

FROM WORDS TO ACTION: Towards a community-centred approach to preparedness and response in health emergencies



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Executive Summary

Overview

A coordinated and considered community-centred approach taken by all actors across preparedness, response and recovery interventions is critical to reduce the spread of infectious disease. Interventions will only be their most effective when they are relevant, contextually appropriate and co-owned by affected populations and when two-way trust between providers and affected populations is established and respected. This is particularly true in fragile contexts in which trust in state authorities has been eroded, but also in the increasingly complex operational environments of the twenty-first century, characterized by increased migration, urbanization and population density, widening societal divisions and inequities, and climate change-related challenges. Whilst advances have been made in recent years, we remain sorely underprepared to tackle a global pandemic, and significantly greater investment needs to be dedicated to longer-term community engagement.

Difficult lessons have been learnt in many infectious disease outbreaks when initially inadequate communication and engagement with communities in the design of emergency response measures fuelled fear and mistrust. This impacted the quality of services and their utilization by the population, causing further tensions and social disruption and leading to the perpetuation of disease transmission. The root causes of mistrust and community frustrations are different in different areas, and they play out in varied, often unpredictable ways. There is therefore a need for continual granular analysis and localized, agile response strategies that are informed by evidence and experience. In relation to the 2018-2019 outbreak of Ebola in the Democratic Republic of Congo (ongoing at the time of writing), the complexity of the operational environment, with its existing socio-political, economic and security concerns, must not be underestimated. Here the response is layered on top of decades of conflict and tension in which individuals and communities rapidly shift allegiances to survive. This response has vividly illustrated the need to find ways to build mutual trust, effectively engage in meaningful two-way dialogue and work with local structures, and adjust interventions over time based on the feedback and perceptions of affected and at-risk communities. Evidence and experience have shown that approaches that incorporate participatory decision-making and action are more successful, more sustainable, of higher quality and cost-effective over time.

Communities and local actors should be equal partners and active participants across all phases of prevention, preparedness, response and recovery. In many cases they are the first responders. Acknowledging this means supporting them with the necessary resources and complementing their existing skills and competencies. Yet supporting capacities at the local level is only part of the story.

Trust works both ways. Whilst communities are frequently told to trust the response, the response must learn to trust the communities it serves. Across the world, communities have great agency and ability to act, and we must support them to do so – this is what it means to have communities at the centre of preparedness and response.

Positive improvements and progress made

- **Increased visibility of community engagement on the global stage.** Community engagement gained greater visibility and traction during the West Africa Ebola outbreak and in other disease outbreaks since, such as Zika. Various global and institutional strategies and guidelines have been produced, with global, national and local initiatives calling for an increase in community engagement and noting its effectiveness. The Joint External Evaluations have also expanded the role of risk communication and community engagement assessments.
- **More attention paid to contextual realities and adapted, agile response efforts.** There is increased recognition of the need to adapt response measures to better fit the needs of affected communities, to ensure interventions are contextually appropriate and sensitive to socio-cultural norms and local authority structures, and to mitigate potential barriers to effective collaboration within communities. Social science has been increasingly valued by development and humanitarian agencies, with approaches and initiatives developed to support its operationalization within emergency response and development settings.
- **Greater focus on collecting perception and feedback data.** Perception and feedback data are now more routinely collected to inform epidemic response efforts, with some recent approaches to collecting community perception data at scale showing promise. These data sets help preparedness and response efforts to better understand the priorities and perspectives of the at-risk and/or affected populations and can form a baseline to measure the impact and challenges of a response at the community level.

Remaining gaps and challenges

- **Lack of consistent engagement of communities and local actors before, during and after an epidemic.** Whilst momentum is gathering around the need to embed community engagement across all preparedness, response and recovery work, this is not currently happening in a systematic way, nor to a sufficient degree. Much community engagement work remains ad hoc and reactive. There is extremely limited investment in prevention and preparedness work at the community level (e.g., to develop health literacy, build trust and understanding, and support broad community-led health programmes that integrate components of epidemic preparedness). Although more resources are introduced during response, these are often piecemeal and are frequently delayed.

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- **Ongoing failure to fully act on local knowledge and community feedback.** Research on community perceptions and feedback is being more routinely conducted, but the architecture of response (which often remains bio-medically focused) does not enable socio-behavioural information to be systematically incorporated so as to shape the trajectory of interventions. Mechanisms for accountability to affected communities remain weak, and there are significant gaps in how underlying anxieties and injustices are recognized, reported and addressed in preparedness and response efforts.
 - **Weak coordination and lack of impact evaluation and continuous learning.** A set of agreed common standards for community engagement are in development; however, there is an urgent need to improve rigorous monitoring, evaluation and continuous learning, and for evaluations to not only use metrics relevant to external reporting, but to keep at the forefront the perspectives and assessments of the community, and link this to accountability. Lessons learnt are not systematically collected and absorbed. Gaps in coordination remain evident at all levels, and investment is required to upskill a cadre of senior coordination experts to effectively manage information flow, enable collaboration and avoid duplication.

Priority actions

1. Understand that communities are the centre of preparedness and response. There is growing recognition that communities must be central partners in the design, implementation and evaluation of health programmes, but this now needs to be enshrined at international, national and local levels through global public health governance and coordination frameworks, and in prevention, preparedness, response and recovery strategies. Ensuring that the position of communities is clearly articulated in policy will help maintain momentum generated about the significance, value and effectiveness of community participation. Leadership and governance structures must be reformed so they are more explicitly accessible and responsive to the influence of at-risk and affected peoples. Strong advocacy across the sector, within agencies and with donors, will be required to ensure the adequate provision of resources so that affirmative action can be taken.

2. Enable consistent engagement of local actors and communities before, during and after an epidemic. Although surge activities at the onset of a response will mobilize community actors, the most effective action builds on already-established structures and systems (e.g., community committees, community-led surveillance). Consistent engagement before, during and after an event is critical and is the cornerstone for enduring trust. Local institutions (both public and private) and a wide range of actors (including the most vulnerable in society) must be collectively supported to act, not side-lined or replaced. Through participatory planning, collaborative learning and capacity strengthening processes, communities can identify the resources they need to complement their existing sets of skills and competencies. In this way, the capacity of communities, frontline workers, volunteers and local organizations to prevent, prepare, respond and recover is strengthened through

the course of any event, and they create and maintain greater levels of resilience to epidemics and other potential shocks. This is true systems strengthening, in which emergency response is rooted in a longer-term sustainable development agenda.

3. Make funding for community engagement more predictable and sustained. Baseline resources dedicated to community engagement must be maintained at all times. The provision of funds during an emergency event should prioritize community engagement, in order to facilitate the rapid scale-up of activities (as to be effective, the whole response depends on collaborative community participation). Donors need to allow flexibility in the allocation of funds during health emergencies to enable course correction based on community feedback, and mechanisms to financially support community structures over time should be better developed.

4. Act on local knowledge and community feedback. Greater attention must be given to the context of preparedness and response so that actions are agile and fully localized. To achieve this, social science needs to be an integral, cross-cutting component of preparedness and response, and community knowledge (e.g., regarding the use of local languages, alignment with public authority structures, preferred communication channels, etc.) must be kept at the forefront. Improved mechanisms to pre-position and rapidly collate existing knowledge, as well as to rapidly generate up-to-date information relevant to operational priorities, must be further developed. As well as yielding critical information to help shape interventions, the process of learning from communities itself helps to further develop trust and integrity. It is essential, however, that knowledge be demonstrably translated into action and used to course correct. Although shifts may happen more organically over a longer time period (e.g., a multiple-year cycle of development programming), the urgency of emergency response requires the rapid operationalization of community knowledge and feedback. Currently, the very architecture of response is a significant barrier to nimble working. Modifications to response architecture must be agreed at all levels so that it becomes feasible and accepted practice to systematically use socio-behavioural data to shape strategies and interventions according to emerging evidence over time. Presenting such data in the right format to influence those in leadership positions is important. However, there is also an urgent need to support local actors, frontline workers and the health workforce to develop the minimum technical competencies needed to assess a situation, analyse data and take action informed by available evidence. Community engagement must be mainstreamed so that it is cross-cutting and is understood to be the responsibility of all response actors who should receive training in interpersonal engagement techniques.

5. Strengthen mechanisms for accountability to affected communities. Preparedness and response efforts must routinely incorporate robust mechanisms for accountability to affected communities. A concerted effort is required to establish fit-for-purpose structures that build on key humanitarian and human rights principles for recognizing, reporting and addressing concerns and injustices. Although structures could be further modified to local contexts during an emergency response, there needs to be sector-wide commitment to implementing agreed mechanisms in a fair and transparent manner.

Agreed measurement frameworks should include indicators based on communities' participation and satisfaction levels and should require partners to evaluate the extent to which they systematically collected, reported and acted on feedback from affected people at key points in the programme cycle. Donors should use their collective leverage to mandate that all programmes and interventions they fund must apply participatory approaches and feedback in their design, real-time implementation and monitoring.

6. Measure community engagement approaches and define standard indicators. Any advancement to monitoring, evaluation and learning would be a welcome development given the current weaknesses. Information management and the sharing of quantitative and qualitative data across the pillars of response must be improved, partly through the recruitment of skilled managers with the remit of coordinating data analysis and information flow. Dedicated resources must be specifically allocated for critical and creative thinking to be applied to the rigorous assessment of community participation and engagement. Reviewing what does / does not work, why, when, with whom and in what contexts should become a routine component of all preparedness and response action. Beyond that, 360° measurement approaches for community engagement indicators must be defined and tested. This stronger evidence base should be used as the basis to design more effective working and to target the efficient use of resources for greatest impact. Donors have an important role to play in ensuring the uptake of standard indicators by all actors.

7. Leadership, coordination and technical expertise. Senior leadership needs to be strengthened and supported to articulate a clear vision of community engagement as both a core and cross-cutting component of preparedness and response. In parallel, a range of professional disciplines should be brought on board to contribute technical expertise in relation to community participation and engagement (such as anthropologists, psychologists, behavioural experts, communication specialists, negotiators and others). To maximize inputs and partnerships and avoid duplication of effort and missed opportunities, stronger coordination is required at global, regional, national and local levels, and must be undertaken with neutrality and the global public good in mind, rather than being aligned to any one response agency. Investment must be made to build a cadre of coordination experts that can work across all levels. It remains imperative that communities and local actors are better represented within such governance structures.

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Introduction

In 2001, a group of Acholi people from a village near Gulu, Northern Uganda, described the following set of rules that were to be strictly followed in the event of a dangerous infectious disease:

“When an illness has been identified and categorized as a killer epidemic (gemo), the family is advised to do the following: 1) Quarantine or isolate the patient in a house at least 100m from all other houses, with no visitors allowed. 2) A survivor of the epidemic should feed and care for the patient. If no survivors are available, an elderly woman or man should be the caregiver. 3) Houses with ill patients should be identified with two long poles of elephant grass, one on each side of the door. 4) Villages and households with ill patients should place two long poles with a pole across them to notify those approaching. 5) Everyone should limit their movements, that is, stay within their household and not move between villages. 6) No food from outsiders should be eaten. 7) Pregnant women and children should be especially careful to avoid patients. 8) Harmony should be increased within the household, that is, there should be no harsh words or conflicts within the family. 9) Sexual relations are to be avoided. 10) Dancing is not allowed. 11) Rotten or smoked meat may not be eaten, only eat fresh cattle meat. 12) Once the patient no longer has symptoms, he or she should remain in isolation for one full lunar cycle before moving freely in the village. 13) If the person dies, a person who has survived gemo or has taken care of several sick persons and not become ill, should bury the persons; the burial should take place at the edge of the village”.¹

This local system of epidemic control predates colonial times, is bio-medically sound and highlights, along with other similar examples,¹ that communities have local knowledge, experience and practices that are relevant in stopping transmission of disease. Communities have the ability to act to protect themselves and others.

