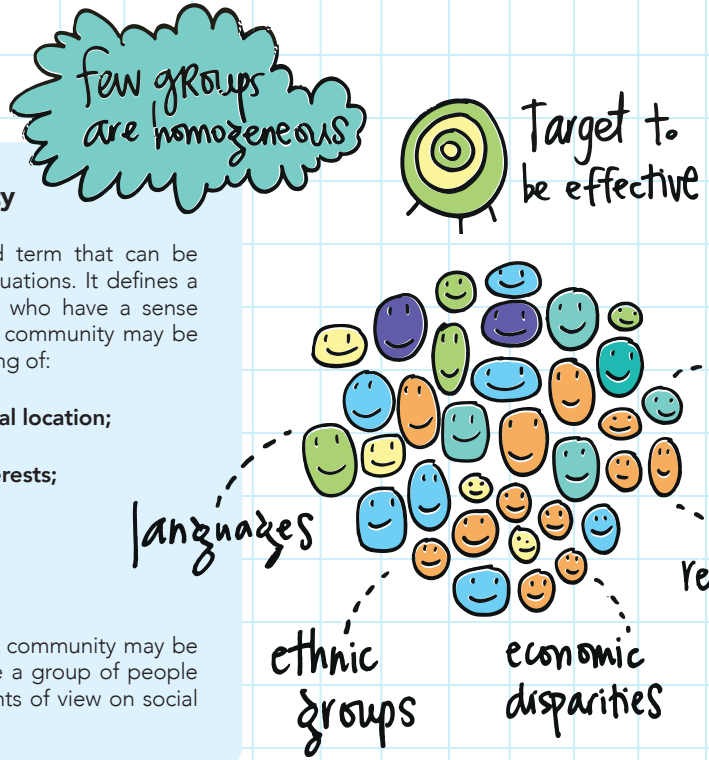
FOCUS 1

Community engagement during epidemics



Defining a community

"Community" is a broad term that can be applied to a variety of situations. It defines a distinct group of people who have a sense of belonging together. A community may be defined through the sharing of:

- **A common geographical location;**
- **Common values or interests;**
- **Common identity;**
- **Etc.**

With new technologies, a community may be totally virtual, for instance a group of people sharing interests and points of view on social media.

Why engage communities

People live in unique social-cultural contexts, with relationship dynamics, and their own perception of risks, and trusted sources of advice. These all influence if they accept health advice or not. Experience has shown that merely telling people what to do, however scientific, does not always work. Engaging them is more effective.

Even more fundamentally, people have a right to information that could protect their health and save lives, social fabric and economic well-being.

Communities, when engaged are the frontline in detecting and managing epidemics. They are most affected and have the greatest influence in anticipation and preparedness as new diseases emerge or old ones re-emerge. They can detect outbreaks, and help in containment to prevent epidemic amplification. They are able to implement mitigation measures (through change of individual and family practices change; implementing community measures and enabling changes at the systems level) to bring epidemics under control.

Three elements of community engagement

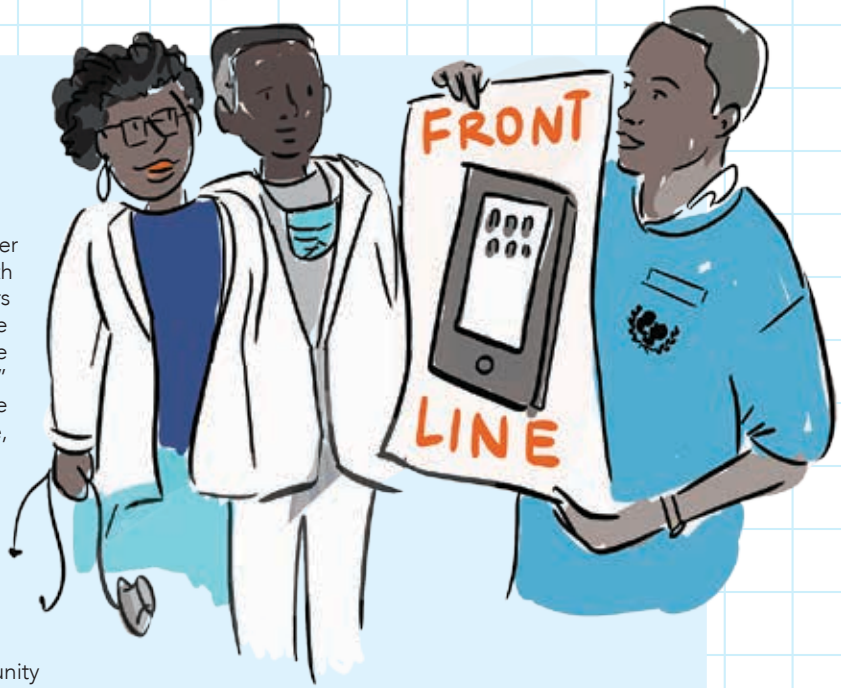
Disease outbreaks and epidemics are complex phenomena with three aspects that are intimately intertwined: medical, social and political. Community engagement is an approach to address the social (and to some degree the political) aspects of epidemics. Community engagement is essential for the effective control of infectious diseases, through acceptance of public health interventions. It is based on three elements:

1. Establishing a dialogue between responders and communities to understand the perceptions and beliefs on both sides, to identify the specific cultural and social patterns of transmission that exist at community level.

2. Building trust through this mutual understanding to find joint solutions to reduce transmission.

3. Empowering communities, providing them with necessary medical and other supplies to implement the measures required to stop the disease, and progressively transferring knowledge for sustained and safe interventions within the community.

A key community to empower during outbreaks are health care workers, and volunteers who are often the frontline responders. These frontline workers are "the face" or representatives of the whole outbreak response, to the community. Their attitude towards community members and their collaboration in implementing health advice can have significant influence on how the advice is perceived and accepted, or rejected by community members.



Key points of health action in epidemics that require intensive engagement of communities (affected populations as well as health care workers and frontline responders themselves) include:

1. Detecting an outbreak and detection of newly infected people (case detection, contact tracing);

2. Minimizing harmful practices (at individual and community levels) that can increase susceptibility and exposure; and adopting protective practices (medical and non-medical);

3. Seeking and providing health care as advised (in the household, community and health facility);

4. Re-integrating of survivors back into the community and to minimizing stigma;

5. Identifying and managing misinformation and rumours.

Ten things to know

1. Disease outbreaks affect the social fabric of communities. A community is a social network, and infectious diseases outbreaks are deeply linked to the social life, the structure of society and people's interactions. They spread through personal and social contacts and links at home or during professional and recreational activities.
2. Communities are the main actors in preventing, identifying, responding and recovering from the physical, psychological, social and economic impacts of epidemics. Communities are not passive subjects of interventions.
3. Epidemics are by nature rapidly evolving. The time pressure is particularly challenging for community engagement. The beginning of the outbreak is a crucial time to build the necessary trust with the population who can break the transmission cycle. Any outbreak response that builds on existing and trusted community engagement systems and work with trusted individuals and interlocutors are more likely to succeed.
4. Community understanding of diseases and their spread is complex, context-dependent and culturally mediated. Thus, a one-size-fits-all approach is neither desirable nor effective.
5. Communities are multi-layered, and power dynamics exist between individuals, groups and networks. Social scientists can help analyse these dynamics and work with specialists in health education, health promotion and local communities. There are simple tools that can assess relevant perceptions and beliefs for any outbreaks response. Together they can design the messages and interventions necessary to raise awareness, and adapt or change behaviours to meet the demands of a new infection. Embedding social scientists in response teams will also help to monitor how people adapt public health measures to different social contexts, and whether these are implemented in a way that respects social and cultural systems.
6. Community engagement helps to strengthen and ensure resilience to future outbreaks: when people have already learned how to implement their own solutions, they will be better able to deal with the next outbreak.
7. The approach and messaging directed towards each community has to evolve with the epidemic and incorporate new messages and communication methods as it unfolds. These messages must also proactively detect misinformation and rumours. Effective community engagement limits the opportunities for misunderstandings and the proliferation of rumours, and it mitigates the spread of fear and anxiety.
8. Identify people that the community trusts and build relationships with them. Involve them in decision-making to ensure interventions are collaborative, contextually appropriate and that communication is community-owned.
9. Two-way communication should be achieved through the most socially-acceptable and effective channels. Messages must be "translated" into local language, local context and to match the education levels and preferences (e.g. visual, written or oral cultures) of the target population. All communication with communities should be transparent, timely, easy-to-understand, acknowledge uncertainty, address affected populations, link to self-efficacy, and be disseminated using multiple platforms, methods and channels.
10. Disease creates fear which often leads to practices that further amplify the epidemic. These can be both individual and collective. They can relate to the transmission of the disease, or the stigma, and extreme stress on the ties that bind communities.

