sustainable change, the local community has to voice the local concerns and participate in defining the healthcare challenges. In turn, we aim for communities to develop a sense of responsibility and ownership of the solutions." (Unit #10 - from content analysis)*

The above excerpt hints at the notion of the "legacy" of the research. We define "legacy" as a concept that synthesizes the idea of sustainability and long-term impact; working toward the creation of long-term improvements that extends beyond the research lifecycle and creates a sense of ownership over the research within communities.

Explored further in the workshop, it was asserted that aligning the research with the communities priorities will keep it relevant to the local context and, ultimately, more likely the resulting intervention will be sustainable. Our findings support literature that show how involving people in the research can help ensure the relevance of the research to local communities (11, 12) as well as the development and maintenance of trust in the research from the local community (7, 11).

Workshop participants also explored the importance of involving local people in the research, which bestowed a degree of legitimacy on the research. The suggestion is that this can help promote consent to participate in the research (7, 22, 26).

> *".... bringing people in from outside that don't match maybe local profiles or local needs, will only alienate people. This is why peer to peer involvement is always so good. Because if one of your group can talk to you about something that they feel is important, then you're more likely to listen to them than to somebody else..." (Workshop participant #1)*

Avoid Overburdening Communities

Avoiding exploiting people (9, 11, 23), ensuring the protection of participants (25) and making sure that communities are not overburdened (22) all feature in the literature. Overburdening communities, in terms of going back to the same community rather than reaching out to other communities, was an issue that emerged from the workshop.

> *"...one thing that we should watch out for that I've seen happening, the University Department gets into a community (...) so anyone who is now going to do research keeps going to that same particular community. Even though there are other areas within let's say, in Harare, they will go to one particular suburb and just engage in work with that community. So then some are saying we are tired of these people." (Workshop participant #13)*

Investment in Long Term Relationships and Research Goals

Ensuring that research benefits the community is an often cited goal of CPE (7, 10, 25). Echoing the work of Pratt (27), workshop participants queried what or whose goals were the priority; the goals of the relatively short term research or the longer term goals of the community.

> *"Whose rights are we prioritising? Is there kind of, you know, premium for what the community needs? And what do they say they need? Is that above, you know, whatever research or academic or even policy and goals there are." (Workshop participant #9)*

Researchers should be mindful of the particular colonial and imperial histories that have shaped past public health interventions and practices in the geographic contexts in which they are working (6, 7, 27–29).

> *"I think it's important to consider colonial history... and having that kind of paternalistic relationship, we know long term might not be the healthiest for us, for example." (Workshop participant #9)*

An obvious example of how power inequities can find expression is in the language used between the community and the researcher, and also between researchers in HICs and LMICs.

> *"I have to speak better English to talk to you – we take on the burden of adjusting ourselves to your system, your protocols." (Workshop participant #9)*

Long term relationships, that went beyond the scope of a single project or funding cycle, were regarded as a key component of the development of trust, addressing power differentials and ensuring the community has real influence.

> *"...I think it's a bit of a challenge when you don't have those existing community relationships and having to develop them fast can feel really uncomfortable, because you know, that you're hurrying people along, and you're not doing it in the way you would want to because, you know, Global Health bid come out, and you've got six weeks to deliver it." (Workshop participant #11)*

This echoes Nelson's (6) assertion that establishing the foundations necessary for long term relationships does not always sit easily with short term fundings cycles. NIHR has recently set up funding arrangements to support the development of research applications and partnerships; it encourages early involvement of community members and the development of relationships between researchers and the community (30).

The sustainability of relationships between the community and researchers was regarded as a key component in ensuring the legacy of the research and this finding echoes the work of others (4, 16).

CONCLUSIONS

Despite the volume of literature on CPE, there is no explicit CPE guidance that researchers can turn to for answers about what "good" CPE looks like and why it should be done. This paper is the first step on the path toward identifying what "good" CPE might look like. The enablers we have highlighted in our discussion have been drawn from the analysis of progress reports and a workshop which covered examples of CPE from multiple countries and a broad range of research areas.

Global health research is still largely led by academics based in HICs where the social, cultural and economic context is likely to be very different from LMICs (23, 26). Therefore, any guidance on CPE should give due consideration and respect to local cultures, as well as encouraging the development of trusting relationships with a variety of stakeholders to adapt the research to the local context. Embracing close relationships with community members throughout the research process can create channels for open communication and ensures that the research is responsive to the needs of the community (31).

Establishing long term relationships between researchers and community members was a key enabler of good CPE that emerged from our work. Clearly, researchers need to be mindful of overburdening sections of the community and sometimes long term relationships may not be feasible or desirable. The suggestion was, however, that relationships sometimes needed to be built beyond the time frame of a single project or research cycle, and only then could trust be sufficiently developed and power differentials addressed. This approach will better ensure that research is focussed on the goals and needs of the community rather than just that of the researchers or funders.

This work was led by a UK-based research funder. Any future work in developing the core components of "good" CPE must ensure that it continues to be done in partnership with, and draws on the knowledge and experiences of, people from LMICs. We intend to explore our emerging enablers further with key stakeholders with a view to further develop our ideas, and possibly guidance, on what constitutes "good" CPE.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, upon request, without undue reservation.

AUTHOR CONTRIBUTIONS

MT, UR, DT, DC, TC, LD, MK, RM, CN, CR, and SS took part in the workshop discussion. GH and KP led the workshop discussion. GH, KP, UR, MT, and DT contributed to the analysis of the results and to the writing of the manuscript drafts. KP attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. All authors contributed equally to the design and implementation of the research, contributed to manuscript revisions, read, and approved the submitted version.

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Mapping for Engagement: Setting up a Community Based Participatory Research Project to Reach Underserved Communities at Risk for Hepatitis C in Ho Chi Minh City, Vietnam

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Background: Approximately 1. 07 million people in Vietnam are infected with hepatitis C virus (HCV). To address this epidemic, the South East Asian Research Collaborative in Hepatitis (SEARCH) launched a 600-patient cohort study and two clinical trials, both investigating shortened treatment strategies for chronic HCV infection with direct-acting antiviral drugs. We conducted ethnographic research with a subset of trial participants and found that the majority were aware of HCV infection and its implications and were motivated to seek treatment. However, people who inject drugs (PWID), and other groups at risk for HCV were under-represented, although injecting drug use is associated with high rates of HCV.

Material and Methods: We designed a community-based participatory research (CBPR) study to engage in dialogues surrounding HCV and other community-prioritized health issues with underserved groups at risk for HCV in Ho Chi Minh City. The project consists of three phases: situation analysis, CBPR implementation, and dissemination. In this paper, we describe the results of the first phase (i.e., the situation analysis) in which we conducted desk research and organized stakeholder mapping meetings with representatives from local non-government and community-based organizations where we used participatory research methods to identify and analyze key stakeholders working with underserved populations.

Results: Twenty six institutions or groups working with the key underserved populations were identified. Insights about the challenges and dynamics of underserved communities were also gathered. Two working groups made up of representatives from the NGO and CBO level were formed.

Discussion: Using the information provided by local key stakeholders to shape the project has helped us to build solid relationships, give the groups a sense of ownership from the early stages, and made the project more context specific. These steps are not only important preliminary steps for participatory studies but also for other research that takes place within the communities.

Keywords: stakeholder mapping, community-based participatory, community research engagement, hepatitis C (HCV), Vietnam, underserved populations

INTRODUCTION

Viral hepatitis is a global health issue needing urgent attention. Globally, it is estimated that 257 million people are living with hepatitis B virus (HBV) (1) and 71.1 million people with hepatitis C virus (HCV) infection (2, 3). Low- and middle-income countries (LMIC) are thought to carry more than 80% of the HCV burden and Vietnam has one of the highest rates of mortality from chronic viral hepatitis deaths, alongside China and Japan (4). Approximately 1.07 million people in Vietnam are living with HCV (3). With the development and rollout of highly effective direct-acting antiviral treatment in 2015, HCV can now be cured and the possibility of elimination of HCV as a major health threat by 2030, a World Health Organization's (WHO) goal, is now a possibility (5). However, if people living with HCV are not aware of their status or they do not have access to treatment, it will be difficult to achieve.

To address this epidemic, the South East Asian Research Collaborative in Hepatitis (SEARCH) launched a 600-patient cohort study and two clinical trials, both investigating shortened treatment strategies for chronic HCV infection with direct-acting antiviral drugs. These studies have primarily recruited from populations already engaged in care at the Hospital for Tropical Diseases (HTD) in Ho Chi Minh City (HCMC), Vietnam. We conducted ethnographic research with a subset of the trial participants and found that the majority were aware of HCV infection and its implications, and were motivated to seek treatment. The absence of certain at-risk communities from the trial population was apparent. Overall, people who inject drugs (PWID), and other groups at risk for HCV were under-represented, although injecting drug use is associated with high rates of HCV, with an estimated 50–90% of PWID in Vietnam having HCV (6–8). Another group that is disproportionately affected by viral hepatitis are men who have sex with men (MSM). In Vietnam, it is estimated that 36.3–41.2% % of MSM have HCV (3, 6, 9). In healthcare settings, the seroprevalence of dialysis patients was found to be as high as 26.6% (3, 6), although these patients are likely accessing care and treatment. Transmission of HCV in Vietnam is thought to be caused mostly by unsafe intravenous practices, such as injecting drugs or blood-transfusions (3, 6, 10).

We had several questions about the potential underserved populations: who are the underserved populations at risk for viral hepatitis? Are there specific barriers to care? Are people engaged in care elsewhere? What can be done to improve linkages to testing, diagnosis, care, and treatment (if needed)? To explore these questions, we designed a study using community-based participatory research (CBPR) with an overarching aim to engage with communities at risk for viral hepatitis in order to develop community-led strategies to improve linkages to care and treatment. The main principles of CBPR are to build collaborative partnerships between an academic institute (in our case OUCRU), and community-based organizations (CBOs) (11). In CBPR approaches, the community members are involved in all aspects of the project from identifying the research problems, to developing and implementing community-led solutions that build upon the strengths and structures that already exist in the communities (11). When we first envisioned the project, we did not have direct links with relevant CBOs, nor were we fully aware of the resources already existing in the community, or the dynamics between key players within the communities. Therefore, we designed a preliminary phase of the project to focus on learning more about the community dynamics through stakeholder mapping, as well as to form stakeholder groups to advise us throughout the project more broadly.

Stakeholder mapping, as a method, can be useful for identifying and describing the relevant organizations and individuals from the communities who potentially influence decision making and have some working role with the communities (12, 13). Stakeholder mapping can result in several benefits: to assess the capacity of communities, to provide the community with an overview of potential resources, to create a visualization of the individuals and organizations that could influence, support, and help to solve community problems, and to demonstrate relationships and roles of various stakeholders within the communities (14–16). All of these outputs would be useful for the wider project. Fostering involvement and collaboration with stakeholders at various levels is crucial to CBPR projects. As "equal partners" in the relationship and in the project, the involvement of the stakeholders can help to create a more locally driven research focus based on the community's prioritized concerns (13). Involving stakeholder groups can also help to define appropriate research methods and culturally sensitive ways to approach and work with underserved groups (15). Additionally, stakeholder groups can also contribute credibility to the project and promote a higher chance of acceptability from local communities (15).

In this manuscript, we describe the first phase of the study which was set up to identify general characteristics of different underserved groups, their prioritized needs, as well as their potentialities and existing resources. The description of this phase is often limited in other articles using similar approaches and we find it a crucial component. In this article, we describe and discuss the preliminary phase, not only as a preparatory step before implementing the main study, but also as an essential starting point of the CBPR process. The process of mapping stakeholders initiated the partnership process with non-governmental organizations (NGOs) and CBOs, creating the necessary linkages between OUCRU researchers and underserved community groups, as well as helped to shape the research questions for the broader project.

MATERIALS AND METHODS

We used a CBPR approach following the principles described by Israel (1998). Our particular interest was to explore the local perceptions surrounding viral hepatitis, barriers to care seeking, as well as learn more about the strengths and structures of the communities in which we would be working. This phase included stakeholder mapping meetings with advisory groups and the formation of two stakeholder working groups. The goal of this phase was to identify key stakeholders or groups/organizations working with underserved people at risk for HCV in and around HCMC, Vietnam.

Advisory Groups for Stakeholder Mapping

We started the stakeholder mapping by conducting a desk review to identify stakeholders working with potentially underserved populations at risk for HCV in HCMC. We used personal contacts to create an initial list of key stakeholders including representatives from various organizations with an interest in viral hepatitis and/or working with underserved communities, and invited them to attend one of two advisory groups (AGs) meetings, one at the NGO-level and the second at the CBO-level. The goal of the meetings was to conduct stakeholder mapping using two main tools: grid charts and Venn diagrams. We used grid charts to summarize information and identify additional NGOs, CBOs, and informal groups working with underserved populations to expand the initial desk review mapping exercise (16). We then used Venn diagrams to summarize and illustrate the perceived connections, influences, and relationships among and between the stakeholders and key populations. We also hoped that these diagrams would potentially show where and how to gain access to and cooperate with community stakeholders (17). See **Figure 1**.

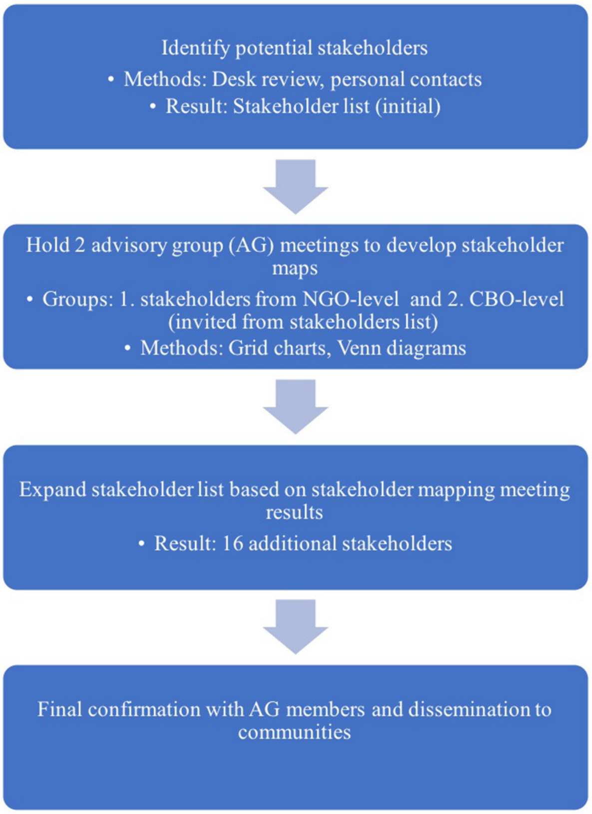

FIGURE 1 | Steps conducted for stakeholder mapping.

Formation of SWGs

From the individuals who attended the AGs mapping meetings, we formed two stakeholder working groups (SWGs) to collaborate and advise us throughout the CBPR process. Before creating the groups, we discussed the SWG roles, commitments and approximate timing for meetings and activities. Additionally, we discussed the voluntariness of joining the SWG, the CBPR groups and the ways we could maximize confidentially within the project more broadly.

Ethical Considerations

Throughout the preliminary phase, two researchers from OUCRU observed and wrote fieldnotes on the process and content of the meetings. At the start of each meeting, the researchers made it clear to all participants that the meeting dialogues would be documented by written notes and we obtained verbal consent to take photos during the meeting. All potentially confidential data from SWG meetings would only be shared between SWGs members and the research team. This manuscript is based on the discussions within the meetings held by the two SWGs and has been co-produced with them. The full study was approved by Oxford Tropical Research Ethics Committee (OxTREC) at University of Oxford (OxTREC 556-20), Imperial College Ethics Committee (20IC6420) and locally by the CBOs under which the CBPR groups are formed.

RESULTS

Results of Mapping Meetings

Based on the desk review and input from the initial stakeholders that we contacted, we held two meetings with representatives from two broad groups: those working at the NGO and CBO levels, to explore a range of perspectives. The contacts informed us that it would be better to separate the AGs into these broad categories for enhanced participation, especially for the CBO-level. We invited relevant participants from NGOs, CBOs, the private sector, and community clinics to join the AG meetings. The AG meeting with the NGO representatives took place on 1st

TABLE 1 | Participant-types in AG stakeholder mapping meetings.

Stakeholder types	Number of organizations	Number of participants
NGO-level AG meeting		
NGO	5	10
Institute	1	2
Private sector	1	1
CBO-level AG meeting		
CBO*	6	13
Community clinic	3	3

**3 of the CBOs were also social enterprises.*

September 2020 with 13 participants and the AG meeting for the CBOs took place on 01st October 2020 with 16 participants. Both meetings lasted approximately two and a half hours (see **Table 1**).

Overall, the individuals who participated in the meetings had experience working with vulnerable communities including MSMTG, PWID, HIV, sex workers and those in poverty. Members from NGOs had experience in consulting and providing technical assistance, capacity building for community organizations related to the implementation of prevention and treatment programs on HIV, STIs, nutrition and other issues. They also played a role in connecting and introducing community organizations to potential donors and funding mechanisms. Within the CBO groups, the leaders were mainly members from within those communities and therefore understood their contexts and needs. In some instances, participants from the CBOs also considered themselves members of the underserved communities. The CBOs conducted outreach to those affected by various diseases, such as HIV, sexually transmitted infections (STIs), HBV and HCV, provided access to health screenings and linkage to care, as appropriate. According to participants from both meetings, the CBOs had close working relationships with members of the community as well as with the organizations providing health services.

In each AG meeting, the participants were asked to conduct stakeholder mapping using grid charts and Venn diagrams. To conduct these activities, we divided them randomly into two smaller groups to facilitate more discussion and build consensus on the key stakeholders working within this realm.

Creating Grid Charts

The stakeholder grid was designed to include the NGO name, year established, funding resources, key populations, and the main projects or activities being conducted. In each AG meeting, the participants created grid charts and selected one member to present the results to the wider group.

In the NGO-level meeting, the participants followed the grid chart template and listed the information as requested. Overall, they listed 15 organizations and other groups working in the communities, including six organizations that were not on the initial desk review mapping list. It also became an opportunity for the participants to introduce groups they knew and/or were part of and learn about each other's organizations. At the end of the exercise, we asked participants to review the draft stakeholders list that the OUCRU team had previously made. They were asked to validate or edit NGOs/CBOs' locations, contact information and program that they were conducting.

During the CBO-level meeting, the participants also divided into two smaller groups to create the grid charts. The first group introduced the key stakeholders by explaining the steps of the process typically used to support underserved community members. Each step described supporting activities, as well as the roles of CBOs and other related stakeholders in those activities (see **Figure 2**). The second group provided a list of stakeholders that had experiences in supporting people with HCV in underserved communities. This exercise contributed updated information about the activities and the background of community stakeholders than the draft that we originally summarized.

We observed two main differences between the NGO-level and CBO-level AG approaches to completing the grid charts. Firstly, in the NGO-level meeting, the participants listed mostly larger organizations that focused on providing funds and technical support to the local organizations; whereas in the CBO-level meeting, participants identified organizations receiving the funds and technical support. Secondly, in the CBO-level meeting, the participants revealed several challenges they encountered when providing services within their communities, and they also identified stakeholders' roles during the different implementing steps for typical activities. For example, if a CBO is involved in all the steps from identifying people at risk of HCV to referring them to treatment, then during the step "referring to treatment," the CBO AG also added the information that "the CBO would collaborate with a clinic/hospital that provides the treatment." At this stage, there is involvement from other stakeholders (e.g., clinic, hospital).

Overall, in the two mapping meetings, we identified 26 institutions or groups working with the key populations, including 16 institutions that were not on our original mapping list. The results of the stakeholder mapping were made available for the CBOs and the wider communities.

Developing Venn Diagrams

The next part of the meetings was to create Venn diagrams from the lists created during the grid chart exercise. In the NGO-level meeting, the influence of stakeholders was divided into different categories (i.e., research, consultations, linkage to care and treatment) and the duration of influence was determined by the category of influence (e.g., research: when a research project lasts for only 2 years, the influence reduces after the project is completed; consultation/raising awareness: might be longer-term engagement and therefore have longer-lasting influence). A few concerns were raised by the NGO AG during this part of the exercise. According to the participants, the Venn diagram is subjective and potentially biased because representatives from the CBOs who were included in the diagram were not present at the meeting and could not contribute their perceptions. Second, the participants recognized that they analyzed their organizations from their perspectives only. Regarding the level of influence of organizations, the participants also mentioned that it was

Reach out	• Reach out to underserved populations at risk for HCV and other illnesses
Consultation	• Provide prevention knowledge and introduction about health care services
Communication	• Provide communication materials • Guide populations on how to use harm reduction products
Referral	• Link individuals to outpatient clinics and hospitals • Note: Treatment provided by doctors
Follow-up and care	• Track and update on community members' statuses
Finance mobilization	• Look for financial resources to help

FIGURE 2 | Stakeholder activities, as defined in the CBO-level AG meeting.

important to note that there are different types of influences, (e.g., influences regarding research, diagnosis, and/or consultancy) and the duration of such influences varies dramatically. See **Figure 3**.

In the CBO-level meeting, the group discussed that the larger institutions, with the potential for more influence, were not always embedded in the community, unlike the CBOs which tended to be embedded within the community. One group gave the example of an international NGO with a variety of projects in the community. Although this organization may have a big influence on communities, they were considered "far from the center" because they do not work directly in the community and therefore were less accessible to the community. The CBOs were "closer to the center" and were typically more accessible. Another point brought up in the CBO-level meeting was that if one changes the middle point of focus (e.g., in the meeting, it was HCV), everything around it changes as well so these dynamics are in constant flux. See **Figure 4**.

The priorities of the stakeholders also determined how the dynamics played out in the community and for specific key populations. For example, the CBO-level participants also discussed a "rupture" in the context of linking patients to treatment. There was a past research team that set up consultation and screening but did not link potential participants to care upon diagnosis. The research team returned to the community months later and asked what people had done with their diagnosis since that time, which was nothing as they did not know where to go for care. The participants felt lost as they were left with a diagnosis but not given advice about what to do with it. "Rupture" often happened when the research or project's aim was solely about screening but not about linking to treatment or longer-term follow-up. When the CBOs connected with the community after this happened, they found that the community did not want to engage with that institution/research team anymore—the relationship was "ruptured."

For the Venn diagram exercise, the NGO-level and CBO-level participants had different perceptions regarding the influences and relationships of the institutions. For example, the NGO-level participants listed only one CBO on their diagram and placed it far from the underserved populations who were located in the center of the diagram. They placed clinics and hospitals closer to the underserved populations. On the other hand, the CBO-level participants placed the CBOs very close to HCV (which was in the center) and clinics and hospitals further away. Interestingly, the CBO group placed the disease at the center, not the key underserved populations explaining that if the disease changes (e.g., from HCV to HIV), then the dynamics surrounding it would also change. Additional key differences between the NGO-level and CBO-level AG approaches to the Venn diagram exercise are included in **Table 2**.

Results on Forming Stakeholder Working Groups

After the AG meetings, we formed two stakeholder working groups (SWGs) made up of representatives from the AG meetings. We invited all the participants from the initial AG meetings to join the two SWGs. We also held the first meetings with each group. During these initial meetings, we defined the roles and responsibilities for each group, discussed the advantages and disadvantages of using CBPR to make sure it was the appropriate approach for the project, explored the exact groups that made up "underserved" groups (with the NGO-level SWG) and identified specific groups with whom we could work (with the CBO-level SWG). Within the CBO-level SWG,

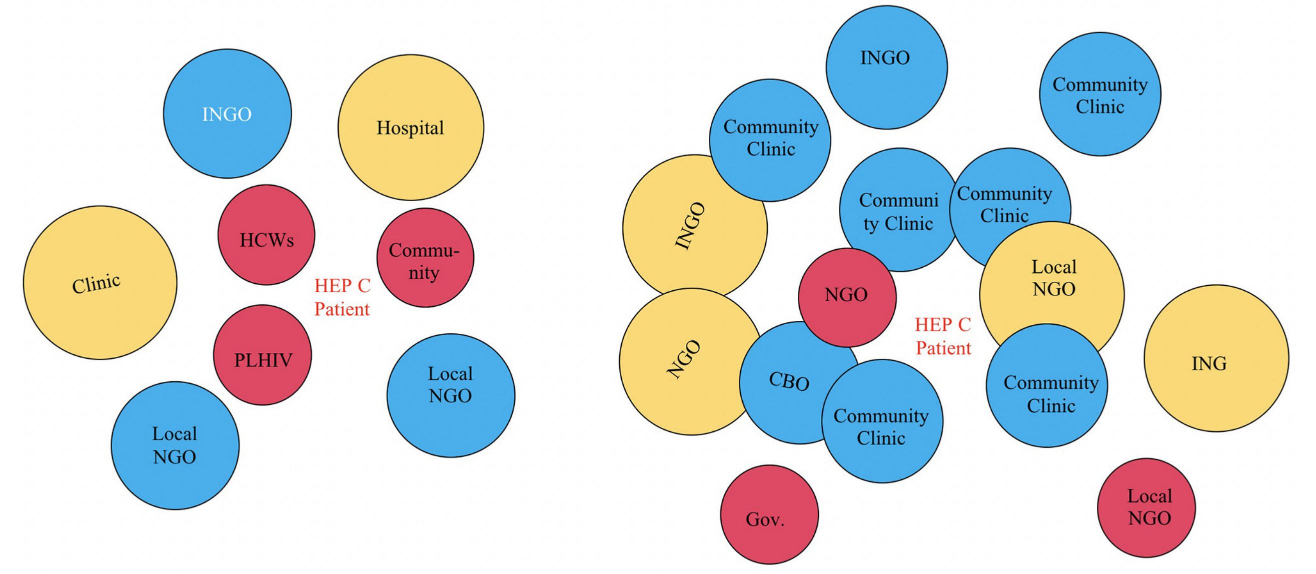

FIGURE 3 | Venn diagrams from NGO-level AG meeting. The circle size implies perceived level of influence from the stakeholder to the center. The distance from the circle to the center point implies access level from the stakeholder to the center. HCWs, Healthcare workers; PLHIV, People living with HIV; CBO, Community Based Organization; INGO, International Non-Government Organization; Local NGO, Local Non-Government Organization.

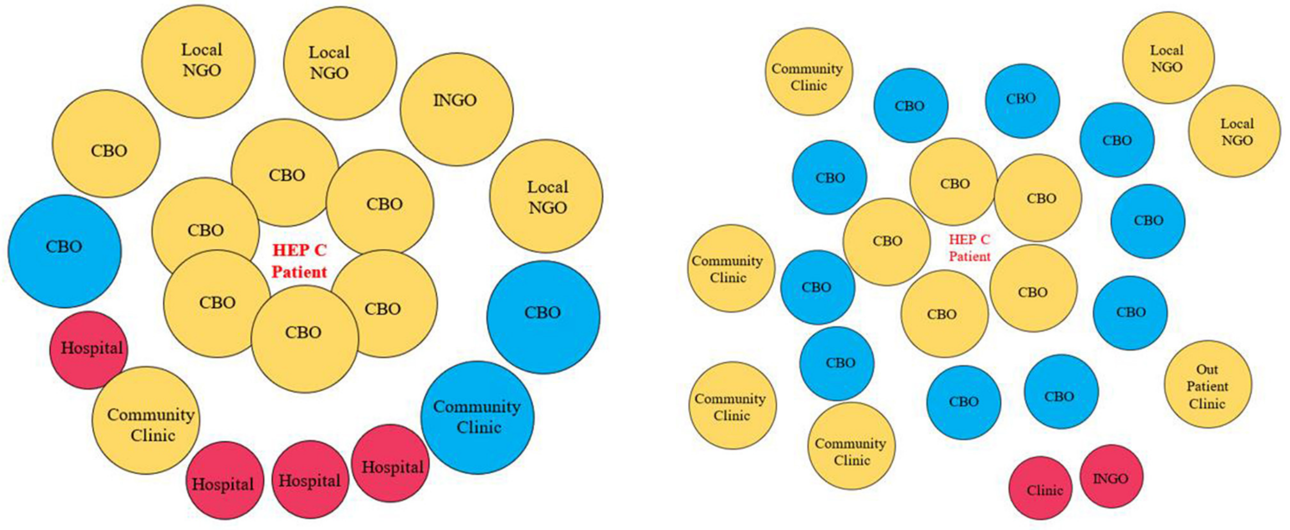

FIGURE 4 | Venn diagrams from CBO-level AG meeting. The circle size implies perceived level of influence from the stakeholder to the center. The distance from the circle to the center point implies access level from the stakeholder to the center. CBO, Community Based Organization; INGO, International Non-Government Organization; Local NGO, Local Non-Government Organization.

we also identified community activators (CAs) who would be instrumental in setting up and leading the CBPR groups.

Roles and Responsibilities

Before the initial SWG meetings, the research team drafted the terms of reference for each SGW, which described the scope of work, roles, benefits, and other necessary terms, and distributed them to the members prior to the meeting to start the discussions. At the start of the meeting, the research team asked the participants to define how they envisioned their roles in the study. We all agreed that the NGO-level SWG would be more of an advisory group while the CBO-level SWG would act more as community consultants. The exact roles discussed and defined by the groups are listed in **Table 3**.

Advantages and Disadvantages of CBPR

Before discussing the strengths and weaknesses in the CBPR approach, we also discussed the approach itself. There were

TABLE 2 | Key differences between the NGO-level and CBO-level regarding key stakeholders in community, based on Venn diagram.

NGO-level AG meeting	CBO-level AG meeting
Community clinics are closest to the key populations (i.e., at the center) which means the populations find it easier to access community clinics than the other stakeholders/institutions included. Stakeholders/institutions that have the highest levels of influence are not always the organizations that are easy for key populations to access.	The CBOs that work directly with key populations (e.g., PWID, sex workers, HIV) have the highest influence and are closer to the communities (i.e., easier for the community to access). There are other stakeholders who have equally high influence but are not that close to center because they are not easy for key populations to access. The community clinics also have high influence but are not as close to key populations because they do not work only with key populations (e.g., transgender, MSM). The public hospitals are quite far from center with less influence noted than the other stakeholders.

TABLE 3 | Roles of SWGs: NGO-level and CBO-level.

NGO-level SWG	CBO-level SWG
Orient CBPR groups on various ways to work with the communities. Provide overarching technical support. Provide suggestions on selection of sites and participant recruitment strategies.	Lead the CBPR groups, as CAs. Plan for research activities that take place in CBPR groups. Refer people to the HCV treatment trial, as appropriate.

differences between what the groups thought about the core principles of CBPR. The NGO-level SWG focused on principles to use during the conduct of CBPR, including honesty, respect, equality, flexibility, and with the focus on the participants. For the CBO-level SWG, the emphasis centered more on the consequences of CBPR for participants (e.g., confidentiality, dedication to helping all, non-discrimination), and the importance of understanding the needs of each situation using two-way communication and evidence-based solutions.

The NGO-level SWG and CBO-level SWG also had different perspectives regarding the strengths and challenges of implementing CBPR in the community. The NGO-level SWG felt that the strengths of the approach included gaining data from multiple viewpoints, flexibility, and the aspects about building trust that would be enhanced. However, they also felt that there could be conflicts between members, there might be too much information gathered, and the NGO-level SWG and research team might have different long term expectations. The CBO-level SWG discussed the strengths of the approach including aspects surrounding how the CBOs are integrated within the communities, therefore could collaborate well with the CBPR groups (e.g., they understand the realities of the populations and there is pre-existing trust). They also thought that the methods, although new, would provide a diversity of information, reach more people, and the underserved populations would be easy (for them) to approach and collect data. Some of the challenges the CBO-level SWG discussed included lack of facilitation skills, information overload or misinterpretation of data, the workload and costs might be too much for the CBPR groups, and there may be a lack of trust in the community toward researchers, and/or different expectations and levels of commitment from the CBPR group members. In the end, both groups agreed that CBPR was the appropriate approach for answering the broader research questions.

Identification of Underserved Populations and Groups to Work With, and CAs

At the NGO-level SWG meeting, the OUCRU research team suggested that the potentially underserved populations included PWID, sex workers, MSMTG, and people living with HIV. The NGO-level SWG members identified an additional at-risk group affected by HCV which included those who have low-income, unsustainable employment, and financial barriers to access regular care and treatment.

During the CBO-level SWG meeting, we invited members to volunteer as CAs to coordinate the CBPR groups and mobilize community members to participate. The role of the CAs was crucial for inviting members to join the group, to support group members during meetings, and to collect and analyze data together with the members of the groups. Each person at the CBO-level SWG meeting was given a card and if they wished to be a CA for a CBPR group, they simply wrote "Yes" on the card (with their name and contact), otherwise, they could leave the card blank. The project team compiled the list and responded to the individual members *via* email to confirm. In the end, each group had at least two CAs appointed by the CBO-level SWG.

Community Activator Trainings

As requested by the CBO-level SWG, the OUCRU team organized training activities to equip the CAs with more knowledge about CBPR background and methods. We held a two-day training on CBPR, which focused on general definitions and principles of CBPR, and introduction to some of the basic tools of participatory research (e.g., Venn diagrams, grid charts, body mapping), as well as facilitation skills. Twelve participants attended the training as we opened it up to other interested participants from the SWGs. One of the most important aspects of this training was to stress how CBPR should be based on the issues of the community and how it is the community members who should decide the solutions for those problem. Listening and respecting differences was key.

DISCUSSION

The importance of understanding and listening to experts in the communities in which we work cannot be overstated. However, taking a step back and trying to understand the range and scope of expertise that already existed in the community was equally important for developing a dynamic within the already well-established community of stakeholders. The mapping exercise, along with the mapping meetings allowed us to achieve this goal. The subsequent dialogues and engagement with potential community leaders were crucial to the success of the development of the project as we had not worked with these communities in the past and we wanted to build the project with the communities from the start.

In our case, keeping the mapping methods fluid resulted in the CBO-level AG group transforming the method into a more informative and applicable method for the purposes of the exercise. With their tailored method, we learned about some of the challenges in implementing public health programs and individual care seeking in those communities. We also noted how the perceptions and priorities were different between the NGO- and CBO-levels working with the same communities. This minor point speaks volumes about the importance of listening and identifying who represents the community and how their actions potentially impact that perception. We intend to also compare these findings with the CBPR groups as their perceptions and priorities might also be different from the organizations that "represent" them.

The stakeholder mapping also provided the initial space for the researchers to start to understand the potential strengths and resources of the community, as it was clear that there was indeed a community prior to the start of this project. From an outsider perspective, it seemed like the stakeholders involved in the meetings were already part of a close-knit community. We also noted quickly how different forms of organizations have different roles in the community. An outcome of the mapping meetings was the fact that the communities themselves were able to start to advise researchers prior to the study officially beginning. These initial meetings set the tone for the future participatory work. Mathur et al. (18) discussed how stakeholder mapping can be a complex technique, but it can be an effective way to better understand stakeholders, their influences on each other, and for assessing the research topics at hand. During the discussions in the stakeholder mapping meetings, the participants from both the NGO-level and CBO-level AGs spoke about the relationships among the stakeholders and their ability to influence the health issues that underserved groups potentially faced, as well as listed out services were provided for these populations in their communities. In reality, most NGOs were involved in policy advocacy, implemented fundraising activities with both local and international stakeholders, and managed and allocated funds to CBOs in specific priority areas. The CBOs worked directly with community members to provide consultations, linkages to screening, treatment, and follow-up care. As an initial exercise and first meeting together, it was useful to start to understand the dynamics of the stakeholders and how they worked within the communities.

One important aspect of the CBPR approach is to create equal partnerships. Participatory stakeholder mapping can be used as a first step to create a shared research environment for community members with more balanced roles prior to implementing CBPR or other community-focused research, as this balance of power dynamics between the researchers and community members, or even between community members is often difficult to achieve (15, 19). In a study conducted by Kue et al. (15) with Hmong communities in the United States, community-based methods were used as well as a community advisory committee formed to provide insights to the communities' social patterns and resources to define culturally appropriate data collection methods. The members of this committee ranged in age and gender but younger members and women were observed to be less active in discussions compared to older and male members because, according to the researchers, the roles (and voices) of these members in the community were already defined (15). The cultural norms played a role in making equal or balanced participation difficult to achieve. With this in mind, while we were setting up the initial AG mapping meetings, we consulted with a selection of stakeholders prior to the meetings and decided together to divide the groups in NGO- and CBO-levels because of the power dynamics that already existed in these communities.

Finally, our assumptions about who was at risk for HCV was missing a key group—the financially vulnerable communities, and by holding these early conversations we were able to expand the research groups for inclusion in the project beyond those that we had planned. Our initial impressions of the communities were incomplete.

One limitation of this paper is that we only present the results from the preliminary phase of the project, however the details of how the CBPR groups formed and progressed will be presented elsewhere. A second limitation is that the majority of the meetings described in this paper were conducted in Vietnamese and therefore some meaning may have been lost in translation into the English version. Third, although the CBO-level participants who were engaged in this stage of the project were working directly with and were sometimes community members themselves, their views and opinions may be different than community members who were not directly involved with the CBOs. In future studies, it may be worth adding a third group including only those from underserved communities to determine how their opinions might differ at this stage.

To conclude, listening early, carefully, and often has helped us to build solid relationships. Using information generated by the community to shape the project has provided a mutual sense of ownership from the early stages of the project and also created a more context specific project. These initial steps are not only important preliminary steps for participatory studies but also for other research that takes place within the communities. The methods allowed all involved to consider their own approaches and activities within the communities and plan for a more collaborative and participant-led initiative.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Oxford Tropical Research Ethics Committee (OxTREC) at University of Oxford (Ref: OxTREC 556-20) Imperial College Ethics Committee (Ref: 20IC6420). The CBPR participants provided their written consent to participate in the study.

AUTHOR CONTRIBUTIONS

JV, MC, and GC initially designed the main study and obtained funding. GN, MN, AB, NN, VV, DN, LP, TP, TL, AN, TNA, TNNN, LN, VN, HN, TNM, MD, TNT, PT, SP, NT, AH, and HD provided input into the development of the project and were involved in the preliminary phase of the study. JV and GN prepared the manuscript draft, with input from MC and MN. All authors reviewed and approved the final manuscripts.

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Community Engagement in Cutaneous Leishmaniasis Research in Brazil, Ethiopia, and Sri Lanka: A Decolonial Approach for Global Health

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Cutaneous leishmaniasis (CL) is a parasitic skin disease endemic in at least 88 countries where it presents an urgent, albeit often “neglected” public health problem. In this paper, we discuss our model of decolonial community engagement in the ECLIPSE global health research program, which aims to improve physical and mental health outcomes for people with CL. The ECLIPSE program has four interlinked phases and underpinning each of these phases is sustained and robust community engagement and involvement that guides and informs all activities in ECLIPSE. Our decolonial approach implies that the model for community engagement will be different in Brazil, Ethiopia and Sri Lanka. Indeed, we adopt a critical anthropological approach to engaging with community members and it is precisely this approach we evaluate in this paper. The data and material we draw on were collected through qualitative research methods during community engagement activities. We established 13 Community Advisory Groups (CAGs): in Brazil ($n = 4$), Ethiopia ($n = 6$), and Sri Lanka ($n = 3$). We identified four overarching themes during a thematic analysis of the data set: (1) Establishing community advisory groups, (2) CAG membership and community representation, (3) Culturally appropriate and context-bespoke engagement, and (4) Relationships between researchers and community members. During our first period of ECLIPSE community engagement, we have debunked myths (for instance about communities being “disempowered”), critiqued our own practices (changing approaches in bringing together CAG members) and celebrated successes (notably fruitful online engagement during a challenging COVID-19 pandemic context). Our evaluation revealed a gap between the exemplary community engagement frameworks available in the literature and the messy, everyday reality of working in communities. In the ECLIPSE program, we have translated ideal(istic) principles espoused by such community engagement guidance into the practical realities of "doing engagement" in low-resourced communities. Our community engagement was underpinned by such ideal principles, but adapted to local sociocultural contexts, working within certain funding and regulatory constraints imposed on researchers. We conclude with a set of lessons learned and recommendations for the conduct of decolonial community engagement in global health research.

