# GUIDANCE NOTE ON COMMUNITY ENGAGEMENT FOR CHOLERA OUTBREAK RESPONSE IN THE EAST AND SOUTHERN AFRICA REGION

SSHAP
Social Science in Humanitarian Action Platform

## INTRODUCTION

Cholera outbreaks have been on the rise in the East and Southern Africa Region (ESAR) since January 2023, with widespread and extended transmission in Malawi and Mozambique and outbreaks reported in Tanzania, South Africa, Zimbabwe, Burundi, and Zambia.[1] There is risk of further spread caused by the effects of Cyclone Freddy, which hit Madagascar, Malawi, and Mozambique in March 2023. Outbreaks are continuing in Somalia, Ethiopia, Kenya, and South Sudan, where countries are experiencing drought after multiple failed rainy seasons.[1] The response context in ESAR is complex. This is due to the strained public health resources, including shortages of oral cholera vaccines, and the multiple concurrent public health and humanitarian emergencies, including the re-emergence of wild poliovirus. Community engagement in cholera outbreak responses is essential, especially while the impact of COVID-19 continues to be felt in the region, particularly on trust in public health and vaccination efforts.[2,3]

The purpose of this guidance note is to support Ministries of Health, UNICEF, and other response partners to design and implement effective, community-centred, and data-driven community engagement for cholera outbreak response. This guidance note was written in April 2023 by Megan Schmidt-Sane and Tabitha Hrynick (IDS), with input from Stellar Murumba (Internews), Ngonidzashe Macdonald Nyambawaro (IFRC), Eva Niederberger (Anthrologica), Santiago Ripoll (IDS), Nadine Beckmann (LSHTM), Mariana Palavra (UNICEF), and Rachel James (UNICEF). This guidance note draws on the Social Science in Humanitarian Action Platform (SSHAP)'s past work on cholera.

## BRIEF CONTEXT

Cholera is a disease of inequality that disproportionately affects the most vulnerable populations, particularly those without access to basic water, sanitation, and hygiene (WASH).[4,5] Several major and intersecting conditions and crises are contributing to the current rise in cholera cases in ESAR and to the underlying challenges to WASH and cholera care and treatment. These conditions and crises include ongoing and protracted conflict, poverty, high cross-border movement, rapid urbanisation and inadequate urban infrastructure, and drought and other extreme weather conditions linked to climate change.[4,6–8] Cholera is endemic in some ESAR countries, with seasonal variations in infection rates.[4,9] For example, in Mozambique, cholera has been endemic since the 1970s with increasingly variable seasons since 2017.[4] Populations vulnerable to cholera infection in Mozambique include those who frequently cross borders to other cholera-endemic areas, those living near rivers and lakes, and those displaced due to floods and conflict (see *Key Considerations: Socio-Behavioural Insight For Community-Centred Cholera Preparedness And Response In Mozambique, 2023*).[10] In Malawi, cases typically occur in the wet season (November to April) and in densely populated urban areas (see *Social, Behavioural and Community Dynamics Related to the Cholera Outbreak in Malawi*);[11] however, the current outbreak – the largest the country has ever seen – has continued throughout the entire dry season. In both Mozambique and Malawi, most cholera cases are in men. Men in those countries also have lower health-seeking behaviour and less access to good quality information on cholera prevention and treatment.

The Global Task Force on Cholera Control's report, 'Ending cholera: a global roadmap to 2030' includes community engagement as an important part of any cholera response.[12] However, responders in ESAR are struggling to implement crucial aspects of community engagement in their cholera outbreak responses. Common actions missing from the response in ESAR include:

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- Facilitating strategic, participatory, and locally appropriate community-level action plans based on local risks and vulnerabilities.
- Finding the best strategies to engage communities in community-based surveillance.
- Sharing and promoting the best available information about what causes cholera, how it is transmitted, and how it is managed, while recognising structural barriers that communities face in acting upon that information.[13]
- Scaling up the use of standardised tools for community feedback and reporting.

