

Recent large-scale epidemics and pandemics have demonstrated the importance of engaging communities as partners in preventing, detecting and responding to public health emergencies. Community-based surveillance (CBS), which relies on communities to report public health information, can be an important part of effective, inclusive and accountable responses to humanitarian and public health emergencies, as well as long-term disease control.

This brief offers key considerations for CBS programming to guide policymakers, public health officials, civil society organisations, health workers, researchers, advocates, and others interested in health surveillance. It is based on a rapid review of CBS guidance and social science literature. It was written by Jennifer Palmer and Diane Duclos (both London School of Hygiene & Tropical Medicine, LSHTM) with contributions by Mariam Sharif (École des Hautes Études en Sciences Sociales, EHESS). It was reviewed by Ruwan Ratnayake (LSHTM), Maysoon Dahab (LSHTM) and Luisa Enria (LSHTM). This brief is the responsibility of the Social Science in Humanitarian Action Platform (SSHAP).

## KEY CONSIDERATIONS

Social science lessons on community engagement can, and should, inform the design of CBS programmes. The key considerations below highlight current best practices and understanding. These considerations are also covered in more depth elsewhere in the brief.

- **Pay attention to how ‘community’ is defined.** Simplistic views of communities may obscure power relations and local politics, which can reduce the effectiveness of interventions, including CBS, and further marginalise the most vulnerable.
- **Pay attention to how communities are represented.** Do not rely solely on official channels for engagement. Community health workers should not automatically be assumed to be ‘representative’ of the communities they serve.
- **Be aware of the mistrust and potential negative effects of ‘surveillance’.** Surveillance has particular, often negative, connotations in certain contexts. Social and political dynamics and past experiences can mean that people are suspicious of any form of surveillance. In times of uncertainty, such as during public health, humanitarian, and migration crises, existing mistrust can be magnified.
- **Be participatory from the start.** Identifying public health risks in social context is complex and depends on local expertise. Communities should be engaged from the initial design stage to ensure their full participation. Global CBS guidance should be adapted to local needs, interests, and contexts.
- **Discuss, develop, and apply shared definitions.** Use discussions, training, and supportive supervision to create shared understandings of how priority conditions for health officials may overlap with or differ from local ways of recognising disease and clarify expectations about what conditions should be reported.
- **Build flexibility into surveillance definitions to acknowledge community expertise and priorities.** Community case definitions for ‘unusual events’ are often intentionally flexible to encourage reporting of concerns, with unknown causes, that community members may be uniquely suited to recognise.
- **Facilitate volunteer recruitment that results in a diverse team.** Volunteers should be recruited based on diversity and ideally include all population groups to be engaged through CBS.

- **Provide feedback and explanations to volunteers and community members.** When reported concerns are not acted upon, this erodes trust, especially in the absence of any explanation or other information.
- **Put in place plans to address potential negative effects on volunteers.** For example, the time burden may take volunteers away from other tasks and commitments, or it may be dangerous to travel in areas of conflict or high crime.

## WHAT IS CBS?

CBS is defined as engaging community members to systematically collect and report health information in their communities for public health surveillance purposes.<sup>1</sup> It can be labour-intensive for communities to produce data as well as for health authorities to analyse it. Therefore, there is an expanding area of research into how CBS programmes should be designed and implemented.<sup>1-3</sup>

Despite the wide variety of purposes for which CBS can be used, there is increasing consensus on what effective CBS looks like. The following definition was adopted by the WHO CBS working group in 2018: '[CBS] should be integrated in a formal surveillance structure, be actionable and timely, and have perceived benefits to the community, well-defined reporting mechanisms, a feedback mechanism and a monitoring and evaluation process'.<sup>1</sup>

At the community level, the main actors within CBS programmes are CBS supervisors and CBS volunteers. Supervisors tend to have medical, epidemiological, or public health training and often occupy paid positions in public health departments or in health facilities. Volunteers tend to be selected for their ability to communicate with diverse sections of a population rather than for prior public health experience, but they may have some minimal health training or be community health workers. Volunteers usually live in the community in which they work. They may be paid or may only receive incentives.

CBS programme implementers, such as Ministries of Health, train CBS supervisors and volunteers to recognise and use community case definitions during their surveillance activities. These definitions include those for particular diseases and syndromes and for 'unusual events' (see Box 1) with public health implications.

