


# Barriers to community engagement during the response to an Ebola virus disease outbreak in Uganda

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## ABSTRACT

**Background** Uganda reported an outbreak of Ebola virus disease (EVD) in 2022. As part of the outbreak response, government and partners promoted community engagement, which seeks to involve communities in the design, implementation and evaluation of interventions to raise awareness, build trust between communities and partners and create ownership of interventions. This study, therefore, explored barriers to community engagement during the 2022–2023 EVD outbreak response in Uganda.

**Methods** This qualitative study, conducted in five districts (Kampala, Kassanda, Kyegegwa, Mubende and Wakiso), involved 25 focus group discussions among community members and community health workers (CHWs). In addition, 32 key informant interviews were conducted with staff from the Uganda Ministry of Health, district health officials, local leaders, non-governmental organisation staff and other stakeholders. Data were analysed according to the thematic approach using ATLAS.ti (V.6).

**Results** The main barriers to community engagement identified during the EVD outbreak response are presented under four main themes: (1) delayed consultations between partners and communities; (2) poor communication and misinformation; (3) limited support to human resources; and (4) institutional and coordination challenges. Specifically, these barriers included: limited consultation due to misbelief in community roles; delayed sociocultural discussions; stigma and delayed psychosocial interventions; misinformation, rumours and political influence; poor communication mechanisms; contradictory messages and lack of transparency; language barrier and inappropriate communication media; work overload for CHWs and other community volunteers; failure to prioritise protection of community workers; lack of compensation for CHWs and other community personnel; poor logistical management; inadequate coordination and partner operations; unfavourable institutional structures; and limited funding for emergencies.

**Conclusion** The barriers encountered in community engagement during the 2022–2023 EVD outbreak need to be addressed through strengthening guidelines and standard operating procedures, capacity building for partners and communities, as well as adequate financing to ensure Uganda is better prepared for future health emergencies.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Several epidemics of Ebola virus disease (EVD) have been reported in Uganda, with significant impact on individuals and communities. Community engagement is critical for preparedness and response to health emergencies such as outbreaks, although lessons show critical gaps in the process, including ill-defined objectives, methods and stakeholders.

## WHAT THIS STUDY ADDS

⇒ There was little information on the challenges faced by various stakeholders in community engagement during outbreak response in Uganda. This study used qualitative methods in both urban and rural settings in the most affected districts by the 2022–2023 EVD outbreak in Uganda. Our findings indicate that several challenges affected community engagement during the EVD outbreak response, including delayed consultation with communities; poor communication between partners and communities; misinformation; limited human resource; and institutional and coordination challenges among partners.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The barriers to community engagement identified in this study can be used to guide priority setting during future EVD (and other outbreak) response to improve intervention design and implementation. In particular, the results can be used to prioritise development and implementation of community engagement guidelines (with emphasis on clear roles and responsibilities), adequate financing, as well as strengthening of community engagement systems at all levels (national, district and community).

## INTRODUCTION

Uganda has reported several epidemics of Ebola virus disease (EVD) since 2000, with the latest outbreak (Sudan ebolavirus) declared in the Central, Eastern and Western regions in 2022. EVD is a severe contagious zoonotic haemorrhagic fever, particularly affecting sub-Saharan Africa.<sup>1–4</sup> The Sudan

ebolavirus is a member of the genus *Ebolavirus* of the Filoviridae family (including species such as *Zaire ebolavirus*, *Tai Forest ebolavirus*, *Reston ebolavirus*, *Bundibugyo ebolavirus* and *Bombali ebolavirus*).<sup>5</sup> The outbreak was officially confirmed in Uganda on 20 September 2022, with the first case recorded in Mubende, one of the districts in the central region of the country. The virus spread to 9 (out of 146) districts in the country, resulting in 142 confirmed cases, 22 probable cases and 77 deaths (48%) by the time the end of the outbreak was declared in January 2023. Most patients with EVD were male (58%) and 23% were children (0–17 years) with the highest case fatality rate (74%) among those below 10 years.<sup>6 7</sup>

Given the impact of EVD outbreaks on individuals and communities,<sup>7–10</sup> community engagement is critical for preparedness and response to health emergencies.<sup>9 11–18</sup> In public health, community engagement seeks to involve communities in the design, implementation and evaluation of interventions to raise awareness on key issues, build trust between communities and partners, create ownership of interventions and contribute to social cohesion of impacted populations. In addition, community engagement attempts to understand cultural and social practices that drive epidemics, as well as negotiating a contextually acceptable public health response.<sup>16 19–21</sup> However, community engagement during recent EVD outbreaks in sub-Saharan Africa has been haphazard, with little priority given to it by key stakeholders.<sup>9</sup>

