Ethics Guidance for the Public Health Containment of Serious Infectious Disease Outbreaks in Low-Income Settings: Lessons from Ebola

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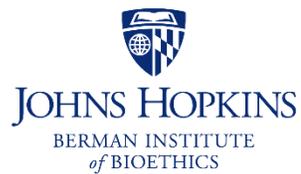
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List of Abbreviations

CHW   Community Health Worker

ETU   Ebola Treatment Unit

EVD   Ebola Virus Disease

HCW   Health Care Worker

HIV   Human Immunodeficiency Virus

LMIC   Low- and Middle-Income Country

NGO   Non-governmental Organization

PPE   Personal Protection Equipment

SARS   Severe Acute Respiratory Syndrome

VHFs   Viral Hemorrhagic Fevers

WHO   World Health Organization

Ethics Responsibilities to Guide Infectious Disease Outbreak Response

Executive Summary

Regardless of geography, public health response to infectious disease outbreaks should be effective, fair, respectful and transparent. Too often, however, outbreaks are met with fear, discrimination, and interventions with limited evidence, raising ethical as well as public health concerns. This ethics guidance is intended to help navigate response challenges that arise particularly where resources are significantly constrained, where core public health functions generally are weak, where there are high levels of economic, social, or political inequities, and where outside personnel are often brought in to aid in the response.

This guidance is the product of an expert working group, which convened four times between November 2015 and September 2016. The working group consisted of 27 members from six countries with backgrounds in ethics, infectious disease treatment and control, health systems strengthening, human rights, law, maternal health, HIV, TB, pediatrics, public health preparedness, mental health, epidemiology, and health communication. The guidance was informed by focus groups and interviews conducted with individuals in Sierra Leone and Liberia affected by the 2014-16 Ebola outbreak, and with response workers who had responded to the Ebola and/or other public health outbreaks. The guidance was peer-reviewed by 20 individuals who also had backgrounds in ethics, infectious disease, international response, healthcare, and Ministry of Health or NGO management. A short video, comprehensive checklists, and a PowerPoint slide set are also available to assist those who may want to teach the contents of this document. For online access to these products, go to bioethics.jhu.edu/outbreak_guidance.

The Goal of an Ethically Optimal Public Health Response

The goal of an outbreak response is to effectively contain the outbreak; yet *how* containment efforts are implemented has a significant impact on the effectiveness, efficiency, and trustworthiness of the response as well as on the social and economic disruption and recovery related to the outbreak. With this in mind, **the goal of a public health response is to prevent disease transmission and minimize illness and death, guided throughout by commitments to support local ownership of the response, and to treat individuals and communities with respect, fairness, and compassion.**

Guiding Ethics Principles

The principle of **respect** requires acting in ways that recognize the inherent and equal moral worth of all individuals, including treating them with compassion, regardless of their circumstances. Perhaps most challenging in this context is the obligation to respect the self-determination of others, particularly when containment policies threaten freedom of movement and association, body integrity, and livelihood.

Justice requires implementing interventions and policies fairly and with regard for the well-being of all affected; it also is concerned with systematic disadvantage and differentials in social standing and power. The

benefits and burdens of policies and programs must be distributed equitably, and where groups experience more burdens—for example, when certain communities have their liberties or livelihoods restricted or response teams assume significant risk—strategies should be implemented to fairly offset those burdens.

Promoting good and preventing harm, together with justice, are the moral foundations of public health. These principles motivate the response goal of keeping healthy people from becoming sick, helping sick people become as healthy as possible given available resources, and addressing the emotional harms of illness as well as the physical ones. Promoting good for individuals and communities is mutually reinforcing.

Chapter 1. Preparing for and Initiating Public Health Response Activities with Local Communities

Outreach activities such as active surveillance, case-finding, clinical care and treatment, and contact-tracing are core strategies to prevent new infections and minimize death and disability caused by an outbreak. Yet, when doing this work, how frontline workers enter communities can be as important as what they do. Frontline workers should approach local communities respectfully, as partners in outbreak response. A response driven by the needs and voices (demands) of the community will pay off in terms of local acceptance, time and trust.