### Box 1. Common definitions for 'unusual events'

The definition of an 'unusual event' is intentionally flexible to encourage reporting of concerns from unknown causes. It can be one event, or a cluster of events, that is unusual for a specific community or during a certain time of year. Examples of commonly adopted definitions in CBS programmes<sup>25</sup> include:

- Two or more people in the same setting (for example, household, workplace, school, or street) presenting similar severe illnesses within one week.
- Any human illness or death after exposure to animals or animal products (for example, after eating or handling).
- Any event in the community that causes public anxiety.

In the Ministry of Health's CBS programme in Sudan, CBS volunteers used the 'unusual event' category to raise concerns about specific local priorities, such as food insecurity and flooding, and the broader needs of people recently displaced from armed conflict. (For more information, see [Strengthening Health Information Surveillance: Implementing Community-Based Surveillance in Sudan](#))

## Community-level responsibilities and engagement

CBS programmes rely on the creation of collaborations and communication pathways with diverse groups and actors. It is this collaboration and communication that builds and sustains strong community health surveillance structures. CBS volunteers and supervisors need to cultivate relationships with existing community leadership structures and groups, networks of civil society and community-based organisations, and local non-health actors in and outside government.<sup>4,5</sup>

CBS volunteers, with support from CBS supervisors, play an important role in community-based activities to improve public health knowledge, share information about surveillance initiatives, and encourage reporting of events of public health significance. CBS supervisors triage and verify the information collected by the volunteers to determine whether there is a public health 'event' that requires reporting to district, state, and national level actors.

CBS volunteers and supervisors often serve as the connection between the community and implementers. Because of its key role, the community team is often a focus of the implementer's training, supportive supervision, and evaluation and research.

## **When and how CBS can be used**

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CBS has become a fundamental component of public health information systems in humanitarian settings, such as during situations of armed conflict or after a disaster. In these settings, state health systems may be chronically weak. CBS programme designs in humanitarian settings are highly variable and individual designs are often modified in response to the changing information priorities of public health actors.<sup>2</sup> For example, a CBS programme may change from estimating levels of and contributors to all-cause mortality in acute emergencies, to focusing on surveillance of an increasing number of epidemic diseases as crisis conditions stabilise and information management structures are strengthened.

In and outside humanitarian settings, CBS can be integrated into early warning, alert, and response approaches, including event-based surveillance.<sup>6</sup> Event-based surveillance involves the rapid collection and immediate reporting of mainly ad hoc information on public health risks, including rumours, collected from diverse sources. These sources include government and non-government actors and the media, and CBS can be another important source of information.

CBS can be used as part of building a long-term national emergency response. The CBS approach is increasingly seen as an essential way for health systems to engage with and respond to the needs and priorities of affected and at-risk communities during the development of emergency response capabilities.

CBS has often been used to support single or 'vertical' disease programmes, where it can help to address the limitations of the routine health system to identify cases. This support is seen in epidemic emergencies (such as Ebola Virus Disease, cholera, and COVID-19) when community contact tracers play an important role in containing the disease. CBS also has a role in longer-term rare disease elimination and eradication programmes, such as those for smallpox and Guinea worm disease. Additionally, CBS has been used to identify people affected by highly stigmatising diseases, such as HIV, who may not report to routine health facilities.

Alternatively, CBS can be developed by independent civil society actors to challenge data reported by official national sources, such as in the collection of information on deaths and injuries from political violence.<sup>7</sup>

## **Benefits of CBS for data collection**

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CBS takes advantage of the diverse forms of expertise in communities to identify risks, by engaging more observers and a mix of observers who can apply local frames of reference to 'sense' the unusual and identify deaths and illnesses from potentially priority public health concerns. In CBS-informed responses to public health emergencies, the expertise and knowledge held by non-health professionals can be used to help identify and address intersecting vulnerabilities shaped by local social and political contexts and inequalities.<sup>8</sup>

CBS extends surveillance beyond health facilities and through this it can reach more people. For example, CBS can collect data which may be missed by health facilities because of poor health facility attendance. Attendance is often limited in settings where services have been disrupted because of a crisis or are difficult to access due to financial or physical barriers. Attendance can also be affected by 'competition' from alternative forms of health care.<sup>3,9</sup> Additionally, in under-resourced

settings, diagnosis of uncommon conditions can take several visits to health facilities, but poor households often cannot afford this extended period of treatment-seeking.<sup>10</sup>

Even when facilities are regularly used by communities, social science literature points to another explanation as to why workers at health facilities can miss the diagnosis of priority conditions. Relatively rare diseases, such as emerging infectious and zoonotic diseases, tend to suffer from under-recognition when health care workers perceive them as uncommon. The internalised ‘diagnostic algorithms’ that health care workers often use can mean, for example, non-malaria diagnoses are often missed.<sup>11</sup> By involving a wide range of people, including those with a non-health background, CBS programmes can go beyond the diagnostic algorithms used by health care workers.