Effective EVD response hinges on surveillance, contact tracing, case management, laboratory services, infection prevention and control measures (in healthcare and community settings), safe and dignified burials; all of which depend on engaging affected communities.<sup>22</sup> Working closely and continuously with communities also ensures that prevention messages are clearly articulated and communicated, while misconceptions and rumours are rapidly addressed.<sup>9 10 22</sup> By designing interventions with communities, public health activities can also capitalise on trusted relations to closely integrate public interventions including home monitoring, placing Ebola treatment centres within affected areas without fear of repercussions, and enhanced monitoring of cross-border movements.<sup>4 23 24</sup>

Following experiences with previous EVD epidemics, the United Nations agencies and partners have since called for genuine engagement with communities during outbreak response.<sup>24</sup> Despite this, barriers to implementing community engagement remain,<sup>25</sup> in particular with a poorly organised process, and ill-defined objectives, methods and stakeholders.<sup>26</sup> Community engagement has historically been underfunded, conflated with risk communication<sup>27</sup> and generally neglected at the expense of medical interventions.<sup>13</sup> In some instances where efforts have been made to engage communities, local resistance to interventions indicates ineffective engagement of the population, raising concerns about whether stakeholders share a common understanding of community engagement.<sup>14 28</sup>

Anecdotal evidence from the most recent EVD outbreak in Uganda (2022–2023) indicates that implementation of community engagement was inadequate, with no clear guidelines on who, how and when communities should be engaged. In addition, little information exists on the challenges faced by various stakeholders such as the government and partners involved in community engagement during outbreak response in Uganda. Community engagement would also not be complete without a voice of the communities that are at the centre of public health emergencies, including their views on community involvement.<sup>14</sup> This study, therefore, used qualitative methods to explore barriers to community engagement during the 2022–2023 EVD outbreak in Uganda.

## METHODS

### Study site and participants

The study was conducted in five of the nine most affected districts by the EVD outbreak, purposively selected to include rural and urban settings. The districts included Kampala and Wakiso (predominantly urban) and Mubende, Kassanda and Kyegegwa (predominantly rural). Kassanda and Mubende districts formed the epicentre of the outbreak, while Kampala and Wakiso were among the most affected urban districts. The total population in the five study districts was 4 747 272 including Kampala (1 507 080), Kassanda (276 800), Kyegegwa (281 637), Mubende (684 337) and Wakiso (1 997 418).<sup>29</sup> Study participants included community members, local leaders, community health workers (CHWs) and village task force members (such as community elders and other influential individuals). Additionally, various stakeholders involved in the study included health practitioners at public facilities, district health officials, Ministry of Health (MOH) officials, non-governmental organisation staff, civil society organisations, as well as other subnational and national stakeholders who participated in the EVD response.

### Study design and sampling

This qualitative study employed focus group discussions (FGDs) and key informant interviews (KIIs), which enabled triangulation of data.<sup>30</sup> In each district, 5 FGDs were conducted (total of 25 FGDs). 5 or 6 KIIs were conducted per district (total of 27 KIIs), and 5 were held at national level (overall total of 32 KIIs). The number of FGDs and KIIs was sufficient to achieve data saturation. FGDs were held in each district so as to be representative of the general population (one for males, one for females, one for mixed-sex adults (>24 years), one for mixed-sex youth (18–24 years) and one for mixed-sex CHWs). Organising the FGDs into these distinct categories was to take into consideration sociocultural and gender aspects, which are predominant across different sections of the country. Subcounties, parishes and villages were purposely selected to include the most and least affected communities in terms of number of suspected

and confirmed cases, guided by district health officers during inception meetings. Community FGD participants were from the same village, while CHWs were from multiple neighbouring villages. In addition, FGD participants were selected from the community, regardless of their involvement in community engagement, to solicit general perceptions. Key informants, identified through the district health offices and MOH, were purposively sampled based on their involvement in community engagement during the EVD response.

### Data collection

We developed KII and FGD guides (see online supplemental material) in English and translated them into the local languages (*Luganda* and *Runyakitara*). These guides, used for data collection in May and June 2023, assessed the community perceptions and experience during response to the EVD outbreak, including community engagement and its barriers. Four research assistants and a supervisor, all with graduate health-related degrees and experience in qualitative research, were recruited and trained on the study objectives and tools, and reorientated on research ethics and community entry. Data collection tools were pretested in the local languages by research assistants in a division of Kampala not included in the study. Quality control measures during the study included spot checks, daily debriefs in evening meetings of research assistants and the supervisor throughout the data collection period.

Communal places convenient for participants to attend, including local council offices, health facilities and places of worship, were chosen as locations for the FGDs. KIIs were conducted at workplaces or other places of preference chosen by the participants. *Luganda* was used for all FGDs in Kampala, Kassanda, Mubende and Wakiso districts, while a mix of *Luganda* and English was used for the local leader KIIs. *Runyakitara* was predominantly used in Kyegegwa among all FGDs and local leader KIIs. All other interviews, including the KIIs at national level, were conducted in English. The KIIs and FGDs lasted on average 60 and 90 min, respectively. Audio recordings of all interviews and discussions were taken after obtaining informed consent from the participants. Field notes were also written in English and used alongside audio recordings.