Keywords: qualitative research, ethnography, low-resourced settings, decoloniality, neglected tropical diseases, empowerment, community partnerships, community advisory boards

> "ECLIPSE is different from all the projects here (*O ECLIPSE é diferente de todos os projetos que passaram por aqui*). You do not have an attitude of superiority. For the first time, we felt we were really participating. Not just giving our opinion but acting. [...] When we saw the result of the videos we made with the [ECLIPSE] arts group, we felt powerful (*nos sentimos poderosas*). It was the result of our work. We realized that we were able to make that beautiful thing. We often feel tired of fighting alone, without the support of government officials. Now we feel we can count on you" (Community health worker, Brazil).

INTRODUCTION

The global health decolonization movement is underpinned by a critical interrogation of what is regarded as "legitimate" in knowledge production (1–3). A colonialist legacy has led to a hegemonic knowledge hierarchy in which eurocentric, northern, and western perspectives are regarded as the primary legitimate knowledge base for global health research and interventions. This way of conducting global health research overlooks and undermines the values, views, and practices of the people living in the communities where the research is conducted. In this article, we argue that embedding meaningful community engagement in a global health project represents one avenue through which we can decolonize research practice and knowledge production. To illustrate this, we draw on the example of community engagement in ECLIPSE (*Empowering people with cutaneous leishmaniasis: Intervention programme to improve patient journey and reduce stigma via community education*)—an interdisciplinary applied health program based in Brazil, Ethiopia, Sri Lanka, and the UK, which aims to improve physical and mental health outcomes for people with cutaneous leishmaniasis (CL).

Cutaneous Leishmaniasis

CL is a parasitic skin disease endemic in at least 88 countries where it presents an urgent, albeit often "neglected" public health problem (4). Transmitted by the bite of an infected sand fly, CL presents as skin lesions in one or more areas of the body. Although not fatal, CL may significantly impair quality of life (5) as visible skin lesions and disfiguring scarring may cause stigma and lead to social exclusion (5). Whilst in many cases CL lesions heal spontaneously, this may take many months and it is better for individuals to receive treatment to limit scarring and secondary bacterial infections. Biomedical treatment usually consists of a course of an anti-parasitic drug (pentavalent antimonial) which is administered *via* daily injections. The treatment may have side effects, including joint pain, muscle aches, abdominal discomfort, headache, and skin rash. More severe side effects include pancreatitis and arrhythmia (6).

CL is recognized by the World Health Organization (WHO) as a "neglected tropical disease" (NTD). It has a high prevalence in poor populations and is more common in area of conflict and in overcrowded living contexts, characterized by poor sanitation (7, 8). Like other NTDs, CL contributes to cycles of poverty and disease and presents significant risks to public health, both physical and mental, and is an impediment to socioeconomic development (9). The lack of an effective human vaccine, limited access to efficient treatment and limited local resources means that the control of CL is difficult and it remains a public health concern in affected communities.

Research on CL

In the past, CL has received little attention and investment from research funders, partly because it is not fatal, certainly in comparison to the life threatening form of leishmaniasis, visceral leishmaniasis (VL). In recent years, though, research focused on CL has increased, partly because of a renewed attention on the control of NTDs (10). The CL research community has many sub-fields. Biomedical researchers and clinicians work toward a better understanding of the host-parasite relationship, as well as advancing drug development and other treatment protocols (11, 12). Applied health researchers are concerned with CL at an individual, community, and population level. Improving health services, public health programs and national policies are at the forefront of this strand of research (13–15). The objective of social scientists working on CL, on the other hand, is to examine how the social and cultural milieu shapes the experiences of those affected by CL (16–18).

We identified two main characteristics in the current CL literature, which influenced our own research program on CL. First, there is a tendency for CL researchers to work in disciplinary silos. Indeed, the majority of CL studies are conducted by researchers from one academic specialty and are single-disciplinary focused. For instance, research carried out with only biomedical or only applied health service researchers involved in the research teams. Second, CL researchers are often detached from the communities affected by CL and may have never engaged with community members. Often, parasitology research has been conducted by "parachute" researchers who collect data at a time and in a manner of their choosing, generally at their convenience, and exit the CL-affected communities as quickly as they appeared (19). Little communication with community members seems to take place before, during and after the study. Interaction between CL researchers and inhabitants of CL affected communities appears to be instrumental in nature—a means to an end.

The shortcomings of opportunistically "parachuting" into a community, without engaging meaningfully with affected stakeholders, are highlighted in the growing literature on community engagement, including in the global health field (19, 20). Scientific and ethical imperatives are generally cited for involving and engaging affected communities in the conduct of a research project. Robust and sincere engagement ensures that knowledge production is not dominated by academics, but that knowledge from local communities is visible and prioritized. Some argue that community engagement is particularly crucial in countries where transcontinental research, legacies of colonialism and structural inequalities may present a high risk of exploitation (21–23).

ECLIPSE: Decolonial CL-Research

In this paper, we discuss our model of decolonial community engagement in the ECLIPSE global health research program, which aims to improve physical and mental health outcomes for people with CL. The ECLIPSE team is comprised of CL researchers from a wide range of academic disciplines (anthropology, sociology, parasitology, public health, collective health, primary care, psychology, arts, humanities, etc.) based in four countries: Brazil, Ethiopia, Sri Lanka, and the United Kingdom (UK).

ECLIPSE has four interlinked phases: (1) qualitative and ethnographic research to explore the experiences and perceptions of CL in the community, (2) quantitative research to measure CL awareness and stigma, (3) development and implementation of context-bespoke community-based CL interventions and (4) a program evaluation. Underpinning all four phases is sustained and robust collaboration with local stakeholders to guide and inform the planning and conduct of research activities in ECLIPSE.

Objectives and Strategy of Community Engagement in ECLIPSE

From the inception of ECLIPSE, we were committed to steering away from a hierarchical and colonial way of conducting global health research, based on a fixed community engagement framework that is often dictated by researchers based in the UK. Our decolonial approach implies that the *model* for community engagement will be different in Brazil, Ethiopia and Sri Lanka. Indeed, we adopt a critical anthropological and postcolonial approach to engaging with community members.

Already from our grant application development meetings, we recognized that embedding meaningful community engagement is paramount to ensure that our research activities lead to decolonial knowledge production. For us, that means knowledge that is valued by community members. As a result, the community engagement strategy in ECLIPSE is driven by our commitment to embrace, amplify and place at the forefront community members' experiential knowledge. Therefore, we designed our community engagement in such a manner that our approach both facilitated and allowed community members to influence and direct the research in a way that is appropriate, relevant, useful, and beneficial to the communities. More specifically, four objectives inform our ECLIPSE strategy to involve and engage community members:

(1) to understand community needs and experiences around CL,
(2) to amplify the voices of community members, as well as maximize their participation and empowerment,
(3) to promote the translation of research findings into policy and practice in ways that positively impact on local communities, and
(4) to enhance cultural awareness among research team and lay foundations for future community-oriented CL and broader health research.

For this purpose, our strategy is based on the establishment of two types of groups in each ECLIPSE country: community- and policy-level groups.

We established community-level groups at village/municipal level. CAGs membership is diverse and includes people with CL and individuals from their social networks, community health workers, traditional and spiritual healers, religious, and community influencers as well as other residents. Engagement *via* community-level groups is inward-facing in that it includes people who live or work in the CL-affected community and specifically focuses on how research activities are to be implemented (see **Figure 1**). Input and joint decision-making is sought around different aspects of the project—such as quality of public-facing material, participant recruitment processes, interpretation of findings, and how to make our activities culturally appropriate and context-bespoke.

The ECLIPSE team convenes policy-level groups at an urban-regional level. These are our Communities of Practice (CoPs). We invited stakeholders who can bring about changes in policy and practice on a regional and national level. Members include policy makers, clinicians, public health officials, religious and municipal leaders, non-governmental organizations' representatives and representatives of key sectors such as education, agriculture and health. CoP meetings are facilitated by ECLIPSE team members and have a fairly formal character given that members are invited in their professional capacity. In these ECLIPSE CoPs, members with diverse areas of expertise but who share an interest in CL are brought together (possibly for the first time) to exchange knowledge, coordinate and collaborate toward a common purpose (24, 25). In contrast to the CAGs, the focus of CoPs is outward-facing as members seek to disseminate ECLIPSE findings and interventions upwards to policymakers to promote their uptake at regional and ideally at national level (see **Figure 1**).

Since the format of ECLIPSE policy-level groups, in the form of CoPs, is very similar to a conventional stakeholder meeting, which is abundantly discussed in the wider literature (26–28), we focus specifically on the community-level groups, the CAGs, in this article.

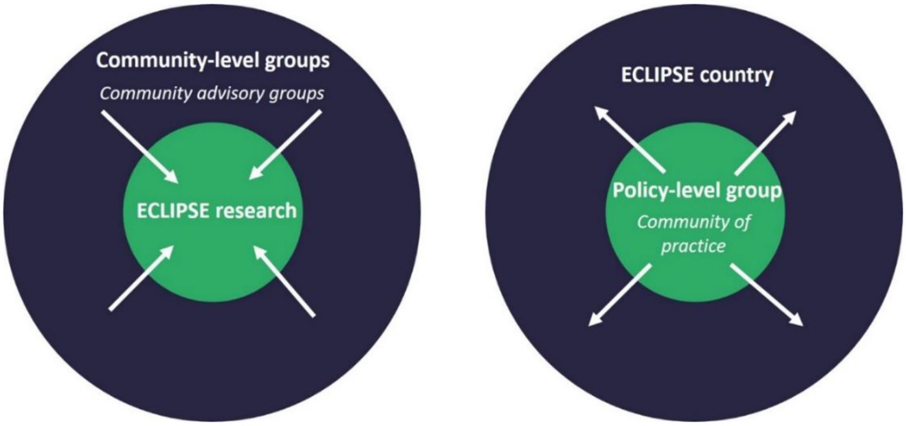


FIGURE 1 | Community engagement strategy in ECLIPSE.

METHODS

The data and material we draw on in this article were collected through qualitative research methods during the monitoring and evaluation of the community engagement practices in the ECLIPSE program.

Monitoring and Evaluation

At the time of writing this article, the ECLIPSE teams in Brazil, Ethiopia, and Sri Lanka have been working for up to 18 months (of a funded 48-month program). This marks our first evaluation time-point (see **Figure 2**).

A community engagement and involvement (CEI) team, comprised of researchers from each ECLIPSE country, is responsible for designing, implementing, and evaluating community engagement activities. This CEI team regularly meets and has detailed discussions, trainings, evaluation meetings, and co-authors progress reports. Such community engagement evaluation is paramount for ECLIPSE, as it allows us to (1) strengthen our future engagement as it progresses, (2) gather evidence about the impact of our engagement, and (3) contribute to the emerging body of literature on community engagement in global health research by disseminating best practice (29, 30). By collating and analyzing evaluation data from these three very different settings, we will be able to evaluate three different cultural models of community engagement.

Data Collection and Analysis

We have adopted a range of qualitative research methods to continually evaluate the practice of community engagement and involvement within the cultural context of each ECLIPSE country. Data has been collected through participant observation, interviews, group discussion with CAG members, and visual methods (photo and video). We opted for such multi-method approach to evaluation as the challenges and opportunities arising from robust engagement with community members requires a sensitive approach to capture a multifaceted and nuanced picture. This might be less possible *via* simple "pre" and "post" survey-style evaluation (31).

Participant observation was undertaken by ECLIPSE team members in every meeting with community members. Researchers took detailed field notes, during and after meetings, capturing representation, atmosphere, dynamics, and details of the discussions. Some of the meetings in the community were audio-recorded, with the consent of all individuals present. Relevant parts of these recordings have been transcribed. Reflections in debrief sessions with team members about the CAG meeting were also recorded in the field notes.

A collective critical reflection—defined by Kelly et al. (32) as an opportunity "for co-learning and strengthening researchers' capacity to engage meaningfully with stakeholders"—informed our approach to data analysis. The datasets from the different country teams (containing field notes, photos, videos, and discussion transcripts) were collated, read, and analyzed by KP and LD on an ongoing and iterative basis. We applied conventional thematic analysis techniques (33, 34) to the qualitative data: cycles of coding data and discussing overarching themes identified during the coding process. Themes were reviewed until consensus was reached in the group of co-authors.

We thus adopt a critical anthropological approach to engaging with community members and it is precisely this approach we evaluate here. As anthropologists do, we critically reflect on the researcher-community members' relationship, on how research engagement and involvement is operationalized in each culturally diverse community across the three countries, and what specific changes and adaptations we made to ensure a decolonial approach to working with local residents.

Ethical Approvals

We received approval from the ethics review committees at the four ECLIPSE institutions: from the Institute of Collective Health, Federal University of Bahia, Brazil [Ref.: 4.238.866], from the College of Health Sciences, Mekelle University, Ethiopia [Ref.: ERC/1793/2020], from the Faculty of Medicine and Allied Sciences, Rajarata University of Sri Lanka [Ref.: ERC/2020/74]

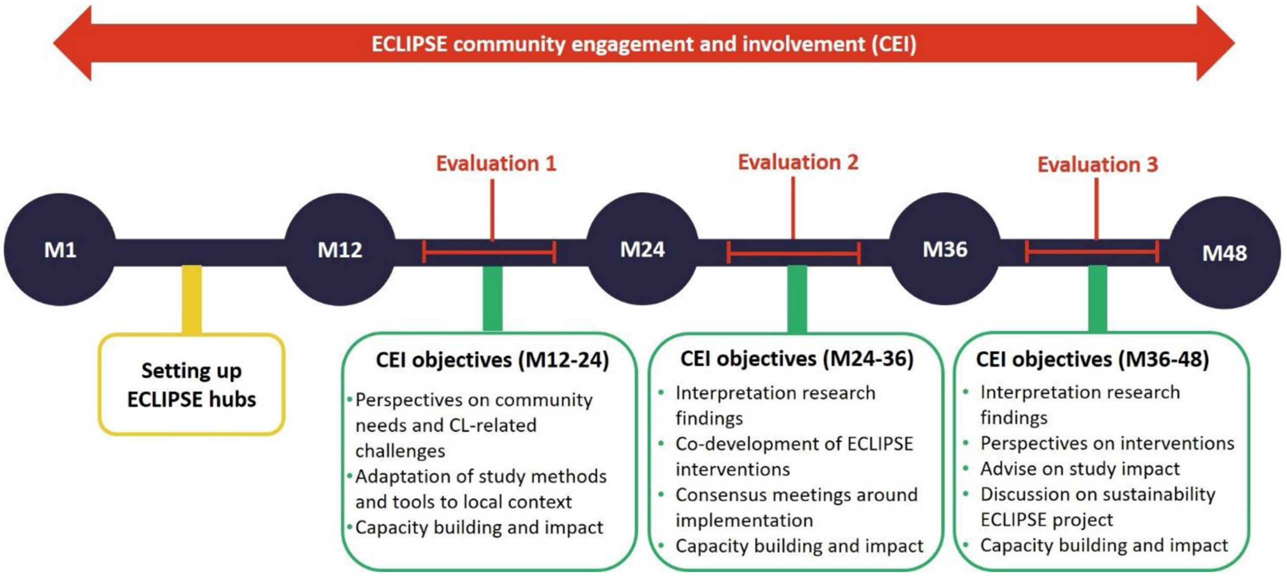


FIGURE 2 | Timeline of ECLIPSE community engagement and evaluation.

and from the Faculty of Medicine and Health Sciences, Keele University, United Kingdom [Ref.: MH-200123].

All names of individuals and the names of small administrative local units within the larger regions (for instance, villages and municipalities) have been pseudonymized. We discuss ethical considerations and challenges in the sections below.

Study Settings

In the first 6 months of the ECLIPSE program, we established ECLIPSE hubs in the state of Bahia (Brazil), the Tigray region (Ethiopia), and the North Central Province (Sri Lanka; see **Figure 3**). Community advisory groups (CAGs) are present in each study site where ECLIPSE activities are taking place. A total of 13 CAGs have been established across the three ECLIPSE countries: Brazil ($n = 4$), Ethiopia ($n = 6$), and Sri Lanka ($n = 3$). The ECLIPSE field sites were selected on the basis of high CL prevalence. We provide here a short summary of the CL and regional context of each ECLIPSE country.

Bahia State in Brazil

CL Context

CL has been endemic in Brazil for a considerable number of years (35) and awareness of CL symptoms is relatively high in affected Brazilian communities. Mucocutaneous and disseminated CL are also found in Brazil. These are more severe forms of the disease which are more difficult to treat and can result in highly disfiguring pathology (36). Brazil is widely recognized to have one of the highest global incidence rates for CL, although most cases are found in the north of the country in the nine states of the Brazilian Legal Amazon and in the state of Bahia. The central coast of Bahia was recently identified as an intensifying hotspot for CL, with a recommendation to target this region for disease surveillance and control (36, 37).

ECLIPSE Hubs

Four hubs have been set up in the coastal state of Bahia, the fourth largest Brazilian state in the north-eastern part of the country (population ∼ 15 million) where Portuguese is the official language. Religion in Bahia is a syncretic mix of Catholicism, Pentecostal Christianity, and the Afro-Brazilian Candomblé religious tradition (38). A rich Afro-Brazilian cultural tradition exists in Bahia, since its capital, Salvador, is the city with the largest Black population in Brazil, due to a colonial history marked by the slave trade which was concentrated in Bahian ports (39). We set up four ECLIPSE CAGs spread across three neighboring municipalities, located in primarily rural and semi-rural areas where agriculture is the main economic mode of production.

Tigray Region in Ethiopia

CL Context

CL was first reported in Ethiopia in 1913 (40, 41). While there is evidence that the disease is highly prevalent in Amhara, Tigray, and South Nations Nationalities Peoples Regional State regions of the country (40), the official numbers of CL cases appear low as disease reporting for CL (unlike visceral leishmaniasis) is not mandatory in Ethiopia (40, 42). It has been estimated that there are ∼50,000 cases of CL per annum in Ethiopia (40) with a small percentage of CL cases progressing to the highly disfiguring mucocutaneous and disseminated forms as in Brazil (42). The actual burden of CL in Ethiopia is unknown: our research indicated that CL is often inaccurately recorded as a "skin

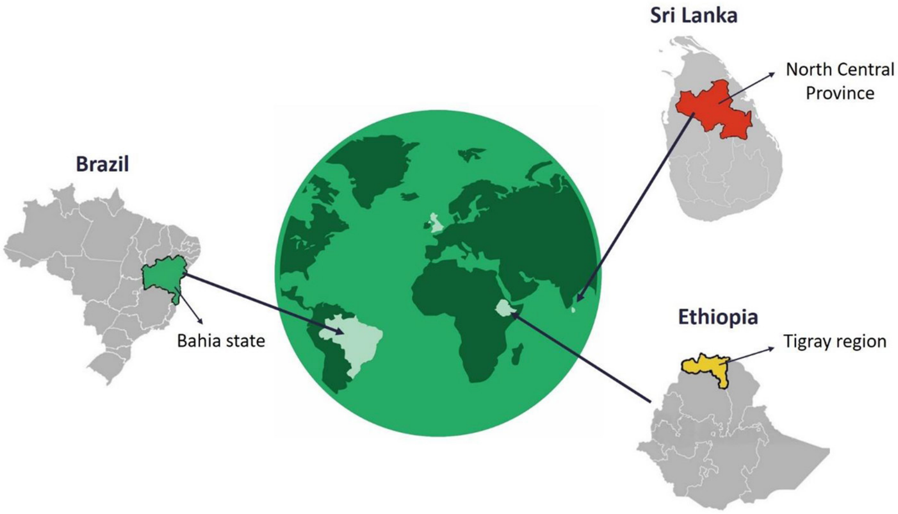


FIGURE 3 | Location of ECLIPSE hubs in the three CL-endemic countries.

infection" by healthcare professionals working at all levels—health posts, health centers, and hospitals. This aligns with what is empirically understood about the low societal awareness of CL in Ethiopia despite a potentially high, and growing, burden of disease.

ECLIPSE Hubs

Six ECLIPSE CAGs were established in Tigray, Ethiopia's northernmost region in the summer of 2020. The main language is Tigrinya and many Tigrayans also speak Amharic which is taught in schools. Almost 96% of the population in Tigray are Orthodox Christians. Tigrayan communities are mainly agrarian, with residents making a living from small-scale subsistence farming. Since November 2020, there has been an ongoing conflict in the Tigray region which has, in autumn of 2021, escalated to other parts of Ethiopia (43). Until time of writing (November 2021), the war was ongoing. We elaborate on this below.

North Central Province in Sri Lanka

CL Context

In contrast to Brazil and Ethiopia, CL is an emerging public health issue in Sri Lanka and there is believed to be little awareness of the condition in newly endemic regions. The first locally acquired case was reported in 1992 (44) and there has been a major increase in new cases in the north of the island over the last decade (45, 46) with a prediction of continued increases unless effective control measures are put in place (47). There is large variability in terms of reported cases across Sri Lanka, and even within districts suggesting that despite there being a mandatory requirement for healthcare professionals to report cases of CL, this is currently not always happening (48). Therefore, the national figures very likely represent an underestimation of the disease burden.

ECLIPSE Hubs

We established three hubs in the North Central Province (population 1.3 million), where 90% of the population is Buddhist. Local languages spoken are Sinhalese and Tamil. The three CAGs are located in rural, agricultural villages where paddy farming is the most common economic activity.

RESULTS

We present here findings from our analysis of data collected in Brazil, Ethiopia, and Sri Lanka, between March 2020 and September 2021, the first of three evaluation points on the community engagement strategy in the 4-year ECLIPSE program (see **Figure 2**). This section is structured in the four overarching themes we identified after data analysis. We illustrate each theme with examples from the ECLIPSE practice of community engagement through excerpts from field notes, ethnographic vignettes, descriptions of events, quotes from interviews, and photos.

Establishing Community Advisory Groups

Brazil

We work in an area that is home to a leishmaniasis reference center. The connection between the ECLIPSE team and the healthcare professionals at that center added greater credibility to the ECLIPSE presence in the communities and boosted confidence for community members, as illustrated in the following quote:

> When Alberto [ECLIPSE team member and healthcare professional at the reference center] invited me to join ECLIPSE, to be part of your group, I thought why not? Because then, when we speak to the people at the reference center, who carry out the projects together with the university in Salvador, you only bring

> benefits to the community and if you invite us to be part of this group, we are going to help, we are here, right? I feel very flattered and satisfied to join you because I did not expect the invitation, honestly, but here I am to help in whatever is necessary and in whatever you need (CAG member, Brazil).

Ethiopia

Following local customs, we employed a two-step process in the establishment of the CAGs in Ethiopia. Firstly, we sought the approval and cooperation of the local cabinets, which are composed of both government-appointed and community-elected members. Obtaining support was crucial both in symbolic terms (cabinets' endorsements legitimized ECLIPSE as a trustworthy program) and in practical terms (to facilitate the arrangement of meetings with community members in the villages). Secondly, the health extension workers, who are the most familiar with all households in one community, played a central role in informing community members about ECLIPSE and mobilizing them to attend the first introductory meetings with members of the research team.

Sri Lanka

We adopted both top-down and bottom-up approaches in establishing the CAGs in the North Central Province. In the top-down approach, we worked with the *Grama Niladhari*, the village officers, who have comprehensive knowledge of the families in their division. We also worked with the agricultural and public health network. These networks assimilate diverse societies such as the Farmers Society, Death and Benevolent Society and the Women's Society in each community. The bottom-up approach included several methods: transect walks through the villages, ethnographic observations, and discussions with the villagers to ask them who they would put forward as CAG members. This enabled us to ensure that community members themselves were closely involved in establishing the CAG membership.

Location of CAGs

The CAGs convened in very different venues, all dependent on the local infrastructure and where community members would feel at ease to engage in meaningful and, at times, difficult conversations and activities. In the low-resource settings of the Ethiopian communities in Tigray, CAG meetings often took place outside health posts or local schools as the local infrastructure was too small to convene the meetings. In Brazil, CAGs convened in venues located in the heart of these Bahian communities: in the local sports gymnasium, school and local associations' buildings. In line with the cultural context in Sri Lanka, CAGs were organized in the *Dharmashalawa* (preaching hall) of the village's Buddhist temple or in the community hall of the Funeral Society of the village.

Social Reality of CAGs

The material culture of the CAGs was also different in the three ECLIPSE countries. The Sri Lankan researchers, for instance, adhered to a more formal dress code and the senior female researchers wore a colorful saree to mark the special occasion of the CAG meeting. The researchers in Brazil wore project-branded T-shirts and trousers and provided community members with objects (e.g., water bottles) with the ECLIPSE logo embossed. It is important to note that the ECLIPSE logo, a bright yellow sphere overlapping with a green globe, was not appropriate to use in Brazil as this color combination is strongly associated with a specific political party. The logo was adapted to a blue-green color combination to use in Brazilian communities.

It is clear from the data that our jointly written ECLIPSE community engagement "protocol" was adapted from the start to a context-bespoke approach in establishing community groups. The different logistical requirements and cultural context in setting up CAGs were, in turn, reflected in human and financial resources ring-fenced for community engagement in each country team.

CAG Membership and Community Representation

It is important to start this theme with highlighting that we had, and continue to have, discussions and reflection sessions on what precisely constitutes "the community" that a diverse CAG membership should reflect? In ECLIPSE, we did not identify the community solely as a geographical and place-bound entity. We employed different strategies, including purposeful invitations, snowball methods and ethnographic fieldwork, to ensure a diverse membership in each CAG. One aspect of our strategy was to seek the assistance of "influential" community figures, those with a high social status who hold symbolic power. However, it is clear from our data analysis, that each CAG ($n = 13$ in total), also includes residents who are less affluent members of already marginalized communities and who may have low visibility in the village's social structures. Here is how a Sri Lankan health official phrased it:

> Let us make sure ECLIPSE is including people who are not involved in the village societies and organizations. We should give them a voice too.

Brazil

The constitution of the four CAGs has a certain fluidity and organicity. Most members are longtime acquaintances, neighbors, and friends, as we work in communities where everyone knows each other. Important in the Brazil CAGs is to take into account the subtle ways that gender, race, class, and age power relations play out in CAG interactions. We observed, for instance, that some members of some groups in society (men, white people, adults, those from a higher social class or members with a political position) find it easier to speak during CAG meetings. For instance, a white male political manager with a university education is more at ease to speak in comparison to a black woman who is a cook and domestic worker. We tried to minimize these subtle power dynamics to the best extent possible, by applying a range of ethical principles to our CAG meetings, including respect for diversity, recognition and appreciation of the knowledge that comes from each CAG members' lived experience. We have implemented these principles in various ways and provide some examples here. Firstly, CAG members sit in a circle (*roda*) to ensure that the seating plan does not designate any hierarchies between members. We write more about the *roda* below. Secondly, moderation of CAG meetings is important to avoid reinforcing community power structures. ECLIPSE CEI researchers do not shy away from subtly signaling those CAG members who are dominating the conversation to conclude their point, while gently encouraging more silent members to join in. Thirdly, the use of less formal language is encouraged to allow everybody, irrespective of educational levels, to participate. Finally, we also promote different communication formats, such as music, dance, and the use of images, so those who do not feel confident in speaking during meetings are able to share their experience in alternative ways. The CAGs are different in size, but have an average of 20 members, and in terms of gender balance, two CAGs have a female majority, one is gender-balanced and one group has a male majority. CAG membership includes community health workers (*Agentes Comunitários de Saúde*), members working in education or agriculture, people with CL and community leaders.

Ethiopia

The membership of the six CAGs established in the Tigray region was the result of a dynamic approach. After initial engagement with residents nominated by local health extension workers, a more democratic approach was viewed to be required, and hence during our next visits, the local community was invited for a meeting. Following a thorough discussion about the aims of ECLIPSE and the roles and responsibilities of CAG members, additional residents were nominated. Then, the names of those nominated by the health extension workers and those interested to join the CAGs were put up for a vote. Everybody voted for whom they wanted to represent them on their CAG. Geographic representation was deemed by community members to be a very important factor, especially for those who came from nearby hamlets (*kushet*) who wanted to ensure that a representative was elected from their locality. To address concerns regarding this, the research team decided to increase the size of the CAGs, by selecting 12 instead of 8 community members for each CAG. The final CAG membership includes community members and elders, health extension workers, people with CL and their families, local administrators, religious leaders, and traditional healers.

Sri Lanka

The three CAGs in Sri Lanka have a balanced composition in relation to age, gender, socio-economic position, and education background. Selection of CAG members was based on a combination of a top-down approach, where members were suggested by others (for instance, by the village officer) and a bottom-up approach, where villagers nominated themselves and other villagers. The Sri Lankan team works in the North Central Province's Anuradhapura district, known as "the cradle of Buddhism," and where ∼90% of people are Buddhists. Therefore, it was important to include Buddhist leaders as CAG members.

> It is true that some members nominated by the *Grama Niladhari* are very active in common work in the village, but some are too old and some are too busy. To balance this, young people and a few women should be included (Buddhist monk).

CAG membership includes community members, religious leaders, traditional healers, people with CL and their families, teachers, local administrators, and representatives of key community groups.

Culturally Appropriate and Context-Bespoke Engagement

All ECLIPSE researchers work within the same ethos of community engagement, which steers away from a one-size-fits-all model of CAG activities (for instance "focus groups to discuss with community members"). This theme discusses how the same set of objectives and principles have been adapted to local customs and practices by ECLIPSE researchers around the globe. For instance, all CAG members consented, in an informed way, to take part in the CAGs and for data being collected during CAG meetings. The *ways* consent was obtained and the *format* of that consent was very different across the three countries. It was tailored to the cultural context of each community, ranging from verbal consent in Ethiopia and Brazil, to written consent in Sri Lanka.

Our community engagement activities were severely affected by the COVID-19 pandemic which was declared in March 2020. We worked within radically different pandemic realities in Brazil, Ethiopia, and Sri Lanka. Some activities with Brazilian community members moved online, but such internet-based engagement was not possible in Ethiopia and Sri Lanka where community members did not have access to the internet.

Brazil

The ethos of our engagement in Brazil is informed by Ubuntu principles that have roots in African philosophy and uphold the cultivation of values such as collaboration, respect, tolerance, empathy, and unity. Our plans for the initial CAG meetings in Brazil were disrupted by pandemic restrictions. Following discussion with community members, we decided to move our engagement activities online since most residents had internet access. For a few months, therefore, our engagement with CAG members was online *via* platforms like WhatsApp and Zoom. Socially engaged artists employed various artistic and creative practices to promote feelings of closeness and intimacy in such virtual meetings. These included the co-production of short videos to which both CAG members and the research team contributed by creating a short clip, filming the world just outside their window accompanied by a brief reflection. Another activity involved an artist drawing the portraits of members present, creatively addressing the challenges of doing community engagement online (see **Figure 4**).

In person CAG meetings, which took place when public health restrictions were eased, were organized as a "talking circle" (*roda de conversa*; see **Figure 5**). This set-up is a popular way of organizing discussions because it facilitates an atmosphere of openness. CAG members collectively created a *mandala* during a CAG meeting, with objects brought by members which represented their community (see **Figure 6**). Food and other refreshments were always present during these meetings, providing an opportunity for members to socialize and connect through sharing food.

FIGURE 4 | Artist and illustrator Flávia Bomfim drew faces of community members and researchers to connect with each CAG member.

FIGURE 5 | A *roda de conversa* during a Brazil CAG meeting.

FIGURE 6 | A *mandala* created by Brazil CAG members representing their community.

Sri Lanka

We were unable to engage with community members online during the pandemic, primarily due to poor internet access and low digital literacy in the villages. Sri Lankan CAG meetings take the shape of an open discussion. Following local customs, meetings informally start with refreshments and sharing food. CAG meetings commence with a Buddhist ritual of laying a white cloth on the monk's chair, which symbolize purity and is an expression of respect. Religious observances are then led by a Buddhist monk, who is a CAG member, which formally signals the start of the CAG meeting (see **Figures 7**, **8**). Participatory methods are employed as a way to facilitate team building and collaborative knowledge production. For instance, CAG members collectively drew large maps of their villages highlighting where they seek health care and localities significant in relation to CL.

Ethiopia

It was not possible to conduct any community engagement during the pandemic lockdowns due to lack of internet access in these remote Tigrayan communities. The first CAG meetings in Ethiopia followed a conventional discussion format. We noted in these initial meetings that community members tended to offer the only available chairs to ECLIPSE team members as an expression of respect (**Figure 9**).

As we reflected on this during our debrief meeting, we considered how such conventions may reinforce hierarchies between the research team and community members. This, of course, posed a dilemma around following local customs (i.e., guests are offered the few chairs) to our commitment to dissolving hierarchies where possible. In Ethiopia, our engagement with community members was abruptly interrupted in November 2020 because of the outbreak of a brutal war in

FIGURE 7 | Religious observance at the start of a CAG meeting in Sri Lanka.

FIGURE 8 | A Buddhist monk during a CAG meeting.

the Tigray region. Until the day of completing this manuscript (November 2021), we have been unable to communicate with a majority of the residents in the ECLIPSE communities because of the complete telephone and internet black-out in Tigray and the ongoing blockades and fighting, which has led to a major humanitarian crisis. In August 2021, when the heavy fighting temporarily subsided, some Ethiopian researchers were able to conduct sympathy visits to the ECLIPSE communities to express solidarity with community members.

Priorities of a community can shift rapidly when a major event or disaster happens and when residents are thus worried about basic needs such as food, shelter and physical safety. While residents in the Tigray region were interested to engage with ECLIPSE activities around CL, it is very likely that CL is not a high priority during the humanitarian crisis as a result of the ongoing war in the region. In a similar vein, as we were finalizing this paper, the state of Bahia, Brazil was hit by severe flooding. As phrased by the state governor Rui Costa, community members are "living through the worst disaster that has ever occurred" in Bahia (49). These are only two examples when ECLIPSE reevaluated the signature concerns of each stakeholder group (researchers, community members, healthcare professionals, funders, and policy makers) to adapt their CEI strategy accordingly at different time points throughout the ECLIPSE program.

Relationships Between Researchers and Community Members

This theme revolves around the CAG members' perceptions of ECLIPSE and the evolving relationships between CAG members and researchers. From our earliest encounters with community members, we emphasized the ECLIPSE ethos of collaboration, respect, and shared decision-making. These two ad verbatim quotes, taken from early CAG meetings, illustrate how we communicate this:

> This project is a little different. We usually come from the Medical Faculty and give you a questionnaire to fill. This is not one of them [...]. We will be collaborating with you for a long time and we want to build this group [CAG] in this village. We are not the ones making all the decisions. It is *you* who should come together and tell us: "This is what this village needs." This should be built on your ideas (ECLIPSE researcher, Sri Lanka).

> We are not in a project that is already created. [...] The great thing about the ECLIPSE project is what we as a *Grupo Consultivo Comunitário* [CAG] bring to it. This is an invitation, an invitation for all of us to build the project together (ECLIPSE researcher, Brazil).

The invitation to join an ECLIPSE CAG generated a mix of reactions among community members, both within and across the three ECLIPSE countries, ranging from skepticism on one end of the spectrum to high expectations on the other. Various factors influenced the community members' reactions. The friendly and open approach and introductions by the Brazil team, for instance, led to this positive first impression:

> I was expecting suited-up people [from the research team]. When you hear "Salvador" and "university," you think of someone with a straight posture and a [particular] way of being, a greater formality (*...a postura, o modo de ser, aquela formalidade maior*). But, what I see are people who came here and humanized us. People who reached out to us about a problem that we have, and therefore, we want to be part of finding a solution. This is the behavior that I saw from you (*Dessa necessidade de chegar nas pessoas, com aquele problema que ela tem e, assim, a gente quer fazer parte de encontrar uma solução. E esse comportamento que eu vi de vocês*). And so, for me it is very positive (CAG member, Brazil).

Community members' perceptions of the ECLIPSE research team were heavily influenced by how "universities," "researchers," and "research" are viewed in the community. In the Sri Lanka ECLIPSE hubs, for instance, researchers were enthusiastically received by community members, as the medical school to which they were affiliated, was held in high regard locally.

FIGURE 9 | ECLIPSE team members convening a CAG meeting in Ethiopia.

This symbolic esteem tied to their identity as "researchers" thus strengthened the legitimacy of ECLIPSE. While this is a favorable starting-point, the perception that the "university" can solve the community's problems places high expectations on the ECLIPSE team, which requires our constant reflection and consideration.

In Ethiopia, we initially encountered negative attitudes from community members who had less positive experiences of being involved in past research.

> We had a number of similar engagements in the past, but once the job is done nothing changes. What makes this research project different from the previous ones? (CAG member, Ethiopia).

Such concerns tied to expectations, rooted in perceived failure by other research projects/researchers to enact actual change in their communities, were particularly raised by Ethiopian and Brazilian CAG members. These perceived power imbalances led some residents to question claims around the shared decision-making. The below extract, taken from a CAG meeting in Brazil, portrays one such scenario:

> ***CAG member*****:** The lady [ECLIPSE researcher] says [the project has not been created], but there's a plan, yes. We are arriving, we will follow this plan, we will bring important points. [but] the thing is set up, we move forward and see little points to get us somewhere. So please, do not say that project is not yet created, no.
> ***Co-leader project 2*****:** I will give an anatomical example. The project is, at most, a skeleton. Organs, muscles, they are missing.
> ***CAG member*****:** But it has a skeleton!
> ***Co-leader project 1*****:** It is not a rigid skeleton (...) There is the theme, cutaneous leishmaniasis, there are some elements that are part of it: thinking about care, thinking about participation [...].
> To be a participatory project, the thing that is most defined in it is precisely that it needs to be carried out with the community.

This scenario clearly shows how Brazilian CAG members are active agents who critically interrogate our intentions, and most importantly, feel comfortable to challenge them during meetings. Our evaluation findings show that we should not assume that the "starting point" is a disempowered community that needs to be empowered and that this research will act as a "savior" for the community. We encountered in a number of occasions a real empowered community during CAG meetings. In summary, we are more than ever convinced that a health message to prevent and/or treat a disease should be co-created with community members rather than presented to them as a fait accompli.

DISCUSSION

> Doing community engagement can be messy. There is no recipe book to follow, or model that can be brought to scale. It does not de-facto generate equitable health outcomes or shifts in structure inequalities. However, if it is done with an openness toward new ways of relating across differing positions of power, and new mechanisms of knowledge production with the otherwise hierarchical world global health research, it has the potential to be a positive force for change (50).

During our first period of ECLIPSE community engagement, we have debunked myths (for instance about communities being "disempowered"), critiqued our own practices (changing approaches in bringing together CAG members) and celebrated (sometimes unexpected) successes notably fruitful online engagement during a challenging pandemic context.

Our evaluation revealed a huge gap between the exemplary frameworks available in the literature and the "messy" reality of working in communities. Identifying and acknowledging that gap is a first step to avoid (re)creating a typical hegemonic model of community engagement in global health research. We have translated the ideal(istic) principles espoused by such community engagement guidance, for instance those by UNICEF and WHO, into the practical realities of "doing engagement" in low-resourced communities (51, 52). We have engaged with community members in a way that it was underpinned by idealistic principles, but adapted to local sociocultural contexts, working within certain constraints imposed on researchers. Various constraints, such as the program budget, deliverables, and milestones agreed with funders and program committees, have thus influenced the way and the degree to which these normative principles of engagement could be implemented in practice.

Colonial legacies, both in societies and global health structures, abound in the ECLIPSE countries. We recognize that the impacts of colonization are not easily reversible, but an important step to understand and change this context is to adopt the postcolonial lens (53). This is especially required in global health research underpinned by community engagement, considering the big difference that is likely to exist in terms of social status and power between researchers and community members. At the same time, we need to recognize that the colonizer exists within the colonized (54).

During the first 18 months of the ECLIPSE program, it has become abundantly clear that global health does not respect borders. The COVID-19 virus itself might not discriminate between race, class or country, but the consequences of the pandemic were certainly not the same for researchers and community members within the same country and for different ECLIPSE communities across countries. The social, cultural, and health contexts are not fixed. The brutal war in Ethiopia has brought this very starkly to the surface. The context of war and the major humanitarian crisis in Tigray will reshape the ECLIPSE activities in Ethiopia. When we are able to reconnect with the communities in this region, it is clear that we will need to rethink and redesign, together with community members, our planned engagement activities, research priorities and CL-related interventions.