A community-centred approach to global preparedness and response builds on the premise that communities have existing competencies, systems and knowledge and that the role of external response partners is to collaboratively identify these existing capacities and any gaps or weaknesses that may require further support. Long-term capacity-building, strengthening of existing systems and attention to broader development priorities are the stepping stones leading to stronger, more resilient communities able to design, plan, lead, implement and evaluate their own responses. To achieve this end, community engagement efforts must aim for the highest level of empowering

¹ E.g., Abramowitz et al. 2015.

participation, supporting communities to make decisions and take actions that will affect, protect and strengthen them. At the World Humanitarian Summit in May 2016, the United Nations Secretary-General committed to making humanitarian action *“As local as possible and as international as necessary”*.² Such a change requires a redistribution of power and authority to identify priorities, design strategies, oversee resources and evaluate programmes.³

In building the health literacy of communities so they understand the transmission routes of highly infectious disease and how to break the cycle of transmission, communities have the ability and opportunity to prevent an outbreak or to significantly reduce the rate and spread of infection (as the above example shows). Preparedness and prevention programmes that operate at the community level not only save lives but are far more cost effective than response interventions.

It has been well documented that community engagement is vital for containing epidemics and shifting the epidemic curve, whilst failure to meaningfully and strategically engage communities across all pillars of preparedness and response can lead to ineffective interventions and can even do harm. Difficult lessons were learnt during the West Africa Ebola outbreak (2014-2016), in which inadequate communication and engagement with communities in designing response measures fuelled fear and mistrust, leading patients to reject lifesaving care, doctors to strike and burial teams to be attacked.⁴ Similar issues of mistrust and miscommunication impacted previous response efforts including the 2009 H1N1 pandemic⁵ and the Zika outbreak in Central and Latin America.⁶

Strengthening health systems, governance and other elements of development are important for establishing trust, which is vital in preparing for emergencies. When the international focus is restricted to potentially global pandemics and ignores the ongoing and immediate concerns that affect people on a day-to-day basis, the intentions of international response partners come under understandable scrutiny. In the Ebola outbreak in the Democratic Republic of Congo (ongoing at the time of writing), communities continue to question why Ebola response teams appear to focus only on Ebola, while people are still dying from more common and treatable illnesses such as malaria, pneumonia and diarrhoea. The following statement is representative of sentiments frequently reported in the community feedback collected by the IFRC: *“You [Ebola responders] will leave when Ebola does, but we will still be here, slowly dying from the diseases that have always killed us.”* There, deep-rooted political, social and economic factors contribute to community members’ reluctance or inability to positively collaborate with response efforts.

² United Nations 2016a.

³ Konyndyk 2018.

⁴ Figueroa 2017.

⁵ WHO 2011.

⁶ Toppenberg-Pejcic 2018.

Community engagement within the Global Preparedness Monitoring Board

The 2016 United Nations Global Health Crises Task Force, and its predecessor, the 2015 United Nations High-level Panel on the Global Response to Health Crises, both recognized the centrality of community engagement in responding to health crises and found that the lack of effective community engagement had been a critical gap in recent outbreak responses.⁷ In its review of the West Africa Ebola outbreak, the High-level Panel concluded: *“Community sensitization efforts were frequently one-sided, conveying messages rather than acknowledging the legitimacy of local concerns and engaging with local populations to address them. Responders often interacted with a narrow subset of local interlocutors - in particular, local government officials - thereby neglecting to engage with the full spectrum of local society, including traditional leaders, religious leaders, women, youth and other members of the community.”*⁸ These challenges were further exacerbated by *“A lack of trust between local communities and the central government and foreigners, which in turn hindered behaviour change programmes carried out by government representatives or international actors. The situation led to the emergence of so-called community resistance, in which some communities passively, actively and, in a few cases, violently sought to avoid cooperating with health workers.”*⁹

In their reports to the UN General Assembly, the Panel and Task Force recommended that greater emphasis be placed on community engagement as part of preparedness and response efforts. Key recommendations from both bodies included incorporation of community engagement in global public health frameworks; community involvement in health systems and interventions; provision of required resources; and increased use of social science (see Annex 1). The reports suggested that protecting individuals from health threats through community involvement should be at the very core of resilience and human security. More broadly, the Panel identified the need to strengthen health systems and to address the broader determinants of health and development necessary for achieving the Sustainable Development Goals (SDGs).

Although progress has been made in many areas, community engagement emerged once again as a central and critical issue in the 2018-2019 Ebola outbreak in the Democratic Republic of Congo. The Independent Oversight and Advisory Committee for the WHO Health Emergencies Programme acknowledged in its report to the 2019 World Health Assembly the *“Difficulty of building trust during this crisis and the need to counterbalance Ebola response efforts with broader development, including*

⁷ United Nations 2016b; United Nations 2016c.

⁸ United Nations 2016c.

⁹ United Nations 2016c.

education, water safety, and health care services for other diseases” and encouraged WHO to “Work with partners to improve social cohesion and community engagement”.¹⁰

In light of these reports, the Global Preparedness Monitoring Board (GPMB) commissioned this paper to explore progress made over recent years, to highlight ongoing gaps and challenges, and to articulate how community engagement can be more effectively implemented to improve outcomes in health emergency preparedness and response.

¹⁰ WHO 2019.

Basic principles of a community-centred approach

For communities to truly be at the centre of infectious disease preparedness, response and recovery means radically changing how communities are perceived and how their role is understood and positioned by response actors. Only then will communities be a catalyst for change. We should always strive to assist communities to be equipped to design, plan, lead, implement and evaluate their own preparedness and response measures, requesting support from external partners if, when and where required. In practice, however, there are usually gaps in the capacity, resources or systems needed for a community to be so assertive. Communities and external response partners must therefore collaborate to identify what the community is already doing in terms of preparedness and response, where gaps or barriers exist, what is needed to overcome these, and what response partners can do in the short-, medium- and long-term to support the affected or at-risk population.

Investing the necessary effort in meaningful community engagement can be time-consuming and requires an ongoing community presence, skilled interlocutors, and a high degree of transparency and accountability. Challenges can arise in terms of addressing community concerns or requests;¹¹ however, research shows that the benefits gained through investment of time and resources will outweigh the costs involved.¹² The following highlights a number of key principles in achieving a community-centred approach:

- **Partner with communities to achieve shared goals.** Communities are not simply beneficiaries or recipients of a service, but often are also first responders. To capitalize on the resilience and resourcefulness of affected communities, a community-centred approach recognizes that affected people are capable of making decisions about and leading interventions that can change their lives. Communities must be considered equal partners who, with the right skills and resources, are capable of designing, planning, leading, implementing and evaluating responses. Whilst local partners and community perspectives may be increasingly considered in design processes, it is rare that they influence decision-making and overall strategy from the start.

¹¹ Dhillon and Kelly 2015; Aizenman 2019.

¹² E.g. Baly et al. 2007.

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- **Build on existing knowledge, skills and structures.** Community-centred preparedness and response begins with the premise that communities have existing capacity, systems and knowledge, and that the role of external response partners is to collaboratively identify and support existing capacities whilst helping to overcome any gaps or weaknesses. Communities often have established practices and mechanisms developed over time in relation to previous shocks. It is beneficial to take the time to understand the current practices that are in place and how best to build upon them by maximizing local strengths and resources, rather than undermining them. This entails shifting the approach from ‘replacing’ to ‘reinforcing’ local capacity. Working with and through existing community structures has proven to be more effective than establishing ad hoc, temporary structures during an emergency. It also builds trust and longer-term capacity that is positively reinforcing.
 - **Recognize that communities have their own valid priorities.** It is important to employ a more integrated, humanitarian approach that not only addresses infectious hazards but also includes other community needs, including child protection, water and sanitation, mental health and psychosocial support, and broader development (non-health-related) issues. Recognizing community priorities and helping to meet identified needs will also help build trust and mitigate potential frustrations.
 - **Facilitate participation and empower communities.** Where a community does not have the capacity to genuinely lead preparedness and response activities without external guidance, response partners can take the role of facilitators (not leaders) in the process of designing, planning, leading, implementing and evaluating preparedness and response measures. Various participatory methods have been used to support communities in their planning and design of community-led action, such as community-based early warning systems and surveillance.¹³
 - **Build two-way trust.** Whilst communities need to trust preparedness and response measures for them to be effective, external actors also need to trust communities to make good decisions. Trust can be nurtured by taking the time to engage in meaningful two-way communication, learning to compromise, and facilitating shared decision-making and bilateral accountability. Conversely, coercive strategies and censorship of controversial issues can lead to misinformation and erode trust.¹⁴

¹³ E.g., IFRC n.d.; Mariner et al. 2012.

¹⁴ Abimbola, Malik and Mansoor 2013.

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- **Understand context and adapt.** Local contexts are highly variable and communities are complex and dynamic. An appreciation of the heterogeneity of ‘community’ has been linked to community engagement success.¹⁵ Meaningful community engagement starts with an understanding of social, political and developmental contextual realities and constraints; customary practices; appropriate language; and communication preferences. A community-centred approach, therefore, requires preparedness, response and recovery plans and measures to be sensitive to context, agile and receptive to change. Adaptive and flexible community engagement programming is more likely to have sustained community acceptance and be able to manage and withstand unanticipated events over time. In fact, many outbreaks are better understood as multiple ‘localized epidemics’, with different health areas or communities experiencing the event at different times and in different ways. A one-size-fits-all model is rarely effective,¹⁶ while tailoring approaches to specific community groups and their needs has proven to be highly effective.
 - **Be inclusive.** Particular groups within a community (e.g., women, youth, people with disabilities, people with less or no education, or those in lower socio-economic quintiles) may have varying attributes, perspectives and vulnerabilities, and experience different opportunities to participate. Negotiating representation of all groups in decision-making (and being sensitive to gender, ethnicity, and numerous inequities) has been found to contribute positively to transformative power structures and community dynamics, as well as more effectively drawing on the knowledge and various skills community members can bring to a response.¹⁷ It is critical to actively seek and involve marginalized groups and people most in need or at risk of exclusion and to ask about their preferred communication methods and engagement opportunities. Failure to pay adequate attention to the complex make-up of affected and at-risk communities when designing preparedness and response interventions can lead to ineffective actions and unintended, even harmful, consequences at the local level.
 - **Promote accountability.** A community-centred approach takes into account what communities say about preparedness and response activities. Accountability can be promoted through the establishment of systems to continuously collect, analyse, and apply feedback and suggestions. This can increase the acceptance and credibility of interventions and foster mutual respect and understanding between international and national partners and affected and at-risk communities.

