

“We Want to Be Partners, Not Just Recipients”: Community Voices Calling for a New Era of People-Centered Ebola Preparedness and Response

Authors:

1. **Dr. Annet Naguudi** -Uganda Alliance of Patients' Organisations (UAPO), Uganda
2. **Joshua Wamboga** - Uganda Alliance of Patients' Organisations (UAPO), Uganda

Introduction

"It is difficult for most people to understand the current outbreak information. Ebola messaging should be in local languages to allow everyone to understand."

This statement from a community respondent in a recent Uganda Alliance of Patients' Organisations (UAPO) consultation captures a critical lesson from decades of Ebola response efforts: communities are not passive beneficiaries of outbreak interventions; they are essential partners in preparedness, detection, and response.

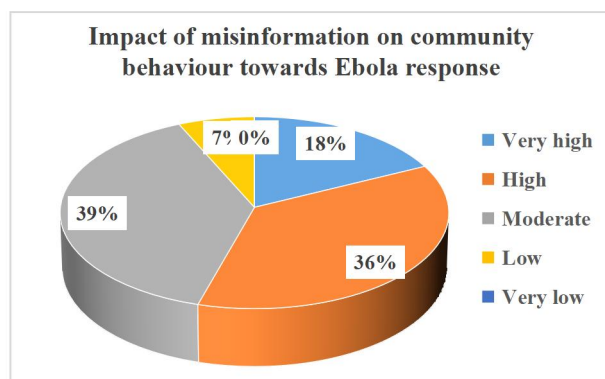
Despite significant advances in Ebola surveillance, diagnostics, vaccination, and clinical management, outbreaks continue to expose persistent gaps in trust, communication, and community engagement. Experiences from the 2014–2016 West Africa Ebola epidemic, outbreaks in the Democratic Republic of the Congo (DRC), and Uganda's recent Ebola responses have consistently demonstrated that technical interventions alone cannot stop outbreaks without community trust and participation (*World Health Organization [WHO], 2021; Wilkinson & Fairhead, 2017*).

In June 2026, UAPO conducted a rapid community consultation involving **91** respondents from **15** districts across Uganda, complemented by discussions with young people and community leaders. The consultation sought to understand community perceptions, concerns, barriers, and priorities related to the ongoing Ebola outbreak in Uganda and the DRC. The findings reveal a clear message: **communities want to move from being recipients of information to active partners in outbreak preparedness and response.**

The Persistent Challenge of Trust in Ebola Response

The importance of trust has been repeatedly documented in Ebola outbreaks worldwide. During the West African Ebola epidemic, mistrust of authorities, misinformation, and fear contributed to delayed reporting, resistance to public health measures, and continued disease transmission (*Abramowitz et al., 2015*). Similar challenges were observed during Ebola outbreaks in eastern DRC, where insecurity and distrust complicated contact tracing and vaccination efforts (*Vinck et al., 2019*).

The UAPO consultation June 2026, found that misinformation continues to significantly influence community behavior. More than 93% of respondents rated misinformation as having a moderate to very high impact on Ebola response behaviors. Common beliefs included perceptions that Ebola is fabricated, caused by witchcraft, or created for political and financial gain.

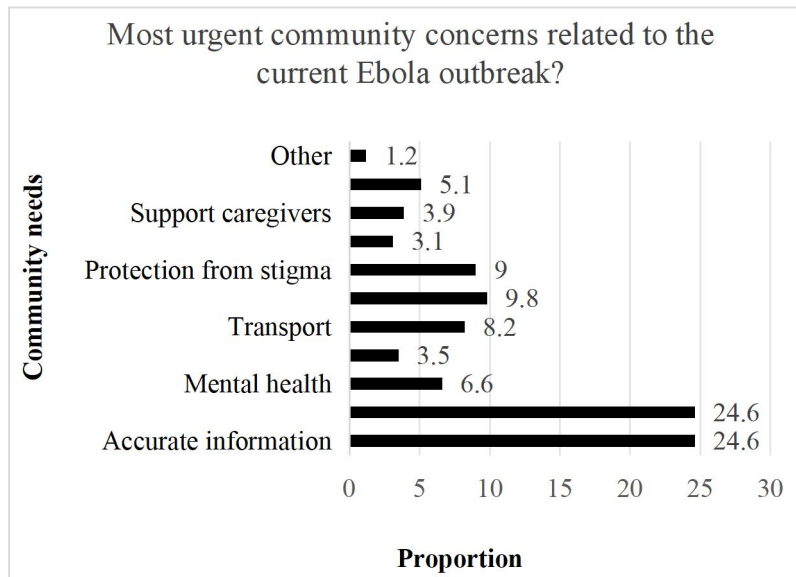


These findings mirror previous research showing that misinformation can lead individuals to seek care from traditional healers, hide symptoms, avoid treatment centers, and delay reporting suspected cases (WHO, 2021).