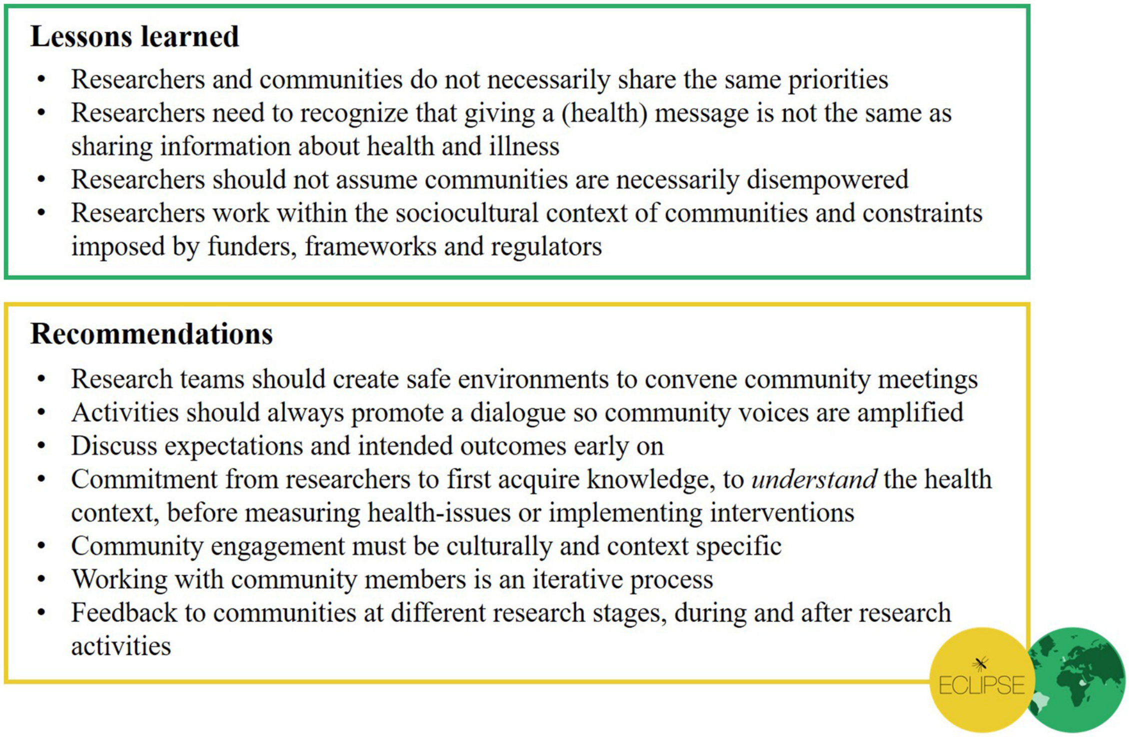
Challenging Often Taken-for-Granted Assumptions

Researcher-initiated community engagement is often seen as a gold standard in global health research (20, 22, 29, 55, 56). This perception presupposes that the exchange and relationships underpinning such engagement is reciprocal, equal, and mutually advantageous for communities and research teams. As we have shown above, we constantly critically evaluate such commonly held assumptions in our approach to community engagement. That means not only analyzing the geopolitics of power relations in global health research, but also activating and implementing the decolonial turn in community engagement in global health research. For ECLIPSE, this means critically reflecting on all too often naïve and easy assumptions that underpin many global health grant applications and global health study protocols. There are too many premises that are often taken for granted. For instance, it is assumed that power structures will not stand in the way of community engagement, researcher-community hierarchies can be dissolved, decision-making around research activities and intervention implementation will be democratic, and expectations from communities will be met. As a first step, we need to recognize the power inequities that are commonly inherent in global health programs. To state the obvious: research is funded and researchers must thus enter into a contract with their funder, an organization that expects to see deliverables and outputs. What we advocate for here, is to prioritize the other important contract, all too often overlooked or ignored, that researchers form with community members to commit to taking their perspectives seriously, maximize their participation in knowledge production, and ultimately derive better solutions for their communities' needs.

A recent, positive turn in the funding landscape of global health research, in an attempt to redress colonial legacy and roots of global research, has been the increased commitment that funding bodies attach to robust community engagement. There is now an expectation to incorporate this as a core element in global health research programs (50, 57). This has been our experience with the UK's National Institute of Health Research which funds the ECLIPSE program (58). The NIHR has indeed selected our program with its motto of "no research about us, without us" on numerous occasions as an exemplar of engaging with community members (59).

Power Imbalances in Community Partnerships

Community engagement is fundamentally about building and sustaining relationships (31, 56, 60). Familiarity, credibility, and trust are indispensable in any research team-community relationship (61, 62). Such qualities do not appear spontaneously, but are the result of consistent, long-term (and often invisible) work on the part of researchers. In contrast to long-standing research programs (e.g., cohort studies, clinical trials) (63–65), which often benefit from a well-established presence and familiarity in the communities, it was the first time that ECLIPSE researchers were working in these specific study sites. This required us to start forging relationships with community residents as early as possible. In our case, we engaged community members *before* the program was awarded funding. We visited communities and discussed plans with local residents at the grant development stage. This was possible through a small grant from the funder. We conducted several months of preliminary work (i.e., before any actual research took place) in the form of regular visits to the study sites, informal exchanges with residents and organizing *ad-hoc* focus groups with a range of community members. Gaining the co-operation of influential bodies and individuals, to act as intermediaries (at least initially) was pivotal to arrange these encounters and attract interest. These early interactions helped to lay out the groundwork for upcoming engagement, by kick-starting a two-way familiarization process:



Lessons learned

- Researchers and communities do not necessarily share the same priorities
- Researchers need to recognize that giving a (health) message is not the same as sharing information about health and illness
- Researchers should not assume communities are necessarily disempowered
- Researchers work within the sociocultural context of communities and constraints imposed by funders, frameworks and regulators

Recommendations

- Research teams should create safe environments to convene community meetings
- Activities should always promote a dialogue so community voices are amplified
- Discuss expectations and intended outcomes early on
- Commitment from researchers to first acquire knowledge, to *understand* the health context, before measuring health-issues or implementing interventions
- Community engagement must be culturally and context specific
- Working with community members is an iterative process
- Feedback to communities at different research stages, during and after research activities

FIGURE 10 | Summary of our lessons learned and recommendations for conducting community engagement in global health research.

the ECLIPSE team getting to know the context, the needs, assets and way of life of local communities, and community members getting to know the ECLIPSE researchers, the ECLIPSE vision and activities.

Nurturing trust and legitimacy among local communities in a program of this size (ECLIPSE employs 60+ individuals) requires particular considerations. In addition to the individual relationships forged between ECLIPSE researchers and community members, we worked toward ensuring that the community members endorsed the program as being meaningful for them. The establishment of the CAGs was our first step in building connections with the wider community, with the members of these groups acting as ECLIPSE ambassadors. We welcomed resistance and disagreements in CAG meetings because, when these are discussed respectfully and productively, they represent another facet of dissolving hierarchies.

Indeed, our aim in this first phase of the ECLIPSE program was to ensure that community members are aware of our commitment to take their perspectives seriously and to include them as equal partners in the knowledge production of CL. After all, we arrived as "uninvited guests" in their communities—they did not invite us. The degree to which trust was readily granted by community members was strongly influenced by contextual factors, and thus varied across the ECLIPSE countries. Mistrust in research is often deeply ingrained and sometimes a legacy of past experiences in working with researchers (66). In our case, particularly in the Brazil and Ethiopia ECLIPSE hubs, initial mistrust shown toward the project and our team members, was symptomatic of wider mistrust in institutional and governmental structures (61) which has been, in part, also reiterated by researchers—"uninvited guests"—who did not engage or engaged in problematic ways with the community, leaving behind a legacy of broken promises and unmet expectations, and thus strengthening the mistrust.

CONCLUSION

Our experiences of practicing and discussing community engagement in global health research have led to important insights related to both theory and practice (see **Figure 10**). Our three main considerations after our first phase of community engagement in the ECLIPSE program are as follows. Firstly, we continue to collaborate with community members in a meaningful way, avoiding shallow tokenistic manners of engaging communities. Our overarching principle, "no research about us, without us," is a motto decided by the community members. In implementing this principle, we aim to co-create, with the ECLIPSE communities, a safe(r), decolonial space through deconstructing dominant, western and eurocentric ways of community engagement. In doing so, we recognize that it is paramount to include the breadth of experiential knowledge of community members. Secondly, we steer away from top-down modes of engagement. If we want the ECLIPSE CAGs to be sustainable and to continue after the lifespan of the funding, it is paramount for community members to have agency and exercise control over the direction of ECLIPSE interventions and implementation. Thirdly, it is also important, during community engagement activities, to acknowledge that the ECLIPSE program will not solve all challenges and problems community members have faced for years. One theme that emerged from the data is that both researchers and community members expressed hope for change, through the planned co-production strategies.

In conclusion, drawing on our experiences to date in the ECLIPSE program, we are convinced that community engagement in global health research can be implemented in an inclusive, collaborative and equitable way, while still acknowledging the difficulties and challenges that we, and colleagues in global health research, will always face in doing so.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article. Further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

We received approval from the Ethics Review Committees at the four ECLIPSE institutions: from the Institute of Collective Health, Federal University of Bahia, Brazil [Ref.: 4.238.866], from the College of Health Sciences, Mekelle University, Ethiopia [Ref.: ERC/1793/2020], from the Faculty of Medicine and Allied Sciences, Rajarata University of Sri Lanka [Ref.: ERC/2020/74], and from the Faculty of Medicine and Health Sciences, Keele University, United Kingdom [Ref.: MH-200117]. The participants provided their informed consent to participate in this study. Informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

KP and LD led on writing this paper: they held regular data analysis meetings, convened meetings with co-authors to discuss findings and co-wrote the manuscript. The ECLIPSE program is co-led by LD and HP. All co-authors have read the draft manuscript, provided detailed comments and suggestions, and approved the final manuscript.

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Evaluating and Engaging: Using Participatory Video With Kenyan Secondary School Students to Explore Engagement With Health Research

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Background: The growing ethical requirement to engage communities with health research has yielded diversification in approaches and targeted audiences. Conventional approaches like community "town-hall meetings," laboratory open-days and focus group discussions, have evolved into new methods and audiences such as community drama and school engagement with health research (SEHR) involving learning interactions between researchers and school students. While engagement practices are diversifying, evaluations of these initiatives are rare in Low- and Middle-Income Countries (LMIC). This article focuses on the use of Participatory Video (PV) to explore the influence of the KEMRI-Wellcome Trust Research Programme's (KWTRP) School Engagement Programme (SEP) on the views and understandings of science and research among Kenyan state secondary school students.

Methods: Twelve male and twelve female students from four coeducational schools were provided with film-making kits (1 per school), and a one-day PV training workshop. They prepared 22 short films over 8 weeks depicting their experiences and views of research and engagement and conveying their career aspirations. Schools were selected based on prior SEP participation; two schools having experienced different engagement approaches, and the others with no prior school engagement. Study data comprised footage and participant observation notes.

Results: PV provided an opportunity to simultaneously engage and evaluate to inform practice. Through student-led filmmaking, PV stimulated conversations with students about research and engagement, enabling them to share their views in a way they felt was appropriate. These interactions offered an understanding of student gains from engagement, the depth of interaction required to address perceptions held about research and the potential unintended consequences of engagement. PV also provided insights into the context and complexity of life in which engagement is situated. Understanding this context is important because of its potential influence on participation in engagement activities. We draw on these insights to make two recommendations for school engagement practice. First is that PV can provide an enjoyable and insightful means of combining engagement with evaluation. Second, given that time for SEHR is competed for against other important curricular and extracurricular activities, SEHR practitioners must ensure that activities are as beneficial and enjoyable as possible to students.

Keywords: schools, public, engagement, participatory, video, co-production

INTRODUCTION

As Public and Community Engagement to support health research is increasingly focusing on the need to inform research practice in low- and middle-income countries (LMICs), the range of approaches and goals have diversified (1–4). School engagement with health research (SEHR) is a growing field of engagement in LMICs which is not yet widely described in the literature (5, 6). At an international SEHR meeting held in Kilifi, Kenya in 2018, practitioners described four main categories of goals for facilitating SEHR (7). These were (a) raising awareness and stimulating dialogue about health research, (b) enhancing science education and nurturing student's interest in science generally, (c) strengthening capacity and nurturing the uptake of research careers by students and (d) promoting positive health behaviors. Given this broad range of goals, it is unsurprising that SEHR approaches are correspondingly diverse in terms of the types of activities they involve and the magnitude of their outreach. "Wide" engagement approaches, for example, day lab tours, online engagement with scientists and science magazine outreach/competitions (7) are likely to reach large audiences. Conversely, "deeper" approaches, including participatory approaches and Young Persons Advisory Groups (YPAGs) (7–11), are more likely to nurture longer-term relationships to facilitate co-learning and incorporating student views into research. Outreach in the latter however, is likely to be considerably smaller (12, 13).

Alongside the diversification in engagement approaches, there have been corresponding calls for appropriate evidence of engagement success (4, 14, 15). However, evaluating engagement is complex and challenging. First, because of the diversity in the ways in which the terms "community," "public" and "engagement" are defined and interpreted (16–19). Second, engagement goals are numerous and sometimes in conflict with each other. For example, raising community awareness of the risks associated with research participation may be at odds with a goal of supporting recruitment (1). Third, challenges emerge in defining indicators to explore the extent to which engagement addresses intrinsic goals, such as trust, respect, and relationship building (20–22). Recruitment rates are argued to be inadequate indicators of the success of community engagement without a thorough understanding of participant's degree of voluntariness and understanding of the proposed research (1, 23). Lastly, the embeddedness of community engagement within health research institutes, with their dominant culture of experimental approaches (24, 25), is likely to influence the consideration of randomized control trials (RTC) for evaluation of engagement. However, while ethicists and funders increasingly describe engagement as critical for health research (2, 26), restricting engagement to only a proportion of a community to allow for a control arm might arguably be ethically challenging. Further, the complex non-linear nature of the engagement processes, and their need to be responsive and adaptable to constantly evolving and diverse contexts, makes the RCT approach practically challenging (27). As engagement approaches and goals continue to diversify, a corresponding broadening in approaches is needed to evaluate their impacts and influences.

Experimental and quasi-experimental approaches have been used to explore the impact of engagement between researchers and school children, ranging from post-intervention comparisons of participant to non-participant responses and attitude/knowledge questions or Likert items (28–31), to pre-post designs and cluster randomized control trials (6, 32). Qualitative methods such as in-depth interviews (IDI) and focus group discussions (FGD), are commonly used in the evaluation of SEHR activities, mainly to explain quantitative findings, but also to gain deeper insights into the influence of engagement and to describe the process (33–39). A few studies have drawn on more novel approaches to explore the effects of various SEHR approaches. For example, comparisons of the questions students have asked researchers before and after interaction (40) or exploring the impact of interactions on the way in which students depict scientists in their drawings (41). While documented evaluations of SEHR in high income countries, for example, USA, UK and Australia are common (33–39), documented research on the impact and influence of engagement between health research and schools in sub-Saharan Africa is very rare (6). The studies described (28–41) focus mainly on the impact and influence of the activities on student attitudes and views, providing only sparse descriptions of the context in which SEHR takes place and how this might influence outcomes for participating students.

Further, it could be argued that the rigidity of surveys, and challenges with facilitating meaningful participation of children in qualitative methods such as FGDs led by researchers (42), may only offer limited opportunities for students to engage with researchers and contribute to steering the conversation.

The use of participatory methods to evaluate SEHR approaches has not been described in the literature. However, participatory methods have long been used in the field of development (43) and a participatory visual method which is currently gaining popularity and use in community engagement for both "development" and "research" is PV (44). PV is a method which has been used to open up spaces for discussion and enable participants to create their own films to voice their concerns and take action in determining their own development (45). It has been used in health promotion (46–50), to evaluate community development projects and programmes (51–53) and other areas such as engaging participants with climate change (54) and neighborhood planning (55). Lemaire and Lunch (51) argue that "outsider"-based evaluations conducted by external evaluators have the potential to be extractive and disempowering. They postulate that PV can mitigate the risks of external evaluation and better reflect the priorities of project beneficiaries by allowing project participants, described as "insiders," to participate in evaluations. While "practical participatory evaluation," directly involving community members and project staff, may enable appraisal of project outcomes (56), using PV is argued to augment evaluation through incorporating a transformative dimension (51). The use of PV in the co-production of knowledge related to participant's experience of a project has the capacity to facilitate communication between several groups through the video outputs whilst enabling the evaluation of project influence (51). "Knowledge co-production" has been recently defined as an "Iterative and collaborative processes involving diverse types of expertise, knowledge and actors to produce context-specific knowledge and pathways toward a sustainable future" (57). Within the context of SEHR, PV can offer an opportunity for students to collaborate with researchers on the co-production of knowledge relating to their experience of engagement and research and its impact on their lives. A co-production process can strengthen relationships between researchers and participants and generate reciprocal and mutual benefits (58). Participatory arts-based approaches such as PV may be particularly suited for evaluating SEHR because they can enable participants to interrogate and question research practices, generating counter-narratives and co-produced knowledge in a way that can transform engagement practice (59).

Participatory visual methods are increasingly being used in research with children and young people (60, 61) in a range of contexts including advocating for climate change adaptation (54), exploring issues facing disadvantaged youth (62, 63), and engaging school children with STEM (Science Technology Engineering and Mathematics) to facilitate deeper learning of scientific concepts (64). PV has been described as a method which respects children as being knowledgeable (62). When carefully facilitated, PV has the capacity to challenge power hierarchies between researchers and study participants (65). This is arguably of particular importance for research involving children because, in addition to social, cultural, ethnic, educational and wealth differences between researchers and participants, age differences could heighten the potential power dichotomy, inhibiting open discussion. In view of this, Thomas and O'Kane (66) present the case that participatory research is particularly suited for research with children because it can address power differentials both through transferring more control of the research to children and making use of enjoyable procedures which align themselves to the way in which children see the world. However, Gallacher and Gallagher (60), though supportive of participatory methods, question their capacity to be universally democratic, emancipatory, and empowering for children. They caution that a pedagogic embodiment of adult researchers "empowering powerless children," could result in children conforming to adult agendas and being disempowered in the process. Existing power dynamics within the participant group need also to be carefully and sensitively managed to ensure that the participatory processes don't reinforce them (62). Like other methodological approaches such as surveys, PV is not without challenges, and like other qualitative approaches, it requires constant reflexivity and awareness of the potential influence of power imbalances on the insights and experiences shared (54, 60, 67).

Given the value of PV outlined above, and acknowledging the power dynamics raised, this paper describes the process and outputs of a PV approach to evaluate a SEP in coastal rural Kenya with the aim of understanding the potential for the use of PV in SEHR. It provides a description and exploration of PV as a method for evaluating SEHR, offering insights into how its use provided understanding of the contextualization of SEHR activities within the lives of students.

METHODS

Study Site

This study was conducted in Kilifi County, on the Kenyan coast, the location of the KEMRI-Wellcome Trust Research Programme (KWTRP). The KWTRP, established in 1989, employs over 800 people and conducts epidemiological, social, laboratory and clinical research aimed at improving health in the region. The KWTRP has a public and community engagement strategy, first established in 2005, which provides a broad range of fora where researchers and the public can engage and learn from each other. One component of the strategy is the SEP which facilitates engagement between researchers from the KWTRP and more than 4,000 students from over 50 Kenyan public primary and secondary schools every year. The SEP was initiated in 2008 to draw from KWTRP's human and lab resources toward contributing to local school science education in a context where public secondary schools are characterized by large class sizes, poorly resourced laboratories (68, 69), and according to local teachers, limited opportunities to learn about science. SEP activities have several aims. These comprise stimulating an interest in science and research related careers, raising awareness of locally conducted health research and promoting positive attitudes toward health research (5).

In 2014, a study funded by Wellcome was established to evaluate the outcomes of various forms of SEHR as implemented by the SEP (6). Forty secondary schools in Kilifi were involved in the KWTRP SEP at the time, and the programme and its development are described in more detail elsewhere (5). To summarize, in collaboration with school principals and the county director of education, 10 schools were invited on an annual rotational basis to participate in "face-to-face" (FTF) SEHR activities. These included student lab tours, interactive discussions with research staff about their work, online interactive discussions about science with researchers through a platform called "I'm a Scientist, Get me out of here!" (IAS) (70), researcher visits to schools to give career talks and inter-school science. The remaining 30 secondary schools

TABLE 1 | Mixed methods evaluation design.

	Arm 1: Face-to-face engagement (5 schools)	**Arm 2: Less intensive engagement (5 schools)**	**Arm 3: Pre-engagement (5 schools)**
Feb–Mar 2014	• Pre-engagement student survey (*n* = 491) across 15 schools		
May–Nov 2014	*Face-to-face activities: Lab tours; researcher visits to school; participation in inter-school science quiz; and "I'm a Scientist"–online platform*	*Less intensive activities: participation in inter-school science quiz; and "I'm a Scientist"–online platform*	*No engagement activities until 2016*
	• Teacher IDIs and Student FGDs	• Teacher IDIs and Student FGDs	
Nov 2014–Feb 2015	• FGDs and IDIs with students, teachers, community leaders, education stakeholders, participating KWTRP staff • Post engagement student survey (*n* = 491) across 15 schools		
Feb–July 2015	• PV with 1 school	• PV with 1 school	• PV with 2 schools

were invited to participate in "less intensive" (LI) engagement activities comprising online engagement and inter-school science competitions only.

Between 2014 and 2016, the SEP activities described above were evaluated using a mixed methods approach summarized in **Table 1**. The purpose of the evaluation was to understand the impact and influence of engagement on: (i) students' interest in science and career aspirations; (ii) awareness of locally conducted health research; and (iii) attitudes toward health research (6). The evaluation was conducted among five FTF schools, five LI schools, and five control schools (C). The five control schools had not previously participated in SEHR, but were scheduled to be incorporated into the SEP after the evaluation was complete. Schools were purposively assigned to arms A, B and C to maximize the similarity between the 3 arms in terms of size of school (numbers of students), boarding/day, IT resources, and performance in external examinations. The mixed methods design, summarized in **Table 1**, is discussed elsewhere (6), and comprised three components. The first was a pre- and post-engagement student survey, and the second was a qualitative component involving interviews and focus group discussions with students, teachers, researchers, parents and community leaders. The third component, and main focus of this article, was a PV component with 24 students (outlined in **Figure 1**: The PV process).

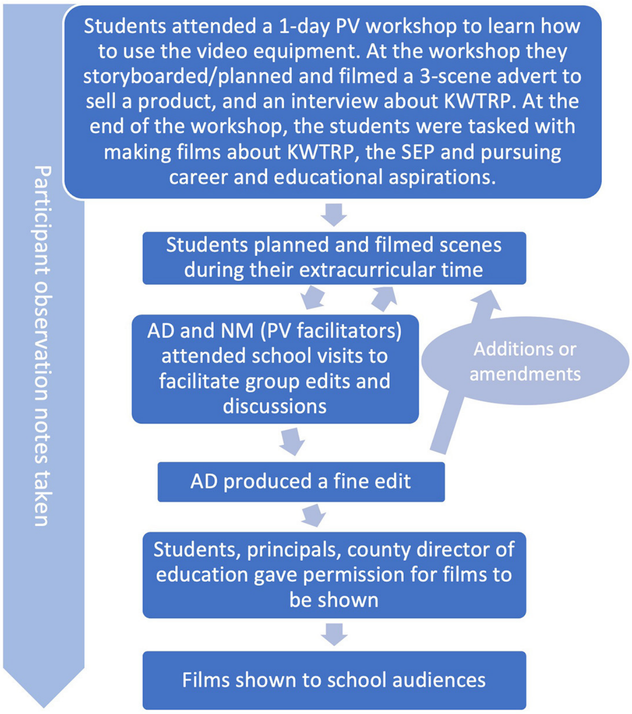


FIGURE 1 | The PV process.

Objectives of the PV Component

Drawing from an ethnographic perspective, we felt that combining PV with participant observation could enable us to draw inferences on SEHR based on observations and discussions of students working on a project over an extended period of time (71). The primary purpose of adding a participatory visual method to the overall mixed methods design was to explore the influence of different forms of the SEP (FTF and LI) on students' understanding of and attitudes toward the KWTRP and health research, and on their career aspirations. Specifically, we used PV to explore the following research questions:

a) What were the students' experience of SEP and how did it influence their views about science and their career aspirations?
b) What is the SEP's influence on student's understanding of and attitudes toward KWTRP and health research?
c) How could a PV process nurture further engagement with KWTRP and SEP?

Procedures

As shown in **Table 1**, the PV component was the last in the sequence of evaluation data collection activities, affording the ability for the purposive sampling of four schools to represent the range of experiences and participation in the SEP activities, and the SEP evaluation. FTF school 1 (FTF1) and LI school 1 (LI1) were selected based on their full participation in FTF and LI activities, respectively, and hence their capacity to share views on all aspects of the SEP. Two control (C1 and C5) schools were selected to explore whether student understanding, attitudes and aspirations differed to those of students who had previously engaged with health research. We purposively selected C1 and C5, schools with high and low survey participation rates, respectively, to yield a range of views in terms of prevailing attitudes toward KWTRP in the schools.

Groups of six students, three male and three female, from each of the four schools were invited to take part in the PV project spanning the second school term between the 4 May and 31st July 2015. A group size of six was selected to enable two students to operate the camera and microphone whilst allowing the remaining 4 to participate in interviews or small plays. In each of the four schools, form 2–3 students, aged between 16 and 18 were selected purposively, through consultation with the principal, to represent a range of participation in SEP activities (for FTF and LI), a gender balance and students who the principal felt would be able to share their views confidently.

The PV process, comprising an initial workshop and several follow-up sessions in described in **Figure 1**. Two initial one-day PV training workshops were held at the KWTRP; one for schools FTF1 and LI1 and the second for schools C1 and C2. The objectives of the workshops were to (a) create a rapport between AD, NM and the students, (b) familiarize the students with the equipment and techniques, (c) get the students started in making storyboards (a sequence plan of film scenes) and short films, and (d) to have fun (45). At the workshop students learned how to assemble and use the kit, how to storyboard and film an interview, and about group-editing. To facilitate this learning the students were tasked with storyboarding and shooting three-scene television adverts to sell a product of their choice. During "group editing," AD, NM and the students reviewed the footage on the laptop editing suite, and the students decided which scenes to be included, omitted and trimmed, and the order of scenes. At the end of the workshops, each group of students were provided with a camcorder to take back to their schools, which the schools eventually retained. The groups were tasked with planning and making several 5-min films in their extracurricular club-time. Given that the primary purpose of the PV was for evaluating the SEP, the students were asked to make films about their experiences of KWTRP or SEP and about pursuing career and educational aspirations (and what might influence this). Beyond this, no restrictions were placed on the content, number, or the type of films made. AD and NM are fluent in Kiswahili and English and students were given a free choice of which language to use for their videos. Students were guided on taking care to only film people if they gave consent for being filmed.

Four follow-up sessions were undertaken at each school fortnightly, involving NM and AD and the six students during "extracurricular club-time." The first three follow-up sessions comprised reviewing, discussing and group-editing of filmed footage. Discussions often led to film modification, which involved an iterative process of re-filming and subsequent group edits. This led to "co-production" of films and knowledge. Each of these sessions lasted between 40 and 90 min depending on the time available during the after-lesson period. In the fourth follow-up session, the films were shown to the school principal and then to school audiences. Observation notes were taken throughout the sessions.

During group editing sessions, student suggestions were noted and later addressed during the "fine edit." Because fine editing is costly in terms of time (46, 72), this was done by AD at KWTRP. This entailed adding scene transitions, titles, sub-titles, name tags, sound effects and soundtracks, based on the students' suggestions. The core content of the films was not altered in the fine editing process. Draft film projects were exported to MP4 media files to show students. The students were free to make alterations, either through re-shooting or making suggestions for further edits, until they were happy to give overall approval for the final film draft.

Within their groups, students decided which audiences to share the videos with. Schools FTF1, LI1 and C1 opted to show the films to their entire form 2 year groups and a separate showing for their teachers, while C2 wanted to show the films to the entire school. All films were reviewed and approved for showing by school principals and the county education officer.

PV Data Collection

The PV process generated two sources of data:

- Participant observation notes from AD and NM collected over all sessions. These were hand-written notes, providing detailed observations of story-boarding, group-dynamics, discussions, decision-making and direct quotes; and
- The edited media produced during the workshops and follow-up sessions.

Following interactions with students, NM and AD had de-brief discussions to reflect on student experiences and session discussions and add to observation notes. Observation notes were also taken during and after the video showing sessions with individuals and audiences. All notes were typed, and PV media were transcribed and translated from Kiswahili to English. All transcripts and notes were entered for coding into NVivo 11.

Data Analysis

A thematic framework approach was used to analyze the data (73, 74). This involved familiarization with the data through repeated reading and re-reading of the observation notes and film transcripts, generating codes, and sorting them into overarching themes. The codes were then placed in matrix charts, which enabled a comparison of student insights, views and experiences across the FTF, LI and C groups. The framework approach allowed flexibility in exploring hypothesized, as well as unintended or unplanned, influences and outcomes of SEP. A combination of inductive and deductive approaches were used in the analysis, generating four overarching themes. The first three themes were predetermined at the outset and focus on the evaluative data generated by PV about the SEP activities. They respond directly to the research questions specified in the section describing the Objectives of the PV Component. In the fourth emerging theme, we explore how PV provided valuable insights into the context in which SEHR is situated. Understanding this context is important because of its influence on participation in, and commitment to, the engagement process.

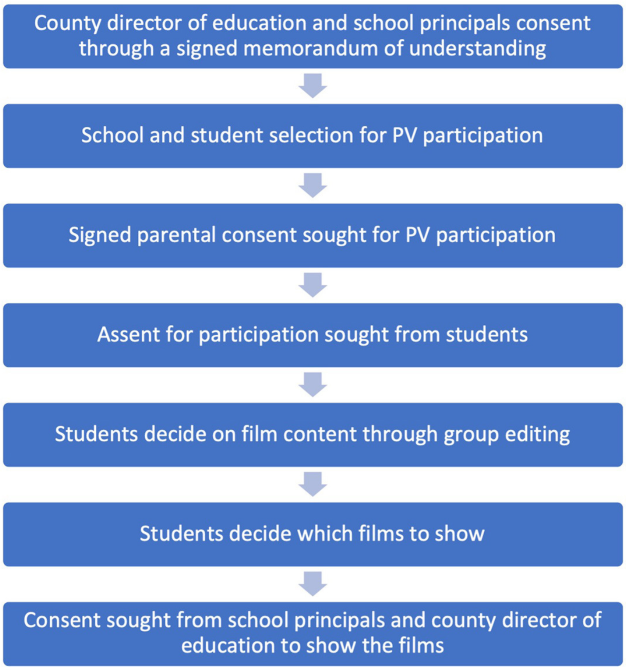


FIGURE 2 | Multi-staged consent/assent process.

Addressing Potential Ethical Concerns

Ethical challenges in this study have been described elsewhere (44). Of specific concern was a potential risk that sharing personal information could lead to participating students being stigmatized. Two strategies were used to address this. Firstly, a multi-staged consent procedure (44, 75) was used in an attempt to ensure that students, parents and teachers and the county education officer were able to consent or withdraw throughout the filming process and the media sharing. This multi-staged consent/assent process is summarized in **Figure 2**. Secondly, the group-editing process enabled students to directly control the content of the films. Once the films were prepared, permission to show the films to different audiences was sought firstly from the participating students, secondly from the school principal, and lastly from the Kilifi Education Office. Students and principals provided signed approval of the films selected for showing to wider audiences. Participant's wishes to not show, or re-edit films were respected and acted upon.

Ethics approval was granted by the Kenya Medical Research Institute Scientific Ethics Review Unit: SSC 2672 - "Evaluation of the scaling up of the KEMRI-CGMR-C's School Engagement Programme in Kilifi."

RESULTS

Video Outputs

Over the 8-week period of the PV process, the students made a total of 22 videos. The videos, their presentation style, who participated in making them and key summary observations are shown in **Table 2**. The films were shown to audiences of students and teachers in the school, and this universally nurtured a great deal of excitement. In this article however, we focus on data generated through the media production and the observation of the student participants.

What Was the Student's Experience of SEP and How Did It Influence Their Views About Science and Career Aspirations?

With varying degrees of engagement, students across all groups were aware of the SEP and articulated their understanding of its roles in their films. Despite having no exposure to SEP activities, students in control schools were also aware of the programme.

> *KEMRI is making these sciences to be upheld positively by the students who really are learning in various secondary schools in Kenya. (Male, School C2 vid 5).*

FTF1 students, who had received the face-to-face engagement package, both in their films and group discussions, articulated a greater depth of understanding the SEPs goals:

> *KWTRP is engaged in [the] school programme by introducing the young generation, the upcoming youth to know what KWTRP is and what it does to the community. It also engages in school activities like providing symposiums, science fairs, and also for the students who have finished their form 4 course, they are being trained on how to come up with best careers in life [through an] attachment for a period of not less than 3 months. (Male, School FTF1 vid 2).*

Of the 11 films made by students from the two intervention schools (FTF1 and LI1), six films referenced experiences of the SEP, described some of the intervention activities and shared their feelings about them (**Table 2**).

> *"Yea, it was interesting because as for me, it was my first time to talk to scientists, so I found it quite good." (Male, School LI1 vid2).*

Students from these schools, through their discussions and in their interviews, described SEP activities as being *"fun," "enjoyable,"* and *"motivating."* In a poem created as part of the PV exercise, students from school FTF1 described specific SEP interactions with researchers influencing their awareness of science related careers, motivation in science subjects and awareness of research:

> *"When I see and interact with scientists, I feel motivated." (Male, School FTF1 poem vid 3).*
> *"As I have interacted with KWTRP in many activities, I have felt motivated, and I have improved in my science subjects." (Female, School FTF1 vid 3).*

LI1 students, in their films and review discussions, placed more emphasis on the novelty of meeting with scientists, and the benefits of learning about communication through the internet. In comparison, the FTFI students focused more on the influence of the SEP on their attitudes to science.

TABLE 2 | Summary of the films produced by students.

Task		Style and participants	Key summary observations
Learning exercise: Make an advert to sell a product	FTF1 vid1	Commercial TV advert aimed at selling a notepad	Students followed the instructions and created a simple TV style advert.
	LI1 vid1	Short 30 second advert promoting the value of education	Students perceived a need to promote education in the community.
	C1 vid1	Short 30 second advert promoting HIV services and voluntary HIV counseling and testing	Students perceived a need to promote education about HIV.
	C2 vid1	Short 30 second promotion of the student's school and it's attributes	Students perceived a need to promote education in the community.
	C2 vid2	Musical 'rap' within the group depicting the value of their school	Students expressing pride in their school.
Task 1: Make films about your experiences of KWTRP	FTF1 vid2	Interviews within the group about KWTRP and SEP	Describes negative impact of Malaria and the benefits of research. Provides evidence that students have learned about KWTRP through SEP.
	FTF1 vid3	Role play-KWTRP researcher giving a career talk followed by a group poem	Evidence of SEP impact on students: role-play references culturing microbes and other SEP activities referenced. Scientists depicted as inspiring and motivating for students
	LI1 vid2	Interviews within the group about KWTRP	Range of community descriptions of KWTRP depicted: "benefit to society;" 'the community do not know;" and "others think badly" of KWTRP. Descriptions of KWTRP as: health providers (lifesavers); educating children; hospital builders; and an AID organization treating people for free.
	LI1 vid3	Interviews about KWTRP	KWTRP perceived as a health provider. SEP activities enjoyed by students but had an unintended consequence of jealousy among non-participants.
	LI1 vid4	Play depicting KWTRP going around the community giving opportunities for people to be trained as health researchers. One decliner suffers the consequence of future joblessness	KWTRP depicted as benevolent-building hospitals; training youth and paying medical bills. Issues raised: limited understanding of qualifications required for KWTRP employment; lack of school fees; joblessness; power relations; peer pressure and lack of belief in education dissuading students from education.
	C1 vid2	Interviews within the group about their understanding of KWTRP	Students were uncomfortable in answering questions about KWTRP and displayed a range of understanding/value of KWTRP: 'they come up with medicines to help cure sick in society and reduce mortality'; 'they provide jobs for locals; limited understanding of requirements for KWTRP employment.
	C1 vid4	Documentary comprising interviews with students, teachers and KWTRP staff aimed at addressing student questions about research and KWTRP	With the exception of one participant ('conducting research on medicines to save lives'), there was limited understanding of the role of KWTRP's census and blood drawing. Range of opinions about KWTRP: good organization; using people like guinea pigs for research; and devil-worshippers.
	C2 vid3	Interviews exploring community views about KWTRP and research	Range of community interpretations and attitudes expressed: KWTRP addressing disease and epidemics; KWTRP as a health provider; creating jobs; believed to be 'devil-worshippers' (related to blood-sampling for research).
	C2 vid5	Interviews with students (outside the group) teachers and the school cook, exploring community views about KWTRP and research	Range of interpretations, attitudes and beliefs: KWTRP described primarily a health provider and so have benefitted people; some described KWTRP as people doing research to reduce mortality; blood samples taken for unknown use–possibly devil-worship; students can benefit educationally from KWTRP.
Task 2: Make films about your educational and career aspirations (and what might influence this)	FTF1 vid4	Play about sexual coercion, peer pressure, pregnancy and school drop-out	A delinquent boy approaches a girl and asks her to arrange a sexual liaison with her friend for money. The girl makes the arrangement (pocketing half of the money) and her friend becomes pregnant and drops out of school.
	FTF1 vid5	Interviews followed by a role play about career aspirations	Students depict receiving careers inspiration from: family members, KWTRP SEP; the need to address HIV; and a perceived lack of doctors. Researchers described as positive contributors to community health. Students demonstrate a good understanding of KWTRP. Financial barriers to pursuit of education acting against aspirations.

(Continued)

TABLE 2 | Continued

Task		Style and participants	Key summary observations
	LI1 vid5	Play within the group with one additional member from outside the group, about poverty education and early marriage	In a poor family, the jobless father decides, against the mother and daughter's will, that the solution to the family's financial problems is to take the daughter out of school and marry her off for dowry. A teacher persuades the father to keep the daughter in school. Societal pressure for early marriage of girls.
	FTF1LI1 (together) vid1	Play students from FTF1 and LI1	Girls receiving unwanted sexual advances from boys on the way to school.
	C1 vid5	Students' information film about their school	Students expressing pride in their school, and highlight: the long distance of the school from nearest town; and resource challenges faced by rural schools.
	C2 vid6	Play within the group expressing students' dissatisfaction with corrupt employment practices	The play highlights barriers to employment: bribery for scarce jobs; the power of employers and wealthy people who can afford to bribe.
	C2 vid7	Role play	Lawyer describes her struggles to achieve career progression through challenging circumstances: single parenting; lack of tuition fees; and long distances to school (specific vulnerabilities for girls implied).
	C2 vid8	Play about the impact of drugs on education	Students tempted by an outsider to take drugs on the way to school, supported by peer pressure. They return to class intoxicated and cause a riot. They are persuaded by the school head that drugs are harmful.

> *P1: that activity was so [much] fun. To most of us [we] didn't know how to use a laptop, we were taught how to use them, to chat with people from different places in Kenya... We are so grateful to KWTRP and we wish them all the best and to continue with more activities to encourage students on those scientific subjects to develop more careers. (Male, School LI1 vid 3).*

These findings might be explained by the opportunities afforded by the LI activities for extended use of the internet and interactions with scientists, and the additional activities experienced by the FTF1 students.

Novel engagement approaches like IAS (and similarly the PV), appealed to FTF1 and LI1 students and offered opportunities for communication and interaction with a range of people using media which was new to them. It is important to note that the majority of comments made by students about SEP were very positive with very few criticisms. This suggests that SEP provided opportunities for students, the first opportunity for some, to interact with researchers in a way that the students reported as being enjoyable and beneficial.