¹⁵ Nic a Bháird 2012.

¹⁶ Niederberger, Ferron and O'Reilly 2016.

¹⁷ ICRC and IFRC 2016; Oxfam 2007.

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- **Integrate social science and real-time community insights.** Rapid yet rigorous social science methods can be used to collect and verify data to inform programme strategies. Methods should be adapted to fit swiftly changing contexts, so that in emergency settings, rapidly collected and analysed 'good-enough data' can be triangulated with existing information. Existing local capacities can be drawn on, such as training volunteers to systematically collect real-time community insights, which can be quickly operationalized to inform community engagement and broader preparedness and response strategies.
 - **Humanize the response.** There is a need to appreciate the psychosocial implications of a health emergency and the impact it has on both responders and the wider community. Integrating psychosocial principles and psychosocial support skills across the response will not only help to 'humanize' interventions and encourage connection and communication but will protect the mental health and well-being of all involved, in both the short- and longer-term. All responders should be trained in empathy and dialogue, and community-centred approaches must be adopted by all actors during routine programming, preparedness, emergency response and recovery.

Effective approaches to community engagement

The importance of community engagement in the prevention and control of a health emergency is increasingly emphasized, but how engagement should occur, and with whom, is rarely straightforward. There are multiple approaches to community engagement, and careful consideration of the context is required in order to identify the most appropriate approach in any given situation. The starting point is a gap analysis that assumes communities have capacity, knowledge and systems in place and asks where external support might be required.

Studies show that strong organizational commitment and leadership are essential factors underpinning successful community engagement. This may include: support for community engagement from donors who understand the need for flexibility to manage unanticipated events; the decision to make community engagement an integral component of programming; and leadership that champions investment in and commitment to community engagement, including dedicating sufficient time and human and financial resources.¹⁸

The section below provides a series of case studies showcasing approaches to community engagement that have been found to be effective. The most successful examples are multifaceted and multisectoral, incorporating a range of approaches tailored to the specific context and need.¹⁹ Meaningful community engagement occurs when communities are involved before and throughout the project or response cycle with the design, implementation and monitoring of data collection, communication and feedback mechanisms, and in all key decision-making processes.

Communicating with communities through multiple channels

Employing a diverse range of channels to communicate with at-risk and affected populations has been found to be more effective than stand-alone mass media campaigns. Mass media can reach a large population rapidly, but if the media is not trusted at the local level and messages are not adapted to be context specific, mis- and dis-information can contribute to panic and anxiety,

¹⁸ Kolopack et al. 2015.

¹⁹ Buchanan-Smith M and Islam S 2018; Castro et al. 2017; Lin et al. 2016; Toledo and Vanlerberghe, et al. 2007; Toledo Romani et al. 2007; Baly et al. 2007; Vanlerberghe et al. 2009.

sometimes placing people at even greater risk.²⁰ Rapid social science research can be undertaken in collaboration with local communities to identify relevant and trusted methods and channels of communication, and to provide an evidence base for the design of appropriate messaging in local languages.²¹

Communication channels can include face-to-face interactions such as community and sporting events, community health forums and house visits by local volunteers,²² mass media such as signboards, posters, pamphlets and loudspeaker transmissions in public places,²³ older technologies including radio, and newer technologies such as social media, SMS and telephone helplines.²⁴ Strategically designed multi-channel approaches contributed to preventing Zika in Cuba²⁵ and curbing the spread of the Nipah virus in India.²⁶

Tanzania Ministry of Health

Harnessing local structures for health promotion with nomadic communities

In tackling an outbreak of cholera in 2018, Tanzania's Ministry of Health used an innovative approach to work with nomadic Maasai pastoral societies in Arusha. In designing response structures and communication systems that would be as mobile as the target population, the intervention involved:

- **Formative research:** An initial situational needs assessment and community mapping were conducted. These highlighted key structural issues such as the lack of toilet facilities faced by nomadic populations, social norms that prohibited the use of toilets, and the community's need to access water sources for their herds during drought even if those water sources were cholera infected.
- **Capacity building:** 'Community cholera committees' were established at ward, village and hamlet levels. The committees included local leaders, health facility and school representatives, influential people such as *Laigwanans* (highly trusted religious leaders), Community Health Workers (CHWs) and other trusted community members. Committee members were trained on cholera prevention, signs and symptoms, risk communication, community engagement and case reporting, and were supplied with relevant materials.
- **Multi-channel communication and health promotion:** Activities included house-to-house health education services; public meetings involving participatory theatre and song; broadcasts of messages on community radio and television (in community kiosks, public buses, health facilities and public boats); training of food and water vendors and motorcycle riders; dissemination of messages in religious institutions; school-based education; circulation of SMS messages; social media engagement; and the establishment of a toll-free hotline.

²⁰ Prati, Pietrantoni and Zani 2011; Ripoll and Wilkinson 2018.

²¹ Ripoll and Wilkinson 2018; 2019; Hou et al. 2018.

²² Andersson et al. 2015; Castro et al. 2017.

²³ Tapia-conyer et al. 2012.

²⁴ WHO 2018b.

²⁵ Castro et al. 2017.

²⁶ WHO 2018b.

The inclusion of ward, village and hamlet representatives in the committees enabled the active engagement of all community members through their trusted representatives and existing local structures. The presence of strong cultural structures and traditional leadership helped the local health promotion team to reach vulnerable communities and to earn trust rapidly. An anthropologist and social science specialist who were embedded in the health promotion team were able to provide technical assistance and to guide the process.

Using new media to communicate and receive feedback

People increasingly rely on mobile phones, social media and the internet to source information and communicate.²⁷ Communication strategies need to capitalize on new forms of media as well as acknowledge the challenges they present, such as the potential for misinformation to circulate rapidly and more widely.²⁸ Examples from the humanitarian and health sectors highlight promising ways in which information communication technology can be used for information collection and processing, with volunteers and communities providing up-to-date, contextually relevant information to those at risk or in need.²⁹

Mobile phones have been used to support flood monitoring,³⁰ to deliver reminders for vaccines and health services,³¹ and to gather data to inform epidemic response strategies.³² In Nigeria, UNICEF's U-Report initiative, a free SMS-based social monitoring tool with over three million users, has been successfully used to communicate with at-risk populations about monkey pox and cholera outbreaks and other health-related issues, as well as to gather information about perceptions and beliefs and collect feedback on health and other services. One reason the platform has been successful in promoting health and influencing changes in behaviour is that it has built a positive reputation over a number of years and is run by a trusted organization.³³ A large-scale mobile phone-based rabies surveillance system in southern Tanzania was found to improve data quality and timeliness at low cost.³⁴ In the 2018-2019 outbreak of Ebola in the Democratic Republic of Congo (DRC), using and monitoring WhatsApp and other social media has helped to track changing messages and perceptions over time and to highlight key challenges related to security.³⁵

²⁷ Ripoll and Wilkinson 2019.

²⁸ McSeveny 2017.

²⁹ Meier 2011.

³⁰ Cumiskey et al. 2015.

³¹ Wakadha et al. 2013.

³² Berman, Figueroa, and Storey 2017.

³³ Anthrologica 2018.

³⁴ Halliday et al. 2017.

³⁵ Sweet 2018; Sweet 2019; O'Neill and Eno-Van Fleet 2019.

Novetta

Media analytics

Novetta has developed a novel approach to detecting perception and behaviour patterns in real time through analysis of open source data feeds, including social media (WhatsApp, Facebook, Twitter), print media and broadcast media (radio and television) and through working with local field teams. Novetta uses innovative technologies to integrate and cross-reference these data in order to discover shifts in messaging trends or emerging threats. The method enables rapid targeted assessments in hard-to-access information environments and aims to provide operational feedback to decision-makers within 24-48 hours. A key strength of Novetta's approach is the ability to observe local conversations without influence, removing some of the bias that can develop through interpersonal methods and direct questioning.

One of Novetta's operational areas is North Kivu, DRC, where the focus is on Ebola Treatment Centres (ETCs) that are actively conducting clinical trials. Collected quotes are coded by source, narrative, sentiment, and geolocation, creating a robust database of contextualized Ebola-related content. These data have provided feedback for the clinical trial operations but have also provided insights on multiple other dimensions of the Ebola response, including where misinformation is originating and how it is spread. The created a near real-time warning system for direct threats on facilities or operations. The system also serves as a feedback mechanism by tracking narratives in relation to community engagement techniques and information campaigns over time. In June 2019, for example, Novetta's analysis identified a small shift in messaging around ETCs in Butembo and Katwa, with media outlets more commonly highlighting success stories and good progress, whilst also noting that the cooperation of local militias was key to stopping transmission of the virus.

Building health literacy, health promotion and behaviour change

Effective health promotion strategies can lead to positive behaviour change, community action and greater social mobilization coverage.³⁶ Health promotion strategies should be grounded in the science of behaviour change and avoid generic messages. Through learning key behaviour change principles, health workers, volunteers and other community members can be empowered to identify the barriers that are preventing behaviour change in their own communities. The International Federation of Red Cross and Red Crescent Societies (IFRC) routinely follows principles of behaviour change in their collaboration with community-based volunteers. During flooding in Cambodia in 2019, they supported volunteers with limited literacy to promote hand washing and sanitation practices at the household level to identify barriers to appropriate behaviours. Evaluation data showed that communities with established health literacy adopted and/or maintained appropriate hand washing and sanitation behaviours.³⁷ A UNICEF behaviour change programme in Namibia and

³⁶ E.g. Alvarado-Castro et al. 2017.

³⁷ Chansana and Vantha 2019.

Ethiopia supported Health Extension Workers to conduct home visits to increase knowledge and shift attitudes around prevention and treatment of common health conditions.³⁸ Ideally implemented as part of a longer-term preparedness initiative, this model can prevent disease through improved health literacy, as well as strengthen community health surveillance. It also has the potential to be equally effective in emergencies and in situations in which two-way dialogue is best achieved at the household level.

IFRC

Community Based Health and First Aid in cholera-hit Sierra Leone³⁹

IFRC's Evidence-based Community Based Health and First Aid (eCBHFA) approach focuses on building health literacy and functions as a primary prevention programme conducted by community-based volunteers. Volunteers are trained in basic first aid, psychological first aid, community mobilisation techniques and other primary prevention topics. The approach is implemented in a wide range of settings in over 154 countries.

During a cholera outbreak in 2012, access to trained long-term volunteers improved IFRC's ability to respond swiftly and effectively to the epidemic. The programme worked with a strong network of thousands of volunteers – many of whom had been active for five years before the outbreak - and had a strong relationship with national and district level government partners through continuous programming. As part of the response, three thousand volunteers were trained in providing eCBHFA. The training included elements of community mobilisation and behaviour change and used a root cause analysis approach to help communities identify social and health issues. Modified barrier analyses were used to develop action plans based on solutions prioritised by the community. Trained volunteers organised house visits, mobile cinemas and youth peer drama groups to raise awareness and establish dialogue around cholera, and to demonstrate the use of oral rehydration salts and Aquatabs for safe water treatment.