### Data management and analysis

All the FGDs and KIIs were audio recorded, followed by verbatim transcription and translation into English (for those recorded in another language). Data analysis was carried out by EA (woman) and DM (man) who are both experienced qualitative researchers. In a back-and-forth process, audio recordings were listened to and field notes and transcripts read several times in order to validate the transcription process and get familiar with the data. The transcripts were then exported to ATLAS.ti V.6 for coding, which was done inductively by the two researchers who compared and harmonised the resultant

**Table 1** Sociodemographic characteristics of focus group discussion participants

Variable	Category	Frequency (n=188)	(%)
Age (years)			
	18–29	55	29.3
	30–39	70	37.2
	40–49	31	16.5
	≥50	32	17.0
Sex			
	Male	91	48.4
	Female	97	51.6
Highest education level			
	None	9	4.8
	Primary	82	43.6
	Secondary	78	41.5
	Tertiary	19	10.1
Religion			
	Anglican	47	25.0
	Catholic	58	30.9
	Muslim	32	17.0
	Pentecostal/born again	37	19.7
	Seventh-day Adventist	14	7.4
Occupation			
	Community health worker	36	19.1
	Farmer	80	42.6
	Employed/professional	22	11.7
	Self-employed (including business, <i>boda boda</i> *)	29	15.4
	Casual labourer/petty trader/not employed)	17	9.0
	Student	4	2.1

\**Boda boda*—commercial motorcycle rider.

codes. Thematic analysis was performed during which codes were discussed, refined iteratively and similar ones grouped to form subthemes and related subthemes formed themes.<sup>31</sup> Memos were taken throughout the entire analysis process which were considered in discussing the codes and themes, as well as reflections to ensure that the results were not influenced by any of the researchers' preunderstanding or experience with the outbreak.

## RESULTS

A total of 25 FGDs were conducted involving 188 participants, mostly 30–39 years old, with primary or secondary level of education and practising farming (table 1). The KIIs were 32 in total (27 at district level and 5 at national

**Table 2** Key informants at district and national levels

Category	Total (n=32)
District level	(n=27)
District Health Team members (including district health officers, assistant district health officers (environmental health), district surveillance focal persons and health educators); resident district commissioners; local council I, II and III leaders; social workers; and health assistant	22
Implementing partners	5
National level	(n=5)
Ministry of Health	2
Implementing partners	3

level) (table 2). They included local government officials (district health officers; assistant district health officers (environmental health), district surveillance focal persons; health educators; resident district commissioners; local council I, II and III leaders; social workers; and health assistants); and national level government (MOH) and implementing partners.

Results from the study are presented under four main themes: (1) delayed consultations between partners and communities (limited consultation due to misbelief in community roles; delayed sociocultural discussions; stigma and delayed psychosocial interventions); (2) poor communication and misinformation (misinformation, rumours and political influence; poor communication mechanisms; contradictory messages and lack of

transparency; and language barrier and inappropriate communication media); (3) limited support to human resources (work overload for CHWs and other community volunteers; failure to prioritise protection of community workers; lack of compensation for CHWs and other community personnel; and poor logistical management); and (4) institutional and coordination challenges (inadequate coordination and partner operations; unfavourable institutional structures; and limited funding for emergencies) (table 3).

**Delayed consultations between partners and communities**

Limited consultations due to misbelief in community roles  
Misbelief by partners in the community’s abilities and roles while planning to respond to the epidemic was

**Table 3** Summary of results (themes and subthemes)

Theme	Subthemes	Sub-sub themes
Delayed consultations between partners and communities	Limited consultations due to misbelief in community roles	
	Delayed sociocultural discussions	
	Stigma and delayed psychosocial interventions	
Poor communication and misinformation	Misinformation, rumours and political influence	Misinformation and rumours
		Political influence
	Poor communication mechanisms	Limited feedback
		Lack of transparency and contradictory actions
Limited support to human resources	Work overload for CHWs and other community volunteers	
		Failure to prioritise protection of community workers
		Lack of compensation for CHWs and other community personnel
		Poor logistical management
Institutional and coordination challenges	Inadequate coordination and partner operations	
		Unfavourable institutional structures
		Limited funding for emergencies
CHWs, community health workers.		

reported. Some participants indicated that there was an attitude by several actors, including clinicians, other health workers, local leaders and partners, that communities could not do anything nor had any role to play in the development of outbreak response interventions. These stakeholders did not think that communities should be consulted when planning interventions, in contrast to the beliefs and expectations of the participants. Indeed, many participants said that consultation was not conducted, leaving communities feeling inferior, disrespected and expected to participate by only obeying top-down interventions.

