



OPEN LETTER

REVISED **Case studies from the experience of early career researchers in East Africa in building community engagement in research [version 2; peer review: 2 approved, 1 approved with reservations]**

Previous Title 'Building community and public engagement in research – the experience of early career researchers in East Africa'

Joel L. Bargul ^{1-3*}, Denna M. Mkwashapi ^{3,4*}, Imelda Namagembe ^{3,5,6*}, Immaculate Nakityo^{3,5}, Annetee Nakimuli ⁵, Josaphat Byamugisha⁵, Daniel Semakula^{3,5}, Janet Seeley ^{3,7}, Nelson K. Sewankambo^{3,5}

¹Animal Health Theme, International Centre of Insect Physiology and Ecology (icipe), Nairobi, P.O. Box 30772-00100, Kenya

²Department of Biochemistry, Jomo Kenyatta University of Agriculture and Technology (JKUAT), Nairobi, P.O. Box 62000-00200, Kenya

³THRIVE, c/o School of Medicine, Makerere University College of Health Sciences, Kampala, P.O. Box 7072, Uganda

⁴National Institutes for Medical Research, Mwanza, P.O. Box 1462, Tanzania

⁵School of Medicine, Makerere University College of Health Sciences, Kampala, P.O. Box 7072, Uganda

⁶Mulago Specialized Women and Neonatal Hospital (MSWNH), Kampala, P.O. Box 7272, Uganda

⁷Department of Global Health and Development, London School of Hygiene and Tropical Medicine, London, WC1H 9SH, UK

* Equal contributors

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Abstract

Background: In this paper, we explain how three early career researchers actively engaged community members in their health research projects in Kenya, Tanzania and Uganda, and what was learnt from the experience. The research project in Kenya was on camel trypanosomiasis and the role of camel biting keds (or louse flies) in disease transmission. The project in Tanzania looked at the effect of human immunodeficiency virus and antiretroviral therapy on fertility and ascertained the trends in the use of family planning services amongst women of reproductive age. The focus of the project in Uganda was the implementation of maternal death surveillance and the response policy to determine the cause of maternal deaths and how they might be prevented.

Methods: In the three different settings, efforts to ensure local community engagement provided a focus for the researchers to hone their skills in explaining research concepts and working in partnership

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1. **Doreen Tembo** , University of Southampton, Southampton, UK
2. **Inbarani Naidoo** , Human Sciences Research Council, Pretoria, South Africa

with community members to co-develop ideas, their research methods and outputs.

Results: Involvement of communities in scientific research, which entailed a two-way mutual engagement process, led to (i) generation of new research ideas that shaped the work, (ii) strengthened mutual trust, and (iii) promoted uptake of research findings.

Conclusion: Our key findings strongly support the need for considering community engagement as one of the key components in research studies.

Keywords

Public engagement, health research, Kenya, Tanzania, Uganda, East Africa

3. **Nadia Tagoe**, Kwame Nkrumah University of Science and Technology (KNUST) in Ghana, Kumasi,, Ghana

Any reports and responses or comments on the article can be found at the end of the article.

Corresponding author: Joel L. Bargul (jbargul@jkuat.ac.ke)

Author roles: **Bargul JL:** Conceptualization, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Mkwashapi DM:** Conceptualization, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Namagembe I:** Conceptualization, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Nakityo I:** Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Nakimuli A:** Conceptualization, Supervision, Validation, Visualization, Writing – Review & Editing; **Byamugisha J:** Conceptualization, Validation, Visualization, Writing – Review & Editing; **Semakula D:** Funding Acquisition, Validation, Visualization, Writing – Review & Editing; **Seeley J:** Conceptualization, Resources, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Sewankambo NK:** Conceptualization, Funding Acquisition, Project Administration, Resources, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing

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REVISED Amendments from Version 1

We have refocused the background information of the case studies to emphasize community engagement, the main focus of this paper, as suggested by the reviewers.

We also provide more information on ethics and describe procedural details for ethical approvals prior to research engagement of community members and secondary school students.

Further, we have added the following six references to widen the scope of the paper:

1. MacQueen KM, Bhan A, Frohlich J, Holzer J, et al.: Evaluating community engagement in global health research: the need for metrics. *BMC Med Ethics*. 2015; 16: 44. DOI: [10.1186/s12910-015-0033-9](https://doi.org/10.1186/s12910-015-0033-9).
2. Musesengwa R, Chimbari MJ, Mukaratirwa S: A Framework for Community and Stakeholder Engagement: Experiences From a Multicenter Study in Southern Africa (2018). *J Empir Res Hum Res Ethics*. 13 (4): 323–332. DOI: [10.1177/1556264618769002](https://doi.org/10.1177/1556264618769002)
3. Tembo D, Hickey G, Montenegro C, Chandler D, et al.: Effective engagement and involvement with community stakeholders in the co-production of global health research. *BMJ*. 2021. <https://doi.org/10.1136/bmj.n178>.
4. <https://www.unicef.org/mena/reports/community-engagement-standards>
5. <https://www.nihr.ac.uk/documents/resource-guide-for-community-engagement-andinvolvement-in-global-health-research/27077>
6. Ministry of Health Uganda. Guidelines for prevention of Covid-19 when conducting meetings at workplaces. Kampala. 2020 <https://www.health.go.ug/covid/project/guidelines/>.

Any further responses from the reviewers can be found at the end of the article

Disclaimer

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Introduction

Over the past decade, there has been a growing awareness of the value of engaging local communities and the wider public in research. The coronavirus disease 2019 (COVID-19) pandemic has highlighted how essential the public understanding of science can be to the acceptance of measures to curtail the spread of infection, with disinformation, often through social media, needing to be countered by authoritative and clearly expressed messages from researchers, epidemiologists, virologists and behavioural scientists throughout the world (Larson, 2020; Pohl & Musil, 2021; Provenzi & Barello, 2020). For many scientists engaged in the rapidly evolving fields of COVID-19 research, the need to respond to media requests for information or explain their findings to particular interest groups, has become an important role in the effort to counter the spread of infection and encourage vaccine uptake

(Safford *et al.*, 2021; Umvilighozo *et al.*, 2020). The societal value placed on funding, doing and sharing the outputs of scientific research is nurtured through effective community and public engagement (Holzer *et al.*, 2014).

Many different terms have been used to describe the involvement, the engagement and the participation of people from the community in which research takes place, and the wider public. Involving local community members in research can improve the relevance and quality of research, as those directly affected by the subject under study, for example an infectious disease, can draw attention to factors in the local environment which can enhance the usefulness of the research (Tindana *et al.*, 2007).

We draw on the definition of public engagement used by Cohen *et al.* (2008: 2): ‘a process that provides people with trustworthy information on key policy issues, elicits their input, and integrates it into decision-making and social action’. They make a distinction between this broader engagement agenda and that of ‘community engagement’, where the people directly participating in or affected by a research project are the focus of engagement. Both are important, and we would argue that as an introduction to broader ‘public engagement’, local community engagement provides a focus for emerging scientists to hone their skills in explaining research concepts and to work with community members to develop ideas, methods and outputs (MacQueen *et al.*, 2015; Musesengwa *et al.*, 2018; Tembo *et al.*, 2021).

In addition, there is an increasing awareness by research funders of the importance of community and wider public engagement, and for researchers to include a public engagement component in grant applications. The case is made in grant calls for public involvement in research to serve ‘broader democratic principles of citizenship, accountability and transparency’ (National Institute of Health Research, 2021) and increase public trust (African Academy of Sciences, 2021). This pressure to include an engagement component in research projects can seem particularly daunting to early career researchers, embarking on an independent research project for the first time. Community engagement has a long history within the space of international development, which provides many examples on which to build. Guidance for researchers exists, in an effort to demystify the terminology and encourage greater involvement in research as well as good practice (African Academy of Sciences, 2021; Wellcome Trust, 2021; <https://www.unicef.org/mena/reports/community-engagement-standards>; <https://www.nihr.ac.uk/documents/resource-guide-for-community-engagement-andinvolvement-in-global-health-research/27077>).