Working through existing networks enabled response partners and government to tap into trusted channels of communication for public health messaging, increasing the acceptance of lifesaving information. The strategy also drew on existing groups, including mothers' and youth clubs.

In behavioural change programmes such as Community-Led Total Sanitation (CLTS) and Participatory Hygiene and Sanitation Transformation (PHAST), communities conduct their own assessments to inform the action they will take to improve local situations.⁴⁰ This approach has been shown to be particularly successful when strong community networks and accountable local institutions are in place and where local infrastructure enables rather than hinders behaviour change.⁴¹ During the Ebola outbreak in West Africa in 2014-2016, for example, it was found that communities in Liberia

³⁸ Mutseyekwa 2015.

³⁹ For more information about this case study please see online resources.

⁴⁰ CLTS has attracted a level of controversy due to its perceived focus on 'shaming' and 'generating disgust' about a community's usual practices of open defecation, which is considered by some to be unethical. There is also little evidence of its sustainability (Fick and Novotny 2018).

⁴¹ Ripoll and Wilkinson 2019.

that had implemented CLTS interventions aimed at eliminating open defecation had a far lower incidence of Ebola than neighbouring communities.⁴² This highlights the transferrable value of community capacity and ownership across health issues, both chronic and acute.

Experience shows that health promotion for communities at risk is best conducted through trusted local networks and interlocutors rather than through broad mass communication strategies. Although community, religious, women and youth leaders are often seen to be trusted local representatives, other stakeholders also have reach and influence, such as those who have survived a disease outbreak⁴³ and marginalized groups that may not normally be included. Children are able to cascade information not only to their peer groups, but also to their households and broader community.⁴⁴ Working together, local interlocutors can reach people quickly and at scale. For example, in an Oxfam project in Oromia, Ethiopia, school children, religious leaders and Red Cross volunteers were trained to educate students, congregations and communities about cholera, reaching hundreds of thousands of people within one week.⁴⁵

UNICEF

Behaviour change in the Rohingya response

To meet the emerging and growing communication needs of the 780,000 displaced Rohingya and their host communities in Bangladesh's Cox's Bazaar, UNICEF implemented a focused, systematic and evidence-based Communicating with Communities (CwC) / Social and Behaviour Change Communication (SBCC) approach to promote desired key behaviours, attitudes and practices. Information and Feedback Centres (IFCs) were set up at strategic locations within Rohingya settlements in collaboration with PULSE, a national NGO. The goal of the IFCs was to ensure two-way communication by providing life-saving messages to communities, as well as receiving and responding to feedback.

Each IFC had two centre-based and 16 mobile Information Service Providers that covered 2,500 households (15,000 people). In addition, 80 Model Mothers and 80 Model Youth Mobilizers were attached to the IFCs to conduct outreach activities for community mobilization. An estimated 3,600 families were covered in 12 locations per day per site, reaching an estimated 90,000 families each month. As of October 2018, 330,000 refugees had been reached with information dissemination, community engagement and accountability mechanisms on life-saving behaviours and available services. In addition, 8,630 adolescent girls and boys from the refugee community had been engaged to provide life-saving information and referral to services as change agents. Another 2,000 adolescent girls and boys were similarly engaged from the host communities. One key lesson learnt was that, given literacy is low and there is no written script for the Rohingya language, communication must be face-to-face, oral, and low-tech.

⁴² Capps, Njiru and deVries 2017.

⁴³ Gray et al. 2018.

⁴⁴ Kay and Nam 2005; Lin et al. 2016; Sommerfeld and Kroeger 2015.

⁴⁵ Lamond and Kinyanjui 2012.

Collecting data to understand context

An essential part of community engagement is the collaborative and ongoing collection of contextual data to inform, adjust and evaluate interventions. During preparedness, emergency and recovery phases, it is important to collect data about the social, political, historical and economic context; local knowledge, attitudes, beliefs and behaviours; and pathways of care and local aetiologies of disease. It is also important to map key community stakeholders and existing local structures. During an emergency, this background information must be supplemented by real-time insights and emerging issues to ensure that response strategies and information sharing can be rapidly adapted as necessary. For example, the importance of adapting standard safe and dignified burial protocols based on community feedback has been widely acknowledged by response partners and is increasingly integrated into routine response measures.⁴⁶ This iterative approach has been shown to not only improve interventions over time, but also contribute to conflict resolution.⁴⁷ In situations in which context has not been adequately understood or taken into account, response measures have failed.⁴⁸

Social science methods are increasingly being used to rigorously analyse local contexts in order to inform preparedness and response design.⁴⁹ In South Sudan, for example, rapid surveys that included an ethnographic component were used to explore knowledge and attitudes towards cholera, its treatment and prevention. The research found that camp dwellers preferred a fixed vaccine post, whereas host populations preferred a mobile vaccine post, and that children in pastoralist communities were more likely to be vaccinated in the same locations where livestock were being vaccinated and where cross-border mobile clinics were available.⁵⁰ Social science methods, including participatory methods that engage communities in the process of data collection and analysis (see below), can be adapted to emergency settings (e.g., taking into consideration the pressured environment, timeframe and need for immediate analysis to shape operations).⁵¹ It should be noted, however, that even research designed to understand how best to engage with a community requires a level of community engagement before data collection can start.

⁴⁶ Anthrologica and IFRC 2015a; 2015b; 2015c; Sáez and Borchert 2014.

⁴⁷ Anoko 2014.

⁴⁸ Ripoll and Wilkinson 2018; Khun and Manderson 2008; Khun and Manderson 2008; Toledo et al. 2008; Zahir et al. 2016; Sulistyawati et al. 2019; Toledo-Romani 2006; Mariner et al. 2012.

⁴⁹ Bardosh et al. 2019.

⁵⁰ Porta et al. 2014; see also Heitzinger et al. 2018.

⁵¹ Bardosh et al. 2019.

Translators without Borders

The role of language in community engagement: cholera in Rohingya refugee camps, Bangladesh

Translators without Borders (TWB) uses data collection and participatory methods to ensure the effective and appropriate use of language within response activities. Their approach involves:

- Collecting, consolidating, and mapping data about the languages people use and understand and about their communication preferences.
- Translating into local languages and field-testing key humanitarian information materials to support immediate and accurate communication with at-risk and affected populations.
- Tailoring data collection tools and community feedback mechanisms to people's language needs to ensure that funding and programming decisions are informed by more reliable data.
- Developing common terminology resources in local languages to enable translators, interpreters and field workers to translate key concepts accurately and consistently.

In 2018, there was a major cholera outbreak in and around the overcrowded Rohingya refugee camps in Bangladesh. The Ministry of Health conducted an Oral Cholera Vaccination campaign for nearly one million refugees and host community members. TWB carried out consultations to identify people's concerns and questions about cholera and the local languages spoken and preferred. Many organizations assumed that the local Chittagonian spoken by the local population was close enough to Rohingya for meaningful communication, but TWB's research confirmed that this was not the case and often refugees did not understand the responders. As such, TWB and other partners translated and field-tested a range of resources on cholera and the vaccination campaign in relevant formats and languages tailored to the specific information needs of the target populations, and developed a common glossary of health terms in five languages.⁵² These were shared with partners across the response and via the Government's coordination platforms, and staff who were directly interacting with affected communities were trained to use the materials. As a result, community engagement was better coordinated and consistent information in the right languages and formats was disseminated and widely circulated. This contributed to more effective communication with communities and helped to control the outbreak.

Collecting real-time community feedback and using it to shape interventions and ensure accountability

Recent developments have shown promising approaches to collecting community feedback and perception data in infectious disease outbreaks at scale to shape response activities and provide a higher level of accountability.⁵³ Approaches include the use of various media such as face-to-face dialogues, community meetings, SMS and social media, telephone and email.⁵⁴

⁵² <http://www.shongjog.org.bd/resources/?id=80984afd-9a63-4803-a155-dd6ce17c9cbf>; Translators without Borders 2018.

⁵³ Baggio, Camara & Prue 2019.

⁵⁴ E.g. Utarini 2016; Boegler et al. 2017.

During the West Africa Ebola outbreak (2014-2016) and the outbreaks in DRC (2018-2019), multiple initiatives were set up to collect, investigate and respond to citizen feedback from affected areas. In Liberia, for example, Internews, in partnership with UNICEF, USAID and Johns Hopkins University, set up a 'rumour reporting system' called 'DeySay', in which they collected and routinely responded to information (and requests for information) from communities.⁵⁵ In Ebola-affected areas in the eastern DRC, Oxfam are using mobile technology that automatically uploads data to an online platform to systematically collect and analyse qualitative information relating to people's perceptions, beliefs, knowledge and suggestions. The technology makes it possible to share data in short, effective reports to facilitate effective uptake. Oxfam used similar mobile-based survey software in Haiti as part of their cholera programme following Hurricane Matthew, and it was found to be both user-friendly and replicable at scale.⁵⁶

IFRC

Community feedback mechanism: lessons from the Democratic Republic of Congo (DRC)

"We don't trust the response team because they started their operations badly and the team was made up of foreigners" (community feedback quote, DRC 2019).

Misinformation, mistrust of outsiders and conspiracy theories spread quickly across areas of the Eastern DRC affected by the 2018-2019 Ebola epidemic. Decades of violence and displacement, along with unfamiliarity with the disease and response activities, contributed to a lack of trust that hampered the response.

In order to respond to communities' objections to the response and to improve it based on people's concerns, an innovative community feedback system was launched in August 2018 by the IFRC in close partnership with the US Centres for Disease Control and Prevention (CDC). At the time of writing, over 800 volunteers continue to regularly gather granular, near real-time community perception data incorporating key beliefs, misinformation, questions, suggestions and concerns across all affected areas. The information is analysed and provided to all first response actors. The information enables the response to understand barriers and drivers related to the uptake of biomedical interventions, to adapt interventions in line with community suggestions, and to better address community concerns and expectations. Nearly 400,000 data points were collected in the first year of the system.

Although the feedback was not always consistently incorporated and operationalized across the response in a timely manner, there have been some successes in its use to influence response measures. For example, resistance towards safe and dignified burials was fuelled in part by the widespread belief among community members that the body bags used by responders were actually filled with rocks or dirt to hide the fact that body parts had been removed and sold. Communities asked for visual confirmation that the body of their loved one was in the bag and had not been manipulated. To respond to this need, the Red Cross acquired semi-transparent bags which were well received by the community and contributed to lowering the opposition

⁵⁵ Ayala Iacucci 2015.

⁵⁶ See the Oxfam case study in the sister report '*From words to action: Towards a community-centred approach to preparedness and response in health emergencies – Case Studies*'.

to safe and dignified burials. Similarly, rapid diagnostic testing was introduced in part due to frequent requests by the community and the pervasive belief that responders are spreading Ebola and treating all patients as Ebola cases,⁵⁷ both of which were captured in the feedback.