For us people in the community, we are of low class. Our voices are never listened to and we are despised by some leaders, especially when they come here in the community. It is not common for them to hear [listen to] our views. We are not on the local council committee, we are not government workers, we do not work for organizations, we do not belong anywhere apart from being in the community. That is why I say we are inferior, we are just members of the community, so we were following whatever they were telling us. Female FGD, Kyegegwa

#### Delayed sociocultural discussions

Nearly all participants indicated that early discussions on sociocultural considerations were not conducted within the existing local structures at the district, subcounty, parish, village and household levels. The sociocultural discussions that were conducted by some partners came in the later phases of the epidemic response, as issues such as safe burials emerged. This created several barriers where the communities felt that some EVD control activities, such as burial practices, were disrespectful and not in line with their culture which made people resistant. Some dead bodies were believed to have been exhumed after safe and dignified burials were conducted by the local authorities.

In our culture, it is risky to bury a person while facing down. I think in most communities, it is a taboo to do so and that is why people began to react negatively towards health workers. This was the same reason why people became rowdy during burials. Mixed FGD, Mubende

The key informants' reflections on the challenges they encountered, especially during the first phase of the response, revealed a strong realisation of the key influence of the sociocultural stakeholders (including leaders from the cultural, religious and traditional sectors) in the outbreak response. Besides private clinics, these stakeholders were among the first contacts for care and information; hence, they were instrumental in how the disease was understood. While emphasising the community resistance the responders experienced by delaying engagement with these structures which later became central in engaging communities, many key informants noted that the outbreak would have been taken much longer to control if traditional healers were not effectively involved.

Certain structures had stronger influence on the behaviour of communities. A good example in this case are the traditional healers. While we have always known that a lot of people go to traditional healers, Ebola brought it into a clear perspective where we noted that people go to them first, then to formal health settings, then to private health facilities, then back to traditional healers, and so on. Therefore, the movement between and among those providers became very clear that if we don't engage traditional healers, it would have taken much longer to control this disease. Key informant, national level implementing partner.

#### Stigma and delayed psychosocial interventions

There were also issues of stigma associated with EVD in the community, which limited people's willingness to participate in engagement activities. Consequently, some patients hid or were hidden in communities for fear of the stigma that was associated with an EVD diagnosis. Furthermore, the delay in engaging communities regarding stigma and how it could be abated was noted as a concern. For example, some survivors were stigmatised to the extent that others were not welcome back to their communities after recovering from the disease.

One of the biggest challenges was stigma. Yet the social and psychological interventions came later in the outbreak response. It was therefore very difficult getting entry into the community due to the issue of stigma and delayed support. Implementing partner, Mubende

#### Poor communication and misinformation

##### Misinformation, rumours and political influence

##### *Misinformation and rumours*

Generally, many people believed that EVD was due to witchcraft and bad spirits afflicted on affected individuals and their households. Misinformation was noted especially in the early phases of the outbreak response, with some community members believing that EVD was a hoax and that people in government were using it as a pretext to enrich themselves. For example, lockdowns were seen as measures taken by government officials to access gold mines (some of the affected areas are rich in this mineral). Other rumours described EVD as a way to illegally harvest human organs for trade, which led to some cases being hidden from health workers.

When an Ebola patient died, the communities would complain as to why they were always buried late in the evening. They were questioning the logic behind this practice that made the community scared to go to the health facility for fear of having their kidneys removed. Youth FGD, Kassanda

Findings also indicated that while social media was appreciated as a useful means of communication in some of the community engagement response activities, it was also used by some people to spread misinformation. Such disinformation made it difficult for CHWs to engage with communities, hence negatively affecting their work. A fast, innovative and contextualised approach to tackle these negative perceptions was lacking in the initial

phase of the response, thereby creating strong mistrust and escalation of rumours within the community.

Another thing that disturbed us was internet platforms like WhatsApp. One would go to their computer and edit something and put someone's face and indicate that they died and had been injected with some kind of drug, and that Ebola is a hoax. So, when such a message reaches another person, and that person sends it to another person, that kind of information spreads widely. CHW FGD, Wakiso

### *Political influence*

Negative involvement of political leaders in the EVD response interventions became a significant barrier across the districts that were involved in the study. Some groups in the community, including youth and political leaders looked at EVD politically, including politicising many of the issues regarding the disease, which contributed to the community's mistrust in the government, particularly MOH. As a result, many people believed that the EVD response was politically engineered to get money from funders given that the COVID-19 pandemic, which they strongly believed was mismanaged, was no longer of great concern.

Political leaders also played a big role in hindering our participation. The Ministry of Health could make a communication and the politicians would speak otherwise, painting a different picture. This changed and shaped peoples' attitudes and beliefs regarding the existence of Ebola. Male FGD, Wakiso

### *Poor communication mechanisms*

#### *Limited feedback*

Findings indicate that community engagement was conducted by various stakeholders (the government and implementing partners) in such an ineffective way that feedback mechanisms with the communities were unclear. Several instances of resistance towards implementing stakeholders were reported, caused by community concerns and questions that went unanswered. For example, there were concerns about the lack of effective communication, especially when patients died, which made the communities question the whole outbreak response.