Ensuring effective community engagement

To ensure effective community engagement: 3 elements are needed for communities and for field responders.

For communities:

- ***Knowledge:*** communities must know what the disease is, how it is transmitted, and how to protect against it (social mobilisation messages);
- ***Trust:*** it is the most important determinant to ensuring communities heed public health advice. Communities must be consulted, engaged, and whenever possible participate in identifying and implementing response measures that communities and responders want above all to treat patients and stop the epidemic;
- ***Self-efficacy:*** communities must be able to implement control measures (e.g. access to soap and water, to gloves, to waste management services, to transportation, to safe burial teams, etc.).

For field responders:

- ***Understand:*** Field responders need to understand the local perceptions of the disease and of the response measures;
- ***Listen:*** Field responders need to listen to communities' fears and beliefs and adapt their own behaviours accordingly;
- ***Support:*** Field responders need to support communities' participation, ownership and resilience.

FOCUS 2

Risk communication – a life-saving action in public health emergencies

The essence of risk communication

Risk communication is one of the key pillars of response to outbreaks. It refers to the real-time exchange of information, advice and opinions between health experts or officials and people who face a threat (hazard) to their survival, health or economic or social well-being. Its ultimate goal is that everyone at risk is able to take informed decisions to mitigate the effects a disease outbreak and take protective and preventive action.

Effective risk communication not only saves lives and reduces illness (by informing people on how to protect their health), it also enables countries and communities to preserve their social, economic and political stability in the face of emergencies.

For these reasons, risk communication is one of the core capacities that all countries have agreed to develop in order to prevent the international spread of disease and other dangers as required under the International Health Regulations (2005).

21st century aspects change and complicate risk communication

There has been a paradigm shift from telling people what to do (message-based communication) to systematically listening to those affected, mainly due to new communication and media technologies and the way practices have evolved in the 21st century. The three big changes here are:

1. Experts and authorities are less trusted;
2. People now seek health advice mostly on public on-line sources, and their trusted social networks;
3. News media now function all day, every day. In addition, there is an increase of citizenship journalism and social media, as well as the rise of opinion versus well-sourced and referenced stories.

In disease outbreaks and epidemics, life-saving decisions need to be made rapidly and actions must follow promptly, with the support of an informed public. Epidemics are unpredictable and alarming events that generate great anxiety in the general public, which can lead to extreme behaviours. Epidemics and the way they are managed have a high political profile and capture the news media's attention quickly leading to intense media interest (at national and international levels).

Furthermore, emergency and outbreak communications now take place in a variety of contexts:

- In a shifting complex, crowded environment: information is incomplete and many different actors are exchanging public health information and competing for authority.
- Where communications are diverse: these include public communication, supporting national governments in risk communication, strategic communication, communication with affected communities and response personnel, media relations, knowledge transfer, message development, partner communication, internal communication and health promotion functions, etc.
- Where risk communication is an under-resourced priority with a lack of investment in skills, resources and expertise at country level.
- Where there is an increased public demand for participation in policy-making and for self-determination.