Ground Truth Solutions

A Practical, Response-Specific Accountability Approach

Ground Truth Solutions (GTS) supports affected populations to communicate their views to aid providers and policy-makers by tracking whether they consider humanitarian services relevant to their needs; whether services are provided in a fair way; whether they trust aid agencies; whether they feel respected by aid providers; and whether they feel empowered and enabled to live without aid in the future. The organization presents these perceptions and demands to humanitarian agencies in a digestible, actionable way, to ensure effective uptake in humanitarian operations. GTS aims for influential donors and aid agencies to include accountability requirements in their grant agreements and to demonstrate how they take affected people's views into account in the design and implementation of their programmes. The organization advocates for the integration of accountability into the humanitarian architecture by injecting the perspectives of affected people at strategic points along the response planning and implementation cycle.

In Chad (2018-2020), GTS continues work to include the perspectives and priorities of refugees, returnees and displaced people directly into the humanitarian response plan (HRP).⁵⁸ Their approach has four parts:

- Systematically collecting views on progress of the HRP
- Analysing and linking the findings to the strategic objectives of the HRP
- Helping agencies interpret and act on the findings by devising perceptual indicators
- Communicating the results back to affected communities whilst encouraging the Humanitarian Country Team to adjust implementation

This metric-based approach helps humanitarian agencies to better monitor their impact from the perspective of affected populations and informs decision-making, strategic planning and programme monitoring. The perception indicators have been integrated within the Core Humanitarian Standards to help bring focus to disparate activities implemented across various sectors. The indicators go beyond activities of specific agencies or clusters, are relatively simple and involve independent third-party monitoring to ensure impartiality. They provide a sense of how the collective response is performing based on the views of affected people. With funding from DFID, the Swiss Agency for Development (SDC) and others, the approach is now being rolled out in country operations in Somalia, Uganda, Central African Republic and Iraq.

⁵⁷ The following community comments are representative of community feedback related to the need to take quicker actions in the response and avoid delay in testing: "The responders who are in charge of testing take a long time with the results so that the inhabitants can be infected by their dead body." (Apr 2019); "The results on the dead body must be brought after the testing so that the afflicted family can do the burial in a timely manner." (Mabalako, 26 Apr 2019). Community feedback also relates to health-seeking behaviours with extensive belief that health care workers are labelling all diseases and symptoms as Ebola: "We no longer go to the hospital because all diseases are declared Ebola." (June 10, 2019); "People are held in the hospital without [having] the Ebola virus." (2018); "We always have fear of going to the hospital because any time one has a fever, it is said that it is Ebola." (2018).

For more information about the community feedback work in DRC, please see online resources.

⁵⁸ Humanitarian Country Team OCHA N'Djamena 2019.

Using participatory approaches to inform communication strategies and programme design

There are numerous participatory methods which can be used to inform programme design. One approach that has gained considerable traction over recent years is human-centred design, a people-centred approach to problem-solving that aims to identify solutions that are tailor-made to suit a specific group's needs. It uses brainstorming, prototyping and testing with the target group to arrive at a solution to a specific problem. In Sierra Leone, the approach was used to design and test improved personal protective equipment (PPE) with health workers; the new PPE was quicker and safer to take on and off, better adapted to the climate, and had improved visibility to allow for improved communication between health workers and patients.⁵⁹

Participatory Action Research (PAR) facilitates communities to carry out their own research, to generate, analyse and use their own knowledge of the local context to identify priority actions to address the cause of problems, and to take action as a community to improve their situation. In post-Ebola Liberia, PAR was used to rebuild maternal health services.⁶⁰

Participatory mapping is being used to document population movements to predict the spread of diseases, including across borders,⁶¹ whilst participatory modelling of diseases (such as Lassa Fever and Ebola) has been shown to complement quantitative models.⁶² In Tanzania, researchers trained community members to map the locations in their communities where mosquitos were thought to be most abundant, and the results were found to be equally as accurate as entomological surveys.⁶³

Building Resilient Communities in Somalia (BRCiS) Consortium

Participatory People First Impact Method (P-FIM) to inform decision making in Somalia

P-FIM is an approach that gives communities a voice and allows them to shape the decisions that affect them. The process emphasizes trust, active listening, and shared ownership and responsibility for programming, with a focus on enabling agencies to support and build upon community structures. It showcases what is working and what is not, what should be included in development plans and what donors should fund, and highlights issues that require urgent action. The approach has been successfully applied globally.

In March 2019, Save the Children and their local partner, Gargaar Relief Development Organization (GREDO), used the P-FIM method to engage youth, women, elders, religious leaders, persons with disabilities, and businesses in Baidoa, Somalia. The objective was to learn about community priorities and build trust

⁵⁹ Dalberg Design 2017.

⁶⁰ Jones et al. 2018.

⁶¹ Ripoll and Wilkinson 2018; e.g. Falisse 2019.

⁶² Cunningham, Scoones and Wood 2017; Scoones et al. 2017.

⁶³ Mwangungulu et al. 2016.

between Save the Children and the different community groups. The following steps were followed:

- **Day 1 – Goal free communication:** The team started by asking the communities open-ended questions about the most important things that had happened in their lives over the previous five years, followed by probing questions about the differences these factors had made to their lives and the cause of any change.
- **Day 2 – Two-way communication:** The team consolidated the most common problems that emerged from the different community groups and formulated each issue into a discussion point. The community were asked how they were addressing each problem or what additional support they would require to enable them to do so.

Community members emphasized how important it was to have the space to talk and share their experiences. This was particularly true for people with disabilities, who mentioned that it was the first time an agency had spent time discussing with their community.

Participatory and community-led planning, design and implementation

Where communities require external support to design and lead preparedness and response activities, response partners should be aiming to facilitate (not lead) communities' independent decision-making processes and actions. Whilst more evidence is required on what makes a successful approach and how to do this at scale, approaches that incorporate participatory decision-making and action -- involving communities in the planning, design, implementation and evaluation of programmes -- are proving to be successful, and more sustainable and cost-effective over time, than a top-down approach.⁶⁴

Community action planning can be used in conjunction with complementary participatory approaches such as community mapping,⁶⁵ and approaches often involve the formation of committees to work together with a facilitator to develop or adapt preparedness or action plans to be locally appropriate and feasible.⁶⁶

In 2005-2007, a community-based dengue vector control programme in Cuba involved the formation of a local, multi-disciplinary steering committee including epidemiologists, entomologists, social scientists and education professionals, and the creation of Community Working Groups (CWG), composed of community leaders, public health workers and local nurses. Formative social science research was carried out and the findings used to tailor the intervention to the local context. CWG

⁶⁴ Juarbe-Rey et al. 2018; Baly et al. 2007; Toledo Romani et al. 2007; IFRC 2007.

⁶⁵ See the Save the Children case study in the sister report '*From words to action: Towards a community-centred approach to preparedness and response in health emergencies – Case Studies*'.

⁶⁶ Charania and Tsuji 2012; Mariner et al. 2012.

members were trained to conduct their own situation assessments, identify local priorities and develop action plans. Community members participated in the planning of activities and communication to mobilize the community and change behaviour, negotiations with the government to address communal environmental risks, and surveillance of environmental risks using locally-produced maps. Following the intervention it was found that *Aedes* mosquito infestation levels were significantly reduced.⁶⁷

LINCHPIN

Community Action Cycle for improved child-health in Zambia

The Lufwanyama Integrated Newborn and Child Health Project in north-central Zambia (LINCHPIN, 2009-2014) aimed to create an enabling environment for maternal, newborn and child health (MNCH), by increasing access to, quality of and demand for key services and practices through community mobilization. As part of the project, Community Health Workers (CHWs) and Traditional Birth Attendants (TBAs) formed community teams. The project worked in 118 communities through community action groups consisting of traditional leaders, women, youth and the most vulnerable in the community. These groups were trained to develop and implement their own community action plans, which included self-prioritized activities relating to health education, forming and sustaining a series of safe mothers' action groups, and construction of a staff house, mothers' shelters, maternity wings and a primary health care unit. The community action groups drove the process and monitored its progress.

Results of these activities included development of emergency transport plans for women in labour and sick children, establishment of Safe Motherhood Groups with members trained in referring and accompanying pregnant women for antenatal care (ANC), and the raising of local resources for improving MNCH. This resulted in increases in the number of ANC visits (55% to 78%); births attended by skilled personnel (36% to 96%); treatment of children 0-23 months with effective anti-malarial within 24 hours (11% to 55%); treatment for children aged 0-23 months with chest-related coughs and fast/difficult breathing (67% to 97%); and more frequent use of insecticide-treated bed nets for children 0-23 months (51% to 81%).

Key learning showed that the participatory process worked best when communities were enabled to develop their own plans with facilitation, but with limited pressure, from health workers and others in positions of authority. External facilitators supported community groups to come to their own conclusions without external interference.

⁶⁷ Vanlerberghe et al. 2009.

Long-term capacity-building and systems strengthening

A truly participatory community-centred approach to preparedness and response is most likely to be successful and sustainable when a number of enabling elements are already in place including: a certain level of social cohesion within the community that enables stakeholders to work together; a level of interest and concern within the community for the issues at hand; a certain level of relevant technical knowledge on the part of the community; and, perhaps most importantly, trust within the community and two-way trust between the community and external partners.⁶⁸ To achieve these conditions, long-term actions are required to build the capacity of community-based stakeholders and invest in broader development and systems strengthening. The community-based vector-control programme referred to above worked well partly because there was a pool of trained local professionals that could be drawn on, the initiative was embedded into an already-functioning vertical vector control programme, there was good multi-sector cooperation between government and the community, and the political and socio-cultural context supported active community involvement.⁶⁹

Numerous organizations focus on the long-term capacity-building of community members (including volunteers, CHWs, TBAs and medical practitioners) to improve general health indicators as well as prepare for emergencies. These community members may be trained to work in areas such as community case management, community-based active surveillance and contact tracing, community-based infection prevention control, contingency planning, media management and communication.⁷⁰ Long-term capacity-building has shown to reap substantial dividends, as calling upon existing trained volunteer cohorts has resulted in a more effective and rapid scale-up of response activities.⁷¹

Capacity to effectively and rapidly respond to an emergency can also be strengthened by implementing a coordinated early warning system that taps into local, traditional knowledge and utilizes existing social networks.⁷² Community members and health workers can be trained to identify signs, symptoms and events that can increase infection and to take actions to reduce the spread of disease.⁷³ Under its Community Epidemic and Pandemic Preparedness Programme (CP3), the IFRC recognizes that epidemics begin and end in communities, and when communities are engaged and trained in epidemic preparedness and response, they become vital contributors in preventing, detecting and responding to disease threats while playing a significant role in preparing

⁶⁸ See Rabinowitz 2018.

⁶⁹ Vanlerberghe et al. 2009.

⁷⁰ Panday et al. 2017; Khatri, Mishra and Khanal 2017; Chi and Urdal 2018; Heitzinger et al. 2018; Degleh 2017; Ogoina et al. 2019; Ozturk, Li and Sakamoto 2015; IFRC n.d.

⁷¹ Powell 2013; ICRC and IFRC 2016; Toledo Romani et al. 2007; see the IFRC case study in the sister report *'From words to action: Towards a community-centred approach to preparedness and response in health emergencies – Case Studies'*.

⁷² Berrian et al. 2018; Alcayna-Stevens 2018; Laverack 2018; Baudoin et al. 2014.