## SOCIAL SCIENCE LESSONS

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### Lessons for community engagement

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Using social science lessons on community engagement to inform CBS programmes can help those programmes be better anchored in existing local social and political structures, and better account for new social dynamics shaped by emergencies. A well-designed CBS programme can positively change existing social dynamics by empowering people who have local knowledge and making them part of the public health response. Using approaches that are participatory, equity-based and gender-sensitive helps acknowledge and build the agency of people engaged by a CBS programme and allows the target population to ensure that its needs are accounted for.

**Pay attention to how ‘community’ is defined.** CBS programmes define a ‘community’ as the population physically accessible to a CBS workforce and that is socially cohesive.<sup>1</sup> However, in practice, many CBS programmes make use of the existing catchment areas of community health workers and these areas may in fact have very heterogeneous populations. The disconnect between ‘imagined’ communities and how communities are locally experienced needs to be critically examined when designing CBS programmes.<sup>12</sup>

**Pay attention to how communities are represented.** Who does surveillance matters. Existing community health workers should not automatically be assumed to be ‘representative’ of the communities they serve, and different leaders may be considered legitimate by different communities or by different groups within a community.<sup>13</sup> Alternative care-seeking preferences may be driven, at least in part, by mistrust of public health facilities, so involving other care providers (e.g., traditional healers) in programme activities, such as community meetings and case follow-up, can be very beneficial, if done with care.<sup>14</sup> It is important that CBS programmes employ multiple or parallel engagement strategies and do not rely solely on official channels.

**Be aware of the mistrust and potential negative effects of ‘surveillance’.** Surveillance can have negative connotations in certain contexts and some people may be suspicious of any form of surveillance. In times of uncertainty, such as during public health crises, any existing mistrust can be magnified. For example, in the COVID-19 pandemic, surveillance was sometimes perceived to be threatening, especially in contexts where the public health response was militarised.<sup>4</sup> See Box 2 below. Some groups – such as forcibly displaced people, minorities, and other politically disenfranchised populations – may have had previous negative experiences with surveillance, and this could create mistrust to be associated with the actions of a CBS programme.

#### Box 2. Negative connotations of ‘surveillance’ – an example from Uganda

In Uganda, in 2020 and 2021, there was military involvement in COVID-19 health surveillance and the enforcement of lockdowns. In many areas this surveillance was not locally associated with public health but with corruption (e.g., checkpoints could be passed for a ‘fee’), increased physical and economic insecurity, and more pervasive and unaccountable authoritarian rule.<sup>15</sup>

**Be participatory from the start.** Participatory approaches should be employed in all phases of CBS programming, including preparedness, emergency response, closure or integration into existing structures, and evaluation.<sup>3</sup> Communities should be engaged from the initial programme design stage, and global CBS guidance should be adapted to local needs and contexts, including selecting which diseases and events are of interest to communities.<sup>1</sup> Best participatory practices include: enabling and emphasising community ownership, committing to meaningful and regular information exchange, involving a diverse group of community informants, ensuring that systems are designed to build trust and goodwill for health surveillance and response, and enabling community members to make decisions and play multiple roles within the CBS programme.

**Facilitate volunteer recruitment that results in a diverse team.** Most CBS guidance emphasises that CBS volunteers should be recruited on the basis of diversity and ideally from the population groups that will be engaged through CBS. This approach is important to help understand social relations and build trust. These are both needed to effectively identify vulnerabilities, respond to public health needs<sup>16</sup> and for public health interventions to impart new and positive norms and practices.