## WHY IS COMMUNITY ENGAGEMENT IMPORTANT FOR CHOLERA OUTBREAK RESPONSE?

Community engagement during health emergency responses is often confused with risk communication. While these two approaches have some overlap, they are distinct. Community engagement is a collaborative approach in which formal responders and members of cholera-affected or cholera-at-risk communities work together to prevent and respond to cholera outbreaks.[14] Risk communication is often one-way and focuses on providing information. This type of communication is usually used to transmit details about how people can prevent transmission through behaviour change; why, when, and where people can seek help; how people can safely and effectively care for infected family members, and the availability and effectiveness of vaccines.

Community members and responders may collaborate to design and deliver locally relevant risk communication messaging. Community engagement can also be used to more effectively deliver a range of other response activities, including:

1. **Surveillance, early detection, and reporting**. Communities are often the first to identify cholera cases and report them to health actors. Community engagement can help build trust and strengthen this information flow. A stronger flow of information makes it easier for formal responders to promptly identify and respond to cases. The same channel also supports the flow of other critical information, such as how interventions are perceived in the community and what kinds of information, including rumours, are circulating.
2. **Prevention and control**. In addition to helping craft and adapt risk communication messaging that resonates with affected populations, community engagement, such as through feedback and qualitative data collection, can provide critical insights to help ensure other preventative measures are effective and sensitive to the local context. Preventive measures include vaccination, WASH practices, and safe and dignified burial practices, such as in relation to washing the bodies of the dead.
3. **Treatment and care**. Working with community members to design pathways for treatment and care can help ensure these pathways are realistic, accessible, and acceptable, and that they do not exacerbate any stigma associated with cholera. This engagement is an important part of building trust in the response.

**Box 1. Making the difference: Religious community engagement in South Sudan**

In South Sudan, the Risk Communication and Community Engagement (RCCE) partners of Internews engaged the Council of Churches for information sharing and support mobilisation within some of the country's religious communities. However, during the engagement the partners learnt that some religious communities, such as Seventh Day Adventists and Jehovah's Witnesses, were not represented in the council. In addition, they learnt that many religious leaders in remote churches were spreading cholera misinformation, including about the vaccine.

The RCCE partners soon learnt it is important to understand exactly how different religious institutions are structured and to ensure that community engagement work involves religious communities and institutions from the start. This understanding led to improved RCCE activities, including supporting and building on the mass mobilisation efforts of local churches, traditional healers, and other trusted influencers.

Failing to involve community members in the cholera response can lead to activities which are inappropriate and ineffective in local contexts and that feel intrusive, patronising, or otherwise suspect. In settings where people may reasonably feel abandoned, excluded, or even actively marginalised or targeted by 'outsiders' (i.e. people from outside the affected community, including people from other parts of the region or country, and international responders), distrust of interventions 'from the outside' can run deep and can derail response efforts (see Box 2.)[15]

**Box 2. Mistrust in the Malawi cholera response**

Mistrust of health workers by villagers in some districts in Malawi affected by the recent cholera outbreak has led to significant resistance in some areas. This resistance included an attack on the Nandumbo Health Centre in Balaka District after villagers accused health workers of spreading cholera through contaminated needles. Improved community engagement to increase transparency and collaboration could help increase the level of trust between affected communities and responders in this and other settings.

It is vital to understand the current local context before designing community engagement activities. Engaging with 'insiders', such as community leaders, may not be straightforward, as they may have very different ideas of the appropriate response or there may be contentious relationships between different community factions. Ultimately, community engagement plans must be responsive to on-the-ground realities which are often complex and dynamic. It is best practice to regularly evaluate the community engagement plan and adapt it when needed. Community feedback and social and behavioural data can help with this evaluation and adaptation.