Students from all four schools described a variety of desired careers in their films. FTF1, LI1 and C2 expressed a desire for medicine-related careers. In contrast to schools LI1, C1 and C2, students from school FTF1 described a desire for a repertoire of careers similar to those specifically encountered through the SEP activities, in some cases, referring directly to specific research staff they encountered:

> *"My visit to KWTRP laboratories to see microorganisms being cultured has inspired me to become a microbiologist." (Female, School FTF1 vid3.).*
> *"I remember the nurse who talked about human resource management." (Female, School FTF1 vid5).*

Other examples of inspiration described by School FTF1 students, and likely to be related to SEP encounters, were a desire to attend campus, achieve a PhD, become a nurse, study anatomy and be a *"researcher the community can be proud of"* (Male, School FTF1 vid3). The wider range of desired careers related to those encountered at KWTRP and described by FTF1 students, provide some evidence that engagement broadened students' ideas of what they might aspire to or, in other words, their "*repertoires of possible future selves*" (76). Comparison of pre and post engagement student surveys, described elsewhere (6), also yielded evidence that FTF engagement, to a greater extent than LI, promoted positive attitudes toward science, scientists and research-related careers.

What Is the SEP's Influence on Students' Understanding of and Attitudes Toward KWTRP and Health Research?

To explore student understanding of KWTRP across all groups, and the influence of SEP on FTF1 and LI1 students, they were tasked with preparing for and filming group interviews responding to their own questions about KWTRP. Across all groups questions were similar, for example, "Describe the work of KWTRP?" and "What is health research?" Acknowledging that students across Kilifi County learn about KWTRP from a range of sources, NM and AD observed differences across the groups in terms of student confidence in articulating the work of KWTRP. Predictably, students with more exposure to researchers through SEP, specifically FTF1 students, were generally able to describe the work of KWTRP more accurately and with more confidence than the other groups.

> *P1: KEMRI is Kenya Medical Research Institute. KEMRI do research of different diseases such as malaria and pneumonia. They*

> *have come up with means and ways of preventing and curing them for the benefit of Kilifi residents. (Male, School FTF1 vid2).*

Compared to FTF1 students, the C2 group side-lined questions requiring their own understanding of the KWTRP, opting instead to describe community views about KWTRP. In contrast, C1 students more openly expressed their difficulty in responding to the knowledge questions about KWTRP which they themselves had set. This resulted in an observable temporary lapse of confidence and frustration among group members. In a follow-up discussion, the students acknowledged that they found the activity challenging with one student summarizing that *"It's because we don't know about KWTRP" (C1observation notes).*

Student films included a variety of interpretations of the roles of KWTRP. However, the ambiguity demonstrated in the LI1 and C films was less apparent in the draft films made by the FTF1 students. The interpretations of the role of the KWTRP in the LI1 and C school films included descriptions of KWTRP as a healthcare provider (LI1, C1 and C2), in facilitating blood donation/transfusion services (School C1), in conducting individual diagnostic tests, and as educating community members and school students (LI1 C1). The quote below highlights a common therapeutic misconception of research, and how a diagnostic test done as routine care at a hospital where research is also conducted, is interpreted as a medical research procedure.

> *"My baby breathed so fast that I became worried that she might die! But they have done a good research on her and now they are giving her drugs and she is better." (Female, School C2 vid3).*

Given KWTRP's history of equipping and furnishing rural clinics in preparation for clinical trials, treating research participants, engaging with school students, and drawing blood samples for research, it is not surprising that the main roles of KWTRP may have been misinterpreted by students.

A diverse range of attitudes about the KWTRP were expressed across the groups. Positive attitudes relating to benefits community members felt they received from KWTRP were frequently depicted and expressed in the videos from all participating groups. These benefits included a perceived contribution to individual and community health through direct health care provision, provision of transport to hospitals and clinics, building health clinics in the community, research processes leading to reduced mortality, and KWTRP's contribution to employment opportunities in that area.

> *"It has helped the community in research of outbreaks of diseases, yeah, it has done research on diseases and KEMRI has been able to come out with solutions." (Male, School LI1, vid 2).*
> *"KWTRP is all right. And those people who despise it, you know, Swahili people say "you only praise the rain if you've been rained on." Now, the one who hates it is the one that hasn't encountered a problem to go and benefit from there. (Female, School C2 vid 5)."*

The last quote voices an opinion that negative beliefs about KWTRP were a consequence of community members not feeling direct benefits from research or KWTRP. C1 and C2 students described beliefs within the community that KWTRP's work was associated with devil worship. In both cases this was expressed as beliefs among *"some people"* within the community, as opposed to the participants themselves. Students attributed this perceived association with a community suspicion of the need for KWTRP to draw blood from research participants (C2 vid3), or due lack of community understanding of the roles of KWTRP. Student's explanations for the sources of rumors: *"It's because we don't know about KWTRP";* and linking blood drawing to devil-worship, is consistent with the notion proposed by Marsh et al. (77) of "half-knowing" leading to rumor. Interestingly, negative beliefs about the KWTRP were restricted to the films made by the groups from the C1 and C2 schools. This might suggest that the SEP had produced a positive influence on student attitudes toward the KWTRP in the LI1 and FTF1 schools. This was corroborated by the quantitative and qualitative components of the evaluation described elsewhere (6).

How the PV Process Nurtured Further Engagement With KWTRP and SEP

The PV process and follow-up visits offered opportunities, over 6 weeks, to gradually create a conducive rapport between the AD, NM and the students. This facilitated mutual-learning and knowledge co-production. During the initial workshop, anxiety and a lack of confidence, specifically among FTF1 and LI1 girls and the C1 students, were observed through outward expressions of shyness and reluctance to communicate. C1 students were frustrated at being unable to respond to their own knowledge-based questions about KWTRP, and FTF1 and LI1 girls remained quiet during group discussions.

Evidence of shyness among the girls comprised observations of the lowering of their eyes, hiding their faces when films were shown, and remaining very quiet during follow-up discussions. This, to some extent, enabled the boys to dominate the discussion during the first stage of the process. Interestingly, this shyness was not apparent in the films they made but materialized only during group discussions and film showing sessions. Among students from schools FTF1 and C2, both boys and girls expressed enjoyment throughout the process while some of the LI1 and C1 girls expressed periodic shyness. Observation notes describe most students overcoming their shyness over the first couple of sessions.

In response to this initial reticence, AD and NM employed several strategies to make workshops and follow-up visits informal and enjoyable. These comprised, (a) encouraging the students to play with the equipment with minimal facilitator intervention, (b) making students "swap roles" to nurture the participation of less dominant group members, (c) encouraging the students speak in the language they felt most comfortable with. Students were enabled and encouraged to practice and repeat scenes as much as possible and AD and NM made a conscious effort to praise all aspects of their participation.

Over the duration of the PV component, relations between the schools and AD and NM were strengthened and this was evident in various ways. A growth in outward displays of student

TABLE 3 | Summary of gains for the SEP and students from the PV process.

Gains for the SEP	Gains for students
An evaluative understanding of the influence of SEP	Learning about film-production and enjoyment of the process
Insights into the context of SEHR in Kilifi	Increased confidence in communicating with research staff
An appreciation of the depth of engagement required to facilitate learning of research concepts	Greater depth of understanding about research and KWTRP

enjoyment and confidence were observed over the duration of the project, evidenced by increased tendency to smile, laugh and request for repeat showing of films. The warmth in which students and teachers welcomed AD and NM to follow-up visits also increased over the project. This was most marked in control group C2 where big handshakes and youth greetings encountered in some of the student dramas were frequently used by both researchers and students: *"Vipi masela? Mambo shega!"* (Hi guys, things are cool!) (C2 visit3). Further evidence of an increasing confidence and assuming control of their films, across all groups comprised: requesting the equipment be available beyond originally agreed times (extracurricular club time and lunchtime) for independent filming (FTF1 Vids 4&5; LI1 vid 5; C1 vid5; and C2 vids 5,6,7&8); reviewing material independently, and modifying scenes/content/articulation and/or deleting scenes they felt should be omitted (FTF1 vid 3, C1 vid 5, C2 vids 5,6,7&8); active participation in critiquing, editing, and modifying films (all groups throughout); being very definite about which films could or could not be shared with an audience (FTF1, LI1, C1, C2); and a growing confidence to express critical views about KWTRP (C1 vid4; and C2 vids 1&3).

With time, teachers also felt increasingly able to leave AD and NM to conduct follow-up meetings independently with students and frequently made comments such as *"the process is educative for the students and good for their language skills"* (Male, School LI1principal). **Table 3** summarizes the ways in which AD, NM and participating students gained from the PV process.

Figure 3 highlights an iterative example of knowledge co-production between AD, NM and the students during the development (or production) of the C1vid4 film. The process of knowledge co-production was facilitated through the extended engagement afforded by PV which enabled students to critique, question and learn about research. It illustrates that over the PV process, whilst students learned about health research and gained confidence in articulating their questions, NM and AD gained a thorough appreciation of the depths of engagement required to facilitate student's learning about complex research procedures.

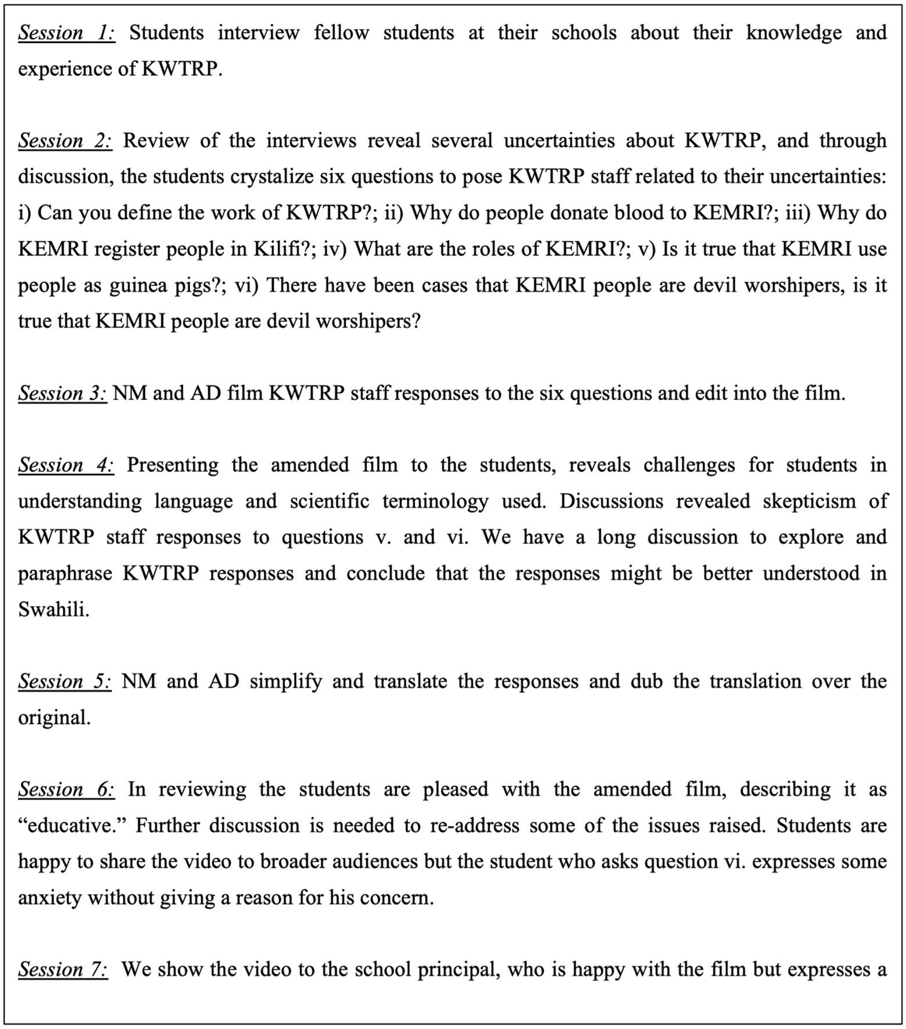
It became apparent throughout the duration of the PV process with all four groups that combining PV with participant observation provided a means of documenting student understanding of research and knowledge gaps whilst facilitating learning about research.

In some cases, the PV process enabled an understanding of how minimal exposure to the SEP activities could contribute to confusion about the role and requirements for employment at the KWTRP in general. For example, in reviewing C1vid4 (see **Figure 3**) with the students, it became clear that students could not differentiate between the use of blood samples in research, compared to blood taken for the transfusion service. Several discussions on consecutive weeks were required to address this challenge. In a second example, students in schools FTF1, LI1, and C1 referenced the KWTRP School Leaver's Attachment Scheme (SLAS) either in their films or in review discussions. They all accurately described the requirement of a mean grade of B+ and above in the Kenya Certificate of Secondary Education (KCSE) exams to apply for the scheme, and expressed that the internship provided valuable career experience. However, students from LI1 and C1, with little or no exposure to the SEP, expressed the misconception that all staff were recruited to KWTRP generally on the basis of their getting a B+ in their KCSE secondary school education exams. In both schools, this led to lengthy and repeated discussions between AD, NN and students about the qualification requirements for the school leaver's attachment scheme, work at KWTRP as a field worker, and qualification requirements needed to become a doctor and a nurse. Following the discussion, a C1 student who had understood the range of qualifications required for different types of jobs attempted to convince his reluctant friend by reasoning: *"Do you think all workers need a B+? Even the toilet workers or cleaners? We have several types of workers there; the toilet cleaners don't need to get a B+"* (Male, School C1 participant observation notes). This belief is likely to have resulted from hearing about the School Leaver's Attachment Scheme through a range of community engagement efforts and concluding that the B+ and above applied to *all* employment at KWTRP. Another alternative interpretation depicted by LI1, C1 and C2 students comprised a belief that KWTRP would provide bursaries either for school or university fees. The PV approach afforded time and a space to discuss and attempt to address alternative interpretations of KWTRP encountered over the duration of the process. The amount of time taken, and reluctance (among some) to accept explanations, highlights that differences in interpretations of research often cannot be resolved through single meetings and require lengthy discussion.

As an appreciation of some of the conceptions held by students about research and barriers to engagement were gained, students developed their confidence in articulating their views and their ability to engage with AD and NM. Gains to students and the SEP are summarized in **Table 3**.

What Valuable Insights Did PV Provide on the Context in Which SEHR Is Situated?

Importantly, PV afforded an opportunity to observe, experience and learn, first-hand, over a period of 6 weeks, about the context in which a joint project between researchers and students was conducted during extracurricular time. This provided valuable insights and considerations for SEPs in general. The first consideration is that, in the context of working in a school in Kilifi, engagement with a small



Session 1: Students interview fellow students at their schools about their knowledge and experience of KWTRP.

Session 2: Review of the interviews reveal several uncertainties about KWTRP, and through discussion, the students crystalize six questions to pose KWTRP staff related to their uncertainties: i) Can you define the work of KWTRP?; ii) Why do people donate blood to KEMRI?; iii) Why do KEMRI register people in Kilifi?; iv) What are the roles of KEMRI?; v) Is it true that KEMRI use people as guinea pigs?; vi) There have been cases that KEMRI people are devil worshipers, is it true that KEMRI people are devil worshipers?

Session 3: NM and AD film KWTRP staff responses to the six questions and edit into the film.

Session 4: Presenting the amended film to the students, reveals challenges for students in understanding language and scientific terminology used. Discussions revealed skepticism of KWTRP staff responses to questions v. and vi. We have a long discussion to explore and paraphrase KWTRP responses and conclude that the responses might be better understood in Swahili.

Session 5: NM and AD simplify and translate the responses and dub the translation over the original.

Session 6: In reviewing the students are pleased with the amended film, describing it as "educative." Further discussion is needed to re-address some of the issues raised. Students are happy to share the video to broader audiences but the student who asks question vi. expresses some anxiety without giving a reason for his concern.

Session 7: We show the video to the school principal, who is happy with the film but expresses a

FIGURE 3 | C1vid4 case study of further engagement facilitated by PV.

group of students can elicit feelings of envy among non-participating students. This was evidenced in schools FTF1 and LI1 in two ways: (a) non-participants expressing jealousy for not being part of the PV group, and (b) students not included in the IAS expressing jealousy of those who were (FTF1 Visit1 notes AD; School LI1 vid 3). Jealousy, in the context of SEHR activity, was evidenced further in school LI1's filmed interview about KWTRP, where one of the students related his experience of IAS: *"many people felt happy and the people who ignored it, they felt jealousy."* (School Male, LI1 vid 3).

The second consideration is the time required for the PV process. Over the duration of the PV project, it became apparent that other competing activities and issues influenced student's ability and desire to participate in PV activities. These concurrent activities comprised county sports competitions and trainings in preparation for these, continuous assessment tests and exams, county poem, recital and drama competitions, after-school clubs (science club, Red Cross club and Straight Talk HIV club), school trips (History trip), and absenteeism. All engagement with schools, including PV, needs to take student's other obligations and commitment into account when planning.

A third consideration for SEP activities is understanding the many challenges students face in their day-to-day lives which can create barriers to their aspirations. While this understanding may have been achieved through alternative qualitative approaches, PV enabled students to dramatize their challenges in pursuing education, providing the viewpoint of multiple characters. The challenges illustrated in their performances comprised poverty and lack of money for fees to pursue studies, peer pressure related to drugs, sex and devaluing education, gender related issues serving as a barrier to girls' education, and corrupt employers with unfair employment practices. Examples of these barriers to education and the achievement of aspirations are illustrated in **Table 4**.

TABLE 4 | Barriers to pursuing education.

Hinderances to education	Illustrative example
Conflicting attitudes to education: A portrayal of positive student attitudes toward education and a need to promote the value of education to the community	*"What is education? Have you ever thought that education helps in life? Be aware that education is the key to success. Don't just sit there, go for it." (Female, School LI1 vid1).*
Financial barriers to education: lack of ability to pay fees giving rise to 'drop-out'	*"School fees is the biggest challenge people face. You can go to school to read but be chased away, it discourages (Male, School C2 vid 7)*
Specific hinderances to girls' pursuit of education: school drop-out due to pregnancy (FTF1 Vid4); approaches from boys on the way to school for relations, transactional sex or both combined with peer pressure (FTF1&LI1 Vid1; and FTF1 vid4); and forced marriage for dowry (LI1 Vid5).	*Teacher: Sidi, you were very bright but now you are pregnant, so you will go home and take care of your pregnancy. [Teacher gives Sidi a note] you will take that to your parent* *Sidi: How much then?* *Lowela: Five hundred shillings* *Lowela [whispering]: Iddi loves you* *Narrator: Sidi agrees to be loved by Iddi so that she doesn't annoy her friend Lowela* *Father: I told you I don't want to her those words of yours. We should marry away our child so that we get dowry money.* *Mother: We will spend that money and it will get finished, my husband. This child should study, do you hear me?* *Father: No, I have said she should drop out. I am the man of this house! (School LI1 vid 5)*
Drugs as a barrier to education portrayed in two films (C1_vid3 and C2_vid8) as causing disruption to studies and to class activities.	*Both films depict intoxication in the classroom following smoking "Bhang" (marijuana) procured from dealers near to the school.*
Corrupt employment practices hampering the achievement of aspirations	*"I try whilst other cry" (C2 Vid6) depicts a job interview where the interviewer asks the candidate interviewees for a bribe: "scratch my back, I scratch yours." The first applicant virtuously refuses to bribe whilst the second is rewarded with the promise of employment after agreeing "to use [his] pocket" and pay a bribe.*

DISCUSSION

The PV process undertaken with groups of students from four Kilifi secondary schools, provided some evaluative evidence of the influence of the SEP in promoting student understanding of research, confidence in articulating their understanding of KWTRP, aspirations toward medical and health related careers, and enjoyment in interacting with research staff. Perhaps unsurprisingly, this was most evident for students who interacted the most with the SEP. Whilst our use of PV, in comparison to traditional evaluation approaches, may be limited in terms of controlling for confounders and making generalizable claims about SEHR, it offered valuable insights into SEHR practice which could not have been made through surveys. Used as an evaluation tool alongside a pre and post survey with intervention and control groups, PV has corroborated impact data (6), but has also provided a greater depth of understanding of the context in which engagement operates and which can be drawn upon to inform future SEHR in Kenya.

A potential complicating factor, though not unique to this study, is the possibility of acquiescence bias (78), which might account for the absence of critical comments about the SEP by students. On one hand, it could be that SEP activities were novel and universally enjoyed by students, but on the other, it is important to consider that students may have avoided being critical of the activities to please NM and AD and to avoid jeopardizing perceived future benefits from KWTRP SEP. The initial shyness of some students may have been caused by limited exposure to KWTRP researchers, including white middle-aged men (AD), and/or a prevailing school/home culture of girls remaining quiet in public discussions where boys are present. Our observation notes document a growth in student confidence and rapport with NM and AD over the project's duration. This is likely to have strengthened the relationship and gradually nurtured the students' willingness to voice their opinions. We argue that the extended interaction is likely to have fostered a willingness among students to share honest opinions.

In addition to providing evaluative information about SEHR, more importantly PV proved to be a valuable engagement method in itself, where KWTRP researchers and students learned about each other. While it could be argued that a similar degree of "openness" may have been attainable if a comparable amount of contact time was spent in creating rapport with students prior to FGDs, PV offered an opportunity for the rapport to be nurtured over a creative "arts-based" collaboration between researchers and students. In a similar way to the IAS online engagement activity, the novelty of the PV approach and activities contributed to the students' overall motivation to participate. Ethnographers participate in the day-to-day lives of research participants over periods of time, to draw inferences based on observations and discussions (71). They describe "ecological validity" as a strength of ethnographic data emerging from observing natural everyday life, compared to data emerging from "experimental" conditions such as surveys and time-constrained FGDs. The PV method in the SEP evaluation, placed students in novel film-making situations, as opposed to observing day-to-day life events, and offered students an opportunity to learn about filmmaking and nurture their communication and confidence. Thus, in using PV as an ethnographic tool, for students unfamiliar with film-making, there is a potential trade-off between the loss of "ecological validity" of data emerging from observing participants in their "natural" environment, and PV's promise of enhancing communication through leveling power differences between researcher and researched (65). The PV may not have fully ameliorated differences between AD, NM and students in all cases, however, its use as an arts-based tool for knowledge co-production (59) afforded time where students nurtured the confidence to share questions, opinions, satisfaction and dissatisfaction, not only in relation to film-making, but also in relation to SEHR, KWTRP, research and their own aspirations. From the point of view of a SEP evaluation, spending time at the schools in a co-production project offered important *in-situ* insights into how a SEHR activity works in the context of day-to-day school life. Further, and perhaps most importantly, with the ability to prioritize, delete, re-shoot and select preferred scenes, over the duration of the PV project, students were able to refine the content they wished to articulate in their videos. This arguably points to the students' growing "ownership" of the film-making process through the experience of having a "stake in the idea(s)" shared, feeling that the ideas shared were relevant and having their ideas valued (79, 80). For the use of PV in evaluation, we feel that increased ownership nurtures participants' confidence in sharing views honestly, therefore contributing to the finding's validity and authenticity.

While SEHR activities, and the PV project may have provided benefits and enjoyment for most participants (**Table 3**), our study provides insights into contextual challenges faced by students in their already busy schedules for curricular and extracurricular activities. For the students, the SEP is comparable to a single book on a wide and crowded bookshelf of competing activities and circumstances. For many, the novelty of the SEP activities, including the PV project, and the opportunity for interaction with KWTRP researchers may have been inspirational and enjoyable, but for others it was another set of activities competing for space in their thoughts. This underscores a priority need for engagement practitioners to carefully plan activities to ensure that they maximize enjoyment and benefits for students and schools. Important to emphasize is that interpretations of "benefits" may differ between the standpoints of researchers, school teachers and students. For example, students and teachers may not necessarily consider an enhanced understanding of locally conducted health research as being a priority benefit. It is also important to recognize the limits of community engagement and related activities in addressing some of the structural challenges faced by students, often related to limited resources and poverty (1).

The PV approach used in this study is not without limitations as an evaluation tool. It requires a broad range of researcher skills, from facilitation, videography and editing, to participant observation and qualitative analysis. It is time- and resource-heavy in ensuring consent at several levels and different time points (44), and only captures the views of relatively few participants. However, in the interest of making SEHR, including its evaluation, beneficial and enjoyable for students, PV, unlike other research methods, presents a considerate way of drawing from student's time, through providing opportunities to gain personally from the experience.

In our experience, as well as other's (51, 65), PV led to AD, NM and students learning alongside each other. As students honed their communication skills, learned about film-making and gained a deeper understanding of research processes through discussion and subsequent amendment of their films, AD, NM and KWTRP engagement team were offered insights into student lives and an appreciation of the depth of engagement required to address alternative interpretations of research.

Enabling the students to decide on the content of the films related to achieving their education and career aspirations has opened a new understanding of the context within which the KWTRP's research takes place and the complexity of community members lives. Lavery et al. (81) describe *"build[ing] knowledge of the community, it's diversity and it's changing needs"* as an important consideration *"for effective community engagement."* This PV process has contributed not only to an understanding about the SEP intervention, but also, and perhaps more importantly, has provided insights into the context in which SEHR takes place, and which in turn can influence participation in activities. This makes PV, in itself, a potentially strong tool for engagement and evaluating engagement.

Conclusion

Our study contributes to the field of SEHR through highlighting the value of PV, not only as an evaluation tool, but also as a means of engaging school students further with health research. PV as an evaluation tool, yielded evidence of the SEP's influence on the students' views, attitudes, and aspirations. It also highlighted unintended consequences of SEP and a greater depth of understanding of the context in which SEHR takes place which can influence school and student participation. Our use of PV has illuminated the many struggles students face in pursuing their aspirations, and the important curricular and extra-curricular activities which compete against SEHR for students' time and attention. These insights compel us to ensure that engagement activities are enjoyable to students, beneficial from their point of view and mindful of their time and busy schedules. In addition to facilitating evaluation, PV was a valuable method of engaging students with health research, enabling researchers and students to learn alongside each other. Given the constraints on student and researcher time, methods which enable concurrent engagement and evaluation, conferring benefits to both researchers and students, should be embraced.

DATA AVAILABILITY STATEMENT

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found at: https://doi.org/10.7910/DVN/VP5K7I.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Scientific and Ethical Review Unit, Kenya Medical Research Institute, Kenya. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

The study was part of AD's Ph.D. project, supervised by CH, RH, and CJ, with assistance in carrying out the fieldwork from NM. CH and NM provided additional methodological support, but the study design and execution was the responsibility of AD. All authors contributed to manuscript revision, read, and approved the submitted version.

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Under the Mask: A Film on Tuberculosis at the Thai-Myanmar Border

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In this paper, we describe the development of the film, "Under the Mask," which follows the lives of three fictional characters who live on the Thai-Myanmar border as they journey from diagnosis of tuberculosis (TB) to completion of treatment. Under the Mask was filmed on location on the Thai-Myanmar border by local filmmakers and former refugee populations. Cast members were chosen from communities living along the border. This paper describes the script development process, filming, and screening in the community. We also report the findings from the pre- and post-screening questionnaires and post-film focus group discussions. A total of 77 screening events took place between March 2019 and March 2020 to 9,510 audience members in community venues such as village squares, temples and monasteries ($N = 21$), schools/migrant learning centers ($N = 49$), and clinics ($N = 4$). The pre-and post-screen questionnaires showed a significant gain in self-perceived TB knowledge on prevention, transmission, signs and symptoms, and related discrimination. Our findings from 18 post-screening focus group discussions conducted with 188 participants showed that there were improvements in knowledge and awareness of the disease and treatment, as well as in the awareness of stigma, and the burdens of tuberculosis on patients and their families.

Keywords: Under the Mask, tuberculosis, community engagement, public engagement, film, Thai-Myanmar border, migrant health

INTRODUCTION

The World Health Organization (WHO) declared that tuberculosis (TB) was a global emergency in 1993, making it the first infectious disease to be declared as such. In 2021, TB remains a major health problem (1), particularly in developing countries (2), and is one of the top 10 most lethal diseases worldwide. Over 10 million people contract TB annually, with a corresponding 1.3 million TB deaths, 45% of which occur in South-East Asia (1). In addition to the significant burden on the healthcare system, TB is often accompanied by severe economic and social consequences, a situation exacerbated by co-infection with HIV-AIDS and the increasing prevalence of multi-drug resistant TB (MDR-TB) (3, 4).

Myanmar and Thailand have a high burden of TB, including MDR-TB, and TB with HIV-AIDS co-infection. Indeed, both countries were among the 14 countries on the WHO's three high-burden country lists for TB, TB/HIV and MDR-TB for the period, 2016–2020 (1). MDR-TB, cross-border migration and border health issues are important barriers to ending TB in both countries.

TB in the population is worsened by specific population characteristics, such as poverty (5, 6), poor education (7), poor access to healthcare (8), and civil conflict (9). In addition, migrants are predisposed to contracting TB (10); their uncertain legal status often limits access to reliable health information and healthcare services, making them more at risk (11, 12). Many migrants also live and work in conditions that may contribute to the spread of MDR-TB due to many contacts, long journeys to and from work, and crowded living conditions (13, 14).

The Shoklo Malaria Research Unit's (SMRU) TB programme, currently funded by the Global Fund to Fight AIDS, TB and Malaria (previously funded by UKAid), provides free diagnosis and treatment services on the Thai-Myanmar border. SMRU is a field research site of the Bangkok-based Mahidol–Oxford Tropical Medicine Research Unit (MORU), which has its offices and laboratories in Mae Sot, Thailand, and clinics located on both sides of the border. SMRU has provided free humanitarian healthcare, including for mothers and children, and conducted health research since 1986.

The majority of the border population have low literacy and are "undocumented," making them more vulnerable to poor health (15). Since the 1980s, political and militarized ethnic conflicts within Myanmar have forced hundreds of thousands of people, especially ethnic minorities, to take shelter, seek work opportunites and healthcare in Thailand, including in SMRU clinics. Thai nationals do not tend to access SMRU clinics as they can access government hospitals and have Universal Health Coverage.

The SMRU TB programme targets Karen and Myanmar migrants, and poor people from surrounding rural areas who face many barriers in accessing good quality healthcare and health information. Some patients come from as far as Yangon in Myanmar (14). In 2018 and 2019, SMRU screened 1,372 and 1,264 people for TB, of which 14.2% and 12.0% tested positive, respectively. On average, 80–90% of detected cases were enrolled for treatment under its TB programme, while others were referred for treatment with Myanmar health facilities.

SMRU has also developed a residential programme, "TB Village," on each side of the border, where patients stay for the duration of their treatment (16). The TB Village can house $\sim$160 patients at any given time, and is staffed by about 50 employees who are mainly Burmese and Karen, including five doctors. Rows of one-room dwellings accommodate patients, and accompanying family members are housed separately. Patients are provided shelter, medication, and food free-of-charge. In total, SMRU has $\sim$300 in-patients and out-patients under their care at any given time.

Studies show that those with a low level of TB prevention and care knowledge have a greater chance of TB disease than those with a high level of TB prevention and care knowledge (17). Health education activities, pamphlets and other printed media have been used to promote TB awareness and health education, but in the context of the Thai-Myanmar border, these approaches have limitations. Low literacy, multiple ethnic languages, and hard-to-reach villagers means that innovative engagement approaches are needed to reach the target audience. In Southeast Asia, science-arts approaches such as folk songs (18), community drama (19–23), forum (24), and puppet theater (25), have been used for health education and to support health research. These blended science-arts events are typically science-themed events co-created by scientists and collaborating artists. Some benefits of this approach in relation to research in Southeast Asia have included facilitating understanding of disease (e.g., malaria), understanding of research, encouraging research participation and strengthening the ethics of research studies (19, 20, 23, 26, 27).

In response to the need to convey clear, accessible messages around TB and TB research to our target communities, the TB film project was created to supplement existing text-based messaging on TB and other efforts by local authorities and non-govermental organizations (NGOs). We set out to produce a full length, context-specific feature film designed to be brought to the community using "mobile cinema." The aim of the project is to spread awareness of TB in the community SMRU serves, to encourage TB screening and early treatment, reduce stigma, and support treatment adherence for TB patients. The project was also an opportunity for our TB doctors and healthcare staff to better understand the experience and emotional journey of TB patients and their families to improve their own practice.

Using film to convey messages about TB is not new. Indeed, it is an approach that has been used since the early twentieth century, when a series of six, one-reel silent films were made by the National Association for the Study and Prevention of Tuberculosis (NASPT) in collaboration with the Edison Company: The Red Cross Seal (1910), The Awakening of John Bond (1911), Hope: A Red Cross Seal Story (1912), The Price of Human Lives (1913), The Temple of Moloch (1914), and The Lone Game (1915) (28). The visual narrative of these films made germ theory comprehensible, intelligible, and acceptable (28).

This paper describes the development of the Under the Mask film, the filming process, screening in the community, and the findings from the pre- and post-screening questionnaires and post-screening focus group discussions.

MATERIALS AND METHODS

Project Team

In 2018, the SMRU TB and engagement teams commenced working with FilmAid Foundation (FAF), an NGO based in Mae Sot, on the TB film project, Under the Mask. Set up by FilmAid Asia (now operating under its Thai name, Sermpanya), FAF uses film and digital media to create accessible education and health information for migrant, refugee and other vulnerable populations. It also conducts media training courses to empower refugees to learn film-related skills to enable them to create films with stories, in their own voice and culture, which are then shared with their communities through interactive mobile cinema activities.

FAF was chosen to co-produce this film with SMRU/MORU due to their experience making impactful films using a participatory production approach, their experience in conducting mobile cinema events as well as their deep understanding of the Thai-Myanmar border context. In addition, FAF had collaborated with SMRU in 2016 to produce a short film to support a TB screening project in a refugee camp.

SMRU has a core engagement team with extensive experience in engaging with local communities on both sides of the border. The team have used multiple engagement approaches including consultation with community advisory boards (29–31), using science-art approaches (21), and participatory visual methods (15).

Script and Narrative

The first step in the development of the script and narrative process saw the organization of a workshop with doctors and healthcare staff involved in the TB programme. The workshop was attended by 13 staff members who discussed the key messages, objectives, and target audience for this film project.

Real-life stories informed the content. To obtain these, the project team interviewed six TB patients undergoing treatment at SMRU TB clinics. In addition, the FAF team spent 6 months (February to August 2018) observing activities in the TB Villages. These observations, interviews with patients and healthcare staff, and patient testimonies informed the development of the film characters, emotions, narrative, and film script. The script was co-authored by FAF and the SMRU project team. The final story follows the lives of three fictional characters who live on the Thai-Myanmar border as they journey from diagnosis to completion of treatment.

The first character, U Tajar Min in his forties, has symptoms of TB but is reluctant to acknowledge it for fear of not being able to work. He uses various traditional medicines to try and cure himself before finally accepting that he must seek professional treatment. The second character, A Tun, in his 20s how, loses his job in a rubber plantation due to chronic back pain, and later discovers he has bone TB, a condition that few are aware of. The third character, Ma Zar Zar, in her 50s, is already having treatment in the TB Village, and faces serious issues of stigma from her family, including her own mother.

In the film, the doctors and healthcare staff explain TB, how to treat it, how to avoid reinfection, and what happens after treatment has been completed. For example, Dr. Banyar Maung, who plays himself, says *"you must make sure your room has fresh air and is kept very clean. You should eat regularly to keep your body strong and healthy," "when a patient has completed their treatment successfully, we give them a certificate which confirms their sputum is clear and that they have tested negative for TB disease. Keep this certificate safely as it will reassure your family and community."*

Verbal consent was obtained from all those involved in the workshops and interviews that informed the development of the film narrative, and all those that appeared in the film provided written consent.

Film Crew, Cast Members, and Filming

The crew consisted of FAF-trained filmmakers from local communities and former refugee populations. Cast members were chosen from local SMRU staff (e.g., doctors, nurses, counselors) and the community living along the Thai-Myanmar border *via* auditions. There were 34 speaking characters and a total of 43 cast and background characters. These "actors," including several who were illiterate, received TB information from healthcare staff, as well as acting coaching from FAF staff.

Scientific oversight was provided by TB doctors and researchers at SMRU, and engagement staff. Filming took place between September to December 2018 in the "TB Villages," and in villages in the surrounding community.

The Film

Initial rough cuts were reviewed by the project team. The near final versions were reviewed for scientific accuracy, context sensitivity and cultural appropriateness by SMRU staff.

The final product was a high quality, 75-min film in Burmese, with subtitles in English, Karen, and Thai. It was later dubbed in Karen. The film took its name, Under the Mask, from the fact that TB patients have to wear masks for the duration of their treatment, which can last for up to 20 months.

Approvals for the project, including filming, screening of the film, and evaluation were obtained from national, provincial and village level authorities on both sides of the border prior to the start of the project.

Pre- and Post-screen Questionnaires and Statistical Analysis

All attendees at the film screening were given questionnaires in hard copy before the screening and again after the screening. They were asked to rank their knowledge on prevention, transmission, signs and symptoms of TB, and TB-related discrimination by choosing one of the following: "very little," "quite little," or "well enough," before and after watching the film.

The comparison of self-knowledge was conducted using a chi-square test for trend. Statistical significance was declared at 5% significance level. The analysis was done using Stata 17 College Station, Texas 77845 USA.

Post-screening Focus Group Discussions

After each film screening, participants were invited to join a post-screening focus group discussion for evaluation of the film and the film screening event, which was held either immediately after the film screening or the next day. Participants were not pre-selected for the focus groups based on a set of criteria. It was not possible to do so because we did not collect their demographic data. Rather, we had an open invitation to all who attended.

The focus group discussions were conducted in Burmese and Karen following a topic guide, by the TB team led by a trained TB counselor (KKA) experienced in facilitating focus group discussions. Interviews were transcribed and translated verbatim to English and manually coded. Coding was conducted using a combination of inductive and deductive approaches.

Verbal informed consent was obtained from all participants prior to focus group discussions. Written consent was not obtained because participants, who were primarily undocumented migrants, could be put at risk by existence of a paper record (15). For this reason too, attendees of events were told that we would not collect any personal information (e.g., name, age, gender, location, occupation).

RESULTS

Film Screening

The film premiered in the SMRU TB clinic in Koko village in Myanmar, on World TB Day on 22 March 2019 to ∼300 audience members. Subsequently, a series of community screening or mobile cinema events were organized by the SMRU and FAF teams, in collaboration with village and community leaders, and school principals. Screening events involved transporting equipment from FAF and SMRU offices to the screening venue. The mobile cinema team consisted of technical persons, SMRU TB team and staff from FAF.

A total of 77 community screening events took place between March 2019 and March 2020 to 9,510 audience members in community venues such as village squares, temples and monasteries ($N = 21$), schools/migrant learning centers ($N = 49$) and clinics ($N = 4$).

Each screening was followed by an hour-long health discussion with the SMRU TB team. These health discussions focused on TB whereas the focus group discussions described above were for evaluation of the film and film screening event. The health discussion included topics such as where to get screened for TB, how to recognize symptoms, and how to prevent getting TB. For evening film showings, these discussions were conducted the following day. Audience members, who sometimes included recovered TB patients, took the opportunity to ask questions, share stories and experiences.

Film screenings took place in the evenings after villagers have returned from work, and school screenings took place during

TABLE 1 | Details of Under the Mask screenings to TB stakeholders.

Date	Venue; occasion	Type of audience	Number (approx.)
24 March 2019	Shwe Ko Ko township, Myawaddy, Myanmar; worldwide premier	Local authorities, villagers	300
3–4 April 2019	Kickstart Art Summer School, Mae Sot, Thailand; in conjunction with another TB engagement project, Imaging In and Expressing Out. Children attending the Kickstart art summer school produced piece of drawing reflecting their feelings and impressions about the impact of TB on patients after watching the movie.	Children (12 to 18 years old)	30
6 May 2019	Ko Ko TB clinic, Ko Ko, Myanmar	TB patients, staff in TB clinic	Staff: 17 Patient and caregivers: 70 (number of patient and care givers are an estimation, please note that some patients also have their family living at the clinic).
14 June 2019	Child Development Center (CDC), Mae Sot, Thailand	Student High school and post-high school students Aged 16 to 25 (some audiences are other visitors in the area)	78
17 June 2019	Bangkok Screening Room, Bangkok, Thailand; Bangkok premier followed Q&A with director and producers	Media personnel, funders, NGOs such as The Border Consortium (TBC), Raksthai Foundation, and International Rescue Committee (IRC)	40
19 August 2019	Vientiane, Laos; Global Health Bioethics Network (GHBN) annual conference	Bioethicists, biomedical researchers	50
2 September 2019	The Foreign Correspondents' Club of Thailand, Bangkok, Thailand; followed Q&A with director and producers	Foreign correspondents in Thailand	10
3 September 2019	MORU office, Bangkok, Thailand	TB stakeholders working Thailand e.g., IOM, World Vision, and Raksthai Foundation	22
23 November 2019	National Harbor, USA; American Society of Tropical Medicine & Hygiene Annual Meeting	Tropical medicine researchers, attendees at ASTMH	88
28 November 2019	Wellcome Trust, London, UK	Wellcome Trust employees	12
4 February 2020	Shoklo Malaria Research Unit, Mae Sot, Thailand	Senior University of Oxford and Wellcome Trust staff and international experts on tropical medicine; as part of the quinquennial review of MORU	30
Total			747 (estimation)

school hours. Participation in these events was free. Snacks and beverages were provided.