In this paper we explain how three early career researchers actively engaged community members in research in Kenya, Tanzania and Uganda, and what we learnt from the experience. While the studies were affected by the COVID-19 pandemic, the work proceeded during the pandemic, albeit at a slower pace due to travel restrictions, among other guidelines put in place by the governments to control the spread of the disease (Ministry of Health Uganda, 2020).

Our research was supported through the Training Health Researchers into Vocational Excellence in East Africa (THRiVE) project which is a collaborative research capacity building project involving five universities (Makerere University - Uganda, Gulu University - Uganda, Kilimanjaro Christian Medical University College - Tanzania, University of Cambridge – United Kingdom, UK, London School of Hygiene and Tropical Medicine - UK); and three research institutes (Uganda Virus Research Institute, International Centre of Insect Physiology and Ecology in Kenya and the National Institute of Medical Research, in Mwanza - Tanzania). The goal of THRiVE was to develop a critical mass of world-class researchers and research leaders capable of conducting high quality independent research and transforming communities where they live and work.

Our approach has been to build a cohort of researchers, providing support and mentoring to scientists at different stages of their research careers, including graduate interns, master's, doctoral and post-doctoral researchers. We have focused on achieving research excellence in the areas of (a) infectious diseases/neglected tropical diseases, (b) maternal, neonatal and reproductive health, and (c) non-communicable diseases. In total, 70 research fellows have benefitted from supervision, training and mentoring in the THRiVE project across the three East African countries.

We begin by describing the research settings, and the scientific research focus of our three case studies – research led by Joel Bargul, Denna Mkwashapi, and Imelda Namagembe, before recounting the engagement activities undertaken, and our learning from that experience.

The settings and the background to the research project

The Joel Bargul study “Camel trypanosomiasis and its transmission in northern Kenya.” Joel’s research project in Kenya was on camel trypanosomiasis and the role of camel biting keds (or louse flies, genus *Hippobosca*) in disease transmission. The study was conducted in Laisamis, Marsabit County, about 450 km northeast of Nairobi City. We learnt from the engagement sessions with the livestock farmers and other community members that camels were preferred to other livestock because of their resilience to survive in harsh climates of the arid and semi-arid regions. They are kept for milk, meat, hides, transport, income, and for social capital. However, camel productivity is constrained by ectoparasites, biting flies, and the diseases they transmit. In northern Kenya, little information is available about the diseases circulating in livestock or their possible transmission by keds. Keds also occasionally feed on humans and in the process, they could transmit zoonotic pathogens from the infected animals.

During field-based sampling, Joel engaged the livestock owners and community field assistants in collection of blood and camel keds. Training of the assistants to understand the research project preceded the assignment of sample collection. These assistants were engaged in preliminary screening of freshly

collected blood samples for pathogens, and later participated in pathogen transmission experiments by camel keds to determine vector competence. Whenever a diseased sample was identified (i.e. infected with trypanosomes), the camel owner was notified and then allowed to observe the infected sample under the microscope to gain knowledge of the disease. All infected animals from sampled herds were immediately treated at no cost to the farmer.

Earlier findings from research in this study area showed that various pathogens including *Anaplasma* and *Ehrlichia* spp. and trypanosomes species *Trypanosoma vivax* and *T. evansi* were present in camels and in keds collected from them (Kidambasi *et al.*, 2020). Therefore, Joel and his team studied the ability of camel keds to transmit trypanosomes and other blood-borne pathogens from naturally infected camels to experimental mice and rabbits via blood-feeding bites by following an established protocol (Oyieke & Reid, 2003). They demonstrated, for the first time, that camel keds, *Hippobosca camelina*, could transmit ‘*Candidatus Anaplasma camelii*’ from camels to mice and rabbits, but not trypanosomes (Bargul *et al.*, 2021).

The Denna Mkwashapi study “Influence of human immunodeficiency virus (HIV) and antiretroviral therapy (ART) on fertility and uptake of family planning services.” The project that Denna undertook for his doctoral studies aimed to understand the effect of HIV and ART on fertility and ascertain the trends in the use of family planning services amongst women of reproductive age in Tanzania.

With the changing of the HIV epidemic to a chronic condition through increased access to ART in Tanzania, it is not clear how HIV has impacted on the fertility gap between HIV infected and uninfected women at different time periods of the ART coverage. Denna and his team wanted to know to what extent uptake of family planning services has been changing with time. For the study, Denna used data from the 25 year old - Magu Health and Demographic Surveillance System (HDSS) (Kishamawe *et al.*, 2015). The study area lies 20 km east of Mwanza City, the region’s capital, with a predominantly rural population. Magu HDSS is comprised of nine villages with a total combined population of 45,000 people in 2020.

The fertility data Denna used were drawn from 35 rounds of household visits from 1994 to 2018, which captured all births in the resident population. HIV status data were drawn from eight rounds of HIV epidemiologic and serologic surveillance, which was conducted every three years, from 1994 to 2018 among all eligible, resident adults aged 15 years and above. Using those data, total fertility rate, age specific fertility rate, general fertility rate, contraceptive use and unmet need for contraception by HIV status and different levels of ART availability were compared over time and factors associated with the changes investigated.

The Imelda Namagembe study “Implementation of maternal death surveillance and response policy: the impact of training and community engagement.” Imelda’s research project in

Uganda was based in the Department of Obstetrics and Gynaecology at Mulago National Referral and Teaching Hospital for the Makerere University initially located just north of central Kampala (the capital city of Uganda), but recently moved to Kawempe on the outskirts of northern Kampala. The hospital has one of the busiest labour wards in Africa with 39,000 deliveries a year (Hughes *et al.*, 2020). The labour ward has about 46 obstetricians and gynaecologists (Namwaya *et al.*, 2020). Health workers provide Reproductive Maternal Newborn, Child and Adolescent Health Services (RMNCAH) to all women attending the facility from all over Uganda. The National Referral Hospital is faced with a high burden of maternal and perinatal deaths and contributes the highest number of deaths to Kampala district within Uganda (Ministry of Health, 2019). This is partly due to the hospital being a referral site and most of the deaths are due to conditions that are preventable, such as excessive bleeding, hypertensive disorders of pregnancy (pre-eclampsia/eclampsia), sepsis (bacterial infection) from obstructed labour and abortion-related complications. Serious conditions are compounded by delay in seeking care, delays in getting transport and delays waiting at health facilities (Kiondo *et al.*, 2021; Nakimuli *et al.*, 2016). Most of the women who die, die young, with a mean age of about 26 years, and of these 10 to 15% are adolescents/young adults (< 20 years) (Ministry of Health, 2018). One of the strategies to improve maternal and new-born outcomes is to conduct timely Maternal Death Surveillance and Response (MDSR) policy where the hospital staff are expected to notify a maternal death within 24 hours, conduct a death audit to identify gaps in care that contributed to the death within 7 days, develop recommendations and follow up implementation to prevent future deaths. However, this was not being done on a regular basis.

The aim of the study conducted by Imelda as part of THRiVE-funded research was to examine the implementation of MDSR policy for a 3-year period (2016 – 2018) as a baseline to determine the cause of maternal deaths and prevention. This was followed by an exploration of the barriers and facilitators to MDSR implementation and to later evaluate the impact of training with stakeholder engagement on MDSR performance.

In the course of her research, Imelda engaged with both the internal stakeholders at the hospital (health workers and administrators) and external stakeholders (lawyers, representatives from the Ministry of Health, study partners with expertise in reproductive health). The engagement aimed at identifying the barriers to the quality improvement process of MDSR through an exploration of stakeholders' perspectives and what could be done to improve on the outcomes for mothers and their babies.

All three research projects described above were conducted in community settings – albeit in three very different places: arid northern Kenya, rural north western Tanzania and the main referral hospital in the capital of Uganda. In the next section, we explain where our idea for the community engagement activities in the projects came from.