Some of the community members were angry with the responders and this was mainly because of many unanswered questions. We would get information that a certain patient died a few days back, but the body would be delivered after some days, and this was raising more suspicion as no information was being provided. Youth FGD, Kassanda

Ineffective government call centres set up for surveillance purposes were reported to have limited two-way communication with communities. Indeed, call centres were frequently seen to fail at responding to phone calls from communities, which also reduced their motivation to engage with government stakeholders. For example, in Kampala and Wakiso districts, it was reported that emergency calls were not answered, especially on weekends. In

other districts such as Kyegegwa and Mubende, the call centres were reportedly overwhelmed by many community calls. Other findings indicated that the toll-free lines were mainly based in Kampala and not easily accessible by callers from elsewhere (Kassanda, Kyegegwa and Mubende), hence airtime costs were incurred by using personal lines. Such limitations reportedly demotivated people and affected the community engagement process, including participation in surveillance and reporting.

We had challenges with the toll-free line. I still remember it even up to now as it had its challenges when it could not save a patient, because a time came when we went and demonstrated and told them that they gave us a fake number to call. They then said we were still using the line for Kampala, and they hadn't yet set one for Mubende. This meant that they had to give us their personal telephone contacts and we had to load airtime before calling them. CHW FGD, Mubende

### *Lack of transparency and contradictory actions*

Concerns regarding a lack of transparency by the government and partners were seen as another factor that prevented communities from engaging fully with the outbreak response. Some participants in the FGDs mentioned that the government was unconvincing in how it handled the outbreak. For example, key information about the outbreak response such as the partners involved and resources mobilised was not openly provided. In addition, allowing multiple people, including suspected cases, to occupy response vehicles was seen as contradictory to public health messages. Some FGD participants reported that health workers in Wakiso told people to observe standard operating procedures, while they themselves did not observe them when managing suspected cases. These contradictory actions further served to strengthen the belief that EVD was made up and heightened levels of suspicion against the government.

We got information from Mubende district that the victim had died on Thursday, yet the hospital was telling us that the person had died on Saturday. There was that conflicting information. Actually, some people had attempted to get the body that Thursday, but they were stopped. Yet within the hospital, we had other patients who knew about this. That is when the community became suspicious and agitated. Mixed FGD, Mubende

### *Language barrier and inappropriate communication media*

Participants reported that besides the information, education and communication (IEC) materials being delayed, they were also only provided in two languages (English and *Luganda*) at the beginning of the outbreak, without consideration of other local languages. Furthermore, the community engagement officers in some districts lacked knowledge of the local languages, which required them to later hire interpreters, a situation that some community members disliked. This was partly because the participants felt that there were suitable members in the

community who knew the local language and could do the job, although they were not considered.

The other thing that I noticed was that most of the materials that were given were in only in Luganda and English. We needed to appreciate that not that all people in Buganda [a kingdom in central Uganda] understand Luganda, and not all people in Uganda understand English. Key informant, Kassanda District Local Government

Study participants also remarked that media houses contracted in some districts were not frequently listened to by the majority of target communities. In Kyegegwa, for example, the radio station that had been contracted by the government to deliver sensitisation messages was not the one that most communities listened to. Such weaknesses in media coverage meant that the district had to, in a haphazard way, rely on partners for other airtime and in-person talk shows for community sensitisation.

### Limited support to human resources

#### Work overload for CHWs and other community volunteers

Participants reported that CHWs were required to do more than they could handle and beyond what was expected of their role. CHWs were in some cases concerned that health workers, before intervening themselves, were asking them to first confirm suspected cases in households. CHWs, therefore, felt that they were being asked to do the work that was the responsibility of health workers, whom they believed were more suited and equipped for the role.

Even when the health workers could come in their vehicles, they didn't move out of them. They used to remain seated there and then send you to the household which had the suspected patient. This affected me as I also did not want to contract the virus. They are the professionals but instead of going and seeing the patient, they were sending me there. CHW FGD, Mubende

Shortage of safe and dignified burial personnel, which primarily included volunteers, was another manifestation of the high workload placed on community members involved in the response. These personnel were overwhelmed with work, at times leading to them arriving late for burials. This impacted the quality of the work, resulting in late evening burials and little soil cover on graves, which further created resentment among communities.

It was a challenging moment. Even the burial teams were not enough in the community and at times, they were overwhelmed by the number of the dead. They would be seen travelling long distances to other areas and by the time they would come back, it was in most cases late. Youth FGD, Kassanda

#### Failure to prioritise protection of community workers

Findings indicated that participants saw a challenge during budgeting and funding allocation, whereby infection prevention and control at health facilities, and surveillance activities were prioritised over

community engagement, including personal protective equipment (PPE) of community workers. Some key informants stressed that protecting health practitioners without providing communities with PPE was unfair and dangerous. Indeed, community empowerment and protection were given little consideration, despite some advocacy for this being done during various meetings.