Making it effective

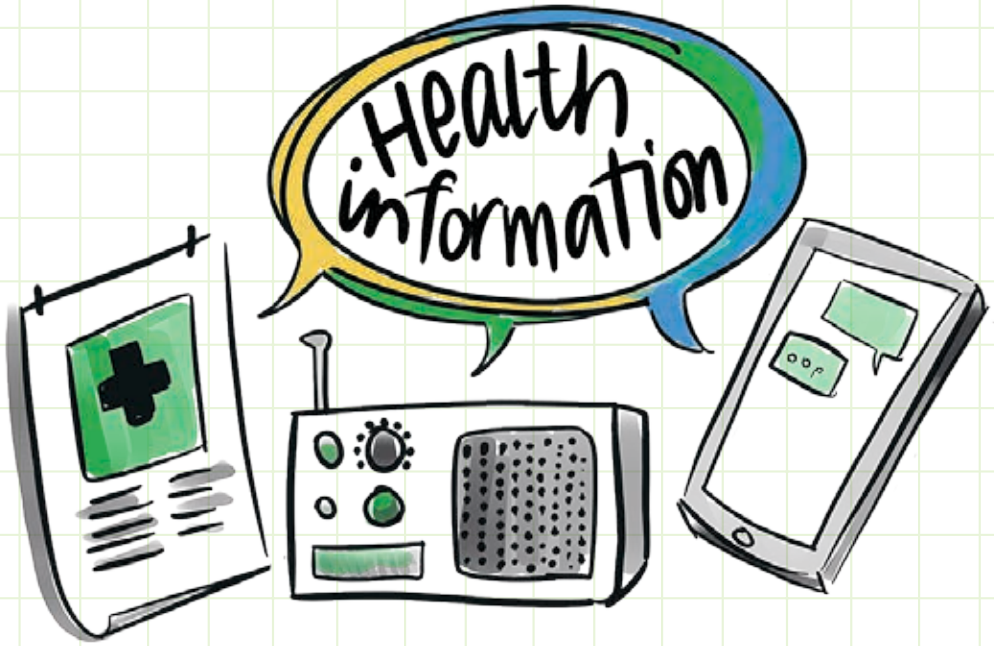
- Risk communication only works when there is communication based on trust between those who know (experts), those in charge (authorities or response teams) and those affected (communities). Without trust, people are unlikely to follow the advice given. Listening to and understanding peoples' beliefs, concerns and perceptions is just as important as providing them with facts and advice. Explaining honestly what is known and admitting what is uncertain is essential. Effective risk communication thus depends on the credibility of those giving advice; their expressions of caring and empathy; and their ability to identify with people at risk.

- Perception is key:

  - Experts and affected communities may not view the same infectious hazard – e.g. a disease outbreak – the same way. While experts depend on risk analysis based on biomedical and epidemiological data, affected communities use more sub-conscious pathways to define risk;

  - People's perception of risk can be affected by their beliefs, culture, education, political viewpoints, social norms and prior experience amongst others;

  - There are tried and trusted social science methods and approaches which can be used in epidemics to gauge perceptions.



Ten things to know and do

1. Build trust

- People must trust those responsible for managing the outbreak and for issuing information about it. Public confidence that a government or agency is acting first and foremost to safeguard their health will influence compliance with recommended control measures, and thus hasten outbreak containment.
- Accountability is key: communicators must demonstrate that they and outbreak managers are accountable for what they say, promise, and do.
- Evidence shows that to build trust, risk communication interventions should link to functioning and accessible services, be transparent, timely, easy-to-understand, acknowledge uncertainty, address affected populations, link to self-efficacy and be disseminated using multiple platforms, methods and channels.
- The building blocks of trust include:

- Being perceived as experts with credibility by providing expert advice that is correct and accurate and being consistent with other trusted agencies and entities;
- Being perceived as having a good character by telling the truth and not omitting important information, and acting on promises;
- Identifying with the affected population as sharing the same concerns and fate;
- Exhibiting good will through empathy and caring in messages and their delivery.

2. Communicate uncertainty proactively

- Communication by authorities to the public should include explicit information about uncertainties associated with risks, events and interventions and indicate what is known and not known at a given time.
- Announce the event as early as possible, even when the information is incomplete. This will establish you as the leader to communicate risk; it will build trust in you and the response; it will help enable changes in practice and behaviors to bring the outbreak under control; and it will minimize misinformation and rumours.
- A good template to communicate uncertainty is as follows:

- State what is known, what is unknown, and what you/your institution is doing about the issue;
- Communicate early, be first to announce the event if possible, communicate often, communicate regularly;
- Provide information on the risk/danger; but supplement it with some advice on how people can protect themselves;
- Speak as a human being, using empathy appropriately;
- Do not over-reassure.