# GUIDANCE FOR GOOD COMMUNITY ENGAGEMENT

## Core principles of community engagement

There is no singular 'best' way to approach community engagement. Rather, what is 'best' depends heavily on the scale and progression of the cholera outbreak and the local context in which the community engagement activities are taking place. For example, appropriate strategies will vary depending on what groups or localities are most affected and who is trusted by the affected community. However, there are some principles that response actors can keep in mind when aiming to initiate effective community engagement for cholera response.[16]

Community engagement should:

- **Be integrated and coordinated**. Community engagement is not just an aspect of risk communication. It should be integrated across all response pillars, as discussed in the next section. Community engagement should also draw on previous and/or existing hygiene promotion activities, rather than starting from the ground up.
- **Be coordinated across borders, where this is important.** Relevant information should be regularly shared between response stakeholders in all countries to ensure a more consistent and coherent response across borders.
- **Be inclusive.** Identify those most at risk of infection – which may differ by context – and focus on their inclusion into community engagement activities. Vulnerability assessments can help to understand who should be engaged and how. For instance, the assessments may point to the need for engagement activities in multiple languages, or at certain times and places, or through certain platforms. Additional efforts may also be needed for locally marginalised groups, such as women, children, elderly people, people with disabilities, and people from minority groups. Their involvement is critical to ensuring that prevention activities and other aspects of the response are effective for all. Men are potentially more vulnerable to cholera than women and other locally marginalised groups. This is may be due to their greater mobility, as well as more limited health seeking and interaction with health facilities which may result in their lesser access to good health information.

- **Be aware of community power dynamics**. Craft community engagement plans and activities that ensure informal leaders and those with less power, such as members of vulnerable groups, can fully participate. Their perspectives and capacities are critical to a successful response. For example, including women-only spaces, child-friendly activities, and spaces accessible to people with disabilities can enhance participation by a wider range of groups, as can going to places and spaces where such groups may already congregate. Consider using stakeholder or power mapping to better understand context before designing community engagement plans.
- **Build trust. Identify, prioritise, and monitor which trust issues should be addressed.** Prioritisation should focus more on making the response and responders more worthy of community trust, rather than attempting to convince community members to change their attitudes towards the response. An important way to build trust in the response and responders is to identify locally trusted people and networks to work with, while recognising that these may not be obvious. For instance, local elites, health workers, and military, police, and government leaders may not be trusted by community members. Herbal and other traditional healers and cultural or religious leaders[10] may be more influential, although this too, should not be taken for granted. Directly ask community members who is trusted locally. Also critical for trust is to ensure communication is open and honest, and that there are measures in place to enhance accountability of response actors.
- **Mitigate stigma and discrimination.** Be aware that poorly designed activities could inadvertently stigmatise affected communities and groups. Cholera outbreaks can lead to the emergence of stigma and discrimination due to the disease's perceived association with a lack of cleanliness and hygiene. Stigmatisation may lead to victim blaming or the labelling of areas or groups as 'backward'.[17] Emphasising structural determinants, such as a lack of access to safe water, can help counter stigma and discrimination.
- **Emphasise two-way communication.** Avoid treating community engagement activities only as message dissemination channels. Rather, focus on eliciting and listening and responding to community members' questions and concerns, their understandings of cholera, and their ideas for how to respond effectively. Two-way communication also relates to accountability. Encourage feedback on the quality and effectiveness of response and commit to change where the community says it is needed.
- **Recognise and support community capacities.** Studies have shown that communities often have their own knowledge and coping mechanisms to deal with disease outbreaks, including cholera. In South Sudan and Sierra Leone for instance, communities initiated quarantining strategies, and changed eating, and dish and clothes washing practices, among other measures.[18] In other settings, home-made oral rehydration salts (ORS) and traditional medicine and prayer have been identified as important.[5] Community engagement efforts should aim to identify and support local strategies and practices, as well as draw on local capacities to support other response measures, such as hiring trusted local people to work as contact tracers or in other aspects of response. Responders should also listen to concerns from the community about its lack of capacity or resources to dedicate to the cholera response, and support accordingly.
- **Work with local government structures and cadres**. Especially in widespread outbreaks, there may be a need to constantly reprioritise between in-depth engagement strategies and broader approaches. Working closely with local government and health system actors – such as community health workers, health surveillance assistants, environmental health officers, and health promotion teams – is critical to ensuring the quality of engagement is not negatively affected when there is a need to broaden the approach.
- **Be flexible.** Like cholera outbreaks themselves, communities' responses to the disease, and to response measures, can shift in unpredictable ways. These shifts, which may come about during different phases of the outbreak, are sometimes influenced by community engagement activities themselves, or by broader political or social processes. Be open to adapting community engagement approaches if things are not working, or if community preferences change. Social and behavioural data and community feedback may signal when it is time to adapt strategies.