You want to prevent an infection from getting a health worker, but you don't want to prevent an infection at community level? You want to keep surveillance, seeing where the infection is, looking for it, but you don't want to empower the communities themselves to prevent the infection from spreading? You don't want to break the chain by changing people's mind sets, you are focused on looking for it and preventing only your health workers from getting the disease? Key informant, District Health Team, Kyegegwa

Shortage of PPE, such as boots, gloves and coats for community personnel, including burial teams and CHWs was reported. Participants worried that health practitioners were only protecting themselves, while CHWs were sent to engage communities with insufficient PPE. The CHWs, therefore, felt that they were being exposed to EVD, which they saw as a further challenge in their efforts in engaging communities. Consequently, some of the CHWs reported not having worked to the best of their ability during the response. For example, some CHWs explained that they would keep a distance from affected families, causing dissatisfaction from community members.

We would just go as we were without any personal protection, but we also had our lives to protect. I would therefore stand meters away and ask: 'Are the people who live here there?' They would answer that 'yes' then I would tell them that 'I have been told that there is a patient here. CHW FGD, Mubende

#### Lack of compensation for CHWs and other community personnel

Community leaders, CHWs and burial teams were not always sufficiently compensated for their services. Therefore, some of them had to travel long distances by foot, or use their own money to perform activities, despite being low-income earners who spent much of their time volunteering. For those CHWs who received payment, it was reportedly too little to maintain motivation. It also emerged that there were discrepancies in payments and lack of standard rates for similar activities. For example, it was felt that CHWs who were newly recruited to specifically support EVD response activities were given additional compensation compared with those in the position before the outbreak. There were also concerns from local leaders who felt unappreciated due to a lack of compensation, which limited their effort in the community response.

Our government doesn't care for our local leadership at all. For example, the local council I chairman is the one who did everything. Honestly, people in government positions

don't care about these local leaders. Even when there was Ebola, those men really fought hard. I therefore see that lack of care for the people in the community also crippled service provision. Mixed FGD, Kyegegwa

Some payment complaints that were of great concern in the community were linked to unhonoured promises by partners. This included failure to pay some community workers, especially as the promised payment should have allowed them to conduct household visits for health education, contact tracing and case monitoring. The participants strongly emphasised that this was a major barrier to effective community engagement by reducing the motivation and engagement of community workers. At the time of the interviews (6 months after the end of the outbreak), most community volunteers and personnel were still waiting for their payment. Most study participants also suggested that payments using mobile money should be avoided, because partners were perceived to misuse it as an excuse for delays and non-payments.

Mobile money payments during such disease outbreaks should be abolished. Some organizations were not paying those who had done various work. When these organizations go away, you hear them saying that they wrote a wrong [telephone] number or that the money has been sent to a wrong number. The next time such a programme comes, money should be paid directly in cash. Male FGD, Kassanda

#### Poor logistical management

Some study participants felt that logistics management posed a barrier to effective planning of community engagement activities. These participants felt that there was a lack of trust between the community and officials in some districts, especially with regard to fuel. They cited an instance where fuel for community engagement in Kyegegwa was stored in Mubende, which required a lot of movement between the two districts, thus frustrating those involved in such a time-consuming activity. These logistical challenges reportedly made it difficult for the teams to move between communities, losing time and trust in the process.

Kyegegwa [district] had all the fuel to use deposited in Mubende [district]. If you needed fuel, you had to go to Mubende. Imagine you have surveillance teams in the community who needed to be taking fuel from Mubende! They would have to go to Mubende, fuel and come back, then go to the community. Key informant, District Health Team member, Kyegegwa

#### Institutional and coordination challenges

##### Inadequate coordination and partner operations

Findings from the study indicate that study participants perceived the partners that were involved in community engagement as uncoordinated. Duplication of activities was reported, which key informants felt could have been avoided through better coordination. Duplication was

also caused by lack of streamlined reporting and failure to attend district meetings by partners.

Some partners would implement activities but not report. They would have an activity but not sharing it with the district. You therefore find that you go and do the activities which maybe already done there. Or we have already implemented the activities and then other partners go there to do the same work. Because not all of them come to meetings, not all of them would report. Key informant, implementing partner, Kyegegwa

Partners overwhelming communities with their presence and interventions was also an issue raised by study participants. KIIs and FGDs indicated that lack of coordination between partners and district officials led to many of them being present in some communities at the same time. In addition to a duplication of efforts, this resulted in increased motor vehicle traffic in communities, causing anxiety among vulnerable populations, such as the elderly. Consequently, partners occasionally had to be stopped from implementing activities in some areas by the local authorities, for example, in Kampala, for the benefit of the communities.