3. Engage communities

- Identify people that the community trusts and build relationships with them and involve them in decision-making to ensure interventions are collaborative, contextually appropriate and that communication is community-owned.
- Community engagement is one important start for communicating risk and facilitating changes in behaviours and practices (**see Focus 1, page 38**).

4. Message well

- According to the latest evidence, risk should not be explained in technical terms as this is not helpful for promoting risk mitigation behaviours. Consistent messages should come from different information sources and emerge early in the outbreak. Messages should promote specific actions people can realistically take to protect their health.

5. Establish and use listening and feedback systems

- Use multiple means (surveys, focus group discussions, community walk-throughs, key informants, feedback from front-line responders, partners' and stakeholders'

feedback, social media, etc.) to listen to the public and affected communities.

- Use these to understand what concerns people regarding the outbreak or the measures we are asking them to adopt.
- Use these systems to test messaging

and materials developed to support risk communication.

6. Use social media as appropriate

- Social media should be used to engage the public, facilitate peer-to-peer communication, create situational awareness, monitor and respond to rumours, public reactions and concerns during an emergency, and to facilitate local level responses.
- Social media and traditional media should be part of an integrated strategy with other forms of communication to achieve convergence of verified, accurate information.

7. Risk communication operations requires resources

- Risk communication in epidemics is a massive operational undertaking and requires people, logistics, material and funds.
- Different types of expertise in many areas are required: media communications, social media, spokespersons, social mobilization, health promotion, community engagement, behavioral change communication; stakeholder communication, communication related to travel and trade, social science methods, etc.

8. Treat Emergency risk communication as a strategic role, not an add-on

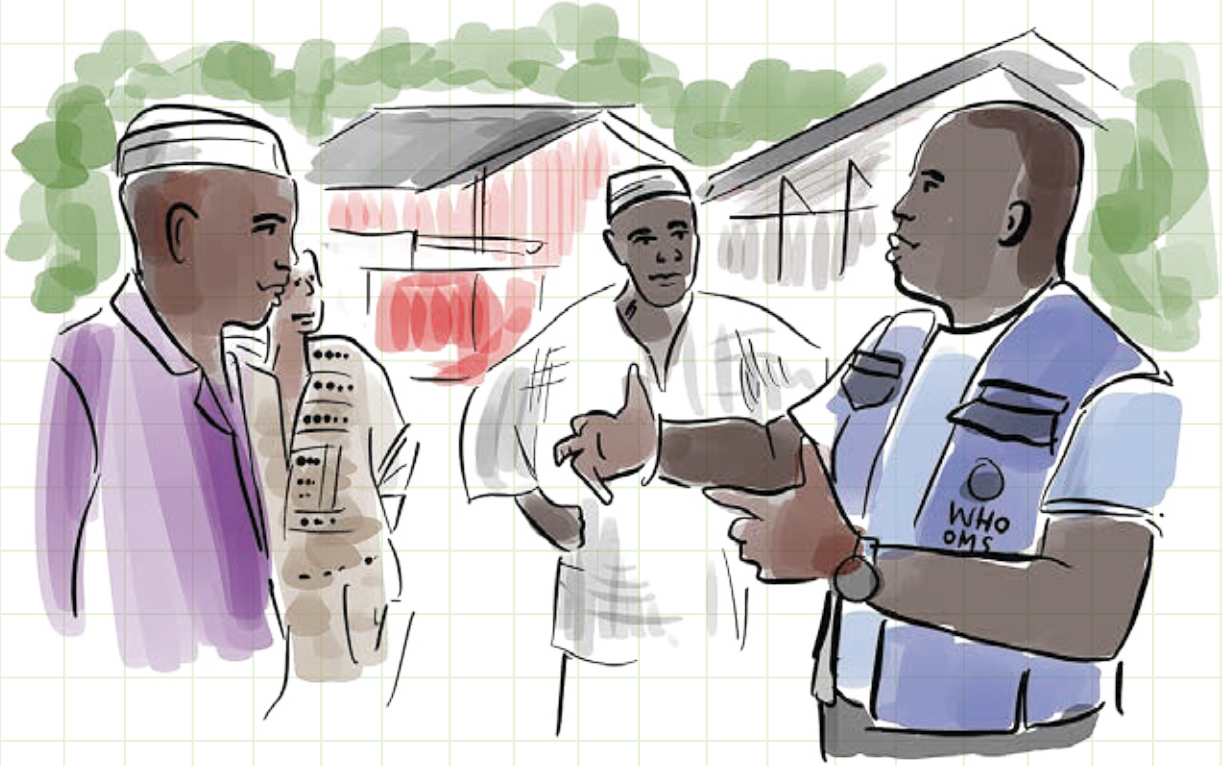
- Emergency risk communication should be a designated strategic role in global and national emergency preparedness and response leadership teams.
- The International Health Regulations (2005) require all Member States to build national capacity to communicate risk in two domains:
  - Systems capacities;
  - People capacities.
- The Joint External Evaluation (JEE) process championed by the Global Health Security Agenda measures national risk communication capacity in six domains:
  - National strategies, policies and plan;
  - Coordination;
  - Stakeholder communication;
  - Public communication (using mass media approaches);
  - Communicating and engaging with communities;
  - Dynamic listening (to misinformation, fears, concerns) and rumour management.