Ethical approval

Joel's study was undertaken in strict adherence to experimental guidelines and procedures approved by the *icipe* Institutional Animal Care and Use Committee, IACUC (REF: IACUC/ICIFE/003/2018). In addition, the study received ethical consent from the Pwani University Ethics Review Committee (REF: ERC/EXT/002/2020) to collect the information for various research activities with livestock farmers – including community engagement. Animals were handled carefully to minimize pain and discomfort during sampling. Permission to engage with pastoralist farmers in research and to sample their livestock was obtained through verbal consent, as most herders were unable to read or write. Engagement of secondary school students in research was conducted after obtaining the permission from Laisamis Secondary School (LSS) principal (the term used for the headmaster/mistress in Kenyan schools). Oral assent was sought from the LSS student volunteers (aged between 15 – 20 years, mean age = 17.32 years) who were provided with sufficient information about the focus group discussions (FGDs) to allow each individual to make informed and independent decisions to participate in the survey. Engagement through FGDs posed minimal risk to the students, thus permission was not sought from their parents, but from the school principal, who granted approval to our request and then linked us to the students. The main ethical challenge that Joel faced in his study was the lack of clear strategies on how to give credit to the many community members who contributed to new study ideas during community engagement meetings.

Denna's project targeting women of reproductive age in Tanzania to determine the influence of HIV and ART on fertility and the uptake of family planning services received ethical approval from the Review Committee of Kilimanjaro Christian Medical College of the Tumaini University of Tanzania (certificate number 2440). This approval covers community engagement activities. Permission to work with secondary school students was granted by the director, Mwanza City Council (REF: MCC/SE/20.VOL.II/127). The secondary school students, who were aged 18 years and above, provided verbal consent to participate in the consultative meetings, drama, and debate activities.

Imelda's study received approval from the Makerere University School of Medicine Higher Degrees Research and Ethics Committee (SOMREC REF: 2018-001) and Uganda National Council for Science and Technology (UNCST REF: SS4797) to conduct the research on MDSR and community engagement. Engagement of secondary school students in research was preceded by permission from the headmaster and the director of studies. In addition, approval to engage with students in Uganda was obtained from the Ministry of Education and Sports (Uganda). Further, there was a waiver of consent from parents since the research was minimal risk. The students who participated in drama activities and qualitative interviews provided written consent for those aged 18 years and above, whereas assent was obtained for those aged below 18 years. The age range of the secondary school students was 16 – 21 years, with a mean age of 17.7 years. The students were keen to have their project

completed before their final exams, which had been shifted to April 2021 (because of the COVID-19 pandemic).

Where did the idea for the community engagement focus come from?

Joel's work was firmly embedded in the day-to-day processes of camel herding, so the goodwill of the herders was critical to the success of the project. Joel had ensured that the key stakeholders, particularly the camel farmers, were familiar with the focus of the research and encouraged the exchange of ideas. The farmers used to freely discuss the key challenges they faced during livestock production, ranging from animal husbandry practices, the burden of pests and diseases, the transmission of diseases, and the traditional and modern ways used for control. Joel knew the work that he and his colleagues conducted would – if successful – help to address these pest and disease challenges.

However, it was another area of daily life that Joel chose to focus his community engagement activities. During field visits to collect samples, the team commonly observed that children of school-going age were not enrolled in school, but engaged in other duties at home, such as livestock herding activities. Joel wanted to understand more about the value placed on education for children and the contribution of children to labour (including camel herding) with a view to trying to support great opportunities for the children to go to school. Joel and the team designed a survey to determine the perceptions of both parents and LSS students towards formal education, gender roles in leadership, and early marriages among pastoral communities in Laisamis, northern Kenya.

The following two video links summarize the engagement activities that Joel undertook in Laisamis, Marsabit County, for his research studies on camel health (<https://www.youtube.com/watch?v=FuM-RUNjpwM>), and access to education by the children from the nomadic pastoralist communities (<https://vimeo.com/531249510>).

The idea that Denna and his colleagues developed for the engagement intervention came from students during an initial consultation meeting with Denna. The school students were keen to discuss their views on HIV, fertility and family planning among young people. They discussed HIV preventive and treatment strategies, and natural and modern methods of contraception. Through the examples the young people gave, they began to discuss the problems and benefits of high fertility. The young people Denna talked about his research, and discussed reproductive health with, wanted to share what they were learning with others at school and to tell the local community at large about Denna's research topic. As a result, the young people working with Denna designed an engagement intervention to tell young people at Mwanza Secondary School about the topic of Denna's research. The intervention activity was a drama sketch, which was performed in front of the young students and evaluated thereafter.

Imelda also worked within a school setting, with the aim of establishing whether the high school students and the

communities they came from were aware of the high burden of maternal deaths in the country, the causes of such deaths, who is at risk of death, and the circumstances surrounding such deaths. The idea was not only to provide information but also to establish what they know about maternal surveillance and response cycle with a view to building that knowledge to feed into safe motherhood initiatives as preventive strategies. In addition, Imelda and her colleagues wanted to understand how to empower students and the wider communities to engage more in Imelda's project to share information about maternal health project.

What the community engagement activity was

Joel and his team have been conducting community engagement activities with livestock farmers and members of the local community during field visits for sample collection. In addition, as noted above, he engaged LSS students in research and mentorship programmes.

At the end of the laboratory studies, Joel and his team organized three scientific data dissemination workshops in Laisamis and Marsabit, northern Kenya, to share research findings with the pastoralist communities and other stakeholders, namely local leaders, County administrators, veterinary officers, and LSS students. As a part of a training workshop, they took a total of 100 students (accompanied by their teachers) for field visits to expose them to sample collection strategies and preliminary analysis. The following samples were collected: camel blood for onsite screening of selected blood-borne pathogens using microscopy, camel keds, ticks, mosquitoes, sand flies, and stable flies. Students were trained on how to prepare preserved insect collections using the field-collected samples for long-term use, for instance in biology practical lessons and as teaching materials for classroom demonstrations. Oral presentations combined with practical sessions were organized to train students about the various insect species they collected from the field and the roles the insects played in transmission of vector-borne diseases. This engagement and practical exposure to scientific research stimulated curiosity in the young learners as evidenced by their active participation during training and the many questions they raised, and could motivate them to perform better in class. Regular engagements of young students in advanced scientific research exposes them to real life applications of science among other taught subjects, thus in the longer term promoting science, technology and innovation.

In another engagement study with students of LSS, Joel and his team conducted FGDs with 14 groups of students to understand their opinions on socio-cultural factors that limit access to education, class performance, and progression to higher levels of education. The perceptions of students on bullying, discrimination, and physical harassment at school, and also the gender roles in leadership and academic performance were discussed. In total, 70 students (43 boys and 27 girls) shared information with the team. The student participants were categorized based on sex and the year of study from 1st to 4th year (of secondary education).

Joel and his colleagues also conducted a survey to understand the perceptions of parents (n=384 households) on gender equality in formal education, leadership, and their opinions on teenage marriage, and school enrolment of both boys and girls. Dissemination meetings were conducted in Laisamis, Marsabit County, in November 2020 to inform key education stakeholders about the objectives of the study and how it would benefit the pastoral communities.

Denna held an initial consultative meeting with school students to think of ideas for sharing information about the research project. The co-designed ideas that the students preferred most included a drama sketch and song as engagement interventions. The two engagement interventions were tested with a selected sample of 412 students. Feedback was openly collected from the audience on whether the language and the content of the activity was easily understood by the target audience, whether the information in the intervention package was trustworthy or credible, whether the intervention type was desired by the target audience and finally whether the intervention package was age, gender, culturally appropriate. Finally, students proposed that a drama sketch to be the final engagement intervention for rolling-out and evaluation.

Denna and the school students then co-developed the state of art drama with the help from a performing art consultant. Students organized and performed the drama in front of the specifically chosen students as the sample for the evaluation study. During the drama they shared information on key concepts on fertility, social economic issues in region with higher fertility, natural and modern family planning methods and the role of science to human development.

Qualitative and quantitative data were collected before and after the final theatre performance. The audience was made up of male and female students in their second and third years of secondary education. The assumption was to compare groups with similar ages. Through the drama performance, we expected to increase awareness to the audience by comparing measured estimates of knowledge before and after the performance.