Key Ethics Actions:

1. Reach out to local leaders to coordinate efforts and gain local insights.
2. Identify and synthesize the best available evidence.
3. Identify and acknowledge local practices that may need to be modified due to transmission risks.
4. Consider the effect of response strategies on most marginalized and determine ways to minimize harmful impact.
5. Identify community leaders and local community groups to accompany or "host" response teams not from the affected community.

ENTERING COMMUNITIES

Respect requires outbreak responders to act in ways that maximize trust, collective efficacy, and social cohesion in communities, including working with local leaders and informants.

Justice requires response teams to identify who within communities is most disadvantaged or excluded, and identify strategies to reduce the likelihood that containment activities will further harm them.

Promoting good and protecting from harm requires teams to identify the best available evidence to inform containment approaches.

Chapter 2. Interacting with Local Communities during Public Health Containment

Workers engaged in health education, active surveillance, active case-finding, contact-tracing, ambulance driving, and other community health measures provide the face of an outbreak response to affected communities. These frontline responders can, through their interactions with community members, influence people's perception of the overall response.

Key Ethics Actions:

1. Demonstrate respect through everyday acts of respect, courtesy, and empathy.
2. Promote transparency about when, why, how, and duration of containment activities.
3. Ensure outbreak response workers clearly distinguish their role and scope of authority.
4. Provide resources and information to act.
5. Respect privacy and maintain confidentiality before, during and after conducting frontline containment activities.
6. Include psychosocial support for all involved in the response.
7. Support two-way communication and feedback between managers and affected communities.
8. Support resolutions between responders as conflicts arise.

COMMUNITY INTERACTIONS

Respect requires providing every day acts of kindness, explaining why containment activities are needed, and maintaining privacy to the extent possible.

Justice requires being fair in how containment measures are implemented.

Promoting good and protecting from harm requires protecting confidentiality and minimizing how long burdensome interventions are sustained.

Chapter 3. Outbreak Communication and Messaging

Communication campaigns are critical to outbreak containment; they set the tone for the response, can foster adoption of infection prevention and control practices, encourage health-seeking behavior, and keep the public informed as information changes. Establishing an informative, trustworthy dialogue with the public can enhance the likelihood that messages will be well-received and acted upon.

Key Ethics Actions:

1. Design communication campaigns so messages reach all individuals and communities at risk, in a language and format they can understand.
2. Identify mechanisms to create appropriate messages.
3. Ensure messages are honest, transparent, evidence-based, actionable, and regularly updated.
4. Ensure that messages do not perpetuate stigma or single out groups unfairly.
5. Pilot test messages before broadcast, even in urgent situations.
6. Listen to and counteract rumors through frequent messaging.

COMMUNICATION

Respect requires engaging local spokespersons and representatives to help ensure that messages and outreach strategies are in alignment with local norms and are perceived as trustworthy.

Justice requires making efforts to reach all at-risk communities in a language, level, and format they will understand.

Promoting good and protecting from harm requires ensuring messages are perceived as respectful and do not exacerbate stigma.

Chapter 4. Special Considerations for Isolation, Quarantine and Social Distancing

Isolation, quarantine, and social distancing are intended to reduce the spread of highly infectious diseases by minimizing the possibility of transmission between infected and non-infected persons. **Isolation** refers to separating people who are sick with a contagious disease from people who are not to protect uninfected people from illness exposure. **Quarantine** involves separating and restricting the movement of an individual who may have been exposed to a contagious person. The goal is to closely observe the exposed person for signs of illness and avoid spread to others. **Social distancing** refers to community-level efforts to restrict the ability of groups of persons to congregate (e.g., closing schools, festivals, or marketplaces) in order prevent or slow the spread of a contagious disease; the term sometimes refers to *personal distancing* directives that establish a minimum distance between individuals.