In addition to screening events in the community, the film was shown at various events and conferences around the world, targeting TB and health stakeholders such as journalists, community representatives, public health researchers, research funders, governmental and NGO partners (e.g., International Organization for Migration, Thai Border Consortium). These additional screenings reached 747 audience members. Some of these events included a post-show Q&A with the director and project team members. See **Table 1** for details. Many more people have watched the film on YouTube, where it is freely accessible (https://youtu.be/kxKHFxcFeJ8).

For screenings in the community, sessions were evaluated quantitatively using pre- and post-test questionnaires, followed by focus group discussions after the screening. The questionnaires evaluated audience's self-perceived knowledge before and after the screening on prevention, transmission, symptoms, treatment, stigma and discrimination.

Pre- and Post-screen Evaluation

A total of 5,761 and 5,803 people completed the questionnaire before and after watching the film. These figures represent 60.1 and 61.0% of attendees of the film screening. The results showed a significant gain in self-perceived knowledge of each of the categories: TB knowledge on prevention, transmission, signs and symptoms of TB, and TB-related discrimination. There was a statistically significant association between: knowledge about prevention or knowledge about transmission or knowledge about signs and symptoms for TB or knowledge about discrimination and test period, whether pre-test or post-test, $p < 0.0001$ for all tests. The proportions having well enough knowledge in the post-test period were very high relative to those observed in the pre-test period for all the knowledge parameters of interest (**Table 2**). The prevalence of "well enough" knowledge increased from 26.3 to 52.6 %; 11.9 to 41.6%; 10.1 to 35.1%; and 6.4 to 14.3% between pre-test and post-test, respectively for knowledge about prevention, knowledge about transmission, knowledge about signs and symptoms for TB or knowledge about discrimination. **Table 2** shows the self-perception of knowledge of TB pre- and post-film screening.

TABLE 2 | Self-perceived knowledge of TB by pre- and post-film screening.

Variables	Total *N* = Respondent who answers the questions		
	Pre-test *n*/*N* (%)	**Post-test *n*/*N* (%)**	***P*-Value (trend test)**
Knowledge about prevention	5,754/5,754 (100)	5,772/5,772 (100)	<0.0001
Very little	2,226/5,754 (38.7)	698/5,772 (12.1)	
Quite little	2,014/5,754 (35.0)	2,038/5,772 (35.3)	
Well enough	1,514/5,754 (26.3)	3,036/5,772 (52.6)	
Knowledge about transmission	5,738/5,738 (100)	5,773/5,773 (100)	<0.0001
Very little	2,101/5,738 (36.6)	595/5,773 (10.3)	
Quite little	2,952/5,738 (51.4)	2,778/5,773 (48.1)	
Well enough	685/5,738 (11.9)	2,400/5,773 (41.6)	
Knowledge about signs and symptoms for TB	5,761/5,761 (100)	5,803/5,803 (100)	<0.0001
Very little	3,011/5,761 (52.3)	1,009/5,803 (17.4)	
Quite little	2,167/5,761 (37.6)	2,757/5,803 (47.5)	
Well enough	583/5,761 (10.1)	2,037/5,803 (35.1)	
Knowledge about discrimination	5,751/5,751 (100)	5,762/5,762 (100)	<0.0001
Very little	3,035/5,751 (52.8)	1,871/5,762 (32.5)	
Quite little	2,349/5,751 (40.8)	3,066/5,762 (53.2)	
Well enough	367/5,751 (6.4)	825/5,762 (14.3)	

Findings From Focus Group Discussions

The following section describes the findings from the focus group discussions conducted with audience members after the film screening. A total of 18 focus group discussions were conducted with 188 adult participants between 23 May 2019 and 3 February 2020.

Our findings demonstrated improvements in the knowledge and awareness of TB disease and treatment, as well as in the awareness of stigma, and the burdens of TB on patients and their families. Audience members endorsed the film as a favorable engagement approach.

Each theme is discussed in turn below.

Improving Knowledge and Awareness of TB Disease and Treatment

By watching this film, many villagers expressed that they have learned a lot about TB, *"we did not know there are different kinds of TB until we watched this movie."* In the film, two characters had pulmonary TB and one had bone TB. They also said that that they now know what they should do and where to go if they think they have contracted TB.

Village chiefs who helped facilitate the community events were key to refer villagers, many of whom had questions following the events, to the appropriate place to get TB information and diagnosis. This was especially important to those living on the Myanmar side of the border, as they did not know where to seek help for TB. Villagers said they learned what facilities are available to them, including the SMRU TB clinic, which they thought only treated malaria.

Villagers gained knowledge they did not know before, such as the symptoms of TB, where to get tested, how it is transmitted and how to support TB patients. Some of the symptoms, such as coughing up blood, was not known prior to watching the film. By watching this film, some villagers learnt that TB is one of the most fearful diseases, but can be cured by taking drugs until treatment is completed. According to one villager, *"after watching this movie, there are two things coming in my mind. One thing is I need to be aware more about TB disease before I get TB disease. Second thing is, if I have TB signs and symptoms, I need to go to the TB clinic as fast as I can."* This is an important message because many villagers prefer to get treated by traditional healers rather than going to a modern clinic or hospital as illustrated by one of the characters, U Tajar Min.

Villagers also expressed that they were not aware that once a patient has completed their TB treatment, they are given a certificate or equivalent documentation to certify their treatment completion. Such documents were thought to be useful to show to neighbors and employers.

Improving Awareness of Stigma, and the Burdens of TB on Patients and Their Families

Film screenings had a positive emotional impact on patients and the community, as the issues and burdens, including stigma, that they faced were acknowledged and discussed. Through the film, the voices of TB patients, their families and health care staff were heard.

Audience members confirmed that the stigma and discrimination against TB patients and their families still exists in the community, for example, friends and relatives will avoid talking to TB patients. Some said they sympathized with the character, U Tajar Min, because he and his family are discriminated against by the people around them. They said the scenes in the film reflect the reality: *"The scene where a TB patient was not allowed to drink water from a communal water jar made me feel sorry for her, and I now understand the patient's feeling."*

Some villagers expressed fear of getting tested for TB or of losing their job, like one character in the film. Most of them said they feel nervous to get tested:*"A lot of people can relate to one character, a patient's husband. He was afraid to test for TB, for he feared that he would have to undergo 6 months TB treatment, which is a long time."*

A villager said that if they have to feed TB patient, they will cover their mouth with a mask and explain to the patient that it is not a discrimination, but rather a prevention measure to avoid getting TB from them.

Film as an Engagement Approach

The film was described as entertaining, and made learning and understanding of TB more interesting compared to conventional health education methods. Villagers especially enjoyed watching their friends and family, and healthcare staff as "actors" in the film.

> *"Health education with the movie is more effective than verbal sessions, because we can memorize a lot and share what's in the movie…pamphlets are not very effective, as most villagers can't read or write."*
> *"Verbal health campaign is boring but watching movie like this is more interesting, I can still remember some of them after watching."*

They also enjoyed the humor in the film, and the affection that develops that bonds all the characters together, for example, when A Tun gets a crush on one of the healthcare workers. The scenes related to this were crafted delicately due to the issue of staff-patient relationships, but it was thought necessary to inject humor into a film about a serious subject. These scenes were really about demonstrating the care of healthcare staff toward their patients, which contributes to TB patients' compliance to treatment and recovery.

DISCUSSION

Engagement Using Film

The method we took to develop the film has been described as "participatory visual methods (PVM)" approach. The term PVM describes an range of facilitated processes that support participants to produce or co-produce with others their own images or visuals such as film, photos, drawings and paintings (32). PVM has been shown to encourage patients and research participants to express themselves in ways that are not made possible by traditional qualitative methods such as formal interviews or focus group discussions (33). PVM can offer participants visual ways of articulating honest information that may be challenging to communicate because of language barriers, topic sensitivity or feelings of *kreng-jai* (Thai) or *arr-nar* (Karen/Burmese) which is a familiar cultural tendency in this part of the world. *Kreng-jai*/*arr-nar* is understood as "the desire to be self-effacing, respectful, humble, and extremely considerate, as well as the wish to avoid embarrassing others or intruding or imposing on them" (34). That means that sometimes, patients and study participants are reluctant to tell doctors and researchers how they really feel because they are embarrassed or do not want to inconvenience them.

In our project, TB patients and carers told us their stories so that they can be told *via* fictional characters in the film. We learnt things that we had not previously appreciated especially the extent of the stigma they faced from family and community members.

The project engaged with TB stakeholders at different levels. In the initial development process of the film and narrative, in-depth interactions with TB patients and healthcare staff enabled the project team, cast and crew to gain a deep understanding of their experiences such as the challenges of living with TB both as a patient and as a family member or carer of a TB patient. These local stories and testimonies were an opportunity for researchers and doctors to listen and learn, and helped embed TB patients and healthcare staff voices in the film. This learning was further enhanced during script development, and later, filming. Through the roles they played in the film, members of the cast more closely understood the experience of being a TB patient or carer.

On location filming and involvement of a large number of cast and crew members also raised awareness of TB in the local area. The non-professional cast and crew members learnt new skills. The co-production of the film by SMRU staff, patients, clinic staff and FAF strengthened relationships between the SMRU team and healthcare stakeholders in the region.

From the pre- and post-screening questionnaires and focus group discussions with audience members, we found that the film and the accompanying post-film health discussion improved knowledge and awareness of TB, as well as awareness of stigma and the burdens on TB patients and their families. We are hopeful that this awareness leads to behavior change around stigma and discrimination, as well as encouraging those who are at risk to seek treatment early.

At the time of writing, nearly 10,000 villagers along the Thai-Myanmar border had watched the film at mobile screening events, with many more having watched *via* other channels. The screenings reached illiterate audiences that traditional modes of communications do not usually reach. The film, now freely available, has the potential to reach a wide range of international audiences, with or without any facilitation by a TB expert.

The film has become popular among villagers living along the Thai-Myanmar border. The original version is in Burmese and dubbed in Karen, the language spoken in the border area. Villagers, village leaders, and healthcare workers have endorsed using the film as an engagement approach, particularly due to its entertainment value above and beyond the educational value. TB stakeholders intend to use the film when teaching medical students and healthcare workers about TB and we have shared the film with colleagues conducting TB research and teaching TB to medical students. Science-arts collaborations have been popular in engagement around TB. For example, in South Africa, the film, The Lucky Specials, explores issues of drug adherence and the risks of MDR TB while the Eh!woza (Hey! Come with us) project saw scientists engage with young people to produce short films about experiences of TB within their communities (35).

Lessons Learnt

Hearing patient narratives and participating in the discussion sessions moderated by the TB team after the film screenings has been an effective way for researchers and healthcare workers to listen and learn from the community. Clinic staff who played characters in the film experienced the lives of a TB patient or a carer at a much deeper level. The questions and comments from the screenings in communities helped the team to understand that TB is still very unknown and stigma is still very prevalent. We also confirmed with our previous findings in a qualitative study that migrants experience particular barriers to seeking diagnosis and treatment due to their legal status, transportation challenges, and lack of finances (12). To come to the clinic for testing, daily wage migrants lose the day's income (12, 15). Undocumented migrants fear being stopped by the police, an incident that may see them face deportation (14, 15, 30).

From this learning, we have increased efforts to encourage villagers to come for TB testing at our clinics. Because some migrants have difficulty reaching our clinics due to transport and financial constraints, we have also set up mobile TB screening initiatives to bring care to them.

The SMRU TB counseling team has been using some of the film's scenes in the counseling sessions, such as a scene revolving around a TB patient losing her rented accommodation because her landlord did not want the her to return to the accommodation, even after her recovery. This has been particularly useful for facilitating discussions on learning how to cope with stigma around TB. Stigma around TB is prevalent (14, 36), and coping with stigma is important because reducing stigma at the community-level is challenging and takes more time.

Strengths and Limitations

In terms of strengths, the film project was the first of its kind for the Thai-Myanmar border population, and has provided engagement practitioners here with much food for thought for future engagement work such as finding alternative ways of engaging with the community taking into account their low literacy and multiple languages used, and limitations in travel. We found that the "mobile cinema" approach was an effective way to engage audiences. In our 77 mobile cinema events, only one person left before the end of the film because he had to guard his crops from wild elephants and other animals.

The film was viewed by audiences as entertainment rather than as an educational film, therefore it has the potential to reach wider audiences. We intentionally limited the purely informational part of the film, but the post-film discussion reinforced the TB messages we wanted to convey.

In addition to spreading knowledge and awareness about TB, the film had other positive impacts on those involved and in the surrounding communities, providing jobs and learning opportunities for the villagers.

The project has already led to more arts-science initiatives by the SMRU engagement team—in TB, as well as other diseases, such as malaria and COVID-19. We have made shorter films for use in other settings, i.e., where mobile cinema events are not possible.

One limitation is that the film was not co-created with patients, unlike TB participatory educational films, such as those evaluated recently in the United States (37). Instead, it was informed by patient testimonies and experiences of TB doctors, and the script was co-developed by TB researchers and local filmmakers, who had a deep understanding of TB and the Thai-Myanmar border context. The director, a refugee from Myanmar, and his team, along with the local cast, made the film authentic; no professional actors were involved. The film was made in Burmese and later dubbed in Karen, but some people spoke other Karen dialects.

Additionally, while the film covered many aspects of TB, it did not discuss MDR-TB or TB/HIV, both of which are becoming increasingly important (1). We will address these in future projects.

Lastly, approximately only 60% of the audience completed the pre- and post-film questionnaires as many were illiterate. This may have caused the results of the questionnaires to be less reflective of the reality. As for the focus group discussions, only people who could spare the time attended the sessions. But we had a larger number than expected (118 participated).

Ethical and Practical Challenges

Under the Mask told the stories of three fictional characters living on the Thai-Myanmar border. The actors were not TB patients but recruited from the community. For example, the "actor" playing one of the TB patients worked as construction worker on a large building development near the TB Village. The writers made every effort to ensure that the characters in the film did not resemble real-life patients.

We obtained verbal but not written consent from participants of the focus group discussions because many were undocumented migrants, and a handful were recovered TB patients. Undocumented migrants are not allowed to travel freely especially outside "safe hours" and "safe zones"

(30). The existence of a paper record could put them at risk of being fined, arrested or deported to their home country (15). For this reason too, no attendee details were obtained during the film screening or focus group discussions. We therefore do not have the demographic details (e.g., age, gender, occupation) of who attended the screening events or focus group discussions.

The challenges of making a film of this nature without a professional cast should not be underestimated. Training community actors, some of which were illiterate, while rewarding took a lot of time. Another challenge was filming on location at the TB clinics and surrounding villages. There was a lot of background noise as there was a large logging entity with saws running throughout the day. In addition, filming on bamboo floors, which are typical of the houses in these villages, was difficult as just one footstep could move the camera. The community screening events was labor intensive and had to be conducted in the evenings which meant staff had to work extra hours.

CONCLUSIONS

Under the Mask was the first of its kind for the Thai-Myanmar border population, and has provided engagement practitioners with much food for thought for future engagement work. There is a need to find innovative ways to spread awareness of TB, to encourage TB screening and early diagnosis and treatment, to reduce stigma, to encourage positive health seeking behavior and support treatment adherence for TB patients. There is also a need for TB doctors and researchers to embed voices of TB patients and communities affected by TB in the management of TB patients and future conduct of TB research.

We found that the “mobile cinema” approach, which brought the film to rural communities, followed by discussion about the film and TB, was an effective way to engage audiences in rural communities on the Thai-Myanmar border. The “mobile cinema” approach brought the film and associated health discussions to the community such villages or schools, rather than asking the community to go to another venue they may not be familiar with. The latter approach to public engagement has been criticized because it tends to miss reaching to some subsets of the community and for “preaching to the converted,” whereby attendees are those already engaged within the scientific field (38).

The pre-and post-screen questionnaires and focus group discussions showed that there were self-reported improvements in knowledge and awareness of the disease and treatment, as well as in the awareness of stigma, and the burdens of tuberculosis on patients and their families. The project was also an opportunity for our TB doctors and healthcare staff to listen to TB patients and their families, so that they can improve their own practice.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

MD and MS conceived and oversaw the project. MD, MS, and PC were producers of UTM and SL was the director. MD designed the evaluation forms. KA and MD conducted the surveys and focus group discussions. MM, KA, and NK conducted the analyses of the pre- and post-screen questionnaires and data from the focus group discussions. WH and BM provided oversight of the project in the TB clinics. PC raised the funding and wrote the first draft of the paper. All authors reviewed the manuscript and approved the final version.

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METHODS
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Power and Powerlessness in a Group Based Digital Story Telling Project-An Exploration of Community Perceptions of Health Concerns in Urban Malawi

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Digital Story Telling (DST) is an art-based research method used to explore embodied experience of health and initiate dialogue with under-represented groups on issues affecting them. It involves engaging participants to create and share their stories using photos, drawings, and audio recordings in short videos. Benefits of DST include enhancing co-creation of knowledge, empowering participants to confront dominant narratives and revise inaccurate representations. We report our experiences and reflections of using DST to explore community perceptions of health concerns in urban Malawi. Community leaders were briefed about the project before and after study related activities. Three participatory workshops were organized to train community members in DST, support them to develop videos and discuss their experiences of DST. Twenty-six participants from two high density urban communities consented to be part of the workshops. They were all new to DST. All the 26 participants were invited together to the three workshops and their DSTs were developed in smaller groups ($n = 7$), based on their geographical location. Although we engaged residents from selected communities to share priority health concerns, all the seven groups presented challenges pertaining to Water, Sanitation and Hygiene (WASH), and their powerlessness to address the complex challenges. The collective focus on WASH showed that DST effectively empowered communities to present priority health concerns. The inability of community members to address the challenges without external assistance or failure to use findings from DST to generate social change however raise questions on the ideals of empowerment and social justice. In addition, lack of financial resources or technical know-how to produce digital stories and unequal power relationships between service providers and community, may affect the use of DST for community activism among socio-economically disadvantaged groups. We conclude that DST empowered participants to articulate genuine health challenges that they felt powerless to address. We question the realization of "empowerment" and social justice of vulnerable participants in cases where structural challenges present obstacles to effectively address social inequalities.

Keywords: Digital Story Telling, participatory visual method, Africa, public engagement, power and powerlessness, WASH

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BACKGROUND

Reducing social inequalities is one of the most important ways of ensuring social justice and improving health. Inequalities in power and resources at global, national, and local levels continue to contribute to health inequities between rich and poor populations. A key component in effective interventions aimed to address health inequities is engagement with affected communities. Top-down bio-medical research and interventions aimed at improving public health have been critiqued for producing knowledge from the perspective of powerful outsiders, inadequately informed by the representations, insights and values of community members (1). Considering that the major determinants of health are social in nature, participatory approaches of engaging communities are promoted to identify and address social conditions that lead to diseases.

Community engagement is defined as 'a process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people' (2). The main purpose of introducing participatory approaches of engaging communities is to empower communities to identify solutions to their challenges, with limited external influence from outsiders (3). Thus, community engagement aims to empower local people to develop a critical consciousness and to determine the best actions to improve their lives. While global health research has been critiqued for privileging the voices of experts and powerful actors, community engagement was introduced to incorporate locally defined priorities and perspectives. In addition, community engagement is also widely promoted in the conduct of health research and interventions to enhance the relevance of projects, address health inequities and ensure social justice (4–6).

Several publications have emphasized the need for community engagement in medical research (7–10), but few studies have used participatory approaches to explore community priority health concerns or experiences of community engagement in Malawi. This study aimed to assess if Digital Story Telling (DST) could be used as a tool to explore community perspectives of health concerns and community engagement approaches or participatory health interventions to allow communities to help shape the terms of engagement with researchers. In addition, we intended to explore if DST can be used as an evaluation tool for community engagement practices to enable us to generate evidence on culturally relevant approaches in urban contexts.

Digital Story Telling is an art based participatory research used to engage vulnerable or under-represented population groups to address health inequities. Participants for DST are engaged in a collaborative process to articulate their own meanings and experiences of health by synthesizing digital photos and audio recordings to present digital stories (11, 12). Thus, DST positions participants as "experts" and allows them to step into positions of power to create and share their lived experiences of disease or health interventions. Since participants take the lead to discuss issues that concern them, this approach is seen as appropriate for marginalized populations because it allows self-representation of a story "from the inside out" and avoids imposition of researcher or "outsider" views of the community (13). This approach also empowers participants to confront or resist dominant narratives and to revise inaccurate representations by using visually appealing accounts. Several studies have shown that DST is acceptable to vulnerable groups, empowering to participants whose voices are rarely heard and that it promotes positive behavior change (11–15). Allowing participants to share their own stories supported by digital photos is also perceived as engaging and relevant to present day technology, as well as visual culture (16). Thus, findings from DST are likely to lead to social justice because they are understood and applied by the general public including low literate groups, rather than text based research outcomes which are predominantly understood by academic readership (13). While many DST projects in health research have focused on individual experiences, we report our experiences of group-based DST with selected participants from urban communities where many health research projects and interventions continue to be conducted.

We draw from Gaventa's theories of power and participation to discuss power dynamics and mobilization of bias in participatory processes. According to Gaventa (17), power involves the capacity of A (individual or groups) to prevail over B in decision making or shaping B's actions about a situation. If the interests of A and B are different, A can potentially exercise power to put barriers around decision making spaces and thereby maintain the quiescence of B and mobilization of bias. Mobilization of bias refers to a dimension in the exercise of power where institutions or knowledge frameworks admit some issues while excluding others (17). The capacity of A to influence which issues to include or exclude in decision making accords A more power which may potentially affect B's response to remain quiescent. Thus, power and powerlessness may re-enforce each other, leading to further inequality which may be difficult to alter unless B acts to overcome A's power.

METHODOLOGY

Setting

Malawi is one of the poorest countries in the world with an estimated population of 19 million; 69% of the population live below the international poverty line of <\$1.90 a day (18). Both the adult and under five mortality rates are among the highest in the world, at 254 and 39 per 1,000 population, respectively (18, 19). Twenty-eight per 100,000 of these deaths are attributed to unsafe water, unsafe sanitation and poor hygiene (18). While statistics show that 17% of the population in Malawi reside in urban settings, a majority of the urban residents (65%) live in urban slums (18).

The DST project was conducted with participants from high density urban locations: Bangwe and Ndirande in Blantyre, the second largest city in Malawi. Due to urbanization, most of the residents have migrated to the city to seek employment or business opportunities. As such, residents in the city have multi-ethnic backgrounds, different traditional beliefs and are socially loosely knit compared to rural communities. Both Bangwe and Ndirande townships are quite similar in terms of socio-demographic characteristics and social organization. Most of

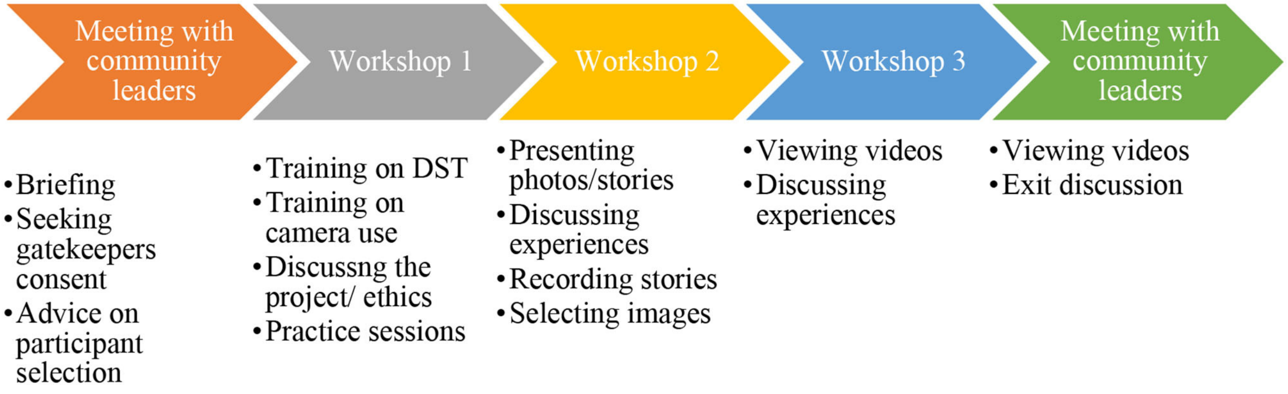

FIGURE 1 | Digital Story Telling workshops.

the urban poor are faced with poverty, food insecurity, poor sanitation, and hygiene. For instance, recent studies conducted in both townships revealed that most of the communal water points were highly contaminated and not safe for consumption (20, 21). Due to high prevalence of diseases such as diarrhea, tuberculosis malaria and HIV/AIDS, several health research projects, and participatory health interventions are conducted in these settings. We chose Bangwe and Ndirande as study sites because residents have been exposed over time to community-based health research projects and interventions on HIV self-testing, tuberculosis, malaria, typhoid vaccine trials and several others.

Both Bangwe and Ndirande fall within Blantyre city council which is mandated to offer services in relation to waste management, communicable disease control and other public amenities. Bangwe and Ndirande are divided into blocks headed by chiefs and sub chiefs on the traditional administrative level while ward councilors operate on the legislative level. The traditional leaders' positions are often nominated by the chieftaincy clan, and they represent communities during meetings with service providers and settle minor disputes. Councilors on the other hand are elected by residents to represent community concerns at the city council and to ensure that relevant services are provided.

Digital Story Telling Research Approach

We used DST because it allows self-representation of experiences visually through photos and participants own voices. We planned to have three participatory workshops with participants from urban communities in Bangwe and Ndirande townships (see **Figure 1**). In this paper, we define community as geographical settings or blocks where DST participants resided.

Prior to the workshops, we had two meetings with community leaders to discuss the study, seek gatekeepers' consent, and consult them on the most relevant approach to identify participants for the participatory workshops. Our plan was to purposively select residents from various community groups, based on age, gender as well as knowledge and experiences of medical research and health interventions to ensure that they express their views about community engagement and health concerns. The community leaders helped to map all community groups in their geographical locations. They also suggested an additional criterion of ensuring that selected participants came from all the geographical locations headed by block leaders, and we took this into consideration. With the help of the community leaders and community advisory group members, we briefed various community groups such as village health committees, women's health committees, youth groups as well as groups of people living with disabilities about the project and collected their contact details. Twenty-six participants were purposively selected from various community groups and contacted by telephone to invite them to the workshops. Text messages were also sent to participants to remind them about the workshop.

All the twenty-six participants (12 men and 14 women) attended the workshops (see **Table 1** for socio demographic details). Most of the participants had secondary education, and all were between the ages of 20–50 as shown in **Table 1**. The workshops were conducted between November 2020 to March 2021 when COVID-19 cases declined and restrictions on public gatherings were relaxed by the Ministry of Health. All COVID-19 preventive measures were observed, participants were encouraged to wear face masks, observe social distance, and sanitize their hands where necessary. All workshop participants were compensated with $10 for attending each workshop, in line with regulations from the local ethics review board. The participants were also served with snacks and drinks during workshops. The research team included two Social Scientists (DN and CP) and two DST and media engagement professionals (JN and RM).

Ethics Approval

The study was approved by the University of Malawi, College of Medicine Research Ethics Committee (P.01/20/2911) and Liverpool School of Tropical Medicine Research Ethics Committee (20-001). All potential participants were contacted by phone to inform them about the project and to give them more

TABLE 1 | Sociodemographic details of workshop participants.

	Bangwe	Ndirande	Total
Gender			
Female	8	6	14
Male	4	8	12
Age			
20–30	5	6	11
31–40	3	3	6
41–50	3	4	7
51–60	1	1	2
Education			
Primary	1	2	3
Secondary	11	12	23
Tertiary	0	0	0

time to consider their participation at the workshops. Written consent was sought on an individual basis from all participants prior to each workshop. We also sought approval from the participants and community leaders to share the videos and experiences with other stakeholders.

Participatory Workshop One

At the first workshop, we presented the project and sought written consent from participants who were interested to participate. Thereafter, we oriented participants to DST, ethics of DST, how to use digital cameras and finally, discussed prompt questions to guide them to develop scripts for their stories. The prompt questions focused on the themes of community concerns, health interventions aimed to address community concerns, perspectives of successes and challenges of community engagement approaches used, perspectives on how they wish to be engaged and finally local ethical issues that service providers must be aware of (see **Appendix 1**, for list of topics that were covered). Participants demonstrated that they understood the prompt questions from the discussions. Most of the participants were new to each other, except for few who knew each other from their respective places of residence. Team building exercises were used throughout the workshop to build rapport and encourage team bonding. Towards the end of the workshop, the 26 participants were divided into seven groups based on place of residence and their DSTs were developed in seven smaller groups. The participants were split into these groups to encourage participation of individuals who were initially not comfortable to use the cameras and to allow them to discuss community health concerns, experiences of community engagement or participatory health interventions. Four women and three men were selected as group leaders by group members based on their own assessment of individual strengths. Each group ($n = 7$) was given a camera to practice telling a story using digital photos. We observed participants in their small groups as they practiced taking photos with the cameras and present their digital stories to the whole group. We did not identify major technical issues or challenges pertaining to gender dynamics that affected participation. Older participants were however reluctant to use the cameras compared to the young ones. Thereafter, we agreed on the timelines for the participants to develop their stories and take photos in their respective communities before the next workshop. The group leaders went home with the cameras and worked in their respective groups to take pictures about their story for 2 weeks. Phone calls were made to group leaders to check on their progress and to invite them for the second workshop.

Participatory Workshop Two

All the 26 participants attended the second workshop where they presented their stories and pictures. Written consent was again obtained from all, prior to the workshop discussions. Representatives from all the seven groups were asked to present their pictures without narrating their story. After showing pictures, the group representative was then asked to explain their story to the audience. To our surprise, we noted that the theme for all the seven groups was about poor hygiene, unsafe water, and sanitation as their main health concern. None of the group members focused on their experiences of community engagement, participatory health interventions and other issues that were included in the prompt questions. Thereafter, each group was asked to finalize their scripts and select one person to narrate their story in the local language for audio recording. We also worked with each group to select images to explain their stories because some of the groups had captured too many pictures while others had captured a few. Thereafter our film makers assisted to align the voice over narrations and pictures to produce short video clips. All the participatory workshops ran smoothly except for a few technical issues pertaining to cameras.

Participatory Workshop Three

We invited all the participants to the third workshop to view the videos and engage them in a discussion about their experiences of being involved in the project. Twenty-five participants attended the workshop and only one participant had traveled out of town. We showed the seven videos to the group and invited them to discuss their experiences of being involved in the project, their views about the videos and why they all focused on one theme. Thereafter, we organized two meetings with community leaders at each site where we showed and discussed the videos. We also informed the community leaders that we had completed the project and thanked them for allowing us to work in their communities. Workshop discussions were audio recorded and documented in field notes.

FINDINGS/RESULTS AND DISCUSSION

Our discussion will focus on two broad themes of (a) power and powerlessness in group-based DST and (b) ethical and practical challenges of group-based DST. While many DST projects in health research have focused on individual experiences, we planned to use DST to explore community's health concerns, group experiences of community engagement and participatory health interventions. The benefits of this approach were that it encouraged participation and contribution from individuals who felt less technologically competent, and it empowered them to reflect on genuine issues of concern to their community.

FIGURE 2 | Selected photos captured by DST participants.

Participants focused their digital stories on Water, Sanitation and Hygiene problems rather than other health issues or experiences of community engagement as intended by the researchers. On the other hand, participants raised concerns pertaining to their safety that could impact on processes and outcomes of community-based DST projects.

Power and Powerlessness in Group Based Digital Story Telling

The group-based DST project empowered participants to raise genuine health concerns that affected their communities and exposed them to high risk of infectious diseases (see **Figure 2**). At the third workshop, we engaged participants to discuss why their focus was on problems related to WASH rather than their experiences of community engagement and other health concerns. They indicated that existing interventions already focused on addressing present social problems and managing diseases such as HIV/AIDS, TB, and malaria. Such diseases or challenges also affected a smaller proportion of the community. As such, experiences with such interventions could only be expressed by the community affected with a particular disease. The challenges in relation to WASH, on the other hand were a shared problem because they affected every community member and were more visible, yet they received less attention from service providers and other powerful actors. Poor hygiene, sanitation and unsafe water was also seen as the main cause of ill health and hence an important problem that needed to be addressed.

In addition, participants indicated that most community members were not often involved in participatory processes to voice out their health concerns and they were usually not consulted on health interventions to deliver to the community, except for few community leaders or community representatives. The participants indicated that communities were usually informed when an intervention is ready to be implemented. As such, they could not speak collectively about their experiences of community engagement or participatory health interventions. The lack of attention on community engagement or participatory health interventions could be a reflection that our participant group was not homogenous to speak collectively on community engagement. On the other hand, their focus on WASH demonstrated that the DST effectively empowered them to discuss priority health concerns that affected them as a collective.

In as much as the DST project empowered participants to articulate genuine health concerns, it also created a platform for participants to express their sense of powerlessness to address structural challenges leading to WASH. During the third workshop, we asked participants to suggest ways of addressing challenges identified in the videos. They stated that challenges related to poor refuse and sewage disposal as well as unsafe drinking water were beyond their control; thus required the attention of powerful actors to improve the sewage system, provide refuse skips and increase water points. Similarly, community leaders felt powerless to address the WASH challenges. They highlighted that previous attempts to educate communities about the importance of good hygiene and introduce penalties for non-compliance to health interventions had not been successful. Regular victims of the penalties were usually the most vulnerable households who could not genuinely afford to have pit latrines, rubbish pits, or afford the penalties for not having them. In addition, most of the refuse was dumped in inappropriate places at night, thereby making it difficult to catch the culprits. As such, they asked for assistance from service providers to provide safe water, skip bins and ensure timely collection and disposal of waste. The community leaders also indicated that community members were used to receiving payments and other handouts from politicians and other service providers for rendering community services. This made it difficult for the community leaders to engage community members to do any voluntary service to clean the streets or markets without any form of payment. The practices of giving handouts for community services and the lack of attention to WASH challenges by powerful actors over time may have led communities to psychologically adapt to a sense of being powerless and re-enforced views of quiescence.

Ethical and Practical Dilemmas of Group-Based DST

Ethical Obligation to Address Challenges Identified in DST

The request from workshop participants and community leaders for academic researchers to address the challenges they identified raise important questions about researchers' ethical obligations to respond to community needs and ensure social justice. Even though the DST enabled participants to voice their concerns, they could not identify immediate solutions to the challenges. On the other hand, failure to use findings from DST to generate social change raise questions on the social value of DST to community participants. The problems raised by DST participants were well-known and visible to powerful actors who were mandated to improve WASH. As academic researchers, we faced dilemmas to use the digital stories to engage powerful actors on behalf of the community because they were already aware, and it implied that community voices can only be heard if other powerful actors intervene. This also implies that communities will remain disempowered if they must depend on powerful actors to support them with approaches such as DST to address inequalities. In addition, Gaventa (17) argues that to address power inequalities, the powerless groups must act to overcome the effects of power and being powerless. As such, DST could be used by participants for community activism to demand services from relevant service providers aimed to address WASH problems.

The Feasibility of Using DST With the Most Vulnerable Groups

Even though DST promises to be a powerful tool for community activism, we questioned the feasibility of using DST as a tool for community activism to allow most vulnerable groups to speak to power. Ideally, empowering communities should aim to equip communities to identify their problems and address them with minimal external assistance. Our experiences however showed that conducting DST projects required human, financial, and material resources to procure cameras, train participants on DST, camera use and produce videos. Even though many residents in townships had access to smart phones with camera, the technical-know how to present their stories live, using a projector to accompany their live voice over and the editing process for the packaged stories was a challenge. Many were handling the camera for the first time and needed more time for training in picture compositing, logical sequencing of telling a cohesive story and editing, which had financial implications. As such, we felt most vulnerable community groups may not be able to organize DST projects on their own without external assistance due to lack of human and financial resources. The fact that less powerful actors must depend on powerful actors like academic researchers to have digital stories produced therefore raise questions on the ideals of empowerment and whether DST is a viable option to engage communities in solving their problems.

Potential Risks to DST Participants

Participants main concerns about the community-based DST project pertained to physical and verbal assault from fellow community members for taking photos of their plight. We asked participants at the first workshop to reflect on challenges that they might experience in their respective communities. Workshop participants presented threats of physical assault from fellow community members if they see them taking pictures or demands for money in exchange for taking their photos. We introduced participants to ethics of DST and consenting processes for taking photos of other community members, but participants avoided photos of fellow community members. We assumed that engaging residents as participants was a way of leveraging their local expertise and that they would be trusted by fellow community members; but they indicated that their embeddedness in the community posed risks in this urban community. Participants who shared this view stated that fellow community members may react because they did not benefit financially while participants of the DST benefited financially from workshop allowances. As researchers, we felt this was a potential limitation for community-based DST because the fear of physical assault for taking photos could potentially lead participants to focus on photos about their physical environment and hence impact on the output of the project. Furthermore, fear of reprisal for speaking to power may also potentially limit participants to focus on issues that were easy to tell and leave out sensitive topics. Some community leaders expressed uneasiness that the videos had selectively focused on negative aspects of their communities in relation to WASH while leaving out other positive stories. While they admitted that the videos reflected their lived reality, they also expressed despair about the magnitude of sanitation challenges presented in their respective areas. This presented another dilemma on whether to disseminate outputs from DST that may cause discomfort to community residents. Apart from safeguarding confidentiality and anonymity of participants, it is important to carefully consider how to prevent discomfort and othering.

CONCLUSION

In conclusion, this paper reports our experiences of using Digital Story Telling to explore community's health concerns in an urban setting in Malawi. We have shown that DST empowered participants to articulate community health concerns and their powerlessness to address structural challenges that were deeply ingrained. Since DST allowed community members to express locally defined health priorities, it can potentially support priority setting for health research, interventions, and co-production of knowledge.

While engaging disadvantaged groups in participatory processes as co-producers of knowledge empowers them to transform their situation (22); our experiences demonstrate that DST empowered participants to express their priority health concerns as well as their powerlessness to address the complex challenges. Community members felt powerless because structural challenges pertaining to WASH were aggravated by urbanization, overpopulation, and poverty; and therefore, require long term multi sectoral approaches. Unequal power relations between communities and service providers in priority setting for health research/interventions may also have led to mobilization of bias where priority problems affecting communities were not considered for interventions.

Though existing literature shows that DST promotes decolonization of knowledge production and minimizes imposition of outsiders views (13); unequal power relationships can potentially lead powerless groups to be more dependent on powerful actors and not critically reflect on alternative solutions. Rather than exploiting the spaces of participation to critique power, reverse dominant narratives or inaccurate representations, unequal power relations may still lead participants to reproduce or re-enforce the dominant narrative that problematise them. We question the realization of "empowerment" in cases where community members must rely on outsiders to amplify their voices through techniques such as DST and existing structural challenges present obstacles to address social inequalities. The inability to immediately respond to the challenges also present an ethical dilemma on social justice.