They made us to overwork from one organization to another, asking us to do so many tasks. Remember, we were the ones in the field, so it was us that they wanted whereby they didn't know the villages, neither did they know where they were going or where the person they were going to meet was. They therefore had to use us CHWs though it become too much work for us. CHW FGD, Mubende

##### Unfavourable institutional structures

Participants noted that risk communication was commonly confused with community engagement. Some key informants were concerned that risk communication and community engagement belonged to different departments at MOH, which often reportedly caused confusion in communities. They reported that this arrangement resulted in conflicts and competition between ministry departments. This lack of adequate cooperation was, for example, evident in delays in getting approvals for some partners who had to contact different ministerial departments before accessing communities.

The main barrier was institutional. There was conflict and a lot of lack of cooperation. The split at MOH level between risk communication and community engagement meant that we had two power centres. We had a commissioner and department that was specifically responsible for risk communication, and a commissioner and department that was responsible for community engagement. Key informant, national level implementing partner

The challenges related to the coordination of the outbreak response at national level were believed by many key informants to be inevitable because experience and practice by the majority of partners confirmed that risk communication and community engagement were implemented jointly. Therefore, separation of these two

activities at MOH without clear guidelines contributed to poor coordination at the implementation level.

During community engagement, we are distributing IEC materials to these people, we are also communicating to them the risk, and giving them all prevention measures in mitigating that risk. You realize that community engagement and risk communication are closely linked. But for some reason, these two activities were separated at national level, seriously hampering coordination. Key informant, District Health Team member, Kyegegwa

### Limited funding for emergencies

A lack of funding and delays in receiving finances at the district level to support the outbreak response, including community engagement, were reported as additional barriers by study participants. In addition, institutional bureaucracy regarding authorisation, allocation and reallocation of funds to enable community engagement was noted. For instance, fieldwork was hindered by the absence of fuel and other financial issues in some districts due to bureaucratic delays.

Where we have funds for primary health care, results based financing or other financial votes, this money is strictly for particular activities. If we have an outbreak, the authorisation of being able to divert this money to other activities such as fuel from the central government was really hard because everyone fears audit queries. Key informant, Kasanda District Local Government

In instances of limited or delayed government funding, implementing partners were left as the only reliable option to facilitate community engagement and other response activities. It was noted that most of the partners were able to provide funding faster than government. However, it emerged that many partners did not have the necessary funding set aside to be quickly released for emergency response.

The only challenge was the funding bit. We always have the documents to use whenever there is an emergency to respond to. However, funding for a specific outbreak once it emerges is not always there as the money we had was for ongoing activities. We therefore had to engage the donors, then discuss re-aligning different budget lines for various activities regarding responding to the outbreak. Key informant, implementing partner, Kyegegwa.

On a positive note, while the barriers to community engagement were several, participants emphasised lessons on the key role of the different implemented approaches including sensitisation, dialogue, survivor testimonies and rumour tracking in reducing mistrust, misinformation, myths, rumours and related resistance. Rumour tracking and dialogues including sociocultural considerations, although delayed, provided an opportunity to listen to communities, appreciate their views about the outbreak, and work with them to provide accurate information on disease transmission and control. Results also indicated that through using mass media, interpersonal communication and key community structures such

as CHWs, local leaders, traditional healers and religious leaders, community engagement positively influenced the community's knowledge, attitudes and practices regarding EVD, its risk factors and consequences, as well as the response efforts. Other community resource people including different workers in public services such as markets and transport were engaged, who were collectively instrumental for enhanced case reporting and management.

### DISCUSSION

According to community members and partners involved in community engagement during the EVD outbreak response in Uganda, several factors hampered the effectiveness of community engagement. These factors included: delayed consultation with communities; poor communication between partners and communities; misinformation; minimal human resource support from partners; and institutional and coordination challenges among partners. This resulted in resistance by the community towards community engagement and reduced response effectiveness, especially at the beginning of the outbreak. The lessons from Uganda's response to the 2022–2023 EVD outbreak in this study should be used by MOH and partners to improve strategies for future management of health emergencies.

Delayed community engagement was reported in the study, however, early and consistent participation, along with the empowerment of affected communities, is essential to understanding local contexts and ensuring an informed, people-centred response.<sup>9 24</sup> Previous studies confirm that absent or limited community engagement in the early stages of a health emergency can lead to community resistance, undermining response efforts that ensure uptake of services and information.<sup>32 33</sup> Despite the urgency and pressure in responding to EVD outbreaks, there is a need to include community engagement interventions as a critical pillar, in equal measure to the biomedical components of the disease response.<sup>34</sup> Assumptions by external stakeholders that the community was ignorant about biomedical knowledge and had weak capacity in epidemic response hampered community engagement efforts. Results from our study also indicate a failure to clearly consider cultural concerns early, which is key in ensuring resilience, highly contextualised risk communication, social mobilisation, as well as community empowerment.<sup>35 36</sup> Our study also shows related challenges to those previously described in other EVD outbreaks in sub-Saharan Africa, including myths, rumours and disinformation, which are best mitigated through community engagement.<sup>37 38</sup>