Equitable CBS volunteer recruitment has been recognised as a driver in the success of CBS programmes working with forcibly displaced people, for example in Cameroon, and with pastoralist groups in Ethiopia.<sup>3</sup> CBS volunteers in many settings have described the benefits of being involved in a CBS programme including increasing their social network, having opportunities for training, and being recognised for contributing to disease control.<sup>3,17</sup> Involving people from diverse groups can help spread the material and symbolic benefits of volunteer employment. Equity-based and gender-sensitive approaches to volunteer recruitment can also help CBS programme designers consider the anticipated and unanticipated social consequences of CBS programmes.<sup>18</sup>

**Put in place plans to address potential negative effects on volunteers.** CBS volunteers often have many competing time commitments beyond their volunteering, especially during humanitarian crises. Therefore, programme implementers must ensure the time spent volunteering does not negatively affect other activities, such as income generation and caregiving. Strategies to reduce volunteer workloads related to case-finding include switching to passive detection when possible<sup>2</sup> and offering free laboratory testing to people presenting at facilities to reduce time spent on diagnosis.<sup>10</sup> Another potential harm for volunteers is insecurity, and programme implementers must have criteria and plans for when it is too dangerous for volunteers to work in areas of conflict or high crime.<sup>3</sup> For example, in some areas of Somalia, surveillance programming moved focus from community volunteers to health facility-based services.<sup>19</sup>

**Avoid creating surveillance-related stigma.** Heightened health surveillance can have unintended consequences, including reinforcing or creating stigma, especially for already marginalised, racialised, and/or overly surveyed groups.<sup>20</sup> The use of quarantine and treatment centres, for example, can create social distress for those who share an identity with the groups perceived to be the focus of other types of security or police surveillance, such as migrants or commercial sex workers. Enforced quarantine can produce fear, and CBS volunteers and other health-related workers may bear the brunt of community displeasure around isolation practices and face personal criticism.

## **Lessons for signal recognition and information management**

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CBS acknowledges the value of involving communities in public health surveillance initiatives and takes advantage of diverse forms of expertise in identifying risks. In many places, communities are the first responders to public health emergencies, especially outside better-resourced urban areas.

**Involve a broader range of sources in sensing and signal reporting.** As highlighted above, CBS can collect data at the community level which may otherwise be missed.

The recognition of symptoms of a disease or adverse event as ‘unusual’ and worth reporting can be complex, as the interpretation of risk depends on the material, social and cultural context.<sup>21</sup> For example, whether ‘fatigue’ is seen as being related to ill health or to a socially or morally salient reason like ‘working too much’ or ‘being lazy’ is connected to many assumptions and may take time to understand.<sup>22</sup> Intersecting vulnerabilities, such as whether a person is a woman or poor, can also affect judgements around what is worth reporting.<sup>12</sup> Non-health professionals, including family



members and neighbours, can be critical in deciding when someone should seek health care and in raising the alert when something feels very unusual.

Additional sensing capacity can be built into vertical programmes through CBS by asking more people, such as representatives of community networks, to get involved in evaluating the social and health-related information around them.<sup>6</sup> See Box 3.

### Box 3. Community members as the ‘eyes and ears’ of a CBS programme

School teachers are recognised as being able to help detect outbreaks of vaccine-preventable diseases by informing a CBS programme of children not attending school.<sup>3</sup>

Factory managers and landlords can also raise alerts in situations when many employees are absent, or people are at home sick. However, this reporting can be viewed by some as a negative form of surveillance driven by economic or political considerations.

Health care workers may make valuable observations outside of working hours as members of their own communities.<sup>22</sup>

Other people with interesting insights through their community role include traditional healers, village health committee leaders, pharmacists, farmers, veterinary health staff, traders, money lenders, and insurance agents.

**Discuss, develop, and apply shared definitions.** For health authorities, who potentially receive hundreds of false event reports, CBS can appear extremely ‘noisy’ compared to other forms of surveillance. Therefore, it is crucial to reach agreement and have effective training on what constitutes a signal or event and how these should be triaged and verified at every reporting step. CBS guidance typically recommends that community training is preceded by discussion among programme implementers and community stakeholders about how community case definitions may need to be developed and adapted. This discussion is important to create a shared understanding of how priority conditions for health officials may overlap with or differ from local ways of recognising disease,<sup>22</sup> as well as to clarify expectations about what conditions should be reported. Building flexibility into some CBS definitions, such as for ‘unusual events’, is a good way to acknowledge both community expertise and priorities. CBS volunteers are likely to require close, supportive supervision at the beginning of a programme to talk through how the instructions shared in the training are applied in practice and to troubleshoot problems with the definitions raised by communities. This process of discussion, training, and supportive supervision can help with not only quality control for the identification of genuine threats but also with the perception of CBS as a useful and worthwhile activity.<sup>16</sup>