## Community engagement in all response pillars

In addition to the general principles for community engagement presented above, community engagement activities can be applied in specific ways in different aspects of response.

### SURVEILLANCE AND CASE DETECTION

Reporting gaps and underreporting of cholera cases persist in ESAR.[4,7] A promising approach is to build community-based surveillance and enhance early warning systems. This work can be done successfully in ESAR, as responses to other outbreaks have shown. In South Sudan, for example, a community-based acute flaccid paralysis surveillance system contributed to an increase in reporting from 0.0% to 56.4% over an 18-month period.[19] Lessons can be learnt from this and other examples and applied to cholera surveillance. A well-designed surveillance system must include truly participatory elements that are grounded in best principles of community engagement.[20]

For good community-based surveillance:

- **Co-design the surveillance** with a range of community representatives, to improve acceptance and local ownership, and ensure the local relevance of the system.
- **Consider a wide range of community-based surveillance workers**, including community health workers and other common health care providers, such as herbalists and traditional healers and drug shop owners. Many people in ESAR seek treatment from both traditional and Western biomedical providers and this should be reflected in the surveillance system. Develop opportunities for community-based surveillance workers to share community perceptions and concerns related to cholera with other response actors.
- **Work with local understandings of cholera**, which are focused on syndromic case definitions and build on local understandings of 'dirt' and pollution.[5] Train community volunteers and disease surveillance staff to use these understandings in their everyday work. Using the right language is important too. For example, different languages may have more than one word for cholera. The Somali words for cholera are *daacuun* or *kaloraa*.[21]
- **Scale-up use of rapid diagnostic tests** by trained community health workers to ensure a rapid reporting of cases and close gaps in surveillance.
- **Recognise that community-based surveillance has logistical, financial, and technical costs.** This includes costs to the community workforce associated with carrying out surveillance activities alongside their existing responsibilities. However, local ownership of a community-based surveillance system is key to its sustainability.

### POINTS OF ENTRY AND BORDER REGIONS

People living in border regions in ESAR are often at higher risk of cholera. Cholera outbreaks have recently been reported in ESAR border areas, including the Uganda-Democratic Republic of the Congo border and the Malawi-Mozambique-Tanzania borders.[22,23] In Uganda's border region, cholera outbreaks in 2015 were linked to contaminated river water from the River Lhubiriha and to sanitation issues, such as open defecation and inappropriate food handling.[22] Border communities are typically highly mobile, with many people having cultural, business, and familial ties across the border. This mobility poses both challenges and opportunities for community engagement and for those seeking health care. People may move frequently, on a daily or weekly basis, making it important to design community engagement strategies that consider cross-border coordination and engagement. Handwashing and screening stations are common at formal points of entry, but informal points of entry remain a challenge for epidemic response.

Best practices for engaging border communities include:

- **Map the current landscape related to cholera outbreaks** in border regions, including local contextual factors, factors affecting mobility, existing health care infrastructure, and current trusted influencers, including faith, business, political, and cultural leaders.

- **Engage with existing regional mechanisms and cross-border structures** to identify potential synergies for community engagement.[24] This might include training the volunteers who conduct health screenings at border entry points and engaging with market associations, truck driver representatives, and community leaders who represent highly mobile populations. Coordinate with partners working in and across border areas to ensure approaches to cholera prevention and treatment are harmonised.
- **Design two-way communication strategies** specific to border regions, such as building on local events, like market days, that bring together people from both sides of the border.