MAIN POINTS IN THE PAPER

- DST offered an opportunity to participants to raise genuine health concerns that exposed communities to high risk of infectious diseases, as well as obstacles to effectively address the challenges.
- Community's inability to address the community health concerns and dependency on external help raise questions on realization of empowerment as well as social justice.
- The high costs and technical expertise required to implement DST projects also raise questions on the ideals of empowerment since most vulnerable community groups may not be able to organize DST projects without external assistance.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. For the purpose of open access, the author has applied a CC BY public copyright license to any author accepted manuscript version arising from this submission.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Malawi, College of Medicine Research Ethics Committee (P.01/20/2911) and Liverpool School of Tropical Medicine Research Ethics Committee (20-001) in UK. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

DN conceptualized the research design, led the research and implementation teams, and drafted the manuscript. CP, JN, and RM were involved in implementation and contributed to the manuscript. PK, MP, and ND mentored DN and contributed to research design and manuscript. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

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COMMUNITY CASE STUDY
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Undertaking Community Engagement for a Controlled Human Malaria Infection Study in Kenya: Approaches and Lessons Learnt

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Human infection studies (HIS) involve deliberately infecting healthy volunteers with disease-causing pathogens under controlled conditions. These studies are "controlled" by way of using specific types of pathogens, including dose, and the availability of emergency medical facilities to research volunteers. Most HIS involve diseases whose treatment is known and are done to accelerate the development of novel therapeutics such as vaccines, to address emerging and existing infectious diseases. Traditionally, HIS have been conducted primarily in high-income countries (HICs) but are now increasingly being conducted in low-and-middle income countries (LMICs). In LMICs settings, HIS are likely to raise concerns among various stakeholders including participating populations and regulatory bodies, that are unfamiliar with this type of research. Deliberately infecting a healthy individual with a disease-causing pathogen seems to go against the normal practice of medicine of "do no harm". Such types of studies can give rise to increased rumors and jeopardize research participation in study activities, including non-HIS research. Community engagement can be one approach to address particular issues that HIS studies raise through meaningfully engaging with communities, where views and voices inform the conduct of HIS studies. In addition, engagement can inform the ethical conduct and acceptability of HIS studies in LMICs settings and provide opportunities for sharing information, listening to, and responding to concerns and views from potential participants, and the larger community in which the study would be conducted. Despite community engagement being an important aspect to consider, very few published and gray literature cover the types of approaches that have been used, and lessons learnt in engagement for HIS. This article outlines the community engagement approaches that were used to engage stakeholders and communities for malaria HIS-controlled human malaria infection (CHMI), undertaken in Kilifi, Kenya. It outlines the engagement activities across the research cycle, from activities conducted during protocol development, to planning, and implementation of the study. We discuss the challenges experienced, lessons learnt, and provide some recommendations for engagement around HIS.

Keywords: community engagement approaches, human infection studies, malaria, stakeholder identification, challenges and lessons

INTRODUCTION

Human infection studies (HIS), otherwise known as controlled human infection studies, challenge studies, and human challenge trials, involve deliberate infection of healthy volunteers through administering pathogens under controlled conditions (1). Controlled conditions refer to the specificity of the pathogen, dose, close monitoring of research volunteers, and availability of emergency medical services. HIS are deemed to be cost-effective as they provide an opportunity for accelerated testing of vaccines to provide estimates of vaccine safety and efficacy (2). Such studies are conducted with the aim of: (i) evaluating candidate vaccines and other therapeutics; (ii) gaining insight into host responses in natural infections; and (iii) developing a model of infection (1).

Traditionally, HIS have been conducted primarily in high-income countries (HICs) but many target infectious diseases occurring mostly in low-and-middle-income countries (LMICs). Some of the reasons why this has been the case include limited (but rapidly growing) infrastructure, skills/training to undertake such studies, and inadequate legal, ethical, and regulatory systems in LMICs. Community understanding and acceptability of such studies can also be a reason why these studies have taken time to be conducted in LMICs settings. In recent years, capacity building initiatives targeting LMICs have significantly addressed some of these gaps, which has also contributed to an increasing number of HIS conducted in these settings (3).

While conducting HIS in LMICs is a welcome idea, these types of studies require careful development of research approaches that support both scientific and ethical conduct. The idea of deliberately infecting a healthy individual with a pathogen goes against the ethical norm in clinical practice and research of "do no harm" (4). Safety concerns, rumors, and misinformation can also undermine willingness to participate in study activities. Thus, community engagement can play a critical role in providing accurate information and opportunities for community members to interact with research and researchers and discuss concerns and how best these could be addressed. Engagement also provides forums to discuss consent, recruitment strategies, inconveniences arising from study participation, ancillary care that could be provided, and how to begin to address many of these issues including potential third-party risks. Importantly, community engagement can inform research teams whether it would be acceptable for HIS to be conducted in a particular community, and thus whether or not to continue with a planned HIS. However, as has been documented widely for other types of studies, community engagement in HIS presents several complexities including what approaches are appropriate to use, whom to engage, and competing goals of the engagement. Despite community engagement being an important aspect to consider, there is limited literature covering the types of engagement approaches that have been used for HIS in LMIC settings specifically, and the lessons being learnt.

COMMUNITY ENGAGEMENT FOR HIS

The HIS can raise concerns among communities and the broader public if appropriate steps to engage communities are not taken. Such concerns can be around: the type of pathogen involved (including perceptions of the immediate and longer-term health and social implications of deliberate infection); the experience and implications of requirements for residency away from home during the study where this is a requirement; discomfort or health risks related to the study procedures (such as frequent blood sampling); perceptions around treatability of disease following deliberate infection (including possibilities of third party risks); and limits to the right to withdraw that may be in place to protect the volunteer (5). Therefore, the researchers need to plan appropriate stakeholder engagement to inform the study design and implementation; an engagement plan should consider who should be engaged and how to engage with the stakeholders right from inception stage of a HIS, through implementation until post-end of the study.

Several published works have demonstrated the importance of community and stakeholder engagement for HIS. In a recent study that assessed the acceptability of SARS-COV-2 HIS, conducted in the UK among 20 to 57-year-olds, volunteers suggested that due to the ethical complexities and public interest in such studies, it was important to ensure transparency to the public and broader scientific communities (6). Similarly, workshops conducted in India (7), Kenya (8), Malawi (9), Uganda (10), and Zambia (1) assessed acceptability of HIS for varying pathogens. Participants of these workshops included researchers from HICs and LMICs, community representatives (10), representatives of ministries of health, community and public health specialists, research funders, journalists, and lawyers. Relevant to some of these workshops was the pre-workshop consultation and engagement of community stakeholders including potential volunteers (1, 10).

In India, workshop participants identified important considerations for HIS, including the role of ethics review committees in safeguarding the rights of research volunteers, considerations of legal implications on deliberate infection of healthy people, and other social considerations such as engaging the media (7). Reviewing these critical aspects of HIS requires that ethics committees have a good understanding of the context within which such studies are conducted (11). Participants of a workshop in Malawi assessed the views of stakeholders on a pneumococcal carriage HIS and found that participants would be supportive of such studies provided stringent safety processes would be put in place and communities and stakeholders were appropriately engaged (9).

Studies have also shown the importance of community engagement for HIS in LMIC settings, especially among populations with either little research experience or where this type of study is implemented for the first time (8). Community engagement can provide early information and understanding in populations from which research volunteers may be drawn, thereby helping with the process of obtaining informed consent (4). Supporting principal investigators to spend time in and interact with communities where participants will be drawn from, including directly engaging with local residents, has been shown to strengthen trust and a sense of mutual respect and understanding (12).

Even though the importance of careful community and stakeholder engagement is emphasized in the literature, there is the little emphasis given to the approaches used or their value. Here, we aim to share our experiences, including challenges and lessons learnt during the development and implementation of engagement activities for malaria HIS conducted in Kilifi Kenya, to provide a resource for researchers and engagement practitioners in other LMIC contexts.

A PROGRAM OF HIS ON FALCIPARUM MALARIA IN KENYA

Over the last 6 years, a program of HIS on falciparum malaria involving over 160 volunteers has been conducted at the Kenya Medical Research Institute (KEMRI)-Wellcome Trust Research Programme (KWTRP) and Center for Geographic Medicine Research Coast (CGMR-C), in Kilifi (peri-urban and rural Kenya), under a program titled "Controlled Human Malaria Infection in Semi-Immune Kenyan Adults" (CHMI–SIKA) (13).

The CHMI–SIKA program of work in Kilifi followed an initial "proof of principle" HIS on falciparum malaria at the KEMRI Center for Clinical Research in Nairobi (urban area and capital city of Kenya), involving 28 healthy semi-immune adults, recruited mainly from medical colleges and those living within the vicinity of the research center in Nairobi in 2013 (14). Given the novelty of this research approach, study implementation was preceded by consultation and engagement with national-level science, ethics and medicines regulatory bodies, and universities within the vicinity of the research center, over a 2-year period (8). This initial and continuing engagement with very high-level stakeholders helped to pave way for the conduct of CHMI–SIKA in Kilifi.

THE CONTROLLED HUMAN MALARIA INFECTION IN SEMI-IMMUNE KENYAN ADULTS STUDY

The CHMI–SIKA study involved residents of low, moderate, and high malaria endemicity areas from the Coast and Western Kenya (15). The study aimed to better understand immunity to malaria with the potential to identify antigen targets that could be developed as second-generation malaria vaccine candidates. This study was set up as an open-label infectivity non-intervention study enrolling healthy Kenyan adults with varying exposure to malaria. A total of 161 healthy adult volunteers were enrolled and infected with *Plasmodium falciparum* (PfSPZ Challenge) sporozoites following successful recruitment and screening to ensure healthy status. These volunteers were admitted to a residential facility a day before infection and monitored for the development of any signs and symptoms of malaria. The study outcomes and procedures have been described previously (13, 15). In brief, the main aim of the study was to investigate how the *in vivo* parasite growth rate of *Plasmodium falciparum* is modified by pre-existing immunity measured by antibody levels to blood-stage antigens with the following objectives:

(a) Measure correlations between antibody levels to defined and well-characterized malaria antigens and growth rates of *P. falciparum* in volunteers undergoing CHMI.
(b) Confirm the safety of CHMI administered by direct venous inoculation in semi-immune volunteers.
(c) Measure parasite growth rates in semi-immune volunteers.
(d) Establish a sample set for the study of immunity to malaria and its effect on parasite growth following CHMI in semi-immune volunteers.
(e) Explore the understanding, motivations for participation, and experiences of volunteers and other stakeholders.

The implementation of this study in a different setting outside of the initial setting of Nairobi provided an opportunity for a context-specific undertaking of community engagement activities with a clearly outlined strategy to inform practice. This community case study focuses on local engagement approaches for the CHMI–SIKA study in Kilifi, which was made possible by the early buy-in of national-level stakeholders.

THE STUDY SITE

The KWTRP has its headquarters in Kilifi, with 2 other research hubs in Nairobi and Mbale (Eastern Uganda). Kilifi County is one of the 47 Counties in the devolved government system of Kenya, located in the Coastal part of the country, bordering the Indian Ocean. It is a rural County, with fast-rising peri-urban towns. The residents of the county are predominantly from the Mijikenda community. The population of Kilifi has low-literacy levels, and the main economic activities include tourism, farming, and fishing.

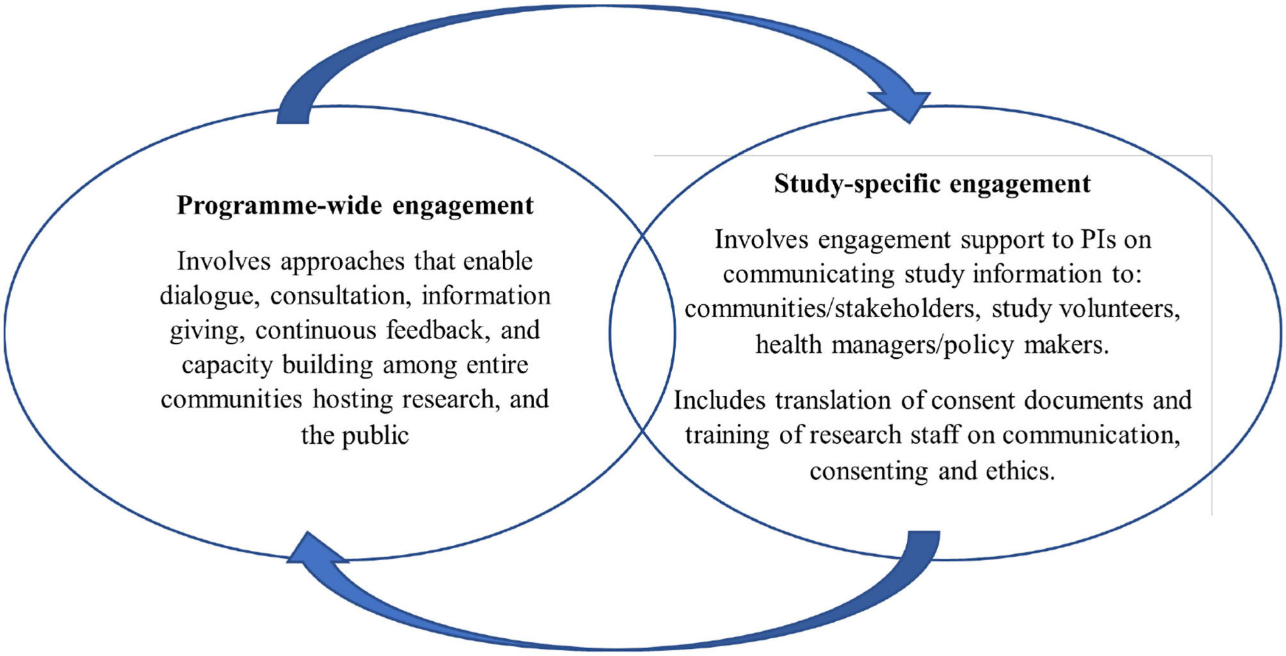

FIGURE 1 | Programme-wide and study-specific community engagement at KWTRP.

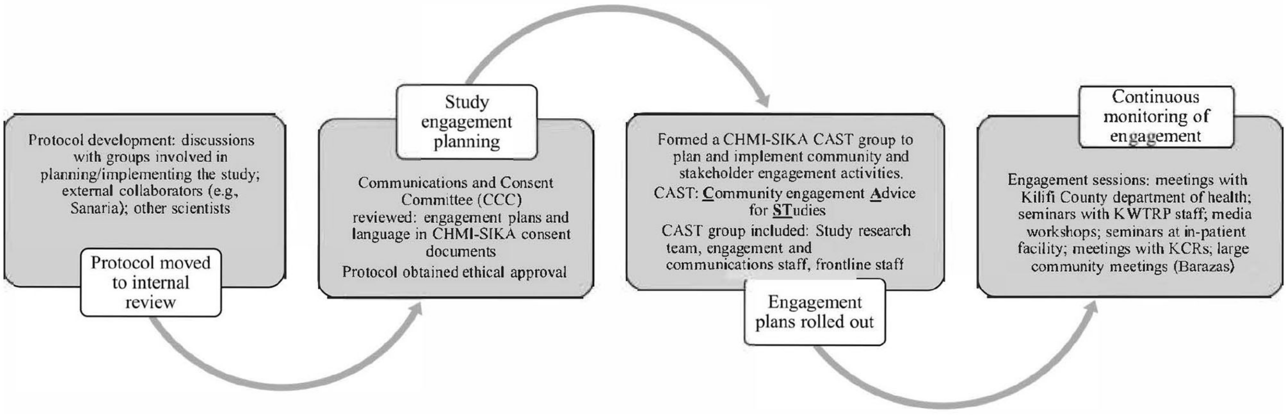

FIGURE 2 | Flow diagram depicting how engagement planning was done for the CHMI–SIKA study.

The KWTRP Kilifi hub hosts a range of international and national collaborative research projects, including epidemiological, social, laboratory and clinical research, to inform local, national, and international health policy. The research activities at KWTRP are supported by a strategic community, public and policy engagement platform, with specific experienced engagement staff (Community Liaison Group, CLG) responsible for implementing engagement activities (16). The program also includes a Kilifi health and demographic surveillance system (KHDSS) of over a quarter million residents (17), from which research volunteers are drawn, for the studies conducted in Kilifi. The overall community engagement goal in Kilifi is building and sustaining mutual understanding and trust between research staff and host communities, in support of generating new knowledge on health. Strategically, engagement is structured around ongoing overarching "program-wide" activities, and activities focused on specific research projects, including the HIS conducted in Kilifi. **Figure 1** above summarizes these components of the KWTRP engagement strategy.

Community engagement at the Kilifi hub of KWTRP is supported by a network of around 200 community representatives (KEMRI Community Representatives, KCRs), elected by residents living within the KHDSS (18). The KCRs are a hybrid community advisory board and serve a 3-year term, after which they retire, and new representatives are elected. Furthermore, engagement activities include open days at the Kilifi research center (including workshops targeting specific gatekeepers such as local registered self-help groups and religious leaders), an innovative schools engagement program, media engagement, and engagement with healthcare providers and managers, and policymakers in local and national departments of health.

PLANNING AND IMPLEMENTING COMMUNITY ENGAGEMENT FOR CHMI–SIKA

Planning

The CHMI–SIKA study began in 2016 with volunteer recruitment and was conducted over 3 years (2016–2018). Healthy adults aged between 18 and 45 years were injected with *P. falciparum* sporozoites and were required to be full-time residents in a study facility for up to 25 days for close clinical and research monitoring. Study procedures and stakeholder experiences are detailed in a series of clinical trial and social science publications (4, 19), including the CHMI–SIKA protocol (15).

Planning for community and stakeholder engagement for CHMI–SIKA began early, as part of the development and preparation of the study protocol for scientific and ethical approval. The flow chart in **Figure 2** here demonstrates the stages for planning for engagement from protocol development, all through to implementation of study engagement activities.

As happens for all other studies, a CAST (Community engagement Advice for STudies) team was formed and deliberated on all aspects of community and stakeholder engagement throughout the planning, review, and implementation of the CHMI–SIKA study (20). The CAST is made up of representatives of the study such as the principal investigator, a study coordinator/clinician, members of the engagement team (CLG), and a social scientist (where relevant). In the implementation of CHMI–SIKA study engagement activities, information giving roles were split between one representative of the CLG, who handled generic research information and specific questions about KWTRP from the audience being engaged, and one or two members of the study team who handled specific study information, as outlined in the key messages document. For example, during engagements with community members, members of the CHMI–SIKA CAST who attended these sessions included: (i) a study investigator with a medical background who was able to respond to questions that were clinical; (ii) a field worker who explained specifics about mobilization and recruitment; (iii) a CLG staff whose main role was moderating the entire session from start to end, including responding to general questions about research and KWTRP functions. A CAST group can have up to 10 members, however about 3-5 members attend engagement events, with different members of the CAST group attending different engagement sessions based on their availability.

A critical first step for the CHMI–SIKA CAST team given the novel research approach in this setting was to identify and consider the implications of research features that were unique to this approach. This was an important step as it laid the foundation for the next steps which included mapping stakeholders and outlining approaches to be used for engagement, and the development of messages for engagement sessions. Unique features of CHMI–SIKA discussed at the initial CAST meeting that were considered sensitive and/or new in our context included: (i) healthy volunteers would be deliberately infected with malaria parasites; (ii) volunteers would be required to stay in full residency during a prolonged period (up to 25 days) during the study; and (iii) volunteers from Ahero, in Western Kenya (about 850 km from Kilifi) would travel to join their Kilifi counterparts participating in the study. This design ensured that healthy adults with a range of levels of prior malaria exposure were included since malaria has high endemicity in Western Kenya and low-to-moderate endemicity across Kilifi. Through their deliberations, the CAST team identified the stakeholders to be engaged and engagement approaches to be used (**Table 1**) and developed key messages that would ensure consistent and correct messaging during engagement for CHMI–SIKA. In developing key messages, the CAST members considered the unique features of this study and framed communication about the study based on these features. This meant that these features were specifically addressed in every engagement session, maintaining correct and consistent engagement messaging. Key messages also included other study procedures such as the amount of blood drawn in the study, which is still a sensitive issue in the Kilifi population (**Table 2**). The process outlined here is specific for Kilifi as a different engagement approach was undertaken in Ahero based on their prevailing stakeholder engagement activities.

Implementation of Engagement Approaches

Stakeholder Meetings

The CHMI–SIKA study team were allocated time to present this study to Kilifi County department of health stakeholders during one of their routine County health management team (CHMT) meetings. The Head of Engagement worked with the coordinator of CHMT meetings to identify a suitable date and time, and then the study investigator was informed. A member of the research team (often the PI or study coordinator) gave a 10-min presentation, and then took questions, comments, and recommendations from the health managers, including discussion and approval of the strategies developed by the study CAST team.

Meetings With Community Representatives

Study sensitization meetings with members of a network of community representatives (KEMRI Community Representatives, KCRs) drawn from 3 locations where study volunteers were going to be recruited from (Junju, Banda-ra-Salama, and Ngerenya), were conducted. The community representatives shared their concerns as community members,

TABLE 1 | Key stakeholders identified by the CAST team for CHMI–SIKA in Kilifi and engagement approaches used.

Stakeholder identified	Engagement approach used
• *Local Department of Health:* as health gatekeepers in Kilifi County this group is charged with ensuring all research is relevant, safe and that volunteers are protected from harm. During the initiation of the CHMI-SIKA study, they provided the researchers with access to participating communities and have more recently evolved to provide formal approval for research studies to be conducted within their jurisdiction.	• *Meetings:* As with other non-HIS studies, the Head of Engagement requested for a slot in the agenda of a weekly county health management team (CHMT) meeting. The CHMT comprises of very senior health managers at County government level (21).
• *KEMRI Community Representatives (KCRs):* a network of local community members serving as a hybrid community advisory board (CAB) (18), and a link with local community members.	• *Meetings:* Conducted specific meetings with KCRs from locations where participants would be drawn from. • *Workshops:* CHMI-SIKA team presented the study during routine KCRs workshops held at KWTRP campus.
• *Chiefs, Assistant Chiefs and Village Elders:* administrative arm of the government at location, sub-location, and village level, responsible for oversight of all activities being implemented at that level.	• *Courtesy calls and meetings:* conducted meetings with administrators and village elders first, as these are the gatekeepers at community level.
• *KWTRP staff:* all staff whose job responsibilities bring them into contact with community members (such as field workers, drivers).	• *Seminars:* a series of seminars were conducted within KWTRP campus targeting all staff, but specifically those whose roles include direct interaction with the community (e.g., frontline staff)
• *Local University population:* the study inpatient facility was located within a local university.	• *Seminars:* conducted a series of seminar targeting students and faculty
• *Media/Journalists:* identified specific local and national media groups (mainly print editorial staff) for study awareness.	• *Media workshops/meetings:* A series of meetings were conducted between CHMI-SIKA investigators and specific journalists from Kilifi, Nairobi and internationally.
• *Study volunteers:* individuals already screened and admitted into in-patient facility	• *Open Days: workshop-like meetings which include a tour of KWTRP laboratories*
• *Community members:* local communities in study areas	• *Large meetings (Barazas):* with the assistance of chiefs, a series of barazas within the community were held.

TABLE 2 | Key messages derived by the CAST team for community engagement in the CHMI–SIKA study.

The key messages were framed around:

- The question researchers wanted to answer with the study, and why it was important
- The study site(s), targeted study volunteers, and study procedures
- Risks/costs of study participation as well as potential benefits
- Safety issues in deliberately infecting healthy volunteers, certainty around the nature of what was being injected
- Health concerns over the possibility that treatment given eventually would fail to achieve a cure
- Safety issues in relation to the total volume of blood taken, given that sampling was to be frequent over a prolonged period of time
- Information around what would happen in the case of serious adverse events or death
- In-patient stay for around 25 days, and how volunteers would be compensated for their time away from employment/business.

and concerns that could come from those they represented in their respective villages. Giving them information about the CHMI–SIKA study and responding to their concerns, meant that they were better equipped to respond to questions from community members whom they represented.

Community Meetings (Barazas)

KWTRP has a well-established relationship with local area Chiefs, their assistants and village elders within the KHDSS. In Kenya, Chiefs form part of the national administrative arm of the government responsible for interior security. As such, part of their responsibility includes maintaining security at the community level and disseminating or enforcing relevant government policies within their localities. Chiefs are considered important gatekeepers in the community and approve activities that involve community members to happen at the community level. Important information is communicated to the general public through organizing community *barazas,* which are large meetings of community members. Chiefs are responsible for calling the *baraza*. Community members are mobilized from their homes by word of mouth, through village elders (these elders work under instruction from a Chief). Meetings cannot begin without the presence of a local Chief. During the meeting, the Chief makes opening remarks, before inviting guests to make their presentation to community members. At the end of the engagement meeting, it is again the responsibility of the Chief to close and disperse the audience. In some instances, the Chief may summarize his/her learning or understanding of the study as part of closing remarks. *Barazas* are typically attended by 100–200 community members if well mobilized and they usually take

TABLE 3 | Common questions and concerns about CHMI–SIKA raised by community members, study volunteers, stakeholders and KWTRP staff who participated in engagement sessions.

- What if the required 18–45 age bracket people who will consent become less than the required number, can an over age person be recruited? (Community members and study volunteers)
- What happens when one dies after being injected with the malaria parasite? (Community members and study volunteers)
- Will you cater for the families of those you will 'admit' because they won't be able to work for their families? (Community members and study volunteers)
- If I come for the screening and you find out that I have a [health] condition, will you treat me? (Study volunteers)
- While 'admitted' at [local] in-patient facility, will I be allowed to go home to [visit] my family and then come back, or not? (Community members and study volunteers)
- What happens if after admission [being challenged and treated] I fall sick again? (Study volunteers)
- What is the possibility of non-clearance of parasites with antimalarials at the end of the study and what could be the effects of that on me? (Community members and study volunteers)
- What if I am a heavy drinker of alcohol? (Community members)
- How do you get the parasites? From people or from the mosquitoes? (Community members)
- Relationships can be affected if one partner consents to participate in this study, and the other refutes their partner's participation. (Community members, study volunteers, KWTRP staff)
- Why does KEMRI take a lot of blood from participants (also linked to devil worship)? (Community members, study volunteers)
- There is no privacy and confidentiality at the study in-patient facility; drawing of blood is done openly (in view of other volunteers). (Study volunteers)

In parenthesis included are examples of stakeholder groups that raised the question(s).

place during mid-morning hours. These meetings provided a forum for directly engaging community members on the CHMI-SIKA study. Between 70 and 150 community members from sub-locations of the 3 main locations named earlier were reached with CHMI-SIKA study messaging. The meetings began with a member of the CLG giving a general overview of KWTRP and research activities conducted by scientists at the center, and then a CHMI–SIKA study team member was invited to talk about the study. This was followed by a question-and-answer session.

Important gaps in a wider understanding of the research context were highlighted through more general questions asked about how KWTRP conducts research activities. For example, community members wanted to understand why KWTRP focuses mainly on certain diseases such as malaria, and not other common illnesses affecting the community such as filariasis or hypertension. These questions were responded to by a CLG staff and CHMI–SIKA study team present in the sessions who explained the process of arriving at a research question, including the review of hospital mortality data.

Seminars

From routine engagement activities, we have come to understand that KWTRP staff are important gatekeepers in the community as they are often asked many questions about the work of the Programme. To ensure that all the staff in the Programme were aware of this study and that any concerns/questions they had were addressed appropriately, the CLG staff organized a series of seminars where the CHMI–SIKA team presented the study and responded to questions that were raised (refer to **Table 3**).

Open Days for Research Volunteers During Residency

The study team came up with the idea of engaging the study volunteers, as a way of keeping them busy during their in-patient stay and improving their understanding of health research during residency. After administration of malaria parasites (between days 2 and 5 post-infection), the research volunteers had a workshop in-residency and then were invited into the research institution for a tour of the research facilities (e.g., laboratories where study samples were being processed and stored) and interaction with scientists. The study team also took this opportunity to further respond to questions from the volunteers, concerning the CHMI–SIKA study. Volunteers were picked in groups from the in-patient facility in a bus and immediately transported back after the engagement meeting. This was done to ensure that all volunteers got back to the in-patient facility without breaking study protocols and going home to visit family/friends. The open days also provided an opportunity for CLG staff to discuss with the study volunteers more broadly about KEMRI as an organization and provide a holistic view of the research conducted.

Media Workshops

The CHMI–SIKA study team participated in a media engagement workshop organized by KWTRP's communications team for researchers at the Programme. During the workshop, scientists shared a round table with one or two journalists and discussed with them their research areas of interest, including ongoing or planned work. Through this workshop, the study was explained to journalists who were present.

Across all Activities

An important feature of the engagement activities undertaken was that CHMI–SIKA study team members (principal investigator, study coordinator, lead clinician, and project manager) attended and participated in all the engagement sessions alongside experienced members of the community engagement team. When the scientists participate in engagement activities, they can hear first-hand, issues that are of concern to potential research volunteers. They are also able to learn about and consider social and cultural aspects that are important to the community where a study is being conducted (22). In addition, this allows for the community to have study-specific procedures thoroughly explained and provides a layer of information given prior to informed consent. **Table 3** provides an example of concerns and questions that were raised during the various CHMI–SIKA engagement sessions.

CHALLENGES, LESSONS LEARNT, AND RECOMMENDATIONS

The CHMI–SIKA research study was the first of its kind in Kilifi. It was also the first time that the study volunteers were drawn from different parts of the country and put together in one site. Thus, the experience of the CLG staff in systematic planning for research studies helped us prepare for this unique study. At first, having a structure such as the CAST group that is set up for every study involving human subjects was important as it aided in carefully thinking through important points of consideration for engagement, using an engagement template. The engagement template has a section for sensitivities in a study; here, unique features of CHMI–SIKA were listed. From this list, key messages were developed to aid in correct and consistent messaging. Secondly, going out into the community gave potential volunteers an opportunity to (i) meet the CHMI–SIKA team, (ii) hear first-hand about the study, and (iii) have their concerns about the study responded to. Having researchers directly interact with community members and discuss planned research is one way to build respectful relations and provide opportunities to discuss areas that worry the community as was the case with CHMI–SIKA and can contribute to building trust. Finally, using a combination of approaches ensured that many different stakeholders were reached with engagement activities and had opportunities to have their concerns responded to. Systematic engagement is very involving and time-consuming; thereby requiring ample planning time so as not to interfere with study timelines.

At the end of every engagement session, conducting what the CLG calls "debrief meetings" in all engagement activities helped to review what worked well and what did not. For every CHMI–SIKA engagement activity, the engagement team met to discuss and formulate strategies for improving what did not work well. Emerging new concerns not captured in earlier developed key messages were shared with the study team and responses fed back to the stakeholder or community group engaged. Such meetings are helpful as the implementing teams can review what works and what does not work well, and how challenges faced can be mitigated in future engagement sessions. To support learnings in engagement, embedding empirical social science work within ongoing HIS has built a better understanding of study benefits and risks (5), and highlighted critical engagement aspects that may be overlooked in the course of activity planning and implementation. The engagement strategy at KWTRP is deliberately linked to social science so as to ensure that there is a continued loop of implementing, evaluating, learning, and adapting/changing.

The social science team was able to draw on some of the similarities and differences in engagement approaches, between Kilifi (Coastal Kenya) and Ahero (Western Kenya). Some similarities included large community meetings, while differences included working with community health volunteers in engagement, which was done in Ahero but not in Kilifi. In addition, in Kilifi, field staff training on communication and consenting forms part of engagement activities. Field workers are often the face of the institution in the community and encounter challenging questions about research being conducted by the organization, as they visit homes to give study information and refer potential volunteers for screening. As such, the CHMI–SIKA field workers went through a communications and consent training before carrying out study activities, as is done for all studies undertaken in the Programme. In addition, the field workers had extensive training including role plays on how to effectively communicate the key messages of the study. This allowed for an internal evaluation and feedback based on the role plays conducted. The role plays involved selected members of the field team acting as potential volunteers who would be approached for information giving about the study with feedback on how the information was relayed and whether reflective of the key messages. The key messages document was useful in ensuring that during the training, field workers understood how to frame messages around the study uniqueness, thereby, ensuring that what they said was consistent with the information shared through engagement activities. Based on sentiments shared by community members in routine engagement activities, consistency in messaging is a key marker for trust. Conflicting messages coming from members of the same institution are considered to be a flag for dishonesty with the potential for breaking trust.

Throughout the CHMI–SIKA study, the community engagement and study teams worked together to address a range of challenges. For example, engagement activities were conducted around April/May, which in the Coastal part of Kenya, is the long rainy period. Often, meetings had to be postponed either due to heavy rains or because community members were busy in their farms. The CHMI–SIKA study team appreciated these challenges and were willing to be flexible. However, the CLG staff understood the tight study timelines and made efforts to negotiate with community leaders to continue with some of the meetings through sourcing for in-door venues where residents would be sheltered from the rain. In planning for community engagement activities, research teams must be cognizant of community socio-cultural norms and practices, as these can sometimes have a direct impact on engagement, recruitment, and study timelines.

Another challenge that faced the CHMI–SIKA study was that after the first cohort of participants had been successfully enrolled and completed follow-up with the publishing of the embedded social science study (4), a news article was published in a widely read national newspaper, that both overstated the risks of HIS for falciparum malaria and the levels of compensation provided to participants (23). Interestingly, the journalist who wrote this article had attended a workshop set up by the public engagement team at KWTRP and gathered information about this novel research approach from the study team present during the workshop. A communication piece had also previously been shared with the national newspaper editorial team before the study started. Perhaps even more interesting, the main public response received was a high level of enquiries about opportunities for participating in studies like this, rather than criticism around the safety of research being conducted. An important lesson to learn here is that despite engaging with journalists, there might be one or two who develop unexpected lines of reporting that the engagement and communications team has no control over. This can be due to the interests of the media not being aligned with those of the investigators. In our case, we responded to the article published through a press statement, which was posted on our institution's social media account (Twitter).

Determining engagement effectiveness is a complex task that involves having first outlined goals and objectives for evaluation. However, we think that our engagement was useful in some ways as the CHMI–SIKA study was conducted successfully from beginning to end without major interruptions. KWTRP's long-standing relationship with the community members in the KHDSS might have helped make engagement sessions smoother. The community is aware and expects that every new study recruiting human volunteers will be brought to a community meeting for dialogue before the study commences. This has helped to build trust with this community, which is critical when conducting research such as HIS.

In addition, the engagement process as well as on-going study interactions and embedded social science studies helped to identify key areas of concerns early on in the study, which helped in addressing these and initial fears, questions about the research design, safety concerns (including potential for third party risks which this study did not present). This we think might have contributed to allaying initial fears and hesitation among potential volunteers.

Administering informed consent took account of views from the community; it was a process with several interactions with study team members, and extended time for discussions with family members, as was requested by community members in engagement activities (4). We postulate that these multiple engagement processes made information accessible to potential volunteers because they had some level of information obtained either from the community meeting, or a friend who had attended a CHMI–SIKA engagement meeting or had been a study volunteer.

Following successful completion of the first cohort in 2016 which enrolled 37 volunteers, the majority of these volunteers became self-appointed "study ambassadors" and communicated their experiences of participation as well as information about the study in the community. Taken together, the initiation of in-residence workshops (that allowed for close cohort-specific volunteer engagement with research) and embedded social science and empirical ethics work, allowed for a volunteer-centered engagement approach for direct feedback into the processes and procedures of the study conduct. This for instance resulted in a better understanding of the need to stay in residence. There was a co-adaption of learnings from each engagement process from one cohort to the other.

CONCLUSION

Despite HIS being relatively new in Kenya, the high-level stakeholder engagement meetings held in Nairobi during the very first "challenge" study paved the way for successfully carrying out the study in Kilifi. In addition, conducting a broad range of engagement activities, right from the protocol development stage to the formation of a CAST, developing key messages and using these for consistent and correct messaging during engagement implementation, minimized the chances of raising rumors about the study. These approaches also provided a forum where multiple stakeholders raised concerns and questions related to CHMI–SIKA and HIS in general and had these responded to. Research and engagement teams can draw on these approaches including lessons that have been learnt as a reference for future HIS engagement planning and implementation.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

NM, PN, PB, DK, and MK contributed to the conception and design of the work. NM, PN, CM, SM, JM, MM, BK, HA, JW, PB, and MK conducted engagement activities. NM wrote the first draft of the manuscript. MK, DK, PB, MH, VM, EA, CM, and PC contributed to manuscript revision, read, and approved the submitted version. All authors contributed to the article and approved the submitted version.

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Steps Toward Engagement Integrity: Learning From Participatory Visual Methods in Marginalized South African Communities

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Community engagement and involvement have been increasingly recognized as an ethical and valuable component of health science research over the past two decades. Progress has been accompanied by emerging standards that emphasize participation, two-way communication, inclusion, empowerment, and ownership. Although these are important and noble benchmarks, they can represent a challenge for research conducted in marginalized contexts. This community case study reports on the methods, outcomes, constraints and learning from an NGO-led community engagement project called Bucket Loads of Health, implemented in the Western Cape province of South Africa. The independent project team used multiple participatory visual methods to foster two-way communication between members of two disenfranchised communities, Enkanini and Delft, and a group of water microbiologists at Stellenbosch University who were conducting research in Enkanini. The project was carried out during the 2018 Western Cape water crisis, under the growing threat of "Day Zero". The resulting visual outputs illustrated the negative impacts of water shortage on health and wellbeing in these community settings and showcased scientific endeavors seeking to address them. Engagement included knowledge exchange combining body maps, role play performances and films created by the community members, with hand maps, posters and presentations produced by the scientists. Whereas these engagement tools enabled reciprocal listening between all groups, their ability to respond to the issues raised was hindered by constraints in resources and capacity beyond their control. An additional core objective of the project was to bring the impacts of water shortage in participating communities, and the work of the research team, to the attention of local government. The case study demonstrates the challenges that politically ambitious community engagement faces in being acknowledged by government representatives. We further the argument that research institutions and funders need to match professed commitments to engagement with training and resources to support researchers and community members in responding to the needs and aspirations surfaced through engagement processes. We introduce the concept of engagement integrity to capture the gap between recommended standards of community engagement and what is realistically achievable in projects that are constrained by funding, time, and political interest.

Keywords: community engagement and involvement, water crisis, two-way communication, ethics, participatory visual methods, hand mapping, body mapping, engagement integrity

INTRODUCTION

Fieldwork for health-related scientific exploration is largely done in settings where the health challenge under investigation has a direct impact. The intention is to improve the health and wellbeing of people experiencing that impact, plus others who reside in similar settings and face the same challenges. Historically, health science research has been designed and implemented by scientists, with minimal engagement or involvement of those who live in the communities where their fieldwork is conducted, other than enrolling them as research participants. Over the past two decades, community engagement and involvement (CEI) has been increasingly recognized as an ethical and valuable component of health research (1, 2). Research approval by funders and institutional review boards is becoming more dependent on CEI being embedded into the proposed activities, and funding for CEI in global health research is more readily available.

UNICEF and others have proposed that core standards of engagement should include community participation, empowerment and ownership, inclusion, two-way communication, adaptability and localization, and should also build on local capacity (3, 4). These are crucial ethical standards, and all of them need to be integrated into CEI initiatives to achieve engagement integrity. By "Engagement Integrity" we mean a situation in which the good intentions of CEI are achieved to the extent that community members end an engagement process in a position of greater knowledge, capacity, power, and inclusion than they started. For example, according to UNICEF's core standards, two-way communication calls for "communities to be able to provide feedback as an indicator of project success" and adaptability and localization require "CEI approaches to be flexible and responsive to local populations' needs, conditions, and concerns". These are ambitious requirements for a field that is still emerging within global health research practice and, as this paper demonstrates, achieving them is not straightforward. UNICEF's core standards (3) provided a framework for us to reflect on the possibilities and challenges of community engagement through the South African case study reported here.

Good two-way communication requires those who are involved to participate in a process of listening and responding that is open, balanced and reciprocal (5). This suggests that research engagement should aim to cultivate a genuine and equal exchange of knowledge and perspectives between multiple stakeholder groups. However, enabling this type of communication within a research project can pose a significant challenge, especially when the research is being done in marginalized settings, the project is not resourced with a dedicated CEI team, and the research group has not received training in CEI.

Participatory visual methods (PVM) provide ways to generate materials that foster good two-way communication and can strengthen co-learning in research engagement initiatives (6). In a PVM process, focus group members create visual materials and/or performances to illustrate their lived experiences and convey their individual and collective perspectives on a situation. These materials then provide platforms for engagement across which opinions, ideas, needs and aspirations can be exchanged, discussed and debated.

The Rationale for the Innovation

This community case study reports on the methods, outcomes, constraints and learning from a project called Bucket Loads of Health (BLH) which aimed to promote community engagement in water microbiology research in the Western Cape province of South Africa. BLH was implemented in 2018 while the province was experiencing its worst drought in over 100 years, raising the prospect of a "Day Zero" when piped water supplies would be shut off (7). Extreme water restrictions resulted in the widespread use of greywater and untreated rainwater for watering gardens, washing clothes and dishes, and flushing toilets. This raised several public health concerns which were the catalyst for the BLH project.