9. Establish coordination and information systems

- Develop and build on agency and organizational networks across geographic, disciplinary and, where appropriate, national boundaries.
- Tailor information and communication systems to the needs of users and involve local stakeholders to guarantee the flow of information across sectors.

10. Build capacity for the next emergency

- Preparation and training of personnel for emergency risk communication should be organized regularly and focus on coordination across agencies.
- Emergency risk communication requires a defined and sustained budget which should be a part of core budgeting for emergency preparedness and response.



Other factors to remember

While there is an increasing body of evidence as to what constitutes effective risk communication, every outbreak is unique. Therefore risk communication must be adapted to:

- The infectious hazard (its severity, lethality, modes of transmission, how it can be diagnosed, treated or managed);
- The geography of the outbreak: contained or widely distributed; national or international spread; affecting certain vulnerable communities or the general population; in a remote forgotten village or major city; affecting to poor or affecting travel and trade;
- The levels of trust that exit between the affected or at-risk populations and their authorities and experts; or the response teams;
- People's underlying beliefs, cultures, traditions, values and practices;
- Education, levels of awareness, access to understandable information; and trusted channels of communication;
- Self-efficacy: do communities have the ability, resources and environment to follow health advice?

FOCUS 3

Treating patients and protecting the health workforce

Advances in medicine: antibiotics, antivirals, vaccines and new treatments

With the remarkable progress in medicine and related technologies, briefly mentioned at the beginning of this publication, many infectious diseases can now be prevented and treated.

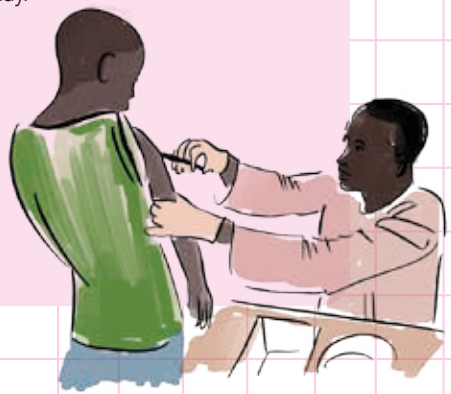
This is the result of a public health revolution that began in the 1940s with the discovery of antibiotics for bacterial diseases, and expanded with improvements in their safety, efficacy and acceptability.

Similarly, the development of vaccines, particularly for infants and young children, has given global protection against a number of childhood killers. For example, WHO estimates that there is now 86% global coverage of the combined diphtheria-tetanus-pertussis vaccine for babies[1]. In recent decades, hundreds of millions of children all over the world have grown up free of the risk of deadly and disabling diseases. Adults have benefited likewise, with protection against a wide range of infections that can explode into epidemics – cholera, influenza and yellow fever, for example. For many deadly diseases, there are vaccines that ideally should be administrated in routine, large-scale immunization to prevent the occurrence of the disease. Some vaccines can also be used during a reactive campaign when there is an epidemic in which the immunity of the population is not high enough.

The public health revolution continued towards the end of the 20th century with the discovery of antivirals, such as that used against HIV.