## COMMUNITY-BASED INFECTION PREVENTION AND CONTROL

Building trust and community engagement can improve the uptake of WASH practices and the acceptability of WASH infrastructure. Past experience with cholera outbreaks points to the importance of community engagement in infection prevention and control. For example, in northern Mozambique, there were episodes of violence when health workers were accused of poisoning the drinking water. In one case, this was due to the similarity between the Portuguese word for chlorine (*cloro*) and the word for cholera (*cólera*).[4]

Some prevention and control activities and strategies can be implemented in cholera hotspot areas. These include: community action to end open defecation; construction of latrines; provision of point-of-use of safe water and enhanced water quality testing and monitoring; encouragement of household water treatment with sodium hypochlorite; management of faecal waste, and increasing access to and use of handwashing and latrine facilities.

Possible approaches include the following:

- **Consider forming local cholera prevention and control task teams** at the village level. These should draw on existing community structures and networks, including trusted and respected leaders. These teams can coordinate cholera response activities with the formal responders.
- **Engage trusted local influencers** to share appropriate information that encourages handwashing, water treatment, and other preventive measures. Health and hygiene promotion activities and messages, adapted to local culture and beliefs, should promote the adoption of appropriate hygiene practices, such as handwashing with soap, safe preparation and storage of food, and the safe disposal of faeces. Activities and messaging must adapt to rumour tracking and community feedback.
- **Build community participation in designing locally appropriate handwashing stations** and recognise the importance of placing these stations in publicly accessible locations.
- **Focus on how to conduct case-area targeted interventions (CATI) in an effective and non-stigmatising manner** to increase trust and uptake of public health measures. CATI are based on the premise that early cluster detection can trigger a rapid, localised response in the high-risk area. Decentralised capacity is important for CATI, as it should enable more tailoring to local context and engagement with existing local capacities and structures.[25]
- **Acknowledge the causes of cholera in hygiene promotion activities** and emphasise that the causes are inadequate coverage and access to WASH services and infrastructure, rather than poor personal or community hygiene practices and behaviours. Address current rumours or misinformation about WASH through community engagement and communication, including through trusted individuals. Use the insights gained from community feedback and engagement to advocate for WASH improvements and raise awareness that many people simply cannot follow the recommended prevention measures, even if they want to. This type of community engagement and communication should also be carried out when there are no outbreaks, to build awareness of cholera and its underlying causes.

## CASE MANAGEMENT

Community engagement can improve case management for cholera – at home, at oral rehydration points, in hospitals or clinics, and during CATI activities. Distribution of ORS at the household level through trusted community health workers has been successful in treating both mild and moderate cases of cholera.[5] Community health workers and other local influencers can also share information about making homemade ORS. During outbreaks, households in hotspots should be made aware of the importance of ORS and encouraged to either have some ready to use or know how to make their own, especially if their symptoms start at night. Critically, community engagement practices can ensure that severe cases are referred to clinics, hospitals, or specialised units for intravenous rehydration therapy.

During community engagement for case management:

- **Set up oral rehydration points, including training and paying** those who work at the points and supporting rapid referrals.
- **Carefully consider the establishment of decentralised care during an active outbreak,** including creating cholera treatment units and centres. Before setting up treatment units, have two-way dialogues with communities to scope their acceptability, and consider co-designing the units with community members. For example, units could provide space and resources for community liaison persons, who can ensure a flow of information between the patient and their family. Additional safeguarding needs should also be considered, especially for children and vulnerable patients. Community dialogues are also an opportunity to provide clear messaging on what is effective for treating cholera and what is harmful (e.g., the use of **harmful** 'remedies' like Coca-Cola mixed with baking soda or chlorine stock solution).
- **Share community feedback and perceptions with health care workers** in Cholera Treatment Units (CTUs). This helps promote empathetic interpersonal communication by CTU staff and can support a community accountability mechanism for CTU workers, through which concerns are rapidly shared and addressed.
- **Use tailored community engagement approaches for CATIs**, including establishing CATI teams that include community representatives. Ensure CATI teams work in close collaboration with local public health officials, CTU staff, and a range of other health providers. Obtain and share epidemiological cholera data daily, as well as outbreak-related rumours and how they can be addressed. Case management must be done sensitively and in ways that avoid stigmatising or discriminating against affected households.[25]
- **Build on past success, such as by working with herbalists to integrate ORS** (purchased or homemade) into their work and adapting traditional remedies to incorporate rehydration properties.[5] Work with herbalists to encourage them to refer patients for facility-based care when needed.
- **Engage a wide range of biomedical providers**, including private clinics, pharmacies, and drug shops, to provide basic education about ORS use, have adequate stocks of ORS for sale, and provide referrals for facility-based care. Urban residents are likely to first seek care in drug shops or pharmacies, which are often quicker and easier to access than clinics or hospitals. ORS costs should also be kept low, including when demand for them rises, and this can be addressed with government policy measures.

## SAFE AND DIGNIFIED BURIALS

Bodily fluids from a person who has died from cholera are highly infectious. From a public health standpoint, bodies require disinfection and safe disposal in a site that is not connected to an aquifer.[5] However, mourning often requires ritual washing and handling of the body by family members, and public health objectives may contrast with the needs of mourners. There are precedents of introducing safe practices (such as gloves and disinfectant) whilst respecting the religious needs of mourners.[21] Safe and dignified burial protocols must ensure that community preferences are safely included and that protocols do not exceed what is medically necessary.
Responders setting up safe and dignified burials should:

- **Consider local and religious funeral practices**. For example, in Islam, the body is ritually washed after death and a perfume called *adar* is applied. Many rituals are not absolute and can be adapted to different contexts. One solution may be to incorporate disinfectant into washing rituals, with the approval of local religious or community leaders. Any adaptations to rituals must be co-designed with family members and religious leaders.[21] During community dialogues, provide information to communities about the necessity of safe and dignified burial practices and about acceptable adaptations to rituals.
- **Ensure preparation of the body by health care workers, if needed, is respectful and transparent**. Allow at least one family member or trusted community or religious leader to observe the process. Also allow the health care worker to be involved in the entire burial process, not only the preparation of the body for burial.
- **Engage with organisers of funeral feasts** to ensure handwashing, and provide handwashing stations or hygiene kits if needed.

## ORAL CHOLERA VACCINATION

In areas where oral cholera vaccines (OCV) are licensed and rolled out, vaccination programmes have had mixed success.[26] Community engagement is crucial to improve confidence in OCV, as misconceptions about OCV persist. Misconceptions include, for example, that vaccines should be injectable and therefore the oral vaccine is ineffective. Community engagement can be used to promote information about OCV, while also answering questions and concerns.[26] Providing clear messages in an OCV campaign enabled success in Nampula, Mozambique[27] and Lake Chilwa, Malawi.[28] OCV are not routine vaccinations and only some households receive vaccination during an outbreak. Vaccination plans, including who was selected and why, must be carefully explained to communities and space must be provided to answer questions or concerns. Ensure the response takes an equitable approach to OCV provision, given the overall shortage of OCV.

Community engagement practitioners should:

- **Ensure vaccine campaign strategies differentiate between urban and rural populations**, recognising the unique challenges to vaccine confidence in urban settings in ESAR.[29] Large community meetings, like those used to share information in rural areas, may be less appropriate in urban settings, which may require door-to-door engagement. Vaccination programmes in urban areas should consider conducting vaccinations on weekends, using fixed sites, and starting vaccination early in the morning and finishing late in the evening.[26]
- **Ensure that equity is at the centre of any vaccination strategy.** The communities most vulnerable to cholera, such as those lacking WASH services or distant from health services, are the ones who are most able to access OCV and have their concerns specifically addressed.
- **Use rumour tracking to understand the latest rumours** regarding OCV, and design relevant two-way communication approaches, including opportunities for community members to ask questions in an open forum and receive relevant answers. Acknowledge unknowns and uncertainty where they exist.[30] Community engagement efforts should identify and address concerns and misconceptions.
- **Engage with locally trusted influencers**, such as religious leaders, to promote OCV where needed. This could include, for example, a religious leader getting publicly vaccinated and/or sharing their experience of vaccination and side effects with their congregation.
- **Use a mix of locally relevant communication platforms** to promote confidence in OCV and create opportunities for dialogue**.** These platforms can include those based on technology (such as SMS, radio, and TV) and traditional platforms and interventions (such as interpersonal communication).[31]