Community members identified trusted local leaders, religious leaders, youth leaders, and local-language communication as some of the most effective tools for countering misinformation.

Information and Healthcare Access Remain Top Community Priorities

One of the most striking findings from the consultation was the consistency with which communities emphasized access to information and healthcare services. Among respondents, accurate information and access to healthcare emerged as the two most urgent concerns, each accounting for approximately one-quarter of all responses.



These concerns are not new. During Uganda's 2022 Sudan Virus Disease outbreak, communities frequently reported uncertainty about symptoms, prevention measures, and available services. Similar findings were reported during outbreaks in Sierra Leone, Liberia, and Guinea, where inadequate communication fueled fear and confusion (Bedson et al., 2020).

The UAPO findings further revealed that lack of information, fear of isolation, and stigma were the leading barriers preventing individuals from accessing Ebola prevention and care services.

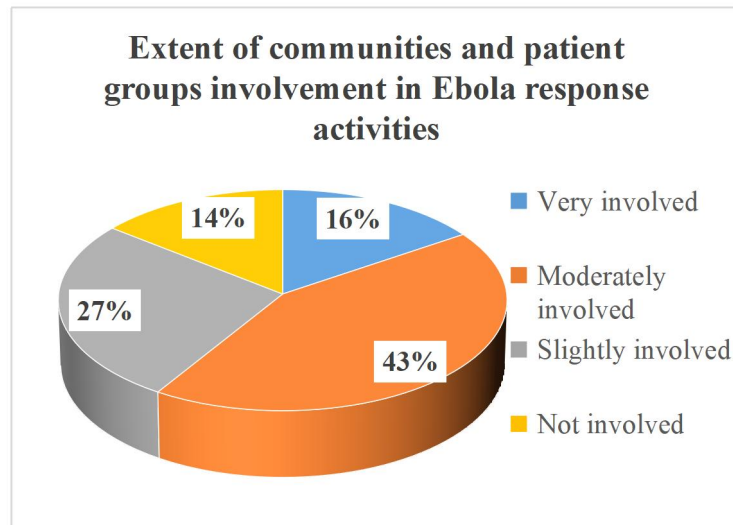
For patients and families, the prospect of isolation often extends beyond clinical concerns. Isolation may mean separation from family, loss of income, social exclusion, and psychological distress. Effective outbreak response therefore requires addressing both biomedical and social dimensions of the disease.

Communities Want Meaningful Involvement, Not Token Participation

One of the strongest messages emerging from the consultation was the desire for genuine community partnership.

Although respondents recognized the important role communities can play in surveillance, contact tracing, information dissemination, and implementation of prevention measures, more than 84% reported that communities and patient groups were either not involved, slightly involved, or only moderately involved

in Ebola response activities. This finding is particularly important because evidence from multiple Ebola outbreaks demonstrates that community-led interventions improve outbreak control. During the West



African epidemic, community-based surveillance systems helped identify cases earlier and strengthened public trust in response efforts (*Richards et al., 2015*).

Similarly, WHO guidance increasingly emphasizes community engagement as a core pillar of outbreak preparedness and response rather than an optional add-on (*WHO, 2023*).

Communities participating in the UAPO consultation clearly articulated the roles they wish to play, including:

- Reporting unusual illnesses and deaths.
- Supporting surveillance and early warning systems.
- Participating in contact tracing.
- Conducting community sensitization.
- Supporting preparedness initiatives.

These aspirations reflect a shift from passive receipt of information toward active co-production of health security.

Vulnerable Groups Must Not Be Left Behind

Respondents identified health workers, children, schools, transport workers, traders, and people living in poverty as among the groups most affected by Ebola outbreaks. Particularly concerning was the observation that persons with disabilities and individuals with low literacy levels remain insufficiently reached by existing communication efforts. This finding aligns with global evidence showing that vulnerable populations often experience disproportionate impacts during health emergencies due to barriers in communication, healthcare access, and social protection (*United Nations, 2022*).