Meanwhile, there have also been great strides forward in the fields of diagnostics and treatments, such as monoclonal antibodies, that are also becoming more widely available but the price of some of them is still very high and they are not yet available for mass administration.

Such advances – and the early problems that followed them – including a degree of public health complacency, and the emergence of antibiotic resistance - have completely changed the way infectious diseases are confronted today.



[1] WHO data, 2016.

Treating patients with supportive care

But whether the focus is on antibiotics, antivirals, vaccines or the whole armoury of other treatments, the vital, universal fact is that they can only be beneficial when they are administered by skilled, qualified and dedicated health personnel, all across the spectrum of care. When, for example, no specific treatment is available for a given disease, adequate clinical management can still protect and save lives. This has been shown by a dramatic reduction in deaths from Ebola in West Africa in 2014 – from 75% to 33% mortality, achieved through the provision of better supportive care for patients.

Protecting frontline responders

The role of the health workforce should never be underestimated nor taken for granted. In general, much of their day-to-day work is mundane and routine, providing tried-and-tested care and treatment for familiar illnesses, disabilities and injuries.

But when an epidemic strikes, they make a vital difference at all levels, whether as community health workers and volunteers, midwives, nurses, or doctors. With little or no warning, they are transformed into frontline responders, thrust into immediate contact with infected communities and individuals. Family members, too, take on the role of caring for their relatives at home, often linking up with health staff in clinics, hospitals and emergency centres.

This transformation is double-edged and dangerous for frontline responders. First, their immediate priorities are to prevent the spread of an epidemic, protect those people who are most at risk, and to care by all possible means for those who are already infected. The related dangers are obvious: health workers are putting themselves at risk. They find themselves in the most dangerous place at the most dangerous time.

Yet, because their job is to care for the sick and injured, health care workers are often viewed as "immune" to injury or illness. Their patients come first. However, human-to-human transmission is a major factor in many infectious diseases that cause epidemics. Patients are highly contagious and can spread the disease at home, at work, in public spaces, but also in hospitals.

Thus, it is essential to protect them from infection – both for their own safety and for the wider protection of the affected community. It is here that emergency planning, preparation, training and coordination are so essential, as is the urgent provision of practical safeguards, especially the necessary personal protective equipment and the knowledge of how to use it properly.

Confronting the human resources crisis

These measures may seem obvious, but the role of frontline responders is frequently shackled by a major disadvantage: there are not nearly enough of them. This unpalatable truth applies to the health workforce in general. It is a global problem, but it is most acute in the poorest countries with weakest health systems, where epidemics are most likely to erupt.

Protecting the occupational health of health workers is critical to have an adequate workforce of trained and healthy health personnel. This is nowhere more true than at the heart of an infectious disease epidemic.

Around the world, health care facilities employ over 59 million workers[2]. Yet at the same time, there is a chronic shortage of them in more than 50 countries. This crisis in human resources for health has persisted for decades, despite numerous attempts to tackle it, but recent actions show notable progress.

It is not just a matter of numbers. While there has long been an exclusive focus on how many there are, against how many are needed, there is growing public health agreement on according equal importance to accessibility, acceptability, quality and performance in addition to availability.

[2] WHO data: *http://www.who.int/occupational_health/topics/hcworkers/en/*

These four factors are inter-related and inter-dependent. The absence or inadequacy of any one of them undermines all the others. Without sufficient availability, accessibility to health workers cannot be guaranteed. If they are available and accessible, without acceptability, the health services may not be used. When the quality of the health workforce is inadequate, improvements in health outcomes will not be satisfactory.

Elaboration of these complex issues at length goes beyond the scope of this handbook. But it is important that they are taken into account in the context of infectious disease prevention, treatment and control. Indeed, they lead to recognition that protecting health care workers has the added benefit to contributing to quality patient care and health system strengthening.

If it is accepted that health begins with health workers, their empowerment is necessary on a general basis. Their voice, rights and responsibilities must play a central role in developing and implementing solid policies and strategies towards universal health coverage. This applies to the context of epidemic disease control as much as it does to other health issues more widely. The engagement of communities during epidemics, including health workforce community, needs to be at the center of the epidemic response.

For more information about protecting the health workforce:
WHO global health workforce alliance website
http://www.who.int/workforcealliance/en/