# DATA AND COMMUNITY ENGAGEMENT

Data are critical for informing every aspect of a cholera response. Responders tend to prioritise epidemiological and public health data, but social data are just as crucial to successful prevention and containment of outbreaks. Social data and community engagement are related in two important ways. First, social data are important for designing successful community engagement strategies. Second, community engagement activities facilitate the collection and sharing of, and reflection on, social data. These processes are critical to the success of the overall response.

This section introduces two critical types of social data – social and behavioural data and community feedback – and explains their relation to community engagement and their role in supporting the overall response.

## Social and behavioural data collection with communities

Social and behavioural data refers to community members' perceptions, capacities, and practices in relation to preventing and responding to cholera infection. Collecting and monitoring this kind of data can provide evidence to inform decision-making on communication, community engagement, and other response strategies to ensure they are appropriate and address people's needs and priorities in shifting situations.

### COMMUNITY MEMBERS AS COLLECTORS OF SOCIAL AND BEHAVIOURAL DATA

Community members are well placed to provide relevant information through engagement activities like dialogues where they might, for instance, share common local beliefs or practices around diarrheal diseases. However, community members may also be well-placed to be directly involved in systematic data collection efforts. This involvement might include surveys and interviews in which trained community members ask others questions, such as what community members know about cholera, where they get their information, and what they might do or have done to prevent or treat infection.[32] Community members' involvement in data collection efforts can increase community trust in the appropriate use of data and in the response overall. It can also increase the community's sense of ownership of the response.

### COMMUNITY HEALTH WORKERS AND OTHER RESPONDERS

Community health workers can be empowered and trained to collect social and behavioural data on things like attitudes towards OCV. However, as these workers are part of the response hierarchy, they may feel pressured to do this work or to report in certain ways such as reporting more positively about local attitudes. They may also feel pressure to emphasise biomedical and public health framings, over social and cultural ones. It is important to weigh the benefits and drawbacks of deploying community health workers – and others who are part of the response hierarchy – to collect data for the response.

### ANALYSING DATA WITH COMMUNITIES

Engaging communities in the analysis of social and behavioural data can provide critical insight into what could be driving certain behaviours in a particular context. For instance, community members may be well placed to understand how local structural factors, social norms, and even the changing outbreak situation may be influencing social and behavioural practices. Such understanding is critical for shaping the response. Factors and norms that may drive behaviours in locally specific ways might include:

- **Accessibility, quality, and capacity of health services.** This includes formal and informal and public and private health systems and providers (e.g., government hospitals, private health facilities, community health workers, private drug sellers, herbalists, and religious healers).
- **Gender norms**. Assumptions about gender roles may prescribe who cares for whom when illness strikes. This is usually, but not always, women, which may put them at risk. Gender roles may also shape behaviour in other ways that influence people's different cholera risks and extent of care seeking. For example, as earlier noted, men may be less likely to have access to critical information about cholera, or to seek care when infected.

In addition to reflecting on what might explain behavioural data with community members after community data collection, it is critical to provide them with relevant information in response to their questions.