⁷³ Namukose et al. 2018; Nyenswah et al. 2015; McNamara et al. 2016; Lamunu et al. 2004; Heymann et al. 1999; Fallah et al. 2016.

for future risks.⁷⁴ Attempts to draw on technologies such as mobile phones, the internet and radio to improve surveillance have also shown promise.⁷⁵ The eradication of rinderpest is a good example of a community-based surveillance system leading to positive outcomes that conventional scientific surveillance was not able to achieve.⁷⁶

Studies highlight how preparedness and response efforts can be compromised if basic public services are not in place and key development priorities have not been adequately addressed.⁷⁷ Conversely, when strong systems or successful long-term programmes are in place, these can be rapidly built upon in an emergency. Numerous examples show that initiatives which build on existing health structures, routine public health processes and community engagement strategies are more successful and more cost effective than those that attempt to create new structures.⁷⁸ In turn, structures set up during an emergency also have the potential for lasting effect and sustained health system strengthening. During the Ebola recovery phase in Liberia, for example, a national integrated community engagement and social mobilization campaign for polio, measles and deworming was implemented based on structures that had been invested in during the Ebola response.⁷⁹ Similarly, lessons learnt from polio eradication indicate that investing in integrating infectious disease eradication efforts within the routine health system, including in door-to-door general vaccination efforts, can increase levels of trust that positively impact health in other contexts.⁸⁰

CORE Group

Capacity-building and behaviour change communication for vaccination

The CORE Group Polio Project (CGPP) is a multi-country, multi-partner initiative that supports community-based activities designed to strengthen host country efforts to eradicate polio, particularly in high-risk populations that are marginalized and hard to reach. Through the project, CGPP community mobilizers work to increase demand for immunization and expand disease surveillance. NGO partners trained and supervised 15,000 community mobilizers in 2018, who in turn reached six million people, supported the vaccination of over two million children with oral polio vaccine, and were instrumental in disease surveillance.

A community engagement model for polio surveillance, vaccination and response trialled in India in 2007-2008 proved to be highly successful and is now being expanded to include other infectious disease threats, such as rabies, viral haemorrhagic fevers (i.e., Ebola, Marburg), Rift Valley Fever, avian influenza, anthrax, and brucellosis.⁸¹ A community mobilizer and community informant/influencer model is replicated in each project site following a set process that includes detailed community mapping, trust-building and feedback. In each of

⁷⁴ IFRC n.d.

⁷⁵ Halliday et al. 2017; Ripoll and Wilkinson 2019; ICRC and IFRC 2019.

⁷⁶ Mariner et al. 2012.

⁷⁷ Lin et al. 2016; Khun and Manderson 2008.

⁷⁸ Halliday et al. 2017; Aimone 2010.

⁷⁹ Bedford et al. 2017.

⁸⁰ Abimbola, Malik and Mansoor 2013.

⁸¹ See the CORE Group case study in sister report 'From words to action: Towards a community-centred approach to preparedness and response in health emergencies – Case Studies'.

the CGPP countries, community volunteers have been the crucial link to strengthening disease surveillance and knowledge, increasing vaccine coverage and providing basic health information to improve health outcomes. Research shows that community volunteers are viewed as credible, highly valued, trusted and well-respected. Mobilizers engage with the community in various ways, including preparation and implementation of immunization campaign days, health education sessions and emergency response activities. Mobilizers are involved in planning services, tracking and mobilizing influential persons and target beneficiaries, and monitoring the quality of services.

Community mobilizers receive intensive training and mentorship in order to effectively engage in (two-way) communication and deliver research-based behaviour change communication messaging. Community Mobilization Coordinators (CMCs) are also trained to ensure they have the skills to support the community mobilizers. Strengthening interpersonal communication skills for mobilizers to be accurate, confident and convincing in the information they are sharing is critical to this approach's success, particularly during house-to-house visits. It is vital to note, however, that building trust takes time and resources.

Mainstreaming **community** engagement: where are we?

Key findings and recommendations from recent outbreaks

- **Community engagement should be ongoing and cross-cutting in all aspects of preparedness and response.** Reflection following recent outbreaks, in particular the West Africa Ebola outbreak and the H1N1 and H5N1 outbreaks, highlighted the critical importance of community engagement in promoting local trust for and acceptance of response activities, and the need to gather and use contextual information and community feedback to inform response design. For instance, the UN High-level Panel on the Global Response to Health Crises (2016) found that the response to Ebola in West Africa only became successful “With the advent of efforts to specifically engage traditional leaders and local civil society groups as part of community sensitization” which “Helped responders to better understand the local cultural practices and societal dynamics that were instrumental in fuelling the epidemic”.⁸² Had this been set up earlier, it is likely that many deaths might have been avoided.
- **Effective and meaningful two-way communication between communities and responders is essential.** Reviews recognized that the need to communicate with affected communities in the midst of a crisis is often overlooked, at a time when they most need information. Transparent and timely communication with appropriate and accurate messages about an outbreak can mitigate the circulation of misinformation, whilst the ongoing collection, analysis and incorporation of community feedback is essential for designing, monitoring and adapting the response to best fit local circumstances over time. For example, during the H1N1 pandemic in 2009, problems with communication led to public distrust of the global response and criticism of WHO. The International Health Regulations (IHR) Review Committee (2011) found that the lack of surge capacity for translation services led to information gaps in a number of countries, and the limited use of new information technologies resulted in limited two-way information flow between affected and non-affected countries.

⁸² United Nations 2016c.

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- **Communities should be involved beyond communication.** Many of the documents reviewed focused on the importance of effective communication, but it was also acknowledged that community engagement goes far beyond communicating with affected communities. The Review Committee on the Role of the IHR in the Ebola Outbreak and Response (2016) noted that partnerships with communities and other stakeholder groups were *“Critical to implementing the IHR and improving global public health preparedness and response”*. The Committee identified the need to *“Move beyond the health sector to engage communities”* by ensuring that community workers and volunteers are well trained and receive the right tools and support to help conduct preparedness and response activities such as surveillance.⁸³
 - **All partners involved in preparedness, response and recovery must assume shared responsibility for working with and through communities.** In light of community feedback about responders’ behaviour gathered by the IFRC during the Ebola outbreak in North Kivu, the CDC recommended that all responders be trained to *“Interact with community members more compassionately/humanely. This could reduce the number of incidents which risk communication and community engagement staff have to ‘react’ to and could free them up to do more pro-active engagement with communities.”*⁸⁴ The UN Global Health Crises Task Force (2016) also advocated for principles of effective community engagement to be featured in all training programmes for national and international responders.⁸⁵ Training should incorporate the core competencies required for effective community engagement: empathy, listening skills, questioning skills and the ability to work collaboratively.
 - **Understanding the local context is imperative for appropriate preparedness and response design.** According to the UN High-level Panel on the Global Response to Health Crises (2016), *“The initial response to the Ebola outbreak [in West Africa] did not adequately take into account the local cultural context in each affected country and early efforts to sensitize communities were largely ineffective.”*⁸⁶ A more rapid understanding of the political, social, cultural, gender, economic and historical factors that impact preparedness and response effectiveness together with better mapping of key stakeholders (e.g., local leaders and influencers, women, alternative health providers and marginalized or vulnerable groups) and local structures, organizations and institutions could have greatly facilitated the response to the West Africa Ebola outbreak.

⁸³ WHO 2016.

⁸⁴ Prue 2019.

⁸⁵ United Nations 2016b.

⁸⁶ United Nations 2016c.

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- **Social science research and practice should be harnessed as an integral, cross-cutting component of preparedness and response.** Reviews acknowledged that fit-for-purpose, rapid and operationally-focussed social science research should be harnessed and built into preparedness and response design in order to understand local context and existing structures. The Global Health Crises Task Force (2016) argued that *“Social science research in community engagement is key to understanding the complexity of the issues, including the evolving nature of communities and the dynamics within and between communities at the local, national and global levels.”*⁸⁷

In the years following these reviews, there have been some notable improvements in the inclusion of community engagement in public health preparedness, response and recovery, although critical challenges remain. The following section outlines both the progress made and the remaining gaps in three overarching areas: embedding community engagement in preparedness, response and recovery; quality evidence-based and accountable programming; and political commitment, coordination and funding.

Embedding community engagement in preparedness, response and recovery

Positive developments

- **Greater efforts to strengthen community engagement as part of preparedness.** Some positive progress has been made in terms of preparedness for communication and community engagement activities in public health emergencies. A range of global research actors (including Johns Hopkins University) have partnered with at-risk countries to work on pre-positioning risk communication and community engagement and developing strategies in advance of a health crisis.
- **More effective collaboration with local actors.** A number of evaluation studies have highlighted that prepositioning partnerships with local actors and community members, instead of employing people from outside, can significantly increase rapid action during an acute outbreak.⁸⁸ Working with National Red Cross Red Crescent Society volunteers is part of the core remit of the IFRC and a focus of their long-term community engagement.⁸⁹

⁸⁷ United Nations 2016b.

⁸⁸ Niederberger, Ferron and O'Reilly 2016.

⁸⁹ Powell 2013.

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- **More effective harnessing of social networks and technology.** Social media can be both a hindrance and a help during a public health emergency, depending on how it is used. Whilst it can contribute to the spread of mis- and disinformation, social media can also play a positive central role at all stages of a crisis situation, including planning and preparedness before an event, providing situational awareness and coordinating response efforts, and facilitating recovery.⁹⁰ Response partners are increasingly harnessing social media channels including Facebook, Twitter and WhatsApp, as well as mobile phone technologies, to collect surveillance data and community feedback, track misinformation and provide targeted information to affected populations.⁹¹

Remaining challenges

- **Lack of understanding community engagement.** Whilst there has been increasing emphasis on the value of community engagement, there remains a lack of consensus around what constitutes community engagement and how best to do it with different stakeholder groups, in different contexts, at different stages of a programme cycle (including prior to, during and after a public health emergency), and over different time periods.
- **Community engagement is not integrated across the response architecture.** Information management is often weak during response. This can result in misunderstandings between partners around responsibilities and roles, and ultimately contributes to a failure of communication and community engagement efforts to effectively link communication strategies with service provision. International and national public health experts and emergency responders are not routinely trained to interface with communities and it has yet to be acknowledged that community engagement is ‘everybody’s business’.
- **Community-based stakeholders are not systematically involved in the design, implementation and evaluation of health programmes and community-led action is not sufficiently supported.** Assessments detailing community strengths, skills and resources are often lacking. While speed is of the essence when responding to public health emergencies, not taking the time to map existing and trusted platforms and actors has proven counter-productive and has contributed to challenges associated with insider/outsider dynamics. There continue to be gaps in understanding how communities can be supported to both make appropriate decisions and lead effective response actions in a context where biomedical knowledge is limited and material resources are scarce.

⁹⁰ McSeveny and Waddington 2017; Meier 2011.

⁹¹ Ayala Iacucci 2015; Fluck 2019; Sweet 2018; Sweet 2019; Bedford 2018; McCallum et al. 2016; O’Neill and Eno-Van Fleet 2019.