As in previous EVD responses in Uganda in recent years<sup>36</sup> and West Africa,<sup>24</sup> top-down approaches to community engagement have historically been used. This approach limits opportunities for two-way dialogue, thereby failing to meet the needs of affected populations from the very beginning of the outbreak.<sup>15 16 34</sup> Our

results mirror previous research that shows partners' coordination with regard to community engagement was haphazard, with no clear processes.<sup>25</sup> This calls for the development of national guidelines that explicitly streamline the process, indicating what responsibilities are to be taken, by whom, how, with whom and when.<sup>26 34</sup> Other challenges to community engagement identified in this study included lack of transparency in operations, as well as limited financial and logistical support for community workers, including CHWs. Previous research also found minimal support to CHWs and other community responders during the West African EVD outbreak in 2014–2016.<sup>39</sup> Strengthening community engagement through capacity building, as well as adequately supporting existing structures up to the community level, can create the needed community ownership and trust.<sup>16</sup> In addition to the timely deployment of trained personnel, transparent and accountable operations, as well as understanding local needs, should be prioritised to fully engage communities.<sup>40</sup>

Insufficient funds were another challenge identified in our study, in line with previous evidence that community engagement requires a significant amount of financial resources that is often not met by governments and donors.<sup>27</sup> Effective financial preparedness, including adequate government investment, is therefore required to ensure that the necessary resources and systems are in place and functional to facilitate timely and effective community engagement in preparation for outbreak response.<sup>41</sup> Strategic partnerships, for example, between districts and implementing partners to coordinate and mobilise resources to support community engagement as needs change over the course of an outbreak should also be explored. Alongside the government's financial commitment to ensure timely and effective community engagement activities, experiences from the COVID-19 pandemic indicate a vast contribution from both the public and private sectors. Such joint contributions could be considered as an avenue to collaborate with government to improve community engagement in preparedness and response to such emergencies. However, it is important to note that such commitment from the public and private sectors was seen to be less during the EVD outbreak which came 2 years after the peak of the COVID-19 pandemic. While this observation could be due to financial fatigue among the various stakeholders, such collaboration needs to be further studied to systematically understand the dynamics involved across outbreaks. Prioritisation of real-time community data collection and analysis to inform outbreak response has also been recommended.<sup>16 34</sup> Investment in research on building trust with local communities will also enhance community entry and effective engagement in future outbreaks.<sup>16</sup>

It was evident from our study that community engagement and risk communication were used interchangeably by various stakeholders. Whereas risk communication is aimed at the exchange of information

between responders and members of the public, community engagement involves working with and through different community groups at a formal and informal level, providing the community with ownership in outbreak response.<sup>42</sup> Close collaboration between risk communication and community engagement pillars is therefore crucial.<sup>43 44</sup> In Uganda, risk communication and community engagement pillars were placed under different departments at ministerial level. However, guidance on how partners should collaborate with both departments during outbreak response was lacking, causing delayed decision-making and sources of occasional tension. It is, therefore, crucial to streamline the mechanism in which the two pillars collaborate before, during and after outbreak response. Strong leadership at national level is a crucial component of a robust health system needed during health emergencies.<sup>45</sup> Relatedly, improved coordination of partners involved in outbreak response by the leadership of MOH and District Health Offices should be prioritised in future community engagement activities.

The findings indicate limitations to the impact of community engagement on the outbreak response across different levels (national to community). However, key lessons from the study included an understanding among stakeholders of how early sociocultural consultations and discussions with communities can significantly improve the response, as seen in previous EVD outbreaks in sub-Saharan Africa.<sup>9 23 37</sup> The sociocultural considerations offer an opportunity for understanding the social fabric, which is a key component in the theoretical frameworks for community engagement practices not only for disease outbreak response but also preparedness.<sup>46 47</sup> Such considerations were delayed, which should not be repeated in future outbreaks in order to address mistrust and stigma among cases and their families throughout the response, including surveillance, case and contact identification, reporting and management at facility or community levels.<sup>48</sup>

It is important to note that the focus of this study on only five districts could have led to missing different perspectives from other parts of the country. Other limitations of the study could include social desirability bias; for instance, some implementers may have underreported the barriers by answering in a way that protects their (or partners') image. Regarding FGD categories, a limitation could have arisen if some groups such as most affected communities within districts were oversampled, thus undersampling their counterparts. However, one of the strengths of our study is that both community and expert views were collected, which enabled triangulation of findings. In addition, the involvement of various stakeholders in community engagement during the EVD outbreak, including policy makers, district health officials and community members, provided an opportunity to obtain varied perspectives.

## CONCLUSION

Several barriers to community engagement were identified during the response to the EVD outbreak. To better prepare for future outbreaks, there is a need to prioritise development and implementation of community engagement guidelines (with emphasis on clear roles and responsibilities), adequate financing and strengthening of community engagement capacity systems at national, district and community levels. Lessons from the 2022–2023 EVD outbreak in Uganda should be used to improve the design and implementation of community engagement interventions in future health emergencies.

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