## Community feedback mechanisms

Community feedback, including queries or complaints, is an important component of community engagement for cholera response. Feedback data focuses on how community members perceive and experience the response and the cholera outbreak more broadly. Feedback supports accountability of response actors to the people they are serving and can be gathered in many ways, including:

- **Informal feedback collection. Informal feedback can be gathered through** various types of engagement activities, such as community meetings and informal conversations at response locations. Such informal feedback can be used to alter the localised response directly, and/or it can be more systematically fed into formal response information flows (including monitoring and evaluation systems) by responders.
- **Proactive and systematic feedback efforts**. Feedback can also be more proactively and systematically collected through surveys and interviews conducted door to door, in public places, or by phone or other means. This feedback collection can take place alongside the collection of social and behavioural data.
- **Passive feedback channels**. Feedback can be passively gathered through in-person channels, such as physical complaint boxes and drop-in office hours, or through scaled-up phone-based or digital mechanisms, such as telephone hotlines, social media channels, SMS-based systems, social media monitoring, and online portals. People should be able to directly and anonymously provide feedback through these channels.

It is important that the type of available feedback mechanism(s) be appropriate to the local context, including the situation, capacities, and preferences of the affected people and formal response actors.

Ideally, the mechanisms for channelling community feedback will ensure that people providing feedback receive timely responses and follow-up when necessary and appropriate. Even if feedback is passively gathered, it must be proactively managed.

### MAKING THE MOST OF COMMUNITY FEEDBACK

Responders aiming to set up community feedback mechanisms, especially those which are more passive, should be wary of potential problems that can render the mechanisms ineffective or considered untrustworthy.[11]

Initial engagement with communities could include discussions about what types of systematic feedback mechanisms would be most accessible and acceptable to people, and how they should be managed and run to maximise effectiveness and trust. It is likely that multiple channels will be needed to ensure everyone is able to provide feedback. It is important to ensure that all feedback channels are actively monitored. If they are not, there is a risk that the feedback of more marginalised people becomes lost or ignored.

To mitigate potential problems and make the most of community feedback, responders should:

- **Ensure awareness of available feedback mechanisms**. Use a range of community engagement strategies to ensure people know about the available feedback opportunities. Using pre-existing mechanisms rather than setting up entirely new systems might help ensure better awareness and access (see Box 3 for an example).[31]
- **Provide physical and in-person opportunities for feedback.** Digital and telephonic platforms may be efficient and have significant reach in some settings, but the degree of digital exclusion and lack of access to phones remains widespread, particularly in poor countries and communities affected by cholera. In such settings, digital options should be regarded as supplementary to in-person activities and options such as complaint boxes or drop-in offices.

- **Provide accessible mechanisms.** In addition to non-digital options, responders should consider mechanisms that cater to people who speak different locally relevant languages and people with disabilities or who are illiterate.
- **Ensure anonymous complaints can be made**. People may have concerns about confidentiality and retaliation when reporting a complaint, and may fear retaliation for doing so. Reinforce measures to support confidentiality and reassure people that this will be maintained.
- **Ensure there is capacity to monitor and adequately respond to feedback.** Absent, delayed, or unsatisfactory responses to complaints can damage trust not only in the feedback mechanism, but in the entire response. Where capacity for immediate, tangible improvement in response to feedback is limited, responders should ensure and communicate that feedback is used to build an evidence base to support further mobilisation of resources.
- **Ensure integrated, cross-pillar feedback.** Feedback mechanisms should be coordinated across response pillars and stakeholders, allowing people to submit feedback about any aspect of the response through any available channel, and to receive follow-up.

**Box 3. Learning from UNICEF's U-Report in Mozambique**

U-Report is a data collection and messaging platform that uses a free SMS system to improve adolescents' and young people's engagement in health issues, to improve advocacy efforts, and to foster positive change. In Mozambique, this platform was adapted for youth sexual and reproductive health and HIV prevention. As part of the Cyclone Idai response, U-Report was used to collect data in the districts most affected by cholera. This data was then used to enable improved and tailored communication for development interventions that could respond to issues in near real time.

Read more in the SSHAP case study *Enhancing Community Engagement Through Data Collection: Controlling the Cholera Epidemic in Mozambique*.

## Further Reading

1. SSHAP cholera resources
2. Community engagement for WASH resource
3. Cholera Questions Bank


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