Imelda began the work on her engagement activities by obtaining permission from the headmaster and director of studies in the school to meet students in classes not doing national examinations in their school year. Once permission was obtained the students were told about the study. Out of 150 students who were available, 81 volunteered to participate in the pre-test. The students were then asked how they would like to disseminate the information they learned through their work. They agreed to use a combination of music, poems and drama.

Imelda set out to establish what the students understood about maternal deaths, the causes and risk factors, the Three Delays (Barnes-Josiah *et al.*, 1998) associated with maternal deaths and the application of pillars of safe motherhood, plus maternal death reviews as preventive strategies. In addition, Imelda wanted to understand how students and communities could feed into the then ongoing research project to improve

implementation of its key outcomes. As the students learnt about preventable maternal deaths, they discussed what they could do in their communities to support maternal death surveillance and an appropriate response.

Overall, the school students gained knowledge about key aspects regarding causes of maternal deaths and preventive measures such as pillars of safe motherhood, and MDSR. In addition, the students appreciated that even adolescents can die from many complications related to pregnancy. Importantly, they were able to disseminate messages from what they had learnt to some members of the communities and their parents, which impressed their families greatly.

When Imelda's engagement project was coming to an end, the COVID-19 pandemic had just begun. So Imelda used the engagement opportunities with the students to share information about the threat COVID-19 posed to the community and pregnant women in particular (including challenges resulting from restrictive measures during lockdown), the impact on the quality of care, and the importance of timely access to health services. Thus, prevention of COVID-19 was included as part of the engagement activities.

Imelda obtained permission to access the secondary school students of St. Aloysius Senior Secondary School (mixed school with day and boarding students). Then, Imelda and Immaculate (coordinator) from THRIVE had discussions with 150 students to inform them about the school engagement plan focusing on maternal health. The lead role of the students was emphasized since it was conceived as student-centred project. Through a brainstorming session, they agreed on the methods used to co-create/ co-design their prototypes (i.e the drama-skit, song and poem). At that same meeting, 6-student champions (3 males and 3 females) were nominated and voted for to work closely with the head prefects to mobilize the fellow students. It was at that point when students who felt comfortable to do the pre-test were requested to register voluntarily. The pre-test was offered at a follow up visit (two weeks later) after which Imelda made a simplified presentation about her research. The pre-test was composed of semi-structured questions on: the definition of research, importance of maternal health research; definition of a maternal death; burden of maternal deaths (national maternal mortality ratio, number of maternal deaths country wide in simple terms), causes of maternal deaths, who is at risk of death, and prevalence of teenage pregnancy. They were asked a few questions about what should be done if a health worker loses a pregnant woman when on duty; steps for maternal death surveillance and pillars of safe motherhood as strategies to prevent maternal and newborn deaths. There was a question-and-answer session after the pre-test to enhance the understanding of various aspects.

After the pre-engagement test, the students received pamphlets containing information on the various topics that were assessed in the test. They were encouraged to read more, ask questions (asking teachers, searching the internet,

and consulting members of the community where possible). The plans for the follow-up activities were discussed, the students worked closely with four teachers (two ladies and two men). A music/drama expert joined the team to help fine-tune their ideas. They continued with practise in the evenings. At the climax of events, around 18th-March 2020, lock down due to COVID-19 pandemic was suddenly put in place. Schools closed for 6-months, and re-opened in October 2020 for students sitting national examinations. Engagement activities resumed in December 2020 after end of term examinations. By then we had only 100 students in the age range 16 to 21 years. The students really wanted to complete the maternal health project, so they proposed dedicating 10 days to practise. The period of upkeep was facilitated by funds from a grant after discussions with the principal of St. Aloysius Senior Secondary School and the Director THRiVE. We were given permission to present to the communities after a mass/service respecting COVID-19 guidelines (Ministry of Health Uganda, 2020). At that time, only 70 people were allowed in the parish church. We were situated in a big compound next to the church, using two 100-seater tents (the students were in one tent and other members of the community in another), masks were given to all, sanitizers put in place and a distance of a minimum of 2 metres between people ensured. We had an average of 40 adult participants per session. Each performance lasted about 20 minutes, with intervals of 40 – 50 minutes as we waited for another group of people to come from church. Three performances were done on that Sunday, to a total of 120 people. We received pre-packed snacks and sodas. Another showcase for the maternal project was conducted on the students' request, when their parents / guardians were allowed to be at school for blessing prayers before examinations in March 2021. Again COVID-19 prevention guidelines were respected. None of the students suffered COVID-19 related illnesses.

What did we learn from the community engagement that we did in THRiVE?

Joel found that the two-way community engagement and involvement of livestock farmers in field experiments improved the quality of research and provided the opportunity for mutual engagement for informing, educating, and training from farmer to scientist and scientist to farmer. The findings of this work showed that livestock rearing and teenage marriages were the major socio-cultural factors in Laisamis that limited the access to formal education for boys and girls, respectively. The findings were disseminated to parents, students, teachers, and the School's Board of Management, and a report providing recommendations to guide policy makers was submitted to the Ministry of Education - Marsabit, focusing on how to improve school enrollment and encourage progression to higher levels of education.

Furthermore, by working with young people in the field research, Joel and his colleagues found that the students were encouraged to become innovative and creative thinkers: one group of students came to Joel with a fly trap they had designed – based on the work they had done in the project.

Denna also found value in talking within the school he worked with about his research – and gaining more knowledge on the context of his research from these interactions. He saw value in the engagement before, during and after research, in terms of ensuring community members understand what research is being done, but also had an opportunity to be able to share their ideas on the topic.

Imelda learnt through her engagement in the schools that students and their families had limited information about conditions that kill mothers and the research engagement activities empowered them with knowledge that they promised to share by becoming champions for safe motherhood. Most students at first thought that young people were not at risk of maternal deaths, except if they induced an abortion. Their knowledge of causes of pregnancy-associated deaths improved by the end of the activity and they portrayed themselves as having been greatly empowered since they are the fathers and mothers of tomorrow. They felt empowered on issues of preventing teenage pregnancy, other maternal health issues. Some shared testimonies of having advised their pregnant sisters and friends on early seeking of antenatal services and health care when the labour started at the time when lockdown measures for COVID-19 control were in place. This was an important learning for Imelda who had originally thought of the young people as being channels for sharing information with adults rather than being themselves key beneficiaries. Together, our findings from the community engagement provide key information that could inform policy.

A limitation of the study

Our case studies would have benefitted from a more rigorous approach to measuring and evaluating the socio-economic impact of the community engagement activities. However, monitoring and evaluation of the engagement outcomes were not conducted due to the limited funding available.

Recommendations

From this experience, we recommend:

1. Making engagement with study participants an integral part of all research studies from start to finish. Listening to what people in the community have to say about the study focus can, as Joel found out, refocus study objectives to address community priorities.
2. Community engagement activities not only allow those who take part in these activities to be informed by the researchers and vice versa, but they can also feel empowered to inform others and make use of research results themselves to influence practice and policy discussions, leading to wider public engagement.
3. Working closely with young people to talk about our research topic allowed Imelda, Denna, and Joel to gain insights into the local understandings of science, and the response to official messaging about health.
4. Community engagement activities cost money – we recommend that this is costed into research projects; indeed, many

fundes now welcome such items in the budget lines. Communities and the wider public with increased knowledge about ongoing research may be empowered to inform others., Community members who share information gained through their engagement in research can aid reaching out to the general public for example in disseminating research findings to a wider audience, especially to those under resource-challenged settings. Other potential opportunities for efficient scaling up of engagement activities, for instance during pandemics (i.e. COVID-19) to include using social media platforms such as Facebook, WhatsApp, and Twitter as most community members in these studies have access to mobile phones, and also using the mass media (e.g. newspaper articles, opinion pieces, discussions on radio and television).

We also learnt to be patient because sharing knowledge and information takes time, time that we may feel should have

been spent on 'our' research. We recognise the enthusiasm and interest exhibited by the students as an important outcome of the projects. We hope that this experience will be a foundation for the students' interest and engagement in science and research as the young people grow into adults. We are all committed to delivering the best science for us and the researchers of the future.

Data availability

No data are associated with this article.

Acknowledgements

We are grateful to the secondary school students, school Principals and teachers, and all members of the community who participated during the community engagement activities on various research topics led by the THRIVE fellows.