The BLH project was conceptualized and led by a representative of the Sustainable Livelihoods Foundation (SLF)[1] with prior experience in using PVM and facilitating community engagement in health science research (8–10). With the support of a Wellcome International Engagement Award, SLF invited a team of microbiologists from the Water Resource Laboratory (WRL) at Stellenbosch University (SUN) to be the research partners in the BLH project. Two consultants with experience in community engagement and participatory methods (visual and musical) supported SLF with the design and facilitation of the BLH project activities (11–13). SLF and supporting consultants are hereafter named as the engagement team.

A core goal of the WRL is to generate alternative, sustainable and safe sources of water through the *in-situ* solar pasteurization and solar disinfection of rainwater harvested from the roofs of shacks in informal settlements (14). At the time of the BLH project, the microbiologists were doing research in the informal settlement of Enkanini near the university. They did not have

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[1] SLF is a Non-Governmental Research Organization based in Cape Town, South Africa https://livelihoods.org.za/.

pre-existing engagement support and had limited resources to interact with community members. The BLH project enabled the microbiology team to creatively engage with a focus group of Enkanini residents. BLH also allowed the scientists to engage with residents of Delft, a large township in Cape Town. The microbiology team were not conducting research in Delft at the time, but residents of the township were heavily impacted by the 2018 water restrictions and had existing relationships with SLF making this an appropriate location for additional engagement. SLF and the WRL partnered for the first time in the BLH project.

The engagement team took a PVM approach to facilitate two-way communication between the community focus groups and the water scientists. This article describes how multiple visual methods were layered into the project and the ways in which the outputs provided effective interfaces for knowledge exchange and co-learning. We also examine the limitations of the project and propose how our learning can contribute to progress in the field of CEI, shedding light on what is needed to advance toward engagement integrity.

CONTEXT

Enkanini is located on the outskirts of Stellenbosch, a prosperous university town. Enkanini—the name is isiXhosa for "taken by force"—was created in 2005 when a group of people from the neighboring township of Kayamandi invaded and built shacks on vacant municipal land. It is estimated that as of 2013, Enkanini was home to between 8,000 and 10,000 people, with current population figures unknown (15).

As an unplanned informal settlement, Enkanini has no sewerage or wastewater infrastructure, and stormwater drainage is absent. Individual shacks have no formal connection to municipal water or electricity services, although there are many illegal connections. By 2013, the settlement had 32 communal taps and 80 waterborne toilets in combined water and sanitation blocks (15). Residents live in a state of perpetual water scarcity, punctuated by floods after heavy rainfall.

Delft is a much larger settlement built between 1996 and 2000 under South Africa's post-apartheid Reconstruction and Development Programme (16). The population of Delft is $\sim$ 152,000; about 47% of residents speak Afrikaans as their first language, 38% speak isiXhosa and 9% speak English (17). Although Delft is moderately well served by formal municipal infrastructure compared to Enkanini, it is socially fractured and subject to high levels of violent crime (8, 18).

Paradoxically, Delft's integration with formal municipal systems increased pressure on residents during the 2018 water crisis. The City of Cape Town municipality (CoCT) implemented extreme water-saving measures including a ration of 50 L per person per days, enforced in some cases by automatic shutoffs at the level of household water meters; reduced flow to entire neighborhoods; and increased tariffs for higher usage. This made a minimal difference in informal settlements, where the need to carry water from communal standpipes had in many cases already limited residents to around 50 L per days (19).

MOBILIZATION OF FOCUS GROUPS

In Enkanini, a community leader who lived in the settlement and had previously worked as a community-based researcher for the WRL was chosen by the microbiology team to mobilize the group of Enkanini participants for the BLH project. In Delft, participant mobilization was done by a community leader who lived in the township and had taken part as a research participant in earlier research projects run by SLF. These community leaders were both given an outline of the goals, methods and timeline of the BLH project and asked to identify up to 15 males and females in their respective communities who were over the age of 18, available and interested to take part according to the project outline provided.

The Enkanini focus group comprised 12 residents, all first-language isiXhosa speakers originally from the Eastern Cape. There were 8 women ranging in age from 18 to 44 and 4 men ranging in age from 23 to 35. The length of time spent living in Enkanini differed among the participants. However, they had all lived in the settlement for over 12 months, having moved there from other informal settlement contexts. The maximum level of formal education among the group was matriculation from high school. None of the Enkanini participants were in sustained employment at the time of the project; their incomes came from government grants and occasional piece work, for example as domestic workers or unskilled laborers. Three participants had previously worked as co-researchers on Stellenbosch University projects conducted in their community, and two had worked with the microbiology team to facilitate stakeholder engagement.

The Delft focus group comprised 15 residents of the township, including three isiXhosa participants originally from the Eastern Cape and 12 participants whose first language was Afrikaans. There were 10 women ranging in age from 23 to 64 and 5 men ranging in age from 27 to 58. Amongst the participant group, the length of time spent living in Delft ranged from 10 to 20 years. As with the Enkanini participants, the maximum level of formal education among the Delft group was matriculation from high school. Some members of the group had part time employment through schools, non-governmental or community-based organizations, though the majority were unemployed and depended on government grants for income. Two members of the group had an existing relationship with SLF through involvement in previous research projects.

The research partners included the group leader, Professor Wesaal Khan, and four members of her research laboratory, including one post-doctoral fellow, two PhD students and a Masters student.

The participants in both community settings, and the microbiology team, committed to the project throughout its one-year duration. The Delft and Enkanini groups functioned independently and did not meet.

KEY PROGRAMMATIC ELEMENTS

The key programmatic elements of the BLH project incorporated three main phases: workshops, knowledge exchange days and public exhibition events. The key content of these phases is outlined below. Workshop and meeting agendas were flexible and provided opportunities for reflection and adjustment, with the intention that participants should have substantial control of the project outcomes. The engagement team was conscious of several barriers to effective two-way communication, including differences in race, multiple first languages, and vast differentials in income, formal education, expertise, experience in public speaking, and power. All activities and events were designed with these differences in mind and were facilitated by the engagement team. In Delft, the existing relationships between SLF and community organizations also helped to mitigate these barriers.

PHASE 1: WORKSHOPS

Separate workshops were held with the focus groups from the two participating communities and the microbiology team.

Community Focus Groups

Inception Workshops

In both Enkanini and Delft, the engagement process began with a one-day inception workshop. This allowed for introductions, a more-in-depth explanation of the goals, methods, and timeline of the project by the engagement team and an opportunity for attendees to ask questions. The inception workshops included a session to review the hopes, fears, and expectations of the potential participants with the intention of managing expectations around the possibilities and limitations of the BLH project. Expectations of project outcomes were revisited and discussed throughout the different phases and activities of the engagement process. Those who wished to participate in the project were asked to give their written consent. Most of the community members who attended the inception workshops in both settings consented to participate in the entire project.

In Enkanini, participants expressed their interest in BLH as wanting to know more about the water research that they could see taking place in their settlement and to understand any direct benefits for the wider community from this research. In Delft, participants said that they were interested to take part in the project because they wanted to be informed about research that was being done to address a household problem that was severely affecting them and their community. In both settings the focus group members expressed enthusiasm for sharing their lived experience of water shortage with researchers and other stakeholders as they had not previously been given an opportunity to do this.

Creative Workshops

Due to poor standards of education and limited employment opportunities for those living in marginalized settings, it was expected that participants from Enkanini and Delft might face difficulty with reading and writing. Differences in first language between the community participants, the microbiologists and the engagement team also brought about a barrier to effective engagement. As reported elsewhere, (20) visual forms of communication can aid challenges of literacy and language. They can also help to balance the dynamics of power and knowledge that are likely to exist when "non-expert" community members are brought into discussion with professionals. Hence a PVM approach with optional writing activities was followed in the BLH project. The creative workshops took place over five full consecutive days in community halls in Stellenbosch and Delft. Activities included the creation of sound, images, movement, performance and video, as well as opportunities for reflection and feedback. Storytelling and story sharing was woven throughout, into almost every activity. Being familiar with informal settlement and township contexts, we considered it unlikely that participants' schooling had included many opportunities for image-making, so paints, pastels and markers were introduced gradually to enable participants to build confidence.

Community Mapping

Early in each workshop, the whole group worked together to create a color-coded water typology, describing the forms in which they encountered water in their daily lives. This included clean tap water, stormwater, sewerage, wastewater from washing, rivers, and streams, puddles and industrial runoff. Small groups then created hand-drawn community maps, highlighting places of importance to them and places where they encountered water in its various forms. This exercise surfaced stories and experiences that were later incorporated into body maps.

Body Mapping

Body mapping was first described as a research method in a comparison of women's identity and the concept of the reproductive system in rural Jamaica and the UK (21). In 2002, Cornwall reported on body mapping as an exercise to build connections between different types of experience and knowledge, including biomedical messages, when exploring sexual and reproductive health with women in Zimbabwe (22). MacGregor has discussed the use of body mapping as a tool for "context sensitive" science education among people living with HIV/AIDS in South Africa (23). Body mapping has also been used as a qualitative method in the fields of social justice, knowledge translation and therapeutic benefit (24).

In the BLH body mapping process participants were asked to create life-size images reflecting their individual embodied experiences of water shortage (**Figure 1**). The body mapping approach that was followed has been described elsewhere (25). The creation of the body maps catalyzed the recollection of water scarcity, which became the building blocks for the narrative content of five collaborative films.

Sound

Music-making activities were woven throughout the five-day creative process. This included listening to water sounds and discussing responses, rhythm play with formal and improvised percussion instruments, singing and song-making. The music facilitator recorded all these activities and used the recordings to build new compositions, which were later used as soundtracks for the videos emerging from the workshops.

Roleplay

Both creative workshops also included a role-playing component, in which small groups developed short dramas about issues that had emerged regarding research and researchers. In Enkanini,

FIGURE 1 | A body map describing the personal experiences and perceived implications of the 2018 Cape Town water crisis, produced by a community participant during the five-day creative workshop in Delft.

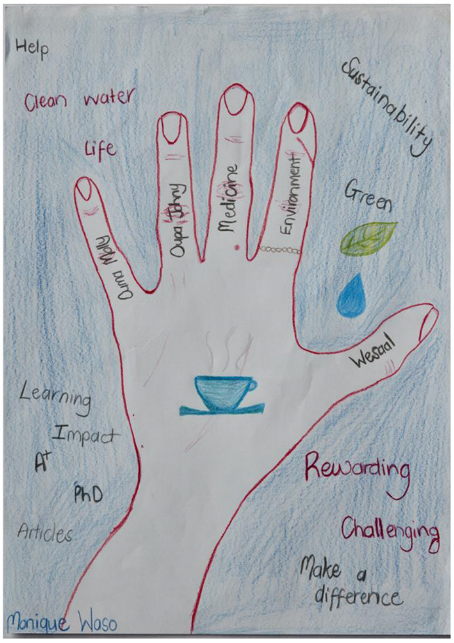

FIGURE 2 | A hand map produced by a PhD student during a planning meeting with the engagement team at SLF; the fingers show five key factors influencing the student's decision to become a water microbiologist.

these dramas focussed on community experiences of working with researchers in the settlement.

Video Production

The video-making phase of the creative workshops took different forms with the two focus groups. In Enkanini, filmed body map presentations evolved into a collaborative film, Our Water Challenges, about the problems of dirty water and waste, and the need for collective action.

In Delft, the filmed body map presentations became the basis of four short videos grouped around themes identified by the engagement team that reflected the diverse impacts of the water crisis: Children, Water and Recreation; Community Spirit; Health, Stress and Sanitation; and Water and Loss[2].

Planning Workshops

Three planning workshops were held with each of the focus groups, during which they rehearsed the presentation of their visual materials and helped to design the engagement and exhibition events.

Research Team

The engagement team led a one-day workshop at the SLF campus to help the microbiologists prepare for the knowledge exchange days and to develop research presentations that would be accessible to the community focus groups. The research team also created hand maps (26) as visual aids for introducing themselves (**Figure 2**). The engagement team had developed a hand mapping process for community safety research (27) that they adapted to fit the BLH project. Each scientist was asked to look at one of their hands and think of the fingers as representing the five major influences that had informed their decision to become a water microbiologist. More detail about the hand mapping method used in the BLH project is given in **Appendix 1**.

PHASE 2: KNOWLEDGE EXCHANGE DAYS

Two knowledge exchange days were held in Stellenbosch, one with each community focus group.

The intention of the knowledge exchange days was to facilitate genuine two-way communication by creating situations in which all groups held roughly equal power and were required to listen and respond to each other. Researchers introduced themselves *via* their hand maps and delivered presentations covering the basics of water science and their own research. They also took each focus group on a guided tour of their research department and laboratory (**Figure 3**).

Each of the community members presented their own body map to the researchers (**Figure 4**). The

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[2] The files for the four themed videos produced with the delft participants are too large to upload as **Supplementary Material**. They can be viewed on YouTube using the following links: Children, Water and Recreation https://www.youtube.com/watch?v=Wk9B2FhqHFM, Community Spirit https://www.youtube.com/watch?v=vDbmr-KKSIM, Health, Stress and Sanitation https://www.youtube.com/watch?v=5pyhtAoNb38, Water and Loss https://www.youtube.com/watch?v=5pyhtAoNb38&t=76s.

FIGURE 3 | The head of the Water Resource Laboratory, Stellenbosch University, demonstrates the use of agar petri dishes to Enkanini participants as part of knowledge exchange activities.

FIGURE 4 | Researchers from the Water Resource Laboratory listen as an Enkanini community member presents her body map as part of knowledge exchange activities.

Enkanini group also presented one of the short dramas they had developed during the creative workshop (**Figure 5**).

PHASE 3: PUBLIC EXHIBITIONS

The final element of the engagement process comprised two public exhibitions, one at the public library in Delft and one at the HB Thom Theater in Stellenbosch. Both exhibitions showcased the community maps, body maps and films created by the focus group participants, as well as the microbiologists' and maps and scientific posters. Both exhibitions were attended by the scientific team and the focus group members, as well as other residents of the participating communities and researchers from multiple academic institutions.

The Enkanini focus group decided to use their collaborative film to raise consciousness about the disposal of wastewater and unused food in their community, and to inspire local behavior change. Our Water Challenges was shown to 20 Enkanini residents during a community mobilization event organized by the focus group and held in a small church hall in the settlement.

Doing It Differently

To document the engagement process for sharing with other community engagement practitioners and researchers, SLF produced a 12 min film called doing it differently[3]. The film has been presented at several meetings and conferences around the world.

Project Evaluations

The engagement team facilitated formative evaluation sessions with the community participants and microbiologists as part of the creative workshops. A summative evaluation was conducted with the Delft participants by an external evaluator from the Human Sciences Research Council at the end of the project.

DISCUSSION

BLH provided two central platforms for engagement between the community focus groups and the microbiology team: knowledge exchange days and public exhibition events. Although each of these events only lasted a single day, their contents were designed over many weeks. In this section, we discuss how effectively the core communication tools used at the engagement event fostered listening and catalyzed responsiveness. We then reflect on the most significant lessons learned through facilitating the BLH project.

Body Maps

The body maps created by the community focus groups proved to be valuable materials for fostering storytelling and engagement. Creating these life-sized personal artworks instilled a sense of ownership among the participants and enabled them to convey their visceral experiences of water shortage, visually and verbally. In Enkanini, the body maps conveyed embodied experiences of exposure to dirty and contaminated water. In Delft, the body maps expressed various personal health and wellbeing challenges related to the 2018 water crisis. Participants presented their body maps and told their stories several times during the creative workshop process. These repeated presentations helped the community members to build their skill and confidence for telling their stories in public, and to reflect on and choose levels of self-disclosure. The body maps also made striking exhibits and proved to be effective conversation pieces during the knowledge exchange days and public exhibitions. To our knowledge, this was the first time that body mapping had been used as a tool for community engagement in water microbiology. At an evaluation session with the research team following the Enkanini knowledge exchange day, one of the PhD students noted:

> *"I was always under the impression that the biggest struggle would be access to water, but looking at the body maps, the discussions and*

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[3] The video file for Doing it Differently is too large to upload as **Supplementary Material**. The video can be viewed on YouTube at Doing it Differently https://www.youtube.com/watch?v=-_7jAhOgGGU&t=3s.

FIGURE 5 | A clip from the film "Doing it Differently", showing a moment in a role play performed by members of the Enkanini focus group for the Water Resource Laboratory team at the knowledge exchange event in Stellenbosch.

> *everything else today it became apparent that it's more an issue with the gray and black water and the health risks associated with that."*

This researcher's response provides an example of how viewing material created through participatory visual methods can promote a more reflexive understanding of research practices' on the part of researchers (28).

Hand Maps

Hand mapping with the scientific team helped to bring the researchers into the knowledge exchange days as equal participants, sharing life experiences and personal reflections through creative media. The resulting vulnerability was not always comfortable but did contribute to a leveling of power between the groups. In a workshop evaluation exercise, one of the microbiologists reported:

> "*I finally understood that the presentation of our hand-maps "Humanized" us in a sense – we could reveal a bit of personal information and we were not just the scientific team!"*

Drama Performance

The knowledge exchange day with the Enkanini focus group included a role-play session in which the group expressed their opinions about research being done in their community. Enkanini's proximity to the University of Stellenbosch makes it a frequent location for research projects across many different disciplines, which are not necessarily co-ordinated. The group expressed that occasional opportunities for a few residents to join projects as co-researchers were insufficient, and strongly expressed their expectation for compensation as research participants, as well as their wishes for further education and employment opportunities through the university. Thus, the community participants used the role play activity to express anger and frustration with the broader relationship between Enkanini and the university that they had not previously had a chance to vent. However, they did not do this as a personal attack upon the research group but rather to show their dissatisfaction with academic research in their community *per se*. After the performance, the engagement team facilitated a discussion that provided a space for the scientists to explain the scope and boundaries of their research programme, and how this prevented them from being able to provide the opportunities that were sought. Although the performance and subsequent discussion introduced some tension to the event, they did not undermine the process of two-way communication. On the contrary, these activities opened a difficult but needed conversation that generated important learning and understanding for the researchers, the Enkanini participants and the engagement team. The roleplay component reinforced the power of community-led drama to strengthen engagement in health science research (29).

Collaborative Films

The five films that were co-created with the focus groups allowed them to work together and convey their collective experiences of water shortage in their communities. The distinctive video-making paths undertaken by the two groups reflected their differing circumstances, difficulties, priorities, and aspirations. The films proved to be effective tools for discussion and debate at all the events, underlining the advantages of participatory video approaches to engagement in health science research (30).

Our Water Challenges evoked a strong reaction and a call for action amongst the Enkanini residents who attended the community mobilization event. At this moment the project had the greatest potential to take on a life of its own. However, the focus group's attempt to expand their awareness-raising campaign was blocked by their own lack of resources, and the 12 months duration of BLH offered limited scope to support their initiative. This is a common frustration, reflecting the fact that communities function as ecosystems within which external financial and other resources are a critical source of the energy required to sustain any initiative for change (11).

Participant Responses

Participants overall reported that they had enjoyed and benefited from the project. On a personal level, they felt validated and empowered by sharing their body maps and stories and indicated that they had gained important learning about water safety and water science. Strong interpersonal bonds were also formed among the Delft participants in particular. The desire to be included in decision making about research priorities was expressed by a focus group participant during the summative evaluation workshop:

> *"I find it ironic that research is only done when an issue becomes critical but never done before or when new developments are in the pipeline. Things that matter to us are not researched in a manner that involves or engages us as community members."*

In a reflection on the need for community engagement that involves listening to the experiences and perspectives of community members, participants expressed surprise and delight at the realization that they were able to teach the researchers something, as opposed to merely being the recipients of knowledge.

> *"The experience was eye-opening as I got to experience the more academic side of the water cycle and what efforts scientists are doing, but it was also surprising to realize how much knowledge the students got from us."*

The only major area of dissatisfaction expressed by the community members was a direct consequence of the relatively short duration and limited funding of the project. Members of both the Enkaninin and Delft focus groups expressed their aspirations to take their learning about water research from BLH further into their respective communities and lamented the lack of resources to allow this. Participants also conveyed regrets about the lack of scope to take their lived experiences of water shortage into interactions with other stakeholders.

An evaluation specialist who reviewed the project with the Delft participants noted:

> *"The group felt that they still had a lot to learn, they wanted greater interaction with more researchers, and they wanted to engage with the public more, telling their stories and informing community members about what they had learned."*

Research Team Responses

The research team entered the project with high enthusiasm along with a degree of trepidation. As one member noted in an evaluation:

> "*I was apprehensive at first particularly as I associated the project with social science. I do not always understand the reasoning or "Thought Process" of social scientists so I fully expected the interaction with the [engagement] team to be challenging. What did not help matters is that they wanted us to talk about our feelings during the hand-map session. My perception of the team changed when the first workshop [Knowledge Exchange Day] was presented to the Enkanini group and subsequently to the Delft group. This is when I became aware of how valuable the tools are that they employ."*

The project enabled the microbiology team to see the significance of their research in a new light and to acknowledge the value and ethical obligation of in-depth community engagement. After the conclusion of the project, the microbiology team leader decided to withdraw WRL activities from Enkanini. This was an unforeseen response and an unintended consequence of the engagement process. The research team did not retreat because they were dissatisfied with the BLH project. They did so because BLH had revealed to them that residents of the informal settlement were aggrieved about the lack of community benefits arising from research in Enkanini (*per se*). Through the CEI project the microbiologists also recognized that alternative water sources may not be a high priority for Enkanini community members, whereas greywater treatment strategies were urgently required.

> *"The high number of research projects being conducted in the settlement due to its proximity to the university made us realize that they [The Enkanini Project Participants] had every right to feel exploited.*"

Although the researchers seriously deliberated the possibility of including Delft as a new research site, because of the high rate of violent crime in the township the risks of doing fieldwork there were considered to be too high.

Engagement Team Responses

The engagement team was committed to allowing the community participants and researchers to shape the activities and outputs of the engagement process. This required holding back on fully defining the project design in advance which, although an effective approach, inevitably introduced a level of uncertainty and unpredictability. Through collective experience, the engagement team was able to facilitate a reflexive and adaptable process. We would advise others embarking on similarly open-ended projects to expect similar uncertainty and to build and capacitate their engagement teams accordingly. On reflection, and with regards to the two-way communication aspect of CEI, we would argue that core standards should include the possibility for feedback from all participants to alter the pathway of engagement. In addition, we regard that to be considered successful, CEI should result in the exchange of information that promotes new learning, is acknowledged as valuable and is actionable by those involved in the exchange process.

In its self-evaluation, the engagement team also noted its own positionality and limited diversity. The only person of color in the engagement team withdrew in the early stages of the project due to circumstances beyond his control and there were no fluent isiXhosa speakers in the team. The continual presence of a isiXhosa-speaking observer during the Enkanini workshops was valuable, as was the involvement of participants who were acknowledged community leaders or had previous experience as community-based researchers, which helped to mitigate disparities of power.

Constraints of the Study

From our perspective, a main methodological constraint of the project was linked to its time frame. There was a substantial imbalance between the time and effort required to generate the communication tools, especially those produced by the two community focus groups, and the actual interaction between the focus groups and the research team. Whilst the knowledge exchange days offered effective interfaces for mutual listening and co-learning, the one-day timeframe of these crucial events limited possibilities for reflection and whole-group discussions about appropriate and pragmatic responses to the learning gained by all participants.

The short duration of the project exhibition events also curbed the level of interaction between the participants and external stakeholders. Although these two forums provided a further opportunity for two-way communication between the research team and community residents, this opportunity was diluted by the presence of others.

We conclude that research institutions, as well as sponsors and funders (2) need to substantiate their professed commitments to community engagement by planning and budgeting for adequate time, support and resources to make such engagement meaningful. Neglect to do so risks the integrity of CEI and could foster a perception that community engagement is "Window Dressing".

The political nature of access to safe water and sanitation was a key conceptual driver for the project, and a core objective was to bring the everyday impacts of water shortage in the participating communities, and the research of the Water Resource Lab, to the attention of local government. The engagement team tried multiple times to invite influential representatives from the Department of Water and Sanitation (DWS) to the exhibition event in Delft. The department did send a junior officer who arrived after the community members had presented their body maps. The officer delivered a promotion of the municipal water-saving campaign which was inappropriate following the emotional presentations given by the focus group. Although taken to task by members of the audience, the government representative did not have the power to escalate the group's complaints about the challenges of enforced water restrictions to decision-makers in his department. The project was purposively carried out during the 2018 Western Cape water crisis and at that time, the CoCT DWS was under extreme pressure to respond to unprecedented drought conditions. It is likely that senior representatives of this department were therefore unavailable to attend events that did not directly address the crisis situation. Whereas, SLF did not have an established link with the DWS, the Foundation was connected with several other CoCT departments. Although it may have been possible to better draw upon these existing connections to link to senior officials in the DWS and organize meetings beyond the exhibition event (31) the circumstances at the time would probably have made this particularly difficult. This scenario provides an example of the challenges that community engagement projects face in being able to influence government responsiveness (32) especially when engagement is addressing a current emergency situation.

Surfacing Vulnerabilities

It has previously been shown that using participatory visual methods to explore connections with water and water governance can surface emotional responses (33, 34). The far-reaching consequences of water shortage surfaced deep and sometimes unanticipated vulnerabilities amongst the BLH community participants. Within the Delft focus group, the body mapping process revealed that a participant had witnessed the deaths of several family members in a house fire due to the lack of water to fight the blaze. Other participants offered strong support which enabled the activities to continue, and the engagement team arranged counseling as per SLF organizational policy. This outcome highlighted the ethical complexity of PVM practice in health science engagement (25, 35) and the need for levels of responsiveness that go beyond the conceptual boundaries of engaged research.

The project also confronted the research team members with their incapacity to make a difference in immediate and tangible ways. In most instances, research groups do not have the scope, training, or funding to be responsive to local populations' needs, conditions, and concerns, especially when these are largely structural in nature. This powerlessness can leave researchers feeling conflicted, ethically concerned, and unable to do what they feel is right (36) and may have detrimental effects on researcher motivation. Appropriate support structures such as debriefing and ethics discussion groups (36) for research teams and community members alike could substantively strengthen the outcome of community engagement initiatives. We would also encourage research groups to consider that moments of conflict and discomfort present opportunities for more meaningful engagement and should not be avoided or suppressed.

CONCLUSION

The BLH project has shown how the participatory creation of personal and collective visual materials, by both researchers and community members, can foster effective CEI and increase engagement integrity. Materials such as community maps, body maps, hand maps and tailored scientific presentations provided effective platforms for reciprocal listening and co-learning. Roleplay performance by community members helped to surface important points of tension and stimulate valuable and needed conversations. Visits to the Water Resource Laboratory were appreciated and enjoyed by the Enkanini and Delft participant groups, and further strengthened interaction and learning. The entire engagement process catalyzed verbal and active responses by the researchers and focus group members. However, further outcomes desired by participants were constrained for multiple reasons, including the limited timeframe and resources of the project and factors that were beyond the control of the community participants, the microbiologists and the engagement team. Policy engagement was almost entirely obstructed by a lack of acknowledgment from local government.

The project has shown that building engagement integrity through participatory visual methods requires a substantial initial investment of time and preparation, especially when engaging with marginalized communities. This can detract from the time available for knowledge exchange and public engagement. The case study also highlights the need for CEI to be reflexive and open to going in unforeseen directions.

The core standards recommended for CEI by global organizations (3, 4) carry no real weight unless participation, empowerment and ownership, inclusion, two-way communication, adaptability and localization, and capacity development are realized to the satisfaction of the communities where research is undertaken. Are funders, researchers, engagement practitioners, community members and government bodies ready to work in partnership and commit the time, energy, resources, and humility that will be required to achieve true engagement integrity?

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the Local Legislation and Institutional Requirements. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

The community case study was conceived and led by GB and PS contributed to the study design and facilitated the participatory workshops and engagement events. GB wrote the first draft of the manuscript. PS wrote sections of the manuscript. Both authors contributed to manuscript revisions, read, and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2022.794905/full#supplementary-material

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Challenges and Lessons Learned in the Development of a Participatory Learning and Action Intervention to Tackle Antibiotic Resistance: Experiences From Northern Vietnam

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Antibiotic use in the community for humans and animals is high in Vietnam, driven by easy access to over-the counter medicines and poor understanding of the role of antibiotics. This has contributed to antibiotic resistance levels that are amongst the highest in the world. To address this problem, we developed a participatory learning and action (PLA) intervention. Here we describe challenges and lessons learned while developing and testing this intervention in preparation for a large-scale One Health trial in northern Vietnam. We tested the PLA approach using community-led photography, and then reflected on how this approach worked in practice. We reviewed and discussed implementation documentation and developed and refined themes. Five main themes were identified related to challenges and lessons learned: understanding the local context, stakeholder relationship development, participant recruitment, building trust and motivation, and engagement with the topic of antibiotics and antimicrobial resistance (AMR). Partnerships with national and local authorities provided an important foundation for building relationships with communities, and enhanced visibility and credibility of activities. Partnership development required managing relationships, clarifying roles, and accommodating different management styles. When recruiting participants, we had to balance preferences for top-down and bottom-up approaches. Building trust and motivation took time and was challenged by limited study team presence in the community. Open discussions around expectations and appropriate incentives were re-visited throughout the process. Financial incentives provided initial motivation to participate, while less tangible benefits like collective knowledge, social connections, desire to help the community, and new skills, sustained longer-term motivation. Lack of awareness and perceived importance of the problem of AMR, affected initial motivation. Developing mutual understanding through use of common and simplified language helped when discussing the complexities of this topic. A sense of ownership emerged as the study progressed and participants understood more about AMR, how it related to their own concerns, and incorporated their own ideas into activities. PLA can be a powerful way of stimulating community action and bringing people together to tackle a common problem. Understanding the nuances of local power structures, and allowing time for stakeholder relationship development and consensus-building are important considerations when designing engagement projects.

Keywords: AMR, PLA, community, participation, partnership, trust, engagement, Vietnam

INTRODUCTION

Antibiotic resistance is a global public health problem that threatens modern medicine, and is projected to result in 10 million deaths a year by 2050 as well as $100 trillion USD cumulative economic costs if not tackled now (1). In 2019, an estimated 1.27 million deaths were attributed to bacterial antibiotic resistance (2). Resistance occurs naturally, but is amplified by the use of antibiotics for human and animal health, as well as environmental contamination through wastewater, sewage and manure (3). Between 2000 and 2010, worldwide antibiotic consumption increased by 35%, including large rises in use of last-resort antibiotic drugs, particularly in middle income countries (4).

Antibiotic resistance in Vietnam is amongst the highest in the world, driven by high levels of antibiotic use for both humans and animals (5). The use of antibiotics in farming accounts for 72% of total antibiotic consumption in Vietnam (6), and of the 28% used for humans, most antibiotics are used in the community, outside of hospital settings (7). Antibiotic sales from private pharmacies make up a large part of community antibiotic consumption (8) and 90% are without prescription (9).

Despite the large consumption of antibiotics outside of formal healthcare settings, the National Action Plan on Combatting Drug Resistance (NAP) 2013–2020 compiled by the Vietnam government (10), mainly focused on antibiotic stewardship and surveillance of antibiotic resistance in tertiary hospital settings. Although raising awareness around antimicrobial resistance (AMR) in the community was included in the NAP, there were no clear policies or targets related to this component, no attention to participation or collaboration, and it did not result in any significant community-level awareness or actions (11).

AMR has been described as a "super-wicked problem" because of the inherent complexity. There are numerous interrelated biological and social drivers, multiple local, national and international stakeholders across different policy sectors, and several conflicting goals that might each be reasonably pursued (12). The drivers of inappropriate antibiotic use are multifactorial, and a problem with complex and interrelated drivers requires complex social interventions, including components that seek to tackle antibiotic use in the community and farming.

Community participation is a major component of people-centered health systems (13), and is enshrined as a key principle in the Alma-Ata Declaration (14). Interventions that mobilize communities through participatory action-oriented approaches have been widely and successfully used to address complex social drivers of poor health outcomes for maternal and child health (15) and other health domains (13). These approaches work through active learning and collective problem-solving to change behaviors and social norms, and have been recommended by The World Health Organization (WHO) for promotion of maternal and newborn health (16). We use "participatory action-oriented approaches" as an umbrella term to discuss several related approaches, including participatory learning and action (PLA) (15), participatory action research (PAR) (17, 18), and community-based participatory research (CBPR) (19). These approaches are inspired by the work of Paulo Freire, Robert Chambers, and others (17, 20), and all have in common the aim of engaging community stakeholders in order to produce meaningful social change, using methods that can empower participants through a bottom-up approach to generate locally appropriate solutions (21). Generating local data for what is or is not working provides a powerful feedback loop, engenders a strong sense of ownership, and fosters an appreciation for the importance of evidence to inform decision-making. Participatory action-oriented approaches may work synergistically with education-based interventions to create sustainable, population-wide changes in knowledge and behavior.

Due to the low priority given to the community components of the NAP in Vietnam, few activities have been undertaken at this level, and there is a huge need to improve understanding and change behavior toward more appropriate use of antibiotics. Interventions that target antibiotic use in the community in other countries have mostly used passive health education approaches, through mass media campaigns, posters, leaflets and websites (22, 23). One Health interventions, working across disciplines to attain optimal health for people, animals, and the environment (24), have also mainly targeted leverage points that are low in the causal chain, without addressing the more distal drivers of the emergence and transmission of AMR, or the context within which antibiotics are used (25). Where there is a complex interplay of social, cultural and economic factors, active engagement of communities, farmers, and health professionals in solving problems may provide a more powerful way to stimulate action, accelerate behavior change, and create context-specific solutions, than simply increasing knowledge (14). Community engagement has been recognized as a promising method to win the fight against AMR because it empowers communities to look for solutions that best suit their context. WHO has recommended the use of community-based actions for raising awareness of AMR and changing behaviors (26), Wellcome Trust has developed a Responsive Dialogues approach (27, 28), participatory film projects have been used in Bangladesh and Nepal (29, 30), and other creative approaches to disseminating AMR knowledge to the public such as visual arts, museum collections, and science books have been implemented in the UK (31). A framework for community engagement for AMR identified sustaining and scaling up engagement interventions as a key challenge (32). A pilot study in Bangladesh using a community engagement approach to co-produce an intervention to tackle AMR reported that co-production of the intervention processes and materials with key stakeholders at policy, health system, and community levels and consideration of the health structure and socioeconomic and cultural context when designing the approach are needed to make the approach scalable (33). However, so far, there is limited evidence for the effectiveness of community engagement approaches toward appropriate antibiotic use compared to more traditional education-based approaches, or for understanding the pathways and facilitating conditions for successful behavior change using this approach.

To address the gaps we identified in the AMR agenda, including little attention paid to antibiotic use in the community, and the lack of evidence for the effectiveness of community engagement approaches to tackle AMR, we designed a multi-component One Health trial with collaboration across sectors. One of the intervention components involves PLA, and here we explore challenges and lessons learned from our formative research developing and testing this intervention component.

MATERIALS AND METHODS

Study Population and Context

Vietnam's administrative structure is made up of 63 provinces, each divided into districts. Districts are further sub-divided into communes, which are made up of several villages. The People's Committee oversees governance at provincial-, district- and commune-level, and each commune has a People's Committee leader and a commune health center.

The research reported here was done in Vu Ban and Giao Thuy Districts of Nam Dinh Province. Nam Dinh is located in the Red River Delta, northern Vietnam, with high levels of antibiotic use in communities (34), and is a known hotspot for AMR (35). Nearly 80% of the population live in rural areas, with an average gross regional domestic product (GRDP) per capita of approximately $1,899 in 2020 (36). The Antimicrobial stewardship agenda had not reached the provincial or district hospitals in Nam Dinh, or into the lower-level commune health centers (37, 38). There had previously been research evaluating interventions targeting antibiotic prescribing in primary care in other districts in Nam Dinh Province (34), but no interventions targeting antibiotic consumers, and no interventions or awareness-raising activities at all in the two districts in which we worked. Target participants included primary caregivers of children under 5-years, women, and farmers. These populations were chosen to represent key groups with knowledge on antibiotic use and healthcare within households and farms.

The research partnership was between Oxford University Clinical Research Unit (OUCRU) (a registered non-profit, research institution in Vietnam), and the National institute of Hygiene and Epidemiology (a national-level health institution). In line with the government administrative structure, the study was managed by health institutions at the provincial-, district- and commune-level. For coordination and logistics, the OUCRU study team worked with all levels of administration. For implementing activities in the communities, the OUCRU study team worked directly with study participants at the village level. The study team included two supervisors, four research assistants, and a study coordinator. Two research assistants stayed in Nam Dinh, while the other two and the study coordinator stayed in Hanoi, and only traveled to the study areas for implementation activities. Prior to implementation, all staff attended a 1-week training on Participatory Action Research organized by OUCRU and PRAXIS UK, but for many of the team, this study was our first experience using the approach in practice. The study team had limited previous experience in planning and implementing such a large and complex study involving stakeholders from different governmental levels. All of the activities happened during the COVID-19 pandemic.

Design

The study we report here was conducted during the development phase of a large-scale One Health trial, aiming to reduce antibiotic use and promote preventive behaviors in healthcare, community, and farm settings. The aim of this development phase study was to pilot a PLA approach and integrate community and partner ideas about using this approach into the development of an intervention for one component of the One Health trial. The lessons learned from this formative experience are reported in this paper.

Our participatory learning and action approach incorporated Photovoice methods as a tool to visually explore the issue of antibiotics and AMR in the community. The Photovoice study used a range of participatory tools and group activities, photo-taking, and discussions about the photos to facilitate exploration of current practices and understanding around antibiotic use and AMR. Photovoice was used as a method to stimulate discussions, provide insights into important issues, and as a medium for participants to share what they learnt with the wider community and raise awareness about AMR. Photovoice methods align well with the PLA approach, as Photovoice seeks to empower participants through active learning, using a bottom-up approach to generate community action (39, 40). However, as this was a formative research study, we did not have time to continue with PLA as an iterative process to support other community actions to tackle AMR.

We planned the study together with the National Institute of Hygiene and Epidemiology. They helped us to organize introduction meetings with local stakeholders from provincial, district, and commune levels, where we introduced the study's purposes and objectives and discussed the logistics. We started in November 2020 with the selection, by local government partners, of one commune from each of two districts in Nam Dinh Province. Two villages were selected from each commune by the study team (four villages in total). Women's groups were formed in two villages that had access to the commune health center and many pharmacies, and farmer's groups were formed in two villages that had livestock production and veterinary supply shops. A combination of purposive and self-selection sampling was used to identify a total of 26 participants across the four villages. The number of participants was determined by the number of cameras available. Participants were informed about the purpose and requirements of the study and gave their written consent to take part.

The Photovoice process consisted of seven meetings and a photo-taking period (**Table 1**). After the mass village meetings, a meeting was held to introduce participants to each other, share expectations and establish group ground rules. In this meeting, we introduced the topic of antibiotic use and AMR, discussed the situation in the community, and provided basic concepts of photovoice and photography techniques. Participants were asked to take photos capturing real situations related to antibiotic use in their community and in livestock production over a period of 2 weeks. After taking photos, the groups came together again and shared their experiences of taking photos and the issues they encountered related to antibiotic use and AMR. There were two rounds of photo selection: the first round was to individually choose favorite and topic-relevant photos and provide narratives; and the second one was to agree on core issues and themes and select photos for the exhibition. In the following meetings participants discussed how to share the stories about antibiotics and AMR with the wider community so that they could encourage appropriate antibiotic use and improve health in their communities. They developed a plan, organized, and held a community exhibition for sharing the photos and raising awareness about AMR. One exhibition combining the photos from women's and farmers' groups in one commune was held, and two separate exhibitions were held for women's and farmers' photos in the other commune. These were followed by wrap-up meetings to acknowledge participants' contributions, gather feedback on their experiences of taking part, and discuss potential follow-up and cooperation between participants, local stakeholders, and authorities to tackle the issue of AMR.