Key Ethics Actions:

1. Implement isolation, quarantine, and social distancing only when there is a strong epidemiologic reason to expect significant public health benefits and no less restrictive approach would achieve the same benefit.
2. Ensure there is timely, reliable access to basic material and communication needs for individuals and/or households subject to either isolation or quarantine.
3. Implement isolation, quarantine, and/or social distancing only when they can be done fairly and in ways that minimize stigma.
4. Show everyday respect and common courtesy to individuals or households subject to isolation or quarantine.
5. Implement restrictive measures with local community support, enforced by authorized personnel.
6. Monitor the effectiveness and acceptability of restrictive measures.

> **RESTRICTIVE MEASURES**
>
> **Respect** requires recognizing human dignity.
>
> **Justice** requires fair and equitable enforcement of containment policy.
>
> **Promoting good and protecting from harm** requires that directives be accompanied by robust surveillance systems with valid diagnostic and contact-tracing capabilities.

Chapter 5. Supporting and Protecting Outbreak Responders

An adequate, capable workforce is necessary for preventing new infections, minimizing death and disability, and addressing other community concerns during an outbreak. Ethics issues arise concerning appropriate risk levels to undertake, fair compensation, and rights of healthcare workers. These ethics questions become more pronounced where resources are severely limited and where there is inadequate protective equipment.

1. Extend governments' and employers' reciprocal obligations to healthcare workers to all outbreak response workers at high risk for infection.
2. Prioritize making working conditions for responders as safe as possible; only then can questions of hazard pay be considered.
3. Prepare and support outbreak responders regarding the psychosocial challenges of participating in the response.
4. Prepare outbreak responders from international agencies for the reality that they will likely have access to more advanced care and support than local counterparts.
5. If hiring survivors to participate in outbreak containment, consider the risks they will face, how best to protect them, and seek to minimize physical, social, and psychological risks.

SUPPORTING RESPONDERS

Respect requires acknowledging and expressing appreciation for responders' willingness to undertake challenging, stressful, and often risky work.

Justice heightens the priority to protect responders from harm because response workers accept heightened risks as part of their service.

Promoting good and protecting from harm requires that outbreak responders are prepared with training and proper protective equipment.

Chapter 6. Providing Care and Treatment during Outbreaks

The provision of care, and treatment, is essential for minimizing suffering, death, and disability during an outbreak. Providing care and treatment brings relief to those who are sick, prevents transmission, and is ethically required. Care and treatment must be evidence-based, accessible to those affected, and must ensure that patients and their families are addressed in respectful ways.

PROVIDING CARE & TREATMENT

Respect requires engagement with community leaders in decisions of how to prioritize resources for outbreak care.

Justice requires that special accommodations are made for the care of rural and hard-to-reach populations, children, pregnant women, and those with mental or physical disabilities

Promoting good and protecting from harm requires providing evidence-based care to patients and their families.

Key Ethics Actions:

1. Provide evidence-based care and treatment to patients and their families.
2. Invest in strategies to improve equitable access to care and treatment if available.
3. Approach care with a commitment to transparency.
4. Prioritize communication and feedback between patients in treatment facilities and their families.
5. Balance outbreak care and treatment with other health needs.

6. Minimize psychological triggers of fear.
7. Respect the privacy and protect confidentiality of those who are ill in all aspects of care.
8. Demonstrate respect and recognize dignity in the provision of care.

Chapter 7. Supporting Survivors

Those who survive an outbreak, or whose illness becomes chronic, often experience significant disadvantage. Survivors might experience clinical sequelae, as has been documented for Ebola, Lassa fever, and polio, requiring ongoing clinical care and potential psychosocial stress or stigma. Physical and/or mental complications can contribute to an inability to work, or to sustain relationships or previous life activities. Stigma might result in employment and housing discrimination.