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Nadia Tagoe

Kwame Nkrumah University of Science and Technology (KNUST) in Ghana, Kumasi,, Ghana

The article presents the community engagement experiences of three health researchers undertaking studies in different settings in Africa. The paper seeks to highlight an aspect of health research which is usually not the primary focus of researchers although critical to the health process. The authors indicate how the community engagement activities were conceptualised and implemented and shared the lessons learnt during the process. The strengths of the paper include sharing learning across contextual heterogeneity in terms of settings, study focus and study participants, and clearly outlining actionable recommendations for readers.

I have a few comments for the authors to consider.

Introduction:

- A clear definition of community engagement should be included as the information only indicates how it is distinct from public engagement and not what it is.
- After stating the distinction between community and public engagement, the authors should clearly state which type of engagement their work focused on.

Ethical approval:

- Joel's engagement on formal education, gender and leadership done through a survey and FGDs is a study on its own. Was ethical approval obtained for it?

Idea for the community engagement focus:

- The authors need to clearly and consistently state the objective of the community engagement activity, the methods used (i.e., how they engaged the community), the results and lessons learned for all the cases studies. For example, Page 8 states that "the findings were disseminated to parents, students, teachers, and the School's Board of Management". How was that done?
- The authors need to differentiate between conducting a survey and FGDs (which is data

collection) and community engagement; and the specific characteristic of the activities that make them community engagement (e.g. two-way). For instance, Denna's community engagement activity which was co-designed by the participants (students) during a consultative meeting is a clear example of community engagement.

Benefits and challenges of community engagement:

- I suggest that the authors highlight the benefits and challenges of the community engagement activities (to both the community and researchers) in the paper. Several examples of benefits are demonstrated including health education, and training on specific areas, skills building, identification of other community priorities, promoting science, technology and innovation, and community/school projects such as developing drama activities.

Reference differing views and opinions:

- I suggest outlining the limitations and disadvantages of the three approaches to community engagement and the activities undertaken.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Partly

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health research systems, capacity strengthening, equity and inclusion in research

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 11 July 2022

<https://doi.org/10.21956/openresafrica.14581.r29256>

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Doreen Tembo 

Wessex Institute, Faculty of Medicine, University of Southampton, Southampton, UK

I have now had a chance to review the revisions and can confirm that with the exception of a minor revision below, I am happy with the responses.

Minor typo:

Please note that the National Institute *for* Health *and Care* Research is still wrongly referred to as the National Institute *for* Health Research.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Mixed-methods Research, Community Engagement and Involvement Specialist, Health Policy, Health Systems

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 27 April 2022

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Inbarani Naidoo 

Human and Social Capabilities Division, Human Sciences Research Council, Pretoria, South Africa

This is a case study approach implemented in three different African settings in Kenya, Tanzania and Uganda and covered vector born disease, HIV and cause of maternal death. That authors differentiate community engagement from public engagement. Community engagements were undertaken with school going children from schools in research catchment area. The engagements are described from the perspective of three early career researchers.

Below are some reflections and suggestions:

Title:

- I recommend reference to the case study approach in the title.

Use of capital letters mid-sentence:

- Introduction, page 3: "Masters" is capitalized.
- Page 5, paragraph 2: Total, Age, General.

Use of abbreviations at first mention:

- MERS, antiretroviral therapy, Laisamis Secondary School.

Use of abbreviations at only mention:

- Total fertility rate, age specific fertility rate, general fertility rate, One Health are mentioned once hence no need for abbreviations to be used for these.

Consistency:

- Consistency in referring to authors in text: first names used at times, then both first and last names are used at other times in text.
- Consistency in referring to high school students and secondary school students.
- Consistency in referring to school principal and headmaster.

Grammar:

- I suggest a grammar check.

e.g. "Therefore, the aim of this study Joel led as a part of THRiVE postdoctoral research fellowship was to determine disease transmission patterns among co-herded livestock and study the role of keds in their spread."

Suggest rewording:

- Page 4: Camels are preferred to other livestock in many communities because of their

resilience to survive in harsh climates with prolonged droughts **downstream of global warming.**

- The authors write that the “study was conducted in Laisamis, Marsabit County, about 450 km northeast of Nairobi City” and then add “field sampling was done in Laisamis located in the south of Marsabit County.”
- "...**laboratory animals** were transported to the field sampling sites in northern Kenya to provide bloodmeals for freshly collected camel keds and thereafter the samples from **those laboratory mice and rabbits** were used to identify transmitted ked-borne pathogens using molecular assays at icipe (Nairobi)."

Clarity:

- I suggest explaining what is meant by "co-herded".
- Page 5: health workers are mentioned separately in the surveillance study. Are the health workers different from doctors, midwives, nurses?

Repetition:

- The authors list the ethical approvals on page 3 and repeat on page 4 that “ethical permissions were already in place”.

References:

- Reference to results published elsewhere should be stated clearly in text Page 4: does the below mean the results of the study are reported in Kidambasi *et al.*, 2020?

"The findings of **this study** show that *Anaplasma* and *Ehrlichia* spp. and trypanosomes species *Trypanosoma vivax* and *T. evansi* are present in camels and in keds collected from them, suggesting a possible role in disease transmission (Kidambasi *et al.*, 2020)."

Ethical approval for community engagement with school children. Informed consent for community engagement with school children, parents/care givers and/or school management:

- The authors state that permission from school principals was obtained. Does the research ethics approvals obtained for all three case studies cover the community engagements? This should be clarified.
- Please state the ethical processes followed to gain access to school children in the community engagements i.e. was consent/assent sought directly from the school children prior to their participation? How were parents engaged to gain access to the school children?

Methods described to carry out the engagements for the case studies:

- The section on the settings and background to the research projects can be shortened to emphasize important aspects related to the public/community engagements. For example in the Kenya study the authors state a cross-sectional study design and convenient sampling of camel keds. How does this impact on the case studies for community engagement? What dates were these samples collected?

- What were the ages of the school children in the community engagements?
- A clear distinction should be made for all three case studies as to which aspects were public engagement and which were community engagement.
- The authors state they "designed a study" to assess perceptions of parents and students in Kenya (page 5) and then "developed" an "engagement intervention" referring to an "intervention activity" on page 6. The authors also "worked within a school setting" to assess awareness of maternal deaths on page 6.
- Sufficient detail should be given on the processes and methods for community and/or public engagement in the three country settings to be able to replicate such case studies.

Reference differing views and opinions:

- I suggest expanding on ethics in community and public engagement.
- I suggest linking the co-development of ideas, research methods and outputs to a theoretical framework such as the co-design approach alluded to in the abstract.

Lessons learnt and recommendations:

- The authors differentiate community engagement from public engagement in the introduction. The authors refer to two-way *public engagement* on page 7 and community engagement in other sections. Aspects of community and public engagement should be clearly described and/or differentiated if applicable, in the three case studies.
- Are *study participants* mentioned in the recommendations on page 7, part of the community or public engagements?
- I suggest highlighting the ethical considerations for such engagements.
- How can the community engagement be scaled up to broader public engagement in resource-challenged and pandemic settings?

Is the rationale for the Open Letter provided in sufficient detail?

Partly

Does the article adequately reference differing views and opinions?

No

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Partly

Is the Open Letter written in accessible language?

Partly

Where applicable, are recommendations and next steps explained clearly for others to

follow?

No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Epidemiology, public health research

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 21 Jun 2022

Joel L. Bargul

This is a case study approach implemented in three different African settings in Kenya, Tanzania and Uganda and covered vector borne disease, HIV and cause of maternal death. That authors differentiate community engagement from public engagement. Community engagements were undertaken with school going children from schools in research catchment area. The engagements are described from the perspective of three early career researchers. Below are some reflections and suggestions:

Title:

- I recommend reference to the case study approach in the title.

We agree and have rephrased the title to read: *"Case studies from the experience of early career researchers in East Africa in building community engagement in research"*

Use of capital letters mid-sentence:

- Introduction, page 3: "Masters" is capitalized.