**Establish and maintain feedback channels.** CBS implementers should clearly discuss surveillance and public health response procedures with community groups from the outset to help manage expectations. Following reporting, volunteers should have clear guidance on how to connect people to local services to address immediate health or other concerns. Volunteers also need to know how to discuss the ways in which data is acted upon, and programmes should set up procedures for two-way communication, including regular community feedback meetings. When communities are engaged in identifying and/or reporting cases, they expect a response. Insufficient feedback reduces a community’s trust in CBS and other response programmes and can make data collection feel extractive. This reduced trust can result in refusals to report illnesses, increased rumours and mis- and dis-information, and threats to volunteers, all of which negatively affect surveillance.<sup>23,24</sup>

## Lessons for CBS volunteer recruitment and management

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As described above, CBS volunteers are integral to any CBS programme. The lessons below highlight some of the ways volunteers can best be recruited and managed.

### VOLUNTEER RECRUITMENT FOR DIVERSITY

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CBS recognises volunteer diversity as an important contributor to different elements of surveillance effectiveness, including identifying health threats, reaching vulnerable populations, avoiding stigma, and having employment equity.

**Do not only recruit volunteers with experience.** Exclusively making use of existing structures and programmes, such as village health teams, may limit the diversity within the CBS volunteers. Recruiting people with no formal health programme experience may mean spending more resources on training and supervision but this extra time is balanced by the benefits of the broader engagement.

**Build flexibility into volunteer requirements.** Programme implementers should carefully consider volunteer requirements to decide what is strictly necessary and what may only hinder recruitment of a more diverse group of volunteers. For example, insisting on higher-level education requirements may exclude those with limited access to this level of education, such as women and those from disadvantaged groups. Similarly, requiring a certain number of years of experience may exclude young people and those whose time has been used for caregiving and income generating activities. Flexibility in requirements for volunteers helps ensure population groups that are the focus of surveillance are represented. This is an important part of building trust.<sup>16</sup>

**Be ready to adapt to local realities.** While there is global CBS guidance, including for volunteer recruitment, what works in one location may not work in another. Implementers must be prepared to adapt their plans in line with what is learnt from the community. For example, a CBS programme based in an area where women culturally tend to not ride motorbikes but where the initial programme design requires volunteers to cover a large area will need to invest in finding a locally acceptable solution to both recruitment and programme logistics.

## **VOLUNTEER MANAGEMENT FOR SUCCESS**

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Good recruitment is only the start of the process. The recommendations below are examples of how volunteer morale, data quality, and community trust can be maintained throughout a CBS programme.

**Discuss health-related language and concepts to create common usage.** Despite differences in their exposure to biomedical education, CBS volunteers and CBS staff often have overlapping frames of reference regarding disease and disease risk.<sup>22</sup> To ensure everyone involved in the CBS programme is using the same definitions, implementers should use training and other opportunities to discuss specific health-related language and concepts, especially those that may have different meanings within the community or for different groups.<sup>6,25</sup>

**Map who is collecting information, how, and from where.** Periodically mapping out who is involved in information collection, how they gather information, and in which kinds of social spaces, will help identify any gaps or weaknesses. For example, this mapping process can identify who is being excluded through current CBS practices. Groups who are vulnerable to being missed in surveillance include mobile populations, pastoralist communities, and seasonal workers.

**Encourage volunteers to expand their collaborative connections.** As well as building trust and acceptance, good relationships can also lay the groundwork for expansion of the CBS programme when needed. For example, the International Red Cross and Red Crescent Movement builds collaborative reporting pathways across human and animal health structures during crisis preparedness phases, so it is ready to launch active case detection during emergencies.<sup>26</sup>

**Promote and enforce confidentiality.** It is critical that CBS volunteers know the important role of data protection and confidentiality during surveillance, as lapses in confidentiality are likely to damage the reputation of the programme and even the wider public health response. Therefore, implementers need to build understanding of confidentiality issues during volunteer training and supervision.

**Help volunteers manage stress and criticism.** CBS volunteers, as well as CBS supervisors and health workers, may become the focus of community members' frustrations around a public health response. To help reduce the impact of this criticism, CBS volunteers should receive mental health and psychosocial support. There is guidance available on how to address stress and criticism through volunteer training.<sup>25</sup>

## Further Reading

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