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- Ongoing challenges in building trust between local communities and international and national public health actors.** This is one of the key hurdles to effectively carrying out public health preparedness and response activities.⁹² A precondition for enhancing trust is the ongoing engagement of communities (i.e., prior to an event) and as the norm, rather than as a reaction to an event. This rarely happens to a sufficient degree, and much community engagement work remains ad hoc or reactive.⁹³ A number of factors can contribute to a debilitating lack of trust -- which can be exacerbated during an emergency situation -- including limited communication and coordination between humanitarian, public health and development actors; a lack of transparency of aid funding and programmes to affected communities; an overall lack of accountability to affected populations; and a failure to address broader community development needs.
 - Psychosocial insights are not systematically integrated.** There is a need to more systematically integrate psychosocial insights into response efforts. Mental health and psychosocial support (MHPSS) should be a core component of any public health response. Specific technical expertise and dedicated resources are required to better integrate MHPSS into public health assessments at both facility and community levels and into preparation, response and recovery plans in accordance with the MHPSS guidelines of the global IASC.⁹⁴ Community engagement teams should coordinate with MHPSS teams to ensure adequate support reaches people who are most in need. All frontline workers (including volunteers, health workers, community leaders, teachers and religious personnel) should be trained on supportive communication, essential psychosocial care principles and psychological first aid. This can help trust-building efforts and support community engagement initiatives.
 - Preparedness and response activities are not sufficiently integrated in health systems and routine public health work.** Outbreak response efforts are rarely integrated with more routine health measures (including longer-term health system strengthening) and this can impede effective community engagement. Lessons learnt from polio eradication efforts highlight that the best way to build trust is to invest in integrating infectious disease eradication initiatives into routine activities of the health system, including in door-to-door general vaccination efforts. This approach capitalizes on already existing and trusted structures and minimizes panic and negative behaviour change by normalizing public health measures in an outbreak.⁹⁵

⁹² United Nations 2016b; Nguyen 2019.

⁹³ IFRC 2018; National Academies of Sciences, Engineering, and Medicine 2019.

⁹⁴ Inter-Agency Standing Committee 2007.

⁹⁵ Abimbola, Malik and Mansoor 2013.

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- **Lack of sustained investment in local organizations and community health workers as part of the Universal Health Coverage (UHC) agenda.** Local health actors and teams of health workers (both staff and volunteers) make significant contributions to the health and well-being of communities, even when they have only received basic training in public health and health literacy activities. The UHC agenda calls for universal access to equitable and resilient people-centred health systems. It promotes health and care that is community-led and multi-sectoral, is linked to the determinants of health across a person's life course, and is delivered in a way that ensures accountability, continuity and sustainability. Despite being a cornerstone of community-centred approaches, community-based health workers and volunteers, in particular, have seen relatively little investment. Although their comparative advantage in reaching these last-mile communities is often observed, their full potential remains underutilized and, in some cases, undervalued.

Quality evidence-based and accountable programming

Positive developments

- **More systematic collection of community feedback.** Recent developments have shown promising approaches to systematically collecting community perception data during infectious disease outbreaks, including community experiences of response measures, questions they may have about the outbreak and response processes, and suggested solutions.⁹⁶ In order to 'close the loop', responses to community queries and suggestions are being provided to affected populations through service providers, development actors and the media.
- **Better integration of applied social science research into preparedness and response.** There is greater recognition of the contribution that social science can make, and a more clearly defined space for social science within global organizations (including GOARN, WHO, UNICEF, OFDA, CDC, IFRC, MSF and others). Multiple fit-for-purpose methods have been developed for the rapid collection and analysis of data and information in preparedness, response and recovery settings. Local and international social scientists have been integrated into rapid support teams (e.g., UNICEF, WHO and the UK-Public Health Rapid Support Team); a GOARN Social Science Research Network has been established to coordinate research; and collaborative social science platforms have been established, such as the Social Science in Humanitarian Action Platform and Sonar Global.⁹⁷ Perhaps more than ever before, partner agencies have started to integrate applied social science expertise in their operations, both at policy and field levels.

⁹⁶ Ayala Iacucci 2015; Baggio, Camara and Prue 2019; Buchanan-Smith and Islam 2018.

⁹⁷ Bardosh et al. 2019.

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- **Greater attention paid to contextual realities.** There is increased recognition of the need to understand local contextual realities (including cultural and social values) and to adapt response measures to better fit the needs and priorities of affected communities. This data is being used to design more locally appropriate and effective response measures and to adapt standard operating protocols to reflect local specificities (e.g., incorporating customary practices into safe and dignified burial protocols).⁹⁸

Remaining challenges

- **Lessons learned from previous health emergencies are not evaluated or fully acted upon.** There is a critical gap in evidence about what works, why, when and where, as related to community engagement in preparedness and response.⁹⁹ In-depth assessments and evaluations of community engagement initiatives are not routinely conducted, and even when lessons are teased out, they are rarely incorporated into future action in a meaningful way that improves practice.
- **Insufficient effort to understand localized contexts at the granular level and across diverse communities.** Many response measures continue to take a one-size-fits-all approach and are ‘copied and pasted’ from one setting to another, which can result in interventions that are inappropriate, ineffective and potentially damaging. This is partly due to limited resources and capacity, a reluctance to rely on community knowledge and structures and a perceived lack of time to collect and analyse relevant contextual information. Ignoring contextual nuances at the local level and across diverse stakeholder groups results in missed opportunities to capitalize on and strengthen local preparedness and response capacity and governance structures and can dilute social cohesion and trust and hamper preparedness and response efforts more broadly.¹⁰⁰
- **Community feedback is not systematically acknowledged, shared and operationalized.** Even where community feedback and perceptions have been systematically gathered, these are not always fully analysed or effectively shared, and it remains challenging to actually implement complex community requests in real-time due to operational constraints.¹⁰¹
- **Transparency and accountability remain low.** Despite numerous global frameworks (see Annex 3), transparency and accountability remain low both in the case of accountability to affected

⁹⁸ Storer and Pearson 2019; Bedford 2018.

⁹⁹ Lurie et al. 2013.

¹⁰⁰ Translators without Borders 2019; United Nations 2016b.

¹⁰¹ Baggio, Camara and Prue 2019.

populations and institutional accountability. Community preferences are often ignored and whilst the mechanisms for affected populations to report concerns and injustices are weak, those issues that are reported are not always adequately or responsibly addressed. The lack of common minimum standards or indicators around community engagement (see point below) makes it challenging to measure impact, but also to hold response partners accountable.

- **No minimum standards and indicators for community engagement.** Without a globally defined and agreed-upon set of minimum standards, it is challenging to measure the impact of community engagement. At the time of writing, there are several examples of good practices, metrics, implementation guidelines, standards and protocols, but there are no agreed-upon international or common standards for designing, implementing, supporting and measuring community engagement (see Annex 3). UNICEF is in the process of developing a set of minimum quality standards and indicators for community engagement for use in development and humanitarian contexts (see Annex 4). When these are agreed upon and released, it will be important for all actors to align and support them.¹⁰²
- **Social science often remains siloed into risk communication and community engagement.** Social science is often folded into risk communication and community engagement efforts, when its value actually extends across preparedness, response and recovery efforts, and more needs to be done to harness its potential. As acknowledged by the UN Global Health Crises Task Force, social science research is key to understanding context and improving communication with communities and therefore has relevance for every pillar of an emergency response.¹⁰³ Qualitative social science knowledge is still not given the same weight as quantitative data,¹⁰⁴ and engagement by social scientists in preparedness is widely acknowledged to be minimal.¹⁰⁵

Political commitment, coordination and funding

Positive developments

- **Increased visibility of community engagement.** Various guidelines, strategies and initiatives at global, regional and national levels have noted the importance of effectively engaging with communities and there are frequent calls for an increase in both the quality and the quantity of community engagement.¹⁰⁶ It is now acknowledged that when community engagement is

¹⁰² UNICEF 2019.

¹⁰³ United Nations 2016b.

¹⁰⁴ Bardosh et al. 2019.

¹⁰⁵ Alcanya-Stevens 2018.

¹⁰⁶ E.g., ICRC and IFRC 2016; Hankins 2016; United Nations 2016c.

properly integrated within the architecture of preparedness, response and recovery, it can positively influence the effectiveness of a humanitarian action. Still, the need to strengthen the role of community engagement in the Joint External Evaluations (JEE) and the National Action Plans for Health Security (NAPHS), and to enhance the participation of community members in the JEE process continues to be highlighted. The JEE has expanded the role of risk communication and community engagement assessments, and community engagement (including risk communication) is now an established pillar within the Incident Management System (IMS).

Remaining challenges

- **Lack of coordination and leadership amongst key players.** A lack of coordination and leadership has been cited as a contributing factor to the failure of the response to the West Africa Ebola outbreak of 2014-2016¹⁰⁷, and there is still much room for improvement in this regard, for it holds true that *"everybody wants to coordinate, but nobody wants to be coordinated"*.¹⁰⁸ The diverse institutions involved in both preparedness and response often have disparate mandates, protocols, processes, motivations and conceptual framings, which can be difficult to align. The nascent development of the 'communication and community engagement initiative' post the West Africa Ebola outbreak represented a move towards a cohesive neutral coordination structure and greater collaboration among key stakeholders, but it was never fully operationalized and failed to contribute to coordination in subsequent epidemics.¹⁰⁹ A clear division of labour and responsibilities at the global level must be better articulated, including more clarity on leadership for cross-sectoral community engagement and risk communication.
- **Lack of consistent and flexible funding for high quality and sustained community engagement.** There is a mismatch between the stated political and operational commitment to community engagement and its translation into resources. Funding for community engagement within preparedness and response remains extremely limited, is unpredictable and promotes ad hoc vertical and reactive interventions rather than sustained longer-term action. Enabling participatory approaches, community-led initiatives and incorporating community feedback requires flexible investment in innovative and adaptive programming, and the pre-positioning of resources across different development domains. Donors need to build flexibility into their allocation of funds during preparedness, response and recovery to enable course correction based on community feedback and changing circumstances over time.¹¹⁰

¹⁰⁷ Medecins Sans Frontières 2015.

¹⁰⁸ Ciro Ugarte, Director of the Health Emergencies Department at the Pan American Health Organisation (PAHO) in National Academies of Sciences, Engineering, and Medicine 2019.

¹⁰⁹ CDAC Network n.d.

¹¹⁰ United Nations 2016b; IFRC 2018.

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- **Insufficient investment in linking preparedness and response for infectious disease outbreaks to longer-term development agendas.** It has been well documented that community engagement initiatives are most successful when run alongside actions that improve the availability and quality of essential services and address basic needs such as water, shelter and peace.¹¹¹ In practice, this is rarely done and response interventions tend to be driven by immediate need (i.e., the infectious disease outbreak) rather than linked to longer-term development agendas. Without commitment and funding to support the development of strong community capacity prior to an event (and to maintain this at the forefront), the effectiveness of public health interventions during an emergency can be undermined. Similarly, without sustained commitment, communities are likely to experience further marginalization and disenfranchisement when the emergency is declared over and external actors pull out. This reduces their ability to foster long-term resilience and negates preparedness initiatives in favour of short-term reactive response interventions.

¹¹¹ ICRC and IFRC 2016; Jones et al. 2018.