The word *Masters* is now correctly written as: *master's* (It begins with lower case letter, and has apostrophe). Page 4 under the *"Introduction"* section of revised article.

- Page 5, paragraph 2: Total, Age, General.

We have now written these three words correctly by beginning with lower case letters, i.e. *total, age, general*. Page 5 under the subheading *"The Denna Mkwashapi study"* of revised article.

Use of abbreviations at first mention:

- MERS, antiretroviral therapy, Laisamis Secondary School.

In the process of rewriting the background information of the study to refocus it on community engagement as recommended by the reviewer, we deleted the sentence containing the abbreviation 'MERS' (Middle East respiratory syndrome coronavirus). We have given the abbreviation of 'antiretroviral therapy' as ART at first use in the main text on page 4 (under the subheading *"The Denna Mkwashapi study"*), and have just used ART on page 4. We have also included the abbreviation at first usage of 'Laisamis Secondary School (LSS)' on page 5.

Use of abbreviations at only mention:

- Total fertility rate, age specific fertility rate, general fertility rate, One Health are mentioned once hence no need for abbreviations to be used for these.

We have deleted the abbreviations TFR, ASFR, GFR, and OH

Consistency:

- Consistency in referring to authors in text: first names used at times, then both first and last names are used at other times in text.

To maintain consistency, the names of the researchers are first written in full, first and surname (page 4; last paragraph of "Introduction" of the revised paper), and thereafter they are referred consistently by the first name. Also, we have named each case study by the researcher's name, i.e. *"The Denna Mkwashapi study "Influence of human immunodeficiency virus (HIV) and antiretroviral therapy (ART) on fertility and uptake of family planning services."* (see page 4 - 5).

- Consistency in referring to high school students and secondary school students.

We have opted to use 'secondary school students' consistently throughout the paper.

- Consistency in referring to school principal and headmaster.

In Kenya, "principal" is commonly used to mean the teacher in charge of a school, unlike in Uganda that prefers "headmaster/mistress" or "head teacher" We have clarified this in the revised paper by stating at first mention: *"...principal (the term used for the headmaster/mistress in Kenyan schools) (Page 5, 1st paragraph under "Ethical approval" section).*

Grammar:

- I suggest a grammar check, e.g. "Therefore, the aim of this study Joel led as a part of THRIVE postdoctoral research fellowship was to determine disease transmission patterns among co-herded livestock and study the role of keds in their spread."

We have refocused the background information to this case study to emphasize community engagement as rightly suggested by the reviewer (page 4 - 5, under *"The settings and the background to the research project"*). Therefore, the above statement has been deleted in the revised article.

Suggest rewording:

- Page 4: Camels are preferred to other livestock in many communities because of their resilience to survive in harsh climates with prolonged droughts **downstream of global warming.**

We deleted this sentence in the process of rewriting the background information.

- The authors write that the "study was conducted in Laisamis, Marsabit County, about 450km northeast of Nairobi City" and then add "field sampling was done in Laisamis located in the south of Marsabit County."

We have deleted this sentence and rewritten the background information.

- **"...laboratory animals** were transported to the field sampling sites in northern Kenya to provide bloodmeals for freshly collected camels keds and thereafter the samples from **those laboratory mice and rabbits** were used to identify transmitted ked-borne pathogens using molecular assays at icipe (Nairobi)."

We have deleted this sentence to emphasize community engagement as suggested by the reviewer.

Clarity:

- I suggest explaining what is meant by "co-herded".

We have deleted the sentence containing the word 'co-herded'

- Page 5: health workers are mentioned separately in the surveillance study. Are the health workers different from doctors, midwives, nurses?

Indeed, health workers are not different from doctors, nurses, and midwives. We have now rephrased this sentence for clarity as follows: *"In the course of her research, Imelda engaged with both the internal stakeholders at the hospital (health workers and administrators) and external stakeholders (lawyers, representatives from the Ministry of Health, study partners with expertise in reproductive health). The engagement aimed at identifying the barriers to the quality improvement process of MDSR through an exploration of stakeholders' perspectives and what could be done to improve on the outcomes for mothers and their babies."* (Page 5, 3rd paragraph under *"The Imelda Namagembe study..."*)

Repetition:

- The authors list the ethical approvals on page 3 and repeat on page 4 that "ethical permissions were already in place".

To avoid repetition and also refocused this section, we have rewritten the background information. We have therefore deleted the sentence that contained the following clause: *"...ethical permissions were already in place."*

References:

- Reference to results published elsewhere should be stated clearly in text Page 4: does the below mean the results of the study are reported in Kidambasi et al., 2020? "The findings of this study show that *Anaplasma* and *Ehrlichia* spp. and trypanosomes species *Trypanosoma vivax* and *T. evansi* are present in camels and in keds collected from them, suggesting a possible role in disease transmission (Kidambasi et al., 2020)." Yes, we earlier published the results of this study in Kidambasi et al., 2020 in *AAS Open Research* journal. Full reference: Kidambasi KO, Masiga DK, Villinger J, et al.: Detection of blood pathogens in camels and their associated ectoparasitic camel biting keds, *Hippobosca camelina*: the potential application of keds in xenodiagnosis of camel haemopathogens [version 2; peer review: 2 approved]. *AAS Open Res.* 2020;2:164. 32510036 10.12688/aasopenres.13021.2 7243205

Ethical approval for community engagement with school children. Informed consent for community engagement with school children, parents/care givers and/or school management:

- The authors state that permission from school principals was obtained. Does the research ethics approvals obtained for all three case studies cover the community engagements? This should be clarified.
- Please state the ethical processes followed to gain access to school children in the community engagements i.e. was consent/assent sought directly from the school children prior to their participation? How were parents engaged to gain access to the school children?

Joel's study: Yes, approval by the Pwani University Ethics Review Committee (REF:

ERC/EXT/002/2020) provided consent to collect the information for various research activities with livestock farmers - including community engagement. Oral assent was sought from the LSS student volunteers (aged between 15 – 20 years, mean age = 17.32 years) who were provided with sufficient information about the focus group discussions (FGDs) to allow each individual to make informed and independent decisions to participate in the survey. Engagement through FGDs posed minimal risk to the students, thus permission was not sought from their parents, but the school principal who granted approval to our request and then linked us to the students. Page 5, 1st paragraph under “*Ethical approval*” section.

Denna’s study: The study, which received ethical clearance, had a component of community engagement. However, research engagement of school children in Tanzania required separate approval from the Director of Mwanza City and the school principal, which was granted (REF: MCC/SE/20.VOL.II/127). Page 6, 2nd paragraph under “*Ethical approval*” section.

Imelda’s study: We now provided the following details on Imelda’s study (page 6, last paragraph under “*Ethical approval*” section): *“Imelda’s study received approval from the Makerere University School of Medicine Higher Degrees Research and Ethics Committee (SOMREC; #REC Ref 2018-001) and Uganda National Council for Science and Technology (UNCST; Ref SS4797) to conduct the research on MDSR and community engagement. Engagement of secondary school students in research was preceded by permission from the headmaster and the director of studies. In addition, approval to engage with students in Uganda was obtained from the Ministry of Education and Sports (Uganda). Further, there was a waiver of consent from parents since the research was minimal risk. The students who participated in drama activities and qualitative interviews provided a written consent for those aged 18 years and above, whereas assent was obtained for those aged below 18 years.”*

Methods described to carry out the engagements for the case studies:

- The section on the settings and background to the research projects can be shortened to emphasize important aspects related to the public/community engagements. For example in the Kenya study the authors state a cross-sectional study design and convenient sampling of camel keds. How does this impact on the case studies for community engagement? What dates were these samples collected?

We fully agree and have now rewritten the background information to respond to the constructive comments raised by both reviewers to put the emphasis on community engagement, which is the key subject of this article. Refer to pages 4 – 5 of the revised article under the subheading titled “*The settings and the background to the research project.*” Whilst rewriting this section, we deleted the following sentence: “*...cross-sectional study design and convenient sampling of camel keds*”.

- What were the ages of the school children in the community engagements?