Data Sources and Development of Themes

We wanted to learn from the Photovoice study about how best to implement a PLA intervention to tackle AMR, so we held extended reflections and discussions about the process of implementing the study and summarized challenges and lessons learned. We made use of sources of information that arose during the process of development and implementation of activities, rather than transcripts from discussions and meetings themselves. These included field notes, photos, informal discussions, and observations, as well as participant, stakeholder, and partner feedback. After each activity, a report was written by the study team to summarize the activities and issues that arose. Reports were based on field notes, observations, and audio recordings of discussions. We also held regular debrief sessions after field activities, in which the study team reflected on implementation challenges and community engagement. Meetings were documented in minutes and meeting notes. Six researchers listed the main challenges and lessons learned that were identified in the above data sources regarding the development and implementation of the community engagement studies. One of the researchers categorized the challenges and lessons learned into preliminary themes. Then five researchers reviewed, discussed and revised the themes and definitions of each theme through a process of reflection and exchange over the course of 22 virtual meetings. Participants and partners were invited to provide feedback on the final themes identified as challenges and lessons learned. The final themes are presented below.

RESULTS

The challenges we identified were grouped into five main themes. These themes are summarized in **Table 2**, and include understanding the local context, stakeholder relationship development, participant recruitment, building trust and motivation, and engagement with the topic of antibiotics and AMR. For each theme we illustrate with examples and discuss the lessons learned that could be applied to address these challenges and enhance opportunities for listening and responding when scaling up this approach.

Understanding the Local Context

Prior to developing and implementing community studies, it is important to understand the local contexts in which the studies will take place. We encountered challenges related to accessing background information, local terminologies, and navigating the process of forming local partnerships.

We began the development of our study by conducting desk research to gather information about the situation related to antibiotic use and AMR in the study area, as well as to provide a general understanding of the economic, socio-cultural, and health contexts of the target populations. However, while some economic reports were available, it was hard to obtain government-published data and reports about the use of antibiotics and the context of AMR in the province. This led to a lack of understanding about the local context by the study team at the beginning of the study resulting in difficulty asking questions in the right way, or about the right things. For example, we were not aware that many pig farmers had lost their animals to recent bouts of swine fever and were no longer engaged in large-scale pig-farming. But this naivety also provided an opportunity for us to ask very basic questions about local healthcare and farming practices with genuine interest, and with fewer pre-conceptions about what we expected to find. We sought additional local information from our partners, and made use of our own research data on antibiotic knowledge and use to fill the information gaps.

While all researchers who worked with the communities spoke Vietnamese, there were some local terms and nuances they did not understand. Misunderstandings may have influenced initial levels of engagement and our ability to communicate meaningfully with participants. To solve the language problem, we developed a local vocabulary through our discussions with participants, including terms relevant to daily life as well as AMR. This local vocabulary also gave us insights into people's behavior. For example, we understood there was an expectation to receive

TABLE 1 | Outline of meetings held in the Photovoice study.

Meeting	Topic	Activities
1	Mass village meeting	- Public gathering - Introduce the study to community members - Recruit participants
2	Introduction and camera training	- Get to know each other - Develop group ground rules and explore participants' expectations - Discuss the aim of the study - Screen video clips about the use of antibiotics and AMR in Vietnam and discuss the issues in their communities - The basics of the photovoice method - The basics of photography and camera usage - Discuss ethical considerations and consent when taking photos
3	Photo-taking (2-weeks)	- Take photographs of antibiotic use in the local community
4	Individual photo selection	- Share photo-taking experiences and issues encountered related to antibiotic use and AMR with the group - Individual review process: - Each participant reviews and writes narratives about their photos, and selects meaningful photos
5	Group photo selection	- Share selected photos and stories about antibiotic use and AMR with the group - Group agrees collective issues and themes - Group selects final photos and stories for exhibition
6	Exhibition plan	- Discuss how to share the stories about antibiotic use and AMR with the wider community to change behaviour and improve health - Discuss venue, time, visitors and invitations, refreshments, reception, other logistics issues - Plan the exhibition layout - Allocate tasks to team members
7	Exhibition	- Hold an exhibition to raise awareness about AMR in the local area
8	Wrap-up	- Present the study summary report to participants, stakeholders, and the local authority - Recognition of participation - Discuss how the results can be used by participants, and local authority to increase awareness about AMR and build a heathier community

drugs for treatment when people go to primary healthcare centers, because they usually said, "they go to ask for medicine" instead of, "they go to see the doctor." Through our discussions and engagement with participants, we gathered more local information and learned context-specific terminologies related to antimicrobial treatment and healthcare-seeking behaviors. It took time to develop this contextual understanding, but it helped us to communicate better and develop more suitable engagement approaches and messages.

At the partnership level, the dynamics of working relationships are highly influenced by historical, political, and cultural contexts, but these are rarely documented or explicit. The study team initially lacked understanding of the communication and operational structures of the health system. An example of this was our underestimation of the importance of dining with partners as way to establish relationships. Being bounded by our organizational and funding structure meant that we missed this opportunity to build rapport with our partners at the initiation of the study. Not understanding the local nuances of working relationships made it difficult to establish partnerships and efficient cooperation.

Stakeholder Relationship Development

Antimicrobial resistance is a complex issue demanding cooperation between multiple sectors as well as vertical coordination between national and grassroots levels. There is a longstanding relationship between OUCRU and the National Institute of Hygiene and Epidemiology, but in order to engage with communities we had to establish new relationships with local authorities inside and outside the health system, at provincial, district, and commune levels in the study area, where neither partner had existing relationships. We encountered challenges related to how to build strong relationships including working effectively with multiple stakeholders, balancing top-down and bottom-up working styles, clarifying roles, and recruitment and retention of local staff with the right combination of skills to coordinate study activities.

Our aim was to engage with community members, and to reach communities, we had to work with multiple stakeholders. Navigating the power and culture dynamics of working with multiple stakeholders required paying attention to each partner's experiences and expectations. Stakeholder preferences about study design and communication, as well as their experience working with the community varied. For example, we planned informal and interactive introduction meetings to create a friendly atmosphere, but this gave the sense that we were unprofessional, and we were advised afterwards to follow a more formal format in such meetings. In general, national-, provincial-, and district-level stakeholders preferred more hierarchical top-down management and formal communication. Meanwhile community-level stakeholders valued familiarity and kin connections and were more comfortable with informal interactions. Local stakeholders provided legitimate entry

TABLE 2 | Summary of challenges and lessons learned.

Themes and sub-themes	Challenge	Lessons learned
Understanding the local context		
Accessing background information	- Limited availability of health-related data about antibiotic use and AMR affected understanding of local context	- Gathering local information improves contextual understanding. Local partners can help to provide information that is not online, and where feasible, surveys and interviews can fill information gaps
Understanding local language and practice	- Study team not familiar with local terminologies and health-related or farming behaviours	- Learning context-specific terminologies, and developing a local vocabulary improves understanding and engagement
Understanding the context of partnership	- Study team not familiar with the local nuances of building relationships with partners	- It is important to understand local working dynamics and practices to build effective partnerships
Stakeholder relationship development		
Working with multiple stakeholders	- Navigating the power and culture dynamics of working with multiple stakeholders with different experiences and expectations can be complicated	- Multistakeholder partnerships have many advantages, including providing legitimate entry to communities and providing guidance and support for implementation of study activities - Feedback from different stakeholders can shed light on what did and did not work in the study, leading to stronger relationships and better implementation of future work
Balancing top-down and bottom-up approaches	- Top-down approaches are the norm for government partners, but are contrary to PLA approaches which require engagement and shared decision-making from the bottom-up	- It is important to take time to build consensus on the value of community engagement and using a bottom-up approach - In order to establish a trusting partnership with high-level stakeholders it may be necessary to strike a balance
Clarifying roles	- The involvement of different stakeholders in the local government management hierarchy proved to be more effective at specific stages of the study than at others - Most attention was given to encourage participation among community participants, and local stakeholders did not clearly understand the vision and methods of participatory research	- Taking time to listen and clarify roles - Identify at which stages of the study cycle each stakeholder should be involved - Involve local stakeholders in decision-making and establishing the shared vision so that they can be more actively involved
Recruiting local staff	- Lack of study team presence in the province and community make it difficult to develop partnerships - Difficult to find staff with both local knowledge and connections and experience of community engagement approaches	- Having local study team members helps to develop relationships with local partners and embeds the study in the community - Continuity of study team members has an impact on relationships with local partners and should be sustained where possible
Participant recruitment		
Recruiting participants	- Purposive sampling is the preferred approach for local and national partners, but is contrary to methods used for participatory learning and action (PLA) in which participants self-select to take part - Participation by self-selection was not always possible due to logistical and time-constraints	- For short-term projects purposive sampling is sufficient, but need to be aware of introducing possible biases - For longer-term engagement projects, taking the time and effort to negotiate and implement participation by self-selection is important - Working closely with local partners to build trust and explain the study and recruitment objectives is crucial for either approach
Building trust and motivation		
Establishing trust with participants	- It was difficult to establish trust due to limited personal interactions, lack of pre-existing connections with the community, and lack of understanding of local context - The study team lacked professional or technical expertise related to health or farming, and our organization was unknown in the study area	- Working with local stakeholders can provide access to their networks and facilitate personal connections - Working with local stakeholders who are trusted and have professional expertise can give credibility to establish relationships and legitimate entry into communities - Previous experience with projects and consent processes also have an important influence on trust
Building rapport between participants	- We needed to establish a safe and trusting environment among the members within each group to allow for open discussion	- It is useful to establish collective ground rules about how the group will work together and re-visit them throughout the process

(Continued)

TABLE 2 | Continued

Themes and sub-themes	Challenge	Lessons learned
Aligning expectations	- Misalignment of expectations in terms of what the study could deliver may have negatively affected motivation	- It is important to discuss participants' expectations and clarify any areas of misconception throughout the study
Maintaining motivation	- There were different levels of motivation and engagement between the groups related to local context, past experiences, competing priorities, recruitment processes, and disruptions - There was an expectation of financial incentives for participation, but this is not something that can be sustained for long-term participation, and creates a power imbalance - Participants expected non-financial incentives in the form of knowledge about health and medical care, but this was not included in our study activities	- It is important to explore and acknowledge differences in motivations and be flexible and responsive to these differences - Financial incentives may be useful for short-term engagement or specific activities - Discussion with participants and stakeholders about motivations for participation can provide ideas about suitable non-financial incentives - Incorporating training or health promotion sessions in engagement activities could provide a strong non-financial incentive for participation
Sustaining longer-term engagement	- Intangible benefits in the form of collective knowledge, social connections, skills, and confidence are less easy to communicate as benefits at the beginning of a study	- Intangible benefits may contribute the most toward sustained engagement in the longer term
Motivation during COVID-19 disruptions	- Movement restrictions dues to COVID-19 prevention measures disrupted some planned activities and made sustaining motivation challenging	- Listening to concerns and following participants' lead on when face-to-face activities could be held ensures participants are comfortable with planned activities - It is important to maintain relationships by keeping in touch about the situation and plans by phone and instant messaging
Engagement with the topic of antibiotics and AMR		
Understanding of AMR	- Limited knowledge about antibiotics and antibiotic resistance was a barrier to engaging with communities on this topic - Participants initially thought that overuse of antibiotics was not a threat, or that it was only a threat for other communities, and not relevant to them	- Careful consideration of local terminology and understanding makes communication clearer - Identifying pre-existing health concerns and showing how antibiotic overuse and resistance are related makes the issue more relevant - Sharing experiences related to antibiotic use revealed that there were impacts closer to home
Ownership	- The project was introduced to the community as a topic they didn't know very much about, but one that we wanted them to take the lead on	- A sense of ownership emerged as the study progressed and participants understood more about the issue and saw their ideas being incorporated into activities

to communities and provided guidance and support on implementation of study activities. Feedback from different stakeholders provided different perspectives and ideas for improving implementation of future work.

The top-down approach preferred by government partners enabled decisions about study implementation to be transferred smoothly from national-level partners to local stakeholders, and gave us the credibility to establish a relationship with local authorities. On the other hand, the preference for top-down management created a challenge in using a PLA approach, which requires bottom-up engagement, involving stakeholders in the study development and implementation process. The prevailing top-down working style made it difficult to encourage an active role in research to those who were more familiar with being involved passively, and they found the bottom-up-approach complicated and time-consuming. It took time to build consensus about using a bottom-up approach, and in order to establish a trusting partnership with national and local partners we had to strike a balance between top-down and bottom-up approaches.

We discussed the breadth and depth of participation with partners through open dialogues to share ideas about the research objectives, ethics, engagement method, logistics, and expected outcomes. This continuous cycle of communication occurred over a period of time, with some disruptions and delays due to administrative processes and COVID-19. The involvement of different stakeholders in the management hierarchy proved to be more effective at some stages of the study than at others. For example, it was necessary to have interactive participation of local stakeholders at every stage in the community engagement process, while stakeholders at national and/or provincial level could participate in the consultative process during the introduction and evaluation phases more than the implementation period. We encouraged shared decision-making with partners throughout the research process, but it was not always successful. We informed partners of our plans and listened to their suggestions and feedback, but they did not clearly understand the participatory method and our vision for using this method for the study, so their participation was passive and mostly took the form of responding to our questions and requests. On reflection, we had failed to engage with local authorities as equal research partners and found that determination of how much involvement and participation was required on what issues and at what stages should be carefully thought through.

Our lack of presence in the study area made the formation of personal relationships with local partners and study communities challenging. This arose due to difficulties recruiting and retaining qualified local study staff so that most activities were managed from Hanoi, and was further exacerbated when staff outside the study area were not able to travel due to COVID-19 restrictions.We tried to recruit local staff who understood the local context, culture, and language, and were already well-connected with local authorities and communities. In order to liaise between the research organization and local stakeholders, a combination of skills in community engagement, facilitation, diplomacy, and project management are required, as well as the ability to communicate in both Vietnamese (local language) and English (language of the research organization). However, it was difficult to identify local candidates with the right combination of skills, and desired candidates were more likely to be based in larger cities and were reluctant to relocate to the provincial town. A high staff turnover in this position caused negative effects on partnership development, due to different working styles, disrupted communication, and difficulty establishing a stable working relationship with partners.

Participant Recruitment

Challenges in recruiting participants were related to achieving the right balance between different approaches, each approach having advantages and disadvantages (**Table 3**). Local partners preferred to assign participants, but participants in PLA activities usually self-select or volunteer to take part, and this was considered a pre-requisite to develop a sense of ownership of the study activities. In the Photovoice study, participation over several months was required, and we wanted participants to have the opportunity to volunteer (self-selection sampling), rather than be assigned by local authorities. Consultations were held with local authority representatives and mass meetings were held in three villages to introduce the study, explain what would be involved for participants, and invite volunteers to take part. Seven participants volunteered from each village, making 21 in total. In the fourth village, it was not possible to hold a large gathering, therefore local commune officers purposively selected five participants. These participants were also informed about the study requirements and gave their written consent to participate. Here we outline the challenges and opportunities of both purposive and self-selection sampling methods.

Purposive Sampling

Purposive sampling has several advantages, including being quick and simple, and allowing local partners to recruit the most "qualified" participants. They proposed that these participants would benefit the study the most and also act as ambassadors providing positive reflections of the community. For the purposively sampled farmers' group, the local commune authorities were provided with information on the nature of the study and recruitment criteria. The local authorities proposed adding selection criteria, including good communication skills and experience, so that the participants would perform better and produce better study outcomes. Although the study team preferred to keep minimal exclusion criteria, the local authorities may have consciously or unconsciously applied their own. With such open criteria, among numerous eligible candidates, individuals with a personal relationship, position associated with their profession, or involvement in government bodies might have a higher chance of being selected. For example, among five of the assigned farmer participants, three farmers were commune officials and two others were heads of farmer groups in two villages. Although all of them met the recruitment criteria, they did not represent the general population well and their levels of motivation and engagement differed from self-selected participants (see Building trust and motivation below).

Using the locally accepted recruitment approach provided an opportunity to develop relationships with local partners, by "doing things their way." Through this, we acknowledged the valuable knowledge of local partners about the community. As a new organization in the area, having the local authorities recruit participants helped to alleviate people's suspicions, and enhance the perception and credibility of the study. To reduce bias with purposive sampling, and obtain more generalizable results, it is crucial to work closely with local partners to develop mutual trust, explain study objectives, and clarify recruitment criteria.

Self-Selection Sampling

Self-selection sampling can take longer than purposive sampling and have a higher risk of failure to identify participants. There were practical challenges to the success of this non-coercive recruitment process, and here we outline two of these.

Firstly, this approach required the study team to invest more time, resources, and preparation as we needed to organize mass meetings to introduce the research and recruit participants instead of relying on the local partners. Moreover, we had to plan for two possible scenarios: not recruiting enough participants through the mass meetings to ensure good group dynamics; or having too many people who wanted to join and managing disappointment.

Secondly, people were hesitant to volunteer for this study, and we identified three main reasons for this: guardedness about working with a new organization, perceived lack of relevance of AMR, and perceptions of their own personal capacity. People in one village were initially suspicious of us as strangers in the area (see Establishing trust with participants below). People who thought the research did not resonate with or provide direct health benefits to them, their family, or their community, doubted its relevance, and were reluctant to take part (see Engagement with the topic of antibiotics and AMR below). Furthermore, potential participants were hesitant to believe in their own capacity to provide valuable input or expertise. Those with little or no educational background were reluctant to volunteer, although the inclusion criteria clearly highlighted that there was no requirement related to personal qualifications.

Overall, purposive sampling was sufficient for short-term participation, but self-selection was more appropriate when intense participation and commitment over a longer period was required, and there were advantages and disadvantages of both approaches (**Table 3**). The level of engagement and

TABLE 3 | Summary of advantages and disadvantages of different sampling approaches.

	Purposive sampling	Self-selection sampling
Management style	- In line with top-down management, which is more in tune with local government approaches	- In line with bottom-up management, which is more in-tune with PLA approaches
Partnership	- Provided an opportunity to develop relationships with local stakeholders, and provided official endorsement for the study	- Enabled better development of relationships with communities and participants
Logistics	- Quicker and simpler for local partners to implement	- Required more time and resources to organise mass recruitment meetings
Recruitment	- The right number of participants were recruited	- Had to plan for the possibility that too many or too few participants would volunteer
Selection	- Introduced bias, such that participants did not reflect the population we wanted to engage	- Participants were hesitant to join due to lack of familiarity with the organisation, lack of perceived relevance of AMR, and perceived lack of personal capacity
Engagement	- Participants were less flexible about meeting times - Some participants did not fully participate or contributed little to discussions	- Flexibility on time and duration of meetings - Dynamic discussions with involvement of all participants
Outcomes	- Photos and narratives were more superficial and did not explore the topic in depth	- Photos and narratives captured thoughtful stories about the topic

participation was higher from the self-selected groups than purposively selected. For example, the dynamics in the discussion were much easier in the self-selected groups and they did not worry about the time/length of the meeting. There was less flexibility in meeting with the farmer's group that was assigned, as their main source of income was salaried employment not farming, and they had other work to do. Several of these farmers did not fully participate in the discussions, contributed little, and were less enthusiastic about the study topic. Both self-selected and purposively selected participants took similar numbers of photos, but the topics were different. Participants in self-selected groups took photos and wrote narratives that contained more thoughtful stories about inappropriate antibiotic use. These self-selected farmers were owners of big farms, so they had decades of experience in livestock production and were more reflective of the issues.

Building Trust and Motivation With the Participants

We identified six sub-themes related to trust and motivation, including establishing trust with participants, building rapport between participants, aligning expectations, maintaining motivation, sustaining longer-term engagement, and motivation during COVID-19 disruptions. Issues around trust and motivation also related to our initial lack of understanding about the local context (as previously discussed) and engagement with the topic of antibiotics and AMR (discussed in the following section).

Establishing Trust With Participants

We were able to leverage the pre-existing relationships and trust that participants already had with local authorities and partners. Mass meetings were endorsed and attended by local authorities, or purposively selected participants were invited by local authorities. As part of the consent process, participants were provided with information about the study, and informed about the ethical approval by a national-level institution, which further extended their trust. To reinforce their initial acceptance and build personal trust, we took time to build rapport and create an open and comfortable atmosphere for sharing ideas at the beginning of each discussion with general conversation and interactive activities. This approach allowed rapport to evolve at a pace the participants were comfortable with.

The main challenges related to establishing trust between the research team and participants were that there were limited pre-existing connections with the community, and there were limited personal interactions due to a lack of study team presence in the area and movement restrictions due to COVID-19. We were not able to spend enough time with and in the study communities to become involved and establish strong trust with them, and we had to rely on local partners to maintain interactions. Our organization is recognized globally for health-related expertise, but participants had not heard of the organization. Additionally, the team did not possess specific professional or technical qualifications related to health or farming that gave us independent credibility, so we relied on our local partners to lend credibility to our study and provide access to their networks. We then gradually built up trusting personal relationships.

Previous experience with fraudulent projects negatively affected trust, in one village. These previous experiences made local authorities and communities suspicious of outsiders, and we had to work harder to recruit participants from the public meeting, and also to build trust with the women's group in that village. It seemed to be easier to build trust with farmers, as animal health was a less sensitive issue than human health, and perhaps less prone to confidence trickery. However, one farmers' group was also assigned to participate, and for this group their trust was an extension of their trust in the local authorities who assigned them. Consent and permission also played a role in establishing trust and were sought before recording any discussions, making materials public. Trust was further developed as we delivered on the study objectives we had outlined and shared photos and stories in a meaningful way with the wider community.

Building Rapport Between Participants

PLA usually requires participation during a series of meetings over several months. In the Photovoice study we needed first to establish a safe and trusting environment, and then build social connections among the participants within each group to allow for open discussion during meetings. Although participants lived in the same village and already knew each other, their relationships were not close enough to make them feel comfortable to share their perspectives about antibiotic use behaviors, especially inappropriate practices. This applied to both women's and farmers' groups.

The series of meetings began with group formation, exploration of participants' expectations, and establishing ground rules. Each group established a set of ground rules which was agreed by all group members. Ground rules differed between groups, but key principles included confidentiality, being respectful, listening to each other, and having an encouraging and learning attitude. Throughout the implementation period, group discussions, and teamwork activities were conducted in adherence to group ground rules, which helped to reinforce trust between group members. Participants' perspectives were considered equal, with no voice carrying more weight than others during the decision-making process.

Aligning Expectations

It was important to discuss participants' expectations and clarify misconceptions at all stages of the study, in order to maintain trust and motivation. To better understand individuals' needs and to facilitate participants working toward shared goals, we explored personal and group expectations. Expectations did not always align with what we were able to deliver, which may have affected motivation (**Table 4**). For example, some participants expected a professional training on health promotion or good farming practices. This was particularly the case for women's groups, who wanted specific guidance on which antibiotics to use for which illnesses when their families were sick. At the start, we explained that we could not offer this kind of training. Some participants remained motivated to work with us, but not all participants remembered this point, and we had to re-visit their expectations during implementation. We explained how participation could help them and their communities to learn more about antibiotics and antibiotic resistance through a process of shared learning rather than a one-off training session. Farmers had a lot of farming experience and seemed to be more satisfied with exchanging ideas about farming practices with each other. During the wrap-up meeting we reviewed the expectation list and evaluated what they received and what we had achieved together. A continuous process of explaining and addressing misconceptions in expectations enhanced engagement and cooperation.

Maintaining Motivation

Maintaining motivation was an ongoing process which required adapting the study design to listen and respond to the community effectively. The most visible indication of lack of sustained engagement was the drop-out of participants in the middle of the study (5 of 26 dropped out). The main reasons for drop-out were not related to trust or motivation, but to competing priorities, such as personal and family issues. In most cases, these activities were not something the study could or necessarily should compete with. But, in order to sustain participation and minimize conflicting engagements, we made the meetings as convenient as possible for participants, by arranging them at times and locations decided by them, to fit into their schedules. This often meant that meetings were scheduled late in the evening or on the weekend. There were different levels of motivation and engagement between the groups, and this was influenced by different prior experience with external projects, different socioeconomic contexts, personal priorities, the sampling strategy, and disruptions to planned activities. Being flexible and responsive to these differences was important.

We think that when deciding whether to take part and to continue to participate, participants had to balance the costs and benefits. Their decisions may have been influenced by incentives and other perceived study benefits, prior expectations about payments from international organizations, as well as the participants' competing priorities, value of their time (e.g., in the form of lost income opportunities), and socio-economic background. We provided financial incentives in the form of reimbursements for transport and time during activities. Some participants said they were reluctant to attend activities unless there were financial incentives, or they only took part in meetings peripherally until they received reimbursements. Financial incentives also acted as a bond with the study. This bond may have encouraged participants to engage in the activities, but also signified a commitment. One farmer returned the reimbursement when he withdrew from the study, explaining that he had broken his commitment and did not deserve the incentive. The importance of financial incentives as a motivation for participation differed between communities, and we hypothesized that this was due to different selection processes, prior study experiences, as well as socioeconomic and other contextual differences.

There were disagreements about incentives between the study team and local and national partners. We listened and asked for advice from our partners and participants, to understand the different perspectives and how to improve motivation and engagement overall. For some participants, financial incentives were expected and were the strongest motivator for their participation. In addition to financial incentives, the community expected to get some non-financial benefits, for example information or knowledge about health or livestock management. They did not expect to benefit from the longer-term goals of the study, to improve community health and save lives from AMR, because this pilot study had limited scope for intervention. Information or training sessions could have been used to provide short-term non-financial incentives to participate, in addition to or instead of financial incentives.

Sustaining Longer-Term Engagement

Apart from the financial incentives, there were few tangible benefits participants gained during the project, and this may have influenced their engagement. However, there were several intangible benefits that included knowledge gained through learning from each other, confidence and skills in taking photos and communicating stories, social connections and solidarity,

TABLE 4 | Participant and study team expectations from the Photovoice study.

	Participant expectations	Study team expectations
Personal expectation	To be capable of taking (a lot of) nice photos	Participants to be able to use a camera and take photos related to experiences of antibiotic use
	To socialize with other community members	Participants would share opinions openly and work together well
	To learn from others	Participants to listen to and learn from each other about antibiotic use in the community
	To learn from experts and/or health professionals about antibiotic use, negative impacts, and risks of antibiotic resistance	Study team to provide a basic introduction to the topic of antibiotics and antibiotic resistance
	To know when and how to take medicine correctly	Not included
	To learn good animal husbandry practices	Not included
	To prevent diseases and have better care for domestic animals	Not included
	No particular expectation, just simply want to participate	To recruit participants who would be engaged and motivated
Inter-personal expectation	To share experiences and lessons about antibiotics and common illnesses with family and friends	Participants would share information with their family members, friends, and neighbors
	To help the community to become knowledgeable about antibiotics and prevent antibiotic resistance	To organize an exhibition to share the issues with the wider community
	To encourage other farmers to pay more attention to meat safety and clean livestock management practices	Not included

and helping their community. These intangible benefits emerged slowly, but over time became apparent to participants and were important for sustaining engagement in the longer term, even in the absence of other financial or non-financial incentives.

Motivation During COVID-19

Disruptions to activities caused by the COVID-19 pandemic created additional challenges to sustaining motivation. Many of our activities were delayed as the study team was not able to visit the communities regularly due to movement restrictions. This led to some loss of engagement, difficulty sustaining rapport and personal connections, and forgetting about the remaining study activities after long breaks. In the Photovoice study, most of the activities were held between November 2020 and April 2021, but the final community exhibitions were held for two groups over 12-months after the last meeting in which preparations were made. To maintain motivation throughout these disruptions, we listened to participants' concerns about the changing situation and local context of COVID-19, what means of communication they preferred, and when and how they were comfortable to hold face-to-face activities. We tried to maintain our relationships by keeping in contact with participants by phone or instant messaging app to keep up-to-date about the situation and plans. However, there was a noticeable loss of interest in the project after the long delay.

Engagement With the Topic of Antibiotics and AMR

Understanding of AMR

Narratives from photographs and discussions showed that participants had ambiguous concepts about what antibiotics are and how they should be used, and had been given little information from health-workers. Farmers seemed to have more knowledge about antibiotics and AMR, as they often received training from companies, and were motivated, self-guided learners, because improving farming practices had direct benefits for their livelihoods and profits. Participants were familiar with the general concept of drug resistance rather than antibiotic resistance, and felt worried about it, but had limited understanding of what either term really means. However, neither women nor farmers thought that AMR was an issue affecting their community. Participants knew that self-medication without seeing a doctor is not recommended, but in practice many did this. Farmers knew about AMR and laws prohibiting the use of antibiotics in animal feeds, but they believed antibiotic products may still be present in some unlabeled products. Due to the lack of local veterinary services, farmers used their own experience and knowledge, and bought animal medicines and vaccines to administer themselves, sometimes including leftover human antibiotics. The study team was cautious with the use of technical and academic words. Community interest was negatively affected when our communication resources contained specialized language and terms that did not fit local understanding. To enable us to listen and respond effectively, we used the local vocabulary we developed (see Understanding the Local Context above). We also consulted local partners and community participants to help us to simplify the language and concepts related to AMR in our future intervention materials.

Participants were interested in health and interventions to improve their health, but their main health concerns were chronic diseases and perinatal and nutritional disorders in children. For those that understood AMR, this was not perceived to be important for them or their community, and they felt it did not affect their life in an obvious way. Participants initially thought that overuse of antibiotics was only a threat for other communities, but after sharing their experiences, they discovered that there were impacts closer to home. One mother shared the experience of side-effects her child had

had after antibiotic injections, another shared how her child's teeth had been damaged from taking antibiotics, and a farmer shared how she used to use leftover human antibiotics for her chickens. We tried to make AMR more tangible for participants by connecting their health concerns with the inappropriate use of antibiotics and AMR. We talked about their specific health concerns, and then we slowly attached our study and AMR issues to these. This helped them to recognize that antibiotic overuse and resistance and other health issues are inter-connected.

Ownership

The study was introduced to the community as a health project about a topic that they did not know very much about, but one that we wanted them to take the lead in finding solutions for. In order to establish a sense of ownership, we informed participants clearly from the beginning about the importance of their participation and their ownership of the outcomes. We encouraged participants to play a dynamic role and take the role of co-researchers, rather than objects of study. Participants were informed that they would use their photos and stories to raise awareness about the problem of overuse of antibiotics and AMR in their own and other communities. Participants developed a sense of ownership as the study progressed and this further contributed to their sustained engagement. As participants understood the issues more and how they were relevant to their lives, and incorporated their own ideas into the implementation of activities, they began to somewhat see the products of the study as their own (rather than the study itself which was initiated by us) and they were more motivated to contribute their time. Exhibitions were an unfamiliar concept in these communities, and participants might have chosen to share their stories and raise awareness in the wider community about antibiotics and AMR in other ways if the project had allowed for this, but participants were still excited and proud to co-organize the photo. Despite their engagement and ownership of the activities, at the end of the project, participants still did not think that AMR was a tangible problem or a high priority in their community compared to other issues. In particular, many farmers said they didn't use antibiotics, they followed guidelines, used vaccines to prevent animal illnesses, and their farming was profitable, so they were not worried about AMR.

DISCUSSION

We identified five themes related to the challenges of implementing community engagement projects related to antibiotic resistance. These included: understanding the local context, stakeholder relationship development, participant recruitment, building trust and motivation, and engagement with the topic of antibiotics and AMR. Similar themes have been cited in literature on community engagement, such as multistakeholder partnerships (41–44), trust (45–48), and the nature of participation and hierarchies in participatory action-oriented approaches (49–51).

Other scholars concur that understanding context, in the form of local agendas, culture, expertise, and organizational structure and process, form a basis to establish trust, respect and fuel further collaboration with partners in participatory research (52, 53). We found that it was difficult to establish connections with local stakeholders at a personal level through non-research activities due to our lack of contextual understanding, and this affected their trust and support during study implementation. This resonates with research on business culture in Vietnam indicating that bonding with partners through non-business activities such as feasts and banquets can foster collaboration (54). A culture-centered approach, that honors community knowledge in research design and implementation, can ensure integration of community voice and agency in health education interventions and can result in more structural change (55).

Partnership development between academic and community partners is an important component of participatory action-oriented approaches, and requires investment in team building, sharing resources, and mutually exchanging ideas and expertise. Incorporating feedback from different stakeholders can lead to stronger relationships and better implementation of future work (56). Partnership with local stakeholders is key to establishing local ownership and longer-term commitment and sustainability (14). However, the Vietnamese public sector has a very strong top-down management style (57), and partnerships with local government meant that we had to incorporate some elements of top-down approaches which conflicted with the bottom-up approaches and shared decision-making required for PLA. The traditional top-down management style also created a power imbalance between our team as researchers and our local partners. Suggestions to address these power dynamics in community-engaged research include understanding of context, having a shared vision, and inspiring leadership, diversifying partners for their expertise (53), and establishing ground rules to ensure all partners, including researchers are clear on their roles and equal in decision-making in all study phases (42). We focused on encouraging participation and shared decision-making among participants, but needed to invest more effort to reach a shared vision with local authorities and involve them as equal research partners in all study stages. In agreement with other practitioners, we found that the development of a collaborative partnership is crucial, but it takes time to build consensus and mutual agreement on study goals as well as emphasize the value of community engagement and using a bottom-up approach (58, 59).

The philosophy and methods used in participatory community development emphasize the importance of using a bottom-up approach to participant recruitment (60, 61). Allowing participants to volunteer or self-select can promote recruitment of participants who have little visibility but share common interests in healthcare issues and are motivated toward making changes in their community (62). In our study, self-selection sampling through public gatherings proved to be a good opportunity to introduce the research team and research activities to a large population. However, we had to employ a purposive sampling approach through local authorities to recruit participants in some activities due to time limitations and partner preference, which conflicts with the bottom-up approach required for engagement and participation. Research from the south of Vietnam reported that using a top-down purposive sampling approach may arouse concerns that participants who are assigned may feel coerced to join, and agree to participate without being well-informed about the study activities and/or their roles and benefits, which may in-turn lead to lower motivation and higher likelihood of dropping out (63). However, misunderstanding study requirements, risks and benefits may equally apply to those who self-select to take part, and early clarification of misconceptions is important to ensure continued participation. Working closely with local partners and building trust is an important prerequisite regardless of the recruitment approach.

Although establishing trust and sustaining motivation has been recognized as essential for participatory action-oriented approaches to be successful (45, 46, 48, 64), it is hard to evaluate trust and trustworthiness (47). Echoing this, we found it difficult to know whether or not we had gained trust from our local partners amid the challenges we faced in communication and study implementation. We recognized our shortcomings in cultural understanding and study management skills as a challenge to establishing our trustworthiness. We were received with some level of trust when we were introduced to community members by people they trusted, such as local authorities or trusted members of the community. However, as trust is a multi-dimensional construct (47), we found that this "abstract trust," though helpful for partnership establishment, was not meaningful enough for engagement. Concerns about safety and confidentiality prevented participants from opening-up and engaging. Therefore, it is important to create an "institutional trustworthiness" focusing on bidirectional communication for listening and addressing concerns (48). Another means for studies to establish trust is to demonstrate their good intentions by providing material benefits such as money, health resources, or farming inputs for community participants (65), but the PLA approach focuses on building capacity rather than providing inputs, so this was not considered to be appropriate in our study. Time and effort was required to create rapport and common understanding and establish trust. Our partnership with national and provincial institutions lent credibility to the study and provided access to local networks at the beginning, but establishing trust directly with participants and gaining their support for the PLA approach, required development of mutual understanding about the research methods and agreement on shared principles. Reaffirmation from the local authority, continuous communication, honest explanation, and recognition of the community's priorities were key elements that helped us build up mutual trust gradually.

Managing motivation and expectations, and when and how to use incentives, are recurring themes in community participation (45, 46, 66). The discussion of incentives raises complex ethical questions about how we can give something back to participants without incentives being seen as coercive (67). Financial incentives may increase participation in research (68), but are not a sustainable means to secure long-term participation and engagement, or to enhance a sense of local ownership of the change process. Giving incentives creates a transactional relationship between the research organization and the community, which has an inherent imbalance of power. But the use of incentives has become standard practice, and sets a precedent for future projects, particularly for international non-governmental organizations (66). This practice can unintentionally become an obstacle to shifting participants' motivation for participation from individual toward community benefits. When there are financial incentives tied to participation, this may also influence who local partners select to participate, perhaps prioritizing their relatives or friends, and creating a sense of nepotism. In our study, we had to decide what type and what level of incentive was possible, desirable, and appropriate. Incentives had both positive and negative effects on participants' motivation, and it was important to balance these to successfully implement community-led activities. On the one hand, incentives encouraged participants to take part in our activities by giving them some financial benefits, motivating them to spend their time on our study, and signifying their commitment to participate. Since participants did not receive any other material benefit for their participation, incentives in the form of cash payments or in-kind payments or gifts were easy tokens for their participation, and may have been enough for short-term engagement. On the other hand, PLA requires engagement over a period of time, and participants may expect and deserve more for their participation. When financial benefits were the main motivation, participants dropped out or did not fully engage. Listening to partners and participants helps develop understanding about norms and motivations. Other researchers concur that longer-term, non-financial incentives or benefits, may include collective knowledge, social connections, skills, and confidence (67). These benefits can be difficult to explain, but may become clearer as the study progresses, and serve to sustain engagement over time. The wider community benefits, such as improved community health, should also be explained, but may only become apparent much later. Financial incentives are a sensitive issue to discuss, but it is important to listen to participants, and understand the implications of different approaches.

It has been widely documented as a barrier to addressing AMR in communities that antibiotics are not clearly recognized and the concept of AMR is not well understood (69, 70). In our study we found that there was low awareness and low perceived importance of AMR in the community, and this made engagement on the issue particularly challenging. Agendas for community-based research or development work have often been criticized for following NGOs'/governments'/funders' interests instead of being based on mutual decisions made with communities (49, 51, 71, 72). We found this argument spoke to us as we struggled to integrate the topic of antimicrobial resistance, which appeals to researchers and funders as an urgent problem, but was not perceived by communities as a major concern. Limited population-targeted messages about antibiotic use and AMR meant that the problem was not visible or prioritized in the communities, there was a lack of interest in participating in study activities, and lack of motivation for change. This situation illustrated a conflict between research and donor interests that will be a challenge in ensuring the methodology of PLA remains true to its purposes when it is scaled up or applied elsewhere.

This study had some limitations. Using Photovoice methods to test the PLA approach gave us the opportunity to learn about stakeholder relationship development, group formation, trust and motivation, and engagement on the topic of AMR, which have informed the development of a larger scale PLA intervention. Participants had lots of ideas to improve and scale-up intervention activities in their communities, but this study mainly focused on the active learning phase of PLA, discussing problems and their causes. Photo exhibitions to raise awareness about AMR were the only community-led actions, and participants did not have a chance to develop their own strategies to tackle AMR. Thus, we cannot apply our findings to the whole PLA cycle. This study also represents experiences from one province and a few communities, and experiences may vary depending on the context and local personalities involved. There were some areas of engagement in which women and farmers may have differed, but with only four groups, it was difficult to tell whether this was because of differences related to human and animal antibiotic use, the fact that one of the farmers' groups was assigned, or other contextual differences between the communities. The themes presented here were refined by the study team, reviewed by our national partners, and a summary was discussed with local partners and study participants, however, the views presented here may be biased toward our own perspective. Due to disruptions caused by COVID-19, some activities were not completed in one community at the time of writing, so we were not able to draw our findings from the full scope of study implementation. These disruptions also affected some aspects of implementation and engagement.

In conclusion, the development of effective partnerships and community engagement is complex. Building relationships, developing contextual understanding, and implementing participatory approaches takes time, which is sometimes beyond the scope of short-term research funding, but is important for sustaining motivation and longer-term engagement. AMR was our research agenda, but was a topic that the participants in our study did not know very much about, and it was challenging to gain their interest. A sense of ownership emerged as the study progressed and participants understood more about the issue, shared experiences that illustrated how antibiotics and antibiotic resistance affected people they knew, and saw their ideas being incorporated into activities. These lessons will be important for our upcoming One Health trial, and other participatory action-oriented approaches to address AMR.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by National Institute of Hygiene and Epidemiology Institutional Review Board in Biomedical Research (IRB-VN01057), and Oxford Tropical Research Ethics Committee, University of Oxford (Reference 529-19). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

SL and TP conceived of the study and were the Principal Investigators. HT designed the community-led media study component with AL. HT, HC, PB, YN, AL, GV, TT, and HN implemented the study activities. HC, HT, and SL conceived of the article. HC categorized challenges and lessons learned into preliminary themes. HN, YN, GV, TT, SL, and JV reviewed themes. JV oversaw review of themes. All authors contributed to the content, reviewed drafts, and approved the submitted version.

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