Priority actions for achieving a community-centred approach

A coordinated and considered community-centred approach taken by all actors across preparedness, response and recovery interventions is critical to ensuring the effective reduction of the incidence and transmission of infectious disease. Interventions will only be their most effective when they are relevant, contextually appropriate and co-owned by affected populations and when two-way trust between providers and affected populations is established and respected. This is particularly true in fragile contexts in which trust in state authorities has been eroded, but also in the increasingly complex operational environments of the twenty-first century, characterized by increased migration, urbanization and population density, widening societal divisions and inequities, and climate change-related challenges. Whilst advances have been made in recent years, we remain sorely underprepared to tackle a global pandemic, and it is clear that significantly greater investment needs to be dedicated to longer-term community engagement.

Communities and local actors should be equal partners and active participants across all phases of prevention, preparedness, response and recovery. In many cases they are the first responders. Acknowledging this means supporting them with the necessary resources and complementing their existing skills and competencies. Yet supporting capacities at the local level is only part of the story. Trust works both ways. Whilst communities are frequently told to trust the response, the response must learn to trust the communities it serves. Across the world, communities have great agency and ability to act, and we must support them to do so – this is what it means to have communities at the centre of preparedness and response.

Based on the review of literature and through consultation with experts from various development and humanitarian organizations, the following actions for achieving a community-centred approach to preparedness, response and recovery in health emergencies have been prioritized:

Priority actions

1. Understand that communities are the centre of preparedness and response. There is growing recognition that communities must be central partners in the design, implementation and evaluation of health programmes, but this now needs to be enshrined at international, national and local levels through global public health governance and coordination frameworks, and in prevention, preparedness, response and recovery strategies. Ensuring that the position of communities is clearly articulated in policy will help maintain momentum generated about the significance, value and

effectiveness of community participation. Leadership and governance structures must be reformed so they are more explicitly accessible and responsive to the influence of at-risk and affected peoples. Strong advocacy across the sector, within agencies and with donors, will be required to ensure the adequate provision of resources so that affirmative action can be taken.

2. Enable consistent engagement of local actors and communities before, during and after an epidemic. Although surge activities at the onset of a response will mobilize community actors, the most effective action builds on already-established structures and systems (e.g., community committees, community-led surveillance). Consistent engagement before, during and after an event is critical and is the cornerstone for enduring trust. Local institutions (both public and private) and a wide range of actors (including the most vulnerable in society) must be collectively supported to act, and not be side-lined or replaced. Through participatory planning, collaborative learning and capacity strengthening processes, communities can identify the resources they need to complement their existing sets of skills and competencies. In this way, the capacity of communities, frontline workers, volunteers and local organizations to prevent, prepare, respond and recover is strengthened through the course of any event, and they create and maintain greater levels of resilience to epidemics and other potential shocks. This is true systems strengthening, in which emergency response is rooted in a longer-term sustainable development agenda.

3. Make funding for community engagement more predictable and sustained. Baseline resources dedicated to community engagement must be maintained at all times. The provision of funds during an emergency event should prioritize community engagement to facilitate the rapid scale-up of activities (as to be effective, the whole response depends on collaborative community participation). Donors need to allow flexibility in the allocation of funds during health emergencies to enable course correction based on community feedback, and mechanisms to financially support community structures over time should be better developed.

4. Act on local knowledge and community feedback. Greater attention must be given to the context of preparedness and response so that actions are agile and fully localized. To achieve this, social science needs to be an integral, cross-cutting component of preparedness and response, and community knowledge (e.g., regarding the use of local languages, alignment with public authority structures, preferred communication channels, etc.) must be kept at the forefront. Improved mechanisms to pre-position and rapidly collate existing knowledge, as well as to rapidly generate up-to-date information relevant to operational priorities, must be further developed. As well as yielding critical information to help shape interventions, the process of learning from communities itself helps to further develop trust and integrity. It is essential, however, that knowledge be demonstrably translated into action and used to course correct. Although shifts may happen more organically over a longer time period (e.g., a multiple-year cycle of development programming), the urgency of emergency response requires the rapid operationalization of community knowledge and feedback.

Currently, the very architecture of response is a significant barrier to nimble working. Modifications to response architecture must be agreed at all levels so that it becomes feasible and accepted practice to systematically use socio-behavioural data to shape strategies and interventions according to emerging evidence over time. Presenting such data in the right format to influence those in leadership positions is important. However, there is also an urgent need to support local actors, frontline workers and the health workforce to develop the minimum technical competencies needed to assess a situation, analyse data and take action informed by available evidence. Community engagement must be mainstreamed so that it is cross-cutting and is understood to be the responsibility of all response actors who should receive training in interpersonal engagement techniques.

5. Strengthen mechanisms for accountability to affected communities. Preparedness and response efforts must routinely incorporate robust mechanisms for accountability to affected communities. A concerted effort is required to establish fit-for-purpose structures that build on key humanitarian and human rights principles for recognizing, reporting and addressing concerns and injustices. Although structures could be further modified to local contexts during an emergency response, there needs to be sector-wide commitment to implementing agreed mechanisms in a fair and transparent manner. Agreed measurement frameworks should include indicators based on communities' participation and satisfaction levels and should require partners to evaluate the extent to which they systematically collected, reported and acted on feedback from affected people at key points in the programme cycle. Donors should use their collective leverage to mandate that all programmes and interventions they fund must apply participatory approaches and feedback in their design, real-time implementation and monitoring.

6. Measure community engagement approaches and define standard indicators. Any advancement to monitoring, evaluation and learning would be a welcome development given the current weaknesses. Information management and the sharing of quantitative and qualitative data across the pillars of response must be improved, partly through the recruitment of skilled managers with the remit of coordinating data analysis and information flow. Dedicated resources must be specifically allocated for critical and creative thinking to be applied to the rigorous assessment of community participation and engagement. Reviewing what does / does not work, why, when, with whom and in what contexts should become a routine component of all preparedness and response action. Beyond that, 360° measurement approaches for community engagement indicators must be defined and tested. This stronger evidence base should be used as the basis to design more effective working and to target the efficient use of resources for greatest impact. Donors have an important role to play in ensuring the uptake of standard indicators by all actors.

7. Leadership, coordination and technical expertise. Senior leadership needs to be strengthened and supported to articulate a clear vision of community engagement as both a core and cross-cutting

component of preparedness and response. In parallel, a range of professional disciplines should be brought on board to contribute technical expertise in relation to community participation and engagement (such as anthropologists, psychologists, behavioural experts, communication specialists, negotiators and others). To maximize inputs and partnerships, and avoid duplication of effort and missed opportunities, stronger coordination is required at global, regional, national and local levels, and must be undertaken with neutrality and the global public good in mind, rather than being aligned to any one response agency. Investment must be made to build a cadre of coordination experts that can work across all levels. It remains imperative that communities and local actors are better represented within such governance structures.

Annex 1 – Recommendations from high level panels

Recommendations and observations from the UN Global Health Crises Task Force, the UN High-level Panel on the Global Response to Health Crises, the Review Committee on the Role of the International Health Regulations (2005) in the Ebola Outbreak and Response, and the Independent Oversight and Advisory Committee (IOAC):

Recommending body	Recommendations
UN Global Health Crises Task Force (2016)¹¹²	<ul style="list-style-type: none">• Community engagement deserves greater emphasis before and during outbreaks to ensure that preparedness and response activities are culturally sensitive and better understood, meet the needs of the people concerned and involve and engage the communities.• Assessment of community engagement needs to be strengthened in the Joint External Evaluations (JEE), and costed action plans developed that include community engagement and that are sufficiently financed through domestic and external funding.• Social science research in community engagement is key to understanding the complexity of the issues, including the evolving nature of communities and the dynamics within and between communities at the local, national and global levels. Social science research capacities and culturally-appropriate communication strategies, and the integration of community engagement practices in training programmes for responders, need to be monitored.• The Steering Group of the Communication and Community Engagement Initiative needs to find ways for the Initiative to contribute to preparedness for health emergencies, including by supporting JEE missions and contributing to the training of Emergency Medical Teams and Public Health Rapid Response Teams.• It would be important to strengthen the area of risk communication and community engagement in the JEE tool, and for the JEE process to allow for the enhanced participation of community members.• It is important to involve communities in all health activities related to crises. Community engagement should be undertaken proactively and on a long-term basis. For communities to have trust in health systems, they must see the systems as capable of delivering reliable and quality care.• Lack of predictable and sustainable financing in a number of areas restricts the implementation of International Health Regulations core capacity requirements, initiatives to promote community engagement, health system strengthening, and

¹¹² UN 2016b.

	<p>research and development.</p> <ul style="list-style-type: none"> • Community empowerment is a holistic issue and synergy must be found between health emergencies and other development issues at the community level. Protecting individuals from health threats through community involvement is at the very core of resilience and human security. • It is essential to have meaningful engagement with communities in the design and implementation, as well as the evaluation, of health programmes. Communities can be involved in surveillance, early action tools, prevention, and promotion of health seeking behaviour as well as contact tracing, identification of bottlenecks in response efforts and design and development of risk communication messages and approaches. Initiatives to promote community engagement will need investment. • All communications about disease threats and outbreaks need to be people-centred with an emphasis and focus on resilience in the face of threats, through pro-active efforts in outbreak preparedness and strengthening of communication and community engagement response mechanisms. • Research into effective community engagement and risk communications is often lacking and missing in research agendas. New research is now being done to better understand the impact of community engagement and risk communications during the Ebola outbreak. The findings of this research will help improve work around engagement and behaviour change in future epidemics.
UN High-level Panel on the Global Response to Health Crises (2016) ¹¹³	<p>At the moment, inadequate understanding of the cultural context and poorly designed messaging undermined the response at the community level. To counter this:</p> <ul style="list-style-type: none"> • Governments should establish properly funded and trained community health workers and related systems that are appropriate to the country circumstances. • Governments and responders should strengthen and streamline their community engagement and promote local ownership and trust, with the support of national and international social science research capacities. Communication strategies should be developed, with due consideration given to the cultural context. • Principles of effective community engagement should be featured in all training programmes for national and international responders. National authorities and partners should draw on the potential for South-South cooperation in this field. • Outbreak preparedness and response efforts should take into account and address the gender dimension and should include women in all levels of the planning and implementation process. Since women tend to act as primary caregivers, specific attention should be given to their needs, including to the economic and livelihood impacts of pandemics.
Review Committee on the Role of the International Health Regulations (2005) in the Ebola Outbreak and Response (2016) ¹¹⁴	<ul style="list-style-type: none"> • Establish robust listening channels (perception surveys, public opinion polls, community feedback) to have a better handle on perception and information gaps, so that they can be addressed in a timely manner to suit local conditions

¹¹³ UN 2016c.

<p>The Independent Oversight and Advisory Committee for the WHO Health Emergencies Programme report to the 2019 World Health Assembly (2019)</p>	<ul style="list-style-type: none"> • The IOAC acknowledges the difficulty of building trust during this crisis and the need to counterbalance Ebola response efforts with broader development, including education, water safety, and health care services for other diseases. The IOAC encourages WHO to work with partners to improve social cohesion and community engagement.
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¹¹⁴ WHO 2016.

Annex 2 – Sources reviewed

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