Joel’s study: We now provide the ages of the student volunteers (1st paragraph under Ethical approval section) as stated below: *“Oral assent was sought from the student volunteers (aged between 15 – 20 years, mean age = 17.32 years)...”* Page 5, 1st paragraph under “*Ethical approval.*”

Denna’s study: The secondary school students who participated in the consultative

meetings, drama and debates activities were high school students and were aged 18 years and above. Page 6, 2nd paragraph under *"Ethical approval"* section.

Imelda's study: Age range of the secondary school students was 16 – 21 years, with a mean age of 17.7 years. The students were keen to have their project completed before their final exams, which had been shifted to April 2021. Page 6, last paragraph under *"Ethical approval"* section.

- A clear distinction should be made for all three case studies as to which aspects were public engagement and which were community engagement.

We thank the reviewer for this constructive comment to distinguish between community engagement *versus* public engagement activities in research for each case study reported here. We define these two terms as follows (see page 3, third paragraph of *"Introduction"* in the revised article): *"We draw on the definition of public engagement used by Cohen et al., (2008: 2): 'a process that provides people with trustworthy information on key policy issues, elicits their input, and integrates it into decision-making and social action'. They make a distinction between this broader engagement agenda and that of 'community engagement', where the people directly participating in or affected by a research project are the focus of engagement. Both are important, and we would argue that as an introduction to broader 'public engagement', local community engagement provides a focus for emerging scientists to hone their skills in explaining research concepts and to work with community members to develop ideas, methods and outputs (MacQueen et al., 2015; Musesengwa et al., 2018; Tembo et al., 2021)." Therefore, all our studies involved community engagement – students are the community in the school. Further, under the sub-section *"What did we learn from the community engagement that we did in THRiVE?"* we state: *"Together, our findings from the community engagement provide key information that could inform policy."* See page 9.*

- The authors state they "designed a study" to assess perceptions of parents and students in Kenya (page 5) and then "developed" an "engagement intervention" referring to an "intervention activity" on page 6.

We now hope that the additional information describing the design of the case study should enable replication in other laboratories. For details on the revisions that address the reviewer's comments, please refer to the following three subsections article on pages 6 – 9 of the revised article:

- *"Where did the idea for the community engagement focus come from?"*
- *"What the community engagement activity was",* and
- *"What did we learn from the community engagement that we did in THRiVE?"*
- The authors also "worked within a school setting" to assess awareness of maternal deaths on page 6.

We have provided details of the study activities undertaken in the school. Please refer to page 8 of the revised paper under the subheading titled *"What the community engagement activity was"*

- Sufficient detail should be given on the processes and methods for community and/or public engagement in the three country settings to be able to replicate such case studies.

We have now provided more procedural details on research processes and methods, community engagement activities, and how the ideas for research engagement developed, to enable replication of the case studies by other laboratories. Please refer to subsection

titled *“what the community engagement activity was”* – on pages 6 – 8 of the revised article for details on each case study. In addition, we provide links to two videos that summarize **Joel’s** study on camel health and community engagement (<https://www.youtube.com/watch?v=FuM-RUnjpwM>), and access to education by the children from nomadic pastoralist communities (<https://vimeo.com/531249510>). Refer to page 6 under the subheading titled *“Where did the idea for the community engagement focus come from?”*

Reference differing views and opinions:

- I suggest expanding on ethics in community and public engagement.

Joel’s study: We have provided more details on page 5, the 1st paragraph under *“Ethical approval.”* We also state an ethical dilemma faced by the study, as follows: *“The main ethical challenge that Joel faced in his study was the lack of clear strategies on how to give credit to the many community members who contributed to new study ideas during community engagement meetings.”* Refer to page 5, last sentence of the *“Ethical approval”* section.

Denna’s study: We have provided more information on ethics. The approval granted covered community engagement activities, whereas student engagement in Tanzania required a separate approval from the director of Mwanza City Council (REF: MCC/SE/20.VOL.II/127), in addition to an informed individual consent process prior to research engagement. Please refer to page 6, 2nd paragraph under *“Ethical approval”* section.

Imelda’s study: We have provided sufficient details on ethics in community engagement Page 6, last paragraph under *“Ethical approval”* section.

- I suggest linking the co-development of ideas, research methods and outputs to a theoretical framework such as the co-design approach alluded to in the abstract.

The context of usage of the phrase *“co-develop ideas”* in the abstract section of our paper refers to new research ideas arising from community engagement aimed at improving relevance of the study. The two-way mutual engagement described in our article was between each individual researcher (THRIVE fellow) and the community members. Thus, there was no research engagement between the three independent case studies led by the early career researchers. In Joel’s study, for instance, mutual engagement and consultation with the camel farmers resulted in co-development of ideas that shaped his work on livestock health as follows: (1) In addition to our initial focus on camel trypanosomiasis and its transmission, another fatal camel disease known as acute camel disease syndrome (ACDS) was reported by farmers during engagement activities. This information led to establishment of a collaborative research study that aimed at understanding the cause and transmission of ACDS for disease control (Getange et al., 2021; Marisol et al., 2022), and (2) we co-identified some insecticidal and repellent plants with potential use in controlling biting keds. This has opened another avenue for Joel’s research on control of keds using plant-derived products. Therefore, our approach to co-design was practical, evolving in each site as we learnt what would be appropriate as engagement activities. We did not have a guiding theoretical framework.

Lessons learnt and recommendations:

- The authors differentiate community engagement from public engagement in the introduction. The authors refer to two-way public engagement on page 7 and community engagement in other sections. Aspects of community and public engagement should be clearly described and/or differentiated if applicable, in the three case studies.

On reflection, we have opted to refer to all our activities as community engagement; all the activities we describe were with local schools. The school students, teachers and parents were a part of the local communities.

- Are study participants mentioned in the recommendations on page 7, part of the community or public engagements?

Engagements with study participants in our case studies qualify as 'community engagement', but not 'public engagement'.

- I suggest highlighting the ethical considerations for such engagements.

We have described details on ethics in community engagement (Please refer to the "Ethical approval" section on pages 5 – 6 of the revised article).

- How can the community engagement be scaled up to broader public engagement in resource-challenged and pandemic settings?

We thank the reviewer for this comment. We have added the following information under bullet #4 of the "Recommendations" on page 9: *"Communities and the wider public with increased knowledge about ongoing research may be empowered to inform others. Community members who share information gained through their engagement in research can aid reaching out to the general public for example in disseminating research findings to a wider audience, especially to those under resource-challenged settings. Other potential opportunities for efficient scaling up of engagement activities, for instance during pandemics (i.e. COVID-19) to include using social media platforms such as Facebook, WhatsApp, and Twitter as most community members in these studies have access to mobile phones, and also using the mass media (e.g. newspaper articles, opinion pieces, discussions on radio and television)."*

Competing Interests: None

Reviewer Report 11 April 2022

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Doreen Tembo

Wessex Institute, Faculty of Medicine, University of Southampton, Southampton, UK

The article provides useful learning from three community engagement case studies of early/mid-career researchers working in three different biomedical/applied health focused research areas and methodologies in low and middle income country (LMIC) settings. The case studies utilised a mix of engagement methods ranging from consultation to co-production. They conclude that two-

way engagement is crucial in research and that it helps to generate ideas to improve research, strengthen mutual trust between communities and researchers and promote uptake of research findings.