A truly people-centered Ebola response must therefore prioritize inclusive communication strategies, accessible information formats, and targeted outreach to underserved populations.

What Communities Want from Global Leaders

The consultation culminated in a powerful call to action.

Approximately **81%** of identified priorities focused on community engagement and risk communication. Respondents emphasized the need to train more health workers and community leaders, provide regular

outbreak updates, strengthen health education, combat misinformation, and support local preparedness structures.

Community members also called for:

- Increased funding and technical support.
- Strengthened community engagement mechanisms.
- Social protection for vulnerable households.
- Enhanced surveillance and preparedness systems
- Improved access to vaccines and treatment.

Perhaps most importantly, communities expressed a desire for sustained preparedness structures rather than temporary engagement that appears only during outbreaks.

This recommendation echoes lessons from previous outbreaks, which have repeatedly shown that resilience is built before crises occur not during them.

The Role of Patient Organizations in Building Trust and Preparedness

Patient organizations are uniquely positioned to bridge the gap between communities and health systems.

As an umbrella body representing patient groups across Uganda, UAPO has demonstrated the value of patient-led engagement in gathering community insights, amplifying lived experiences, and promoting accountability in health responses. The consultation itself illustrates how patient organizations can rapidly generate actionable evidence to inform policy and programming.

Patient organizations bring credibility, trust, and proximity to communities that traditional health structures may struggle to achieve. Their involvement can strengthen risk communication, support stigma reduction, facilitate community surveillance, and ensure that response strategies reflect the realities of those most affected.

Meaningful patient engagement should therefore be recognized not as a supplementary activity but as a strategic investment in outbreak preparedness and health security.

Conclusion: From Community Voices to Community Power

The findings from this consultation reinforce a lesson repeatedly demonstrated throughout Ebola's history: communities are not the problem to be managed; they are the solution to be empowered.

Communities want accurate information, equitable access to healthcare, protection from stigma, and meaningful participation in decisions that affect their lives. They want trusted communication, social protection, and opportunities to contribute to surveillance, preparedness, and response efforts.

The message to governments, WHO, donors, and global health partners is clear: sustainable Ebola preparedness and response requires moving beyond consultation toward genuine partnership. By investing in trusted local leadership, patient organizations, inclusive communication, and community-led preparedness structures, we can build responses that are not only more effective but also more equitable, resilient, and people-centered.

References

- Abramowitz, S. A., McLean, K. E., McKune, S. L., Bardosh, K. L., Fallah, M., Monger, J., Tehoungue, K., & Omidian, P. A. (2015). Community-centered responses to Ebola in urban Liberia. *PLoS Neglected Tropical Diseases*, 9(4), e0003706. <https://doi.org/10.1371/journal.pntd.0003706>
- Bedson, J., Jalloh, M. F., Pedi, D., Bah, S., Owen, K., Oniba, A., Sangarie, M., Fofanah, A. B., Jalloh, M. B., Sengeh, P., & Vinck, P. (2020). Community engagement in outbreak response: Lessons from the 2014–2016 Ebola outbreak in Sierra Leone. *BMJ Global Health*, 5(8), e002145.
- Richards, P., Amara, J., Ferme, M. C., Kamara, P., Mokuwa, E., Sheriff, A. I., Suluku, R., & Voors, M. (2015). Social pathways for Ebola virus disease in rural Sierra Leone. *PLoS Neglected Tropical Diseases*, 9(9), e0003567.
- United Nations. (2022). *Policy brief: Inclusive approaches to emergency preparedness and response*. United Nations.
- Vinck, P., Pham, P. N., Bindu, K. K., Bedford, J., & Nilles, E. J. (2019). Institutional trust and misinformation in the response to the 2018–19 Ebola outbreak in North Kivu, Democratic Republic of the Congo. *The Lancet Infectious Diseases*, 19(5), 529–536.
- World Health Organization. (2021). *Ebola virus disease: Key lessons from recent outbreaks*. WHO.
- World Health Organization. (2023). *Community engagement for public health events caused by infectious diseases: WHO guidance*. WHO.

Primary Data Source

- Uganda Alliance of Patients' Organisations (UAPO). (2026). *Patient perspectives on the Ebola outbreak: Rapid community consultation conducted for the WHO Global Community Reference Group (GCRG)* [Unpublished survey report]. UAPO.