The open letter will be a useful contribution to the field, especially as there is less published that applied to LMIC countries. The authors are encouraged to consider the following to improve the article:

- Community engagement and its importance is highlighted through the modern lens of Covid/disinformation and distrust at the outset of the article which is great for catching the attention of the reader. However the article should highlight that this was gaining traction before Covid, and that it has a long history within the space of international development. The authors reference refreshed/updated UK National Institute for Health Research (which is referenced incorrectly in the article as 'National Institutes of Health Research') INVOLVE's guidance/briefing notes as support for community engagement within the funding landscape being more novel. However it is not novel in the UK context. The original version of the guidance for example is from 2000. Bioethics which include community engagement have embedded in other funders work (see MacQueen *et al.*, 2015¹).
- The authors are advised to name the case studies (either by the researcher name or a number) to better ensure clarity.
- The researchers involved in the case studies can have their names written in full, first and surname, thereafter they can be referred to consistently by the first or surname, but it would be preferable to choose one.
- It is suggested that the context setting for the case studies is carried out before ethics are discussed to minimise repetition.
- There is potential for the case study scientific background to be shortened to sharing only the key information necessary to understand the community engagement aspects of the paper. For example the length and content of the second case study by Denna achieves this purpose. They should ideally also cover the same elements as they currently report on some different elements, e.g. Imelda's case study has information on stakeholder engagement while the others appear not to. It would be useful for each case study to have the same subheadings so they can be structured in the same way.
- The language requires a little review to change it from colloquially spoken to written format e.g. "it is not clear on how" should be "it is not clear how", there are some unnecessary capitalisations of words and missing punctuation in other places. Some sentences need to be broken down, for example some are a whole paragraph long.
- The article would benefit from a longer and more critical discussion that draws on wider literature to discuss cross learning across the case studies. It should also critically reflect on any limitations and things which could have been done differently.
- The recommendations add greatly to the value of the paper.
- The following are suggested additional citations or material the authors may wish to

consider:

- <https://www.unicef.org/mena/reports/community-engagement-standards>
- <https://www.nihr.ac.uk/documents/resource-guide-for-community-engagement-and-involvement-in-global-health-research/27077>
- Musesengwa *et al.* (2018²).
- Tembo *et al.* (2021³).

References

1. MacQueen KM, Bhan A, Frohlich J, Holzer J, et al.: Evaluating community engagement in global health research: the need for metrics. *BMC Med Ethics*. 2015; **16**: 44 [PubMed Abstract](#) | [Publisher Full Text](#)
2. Musesengwa R, Chimbari MJ, Mukaratirwa S: A Framework for Community and Stakeholder Engagement: Experiences From a Multicenter Study in Southern Africa. *J Empir Res Hum Res Ethics*. **13** (4): 323-332 [PubMed Abstract](#) | [Publisher Full Text](#)
3. Tembo D, Hickey G, Montenegro C, Chandler D, et al.: Effective engagement and involvement with community stakeholders in the co-production of global health research. *BMJ*. 2021. [Publisher Full Text](#)

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Partly

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Partly

Is the Open Letter written in accessible language?

Partly

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Mixed-methods Research, Community Engagement and Involvement Specialist, Health Policy, Health Systems

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 21 Jun 2022

Joel L. Bargul

Responses to reviewer's comments The article provides useful learning from three community engagement case studies of early/midcareer researchers working in three different biomedical/applied health-focused research areas and methodologies in low and middle-income country (LMIC) settings. The case studies utilised a mix of engagement methods ranging from consultation to co-production. They conclude that two-way engagement is crucial in research and that it helps to generate ideas to improve research, strengthen mutual trust between communities and researchers and promote uptake of research findings. The open letter will be a useful contribution to the field, especially as there is less published that applied to LMIC countries. The authors are encouraged to consider the following to improve the article:

- Community engagement and its importance is highlighted through the modern lens of Covid/disinformation and distrust at the outset of the article which is great for catching the attention of the reader. However the article should highlight that this was gaining traction before Covid, and that it has a long history within the space of international development.

We agree and have updated the introduction section (page 3) of the revised article to include the following before we mention guidance: *"Community engagement has a long history within the space of international development on which to build"* And on page 4 we have mentioned the effect of the pandemic separately. *"While the studies were affected by the COVID-19 pandemic, the work proceeded during the pandemic, albeit at a slower pace due to travel restrictions, among other guidelines put in place by the governments to control the spread of the disease (Ministry of Health Uganda, 2020)."*

- The authors reference refreshed/updated UK National Institute for Health Research (which is referenced incorrectly in the article as 'National Institutes of Health Research') INVOLVE's guidance/briefing notes as support for community engagement within the funding landscape being more novel. However it is not novel in the UK context. The original version of the guidance for example is from 2000. Bioethics which include community engagement have embedded in other funders work (see MacQueen et al., 2015¹).

Thank you for this observation. We have modified the wording to remove the suggestion that this is a new development. The 's' has been removed from Institute. See page 3 of the revised article under the *"Introduction"*.

- The authors are advised to name the case studies (either by the researcher name or a number) to better ensure clarity.

We fully agree with the reviewer and have chosen to name each case study by the researcher's name as shown by the example below. *The Imelda Namagembe Study "Implementation of maternal death surveillance and response policy: the impact of training and community engagement."* Page 5 under *"The settings and the background to the research project."*

- The researchers involved in the case studies can have their names written in full, first and surname, thereafter they can be referred to consistently by the first or surname, but it would be preferable to choose one.

We agree with the reviewer's suggestion and have therefore adopted consistent format in the revised article, which begins with writing of full names of the researcher, and

subsequently, only the first name is referred.

- It is suggested that the context setting for the case studies is carried out before ethics are discussed to minimise repetition.

We agree with the reviewer, and have now moved the section on *“Ethical approval”* to follow *“The settings and the background to the research project”* section. Refer to page 4 & 5 of the revised article.

- There is potential for the case study scientific background to be shortened to sharing only the key information necessary to understand the community engagement aspects of the paper. For example the length and content of the second case study by Denna achieves this purpose. They should ideally also cover the same elements as they currently report on some different elements, e.g. Imelda's case study has information on stakeholder engagement, while the others appear not to. It would be useful for each case study to have the same subheadings so they can be structured in the same way.

We fully agree with this reviewer's suggestion and have made the following changes for each case study. We have extensively restructured the background information, particularly for Joel and Imelda's studies (the reviewer was contented with the 3rd case study by Denna), to refocus and emphasize community engagement, which is the main idea of our paper. Refer to pages 4 – 5 of the revised article under the subheading titled *“The settings and the background to the research project.”*

- The language requires a little review to change it from colloquially spoken to written format e.g. "it is not clear on how" should be "it is not clear how", there are some unnecessary capitalisation of words and missing punctuation in other places. Some sentences need to be broken down, for example some are a whole paragraph long.

We have corrected these errors. We have now carefully addressed to ensure adherence to Standard English throughout the revised article.

- The article would benefit from a longer and more critical discussion that draws on wider literature to discuss cross learning across the case studies. It should also critically reflect on any limitations and things, which could have been done differently.

We have added more literature by referring to six new sources (references) to widen the scope of the paper. In addition, we have added the following paragraph on the limitations of the study that reflects what we could have done differently (page 9 under *“A limitation of the study”*): *“Our case studies would have benefitted from a more rigorous approach to measuring and evaluating the socio-economic impact of the community engagement activities. However, monitoring and evaluation of the engagement outcomes were not conducted due to the limited funding available.”*

- The recommendations add greatly to the value of the paper.

Thank you very much for this encouraging comment.

- The following are suggested additional citations or material the authors may wish to consider:

References:

1. MacQueen KM, Bhan A, Frohlich J, Holzer J, et al.: Evaluating community engagement in global health research: the need for metrics. *BMC Med Ethics*. 2015; 16: 44. DOI: 10.1186/s12910-015-0033-9.
2. Musesengwa R, Chimbari MJ, Mukaratirwa S: A Framework for Community and Stakeholder Engagement: Experiences From a Multicenter Study in Southern Africa

(2018). *J Empir Res Hum Res Ethics*. 13 (4): 323-332. DOI: 10.1177/1556264618769002

3. Tembo D, Hickey G, Montenegro C, Chandler D, et al.: Effective engagement and involvement with community stakeholders in the co-production of global health research. *BMJ*. 2021. <https://doi.org/10.1136/bmj.n178>.

4. <https://www.unicef.org/mena/reports/community-engagement-standards>

5. <https://www.nihr.ac.uk/documents/resource-guide-for-community-engagement-andinvolvement-in-global-health-research/27077>

6. Ministry of Health Uganda. Guidelines for prevention of Covid-19 when conducting meetings at workplaces. Kampala. 2020

<https://www.health.go.ug/covid/project/guidelines/>.

We thank the reviewer for taking an extra step to suggest these additional references that we have cited in our revised paper. We also have included one more reference, i.e. Ministry of Health Uganda, 2020 (#6 in the above list)

Competing Interests: No competing interests were disclosed.