SUPPORTING SURVIVORS

Treat survivors with **respect** and kindness, acknowledging their dignity in the face of the challenging situation they endured.

Justice requires decreasing the chance of survivors becoming further disadvantaged by allotting resources for clinical follow-up care, psychosocial care and counseling, nutritional supports, job training and livelihood supports.

Promoting good and protecting from harm requires enhancing the health and well-being of survivors.

Key Ethics Actions:

1. Ensure survivors have access to clinical follow-up services.
2. Refer survivors to ongoing social and psychological support.
3. If possible, replace property of survivors that may have been destroyed while receiving care or treatment.
4. Prepare communities for the return of survivors from isolation and care facilities.
5. Collaboratively develop a plan for allocating and distributing material supports to survivors and affected communities.

Chapter 8. Outbreak Recovery

The larger and more severe the outbreak, the more profound its impact. Outbreak response is often accompanied by a temporary influx of resources, infrastructure, and worker training that will stop once the outbreak is under control. Newly created policies and practices, updated systems for delivering services, and use of recently trained personnel will need to be reviewed and ideally sustained after the outbreak is over. Long-term recovery is best characterized as

OUTBREAK RECOVERY

To uphold **respect**, ensure that policies are in place that continue to involve survivors and thank those who served in the response.

Justice requires addressing and ameliorating underlying inequities in care by using resources for crisis response in ways that are most likely to help develop infrastructure that will leave the community better off.

Relevant to **promoting good and protecting from harm**, there may be ways for the tragedy of an outbreak to be a stimulus for the implementation of systems-level public health change.

preparedness through systems strengthening and policy change.

Key Ethics Actions:

1. Find ways to respectfully recognize and remember lost loved ones.
2. Consider long-term recovery goals and community perception of dismantling infrastructure built as part of response.
3. Apply lessons learned during the outbreak to local preparedness planning.
4. Develop a multidimensional recovery plan in partnership with local leaders.
5. Leverage the systems built during the outbreak response to advocate for broader systems strengthening initiatives.

Introduction

Regardless of geography, public health response to infectious disease outbreaks should be effective, fair, respectful and transparent. Too often, however, outbreaks are met with fear, discrimination, and interventions with limited evidence, raising ethical as well as public health concerns. Most of the ethics challenges discussed in this document occur in both high- and low-income settings. Yet in public health and in ethics, context matters. This guidance is focused on contexts where several of the following are true:

- Health service and social service resources are significantly constrained
- Core public health system functions are weak under ordinary conditions—e.g., disease monitoring and surveillance, training, and linkages to healthcare
- Insufficient numbers of people are trained in public health outbreak response
- Much of the population is of low health literacy
- There is a history of political instability, civil conflict, and/or ethnic or religious tension
- There are high background levels of economic, social, and political inequities
- When public health crises occur, outside personnel, equipment, and medicines are often brought in to aid in the response

Pervasive injustices and systemic inequalities often compound the ethics challenges that emerge in outbreak response, and outbreaks often compound the injustices that occurred preceding an outbreak.

This work aims to outline ethics issues that can emerge during outbreak response, to highlight how they might be exacerbated in resource-limited and politically constrained settings, and to provide ethics guidance where possible.

The Goal of an Ethically Optimal Public Health Response

The goal of an outbreak response is to effectively contain the outbreak. However, as experience has consistently shown, *how* containment efforts are implemented has a significant impact on the effectiveness, efficiency, and trustworthiness of the response as well as on the social and economic disruption and recovery related to the outbreak. We frame the goal of a response as follows:

The goal of a public health response to a serious infectious disease outbreak is to prevent disease transmission and minimize illness and death, guided throughout by commitments to support local ownership of the response, and to treat individuals and communities with respect, fairness, and compassion.

This framing of public health containment during infectious disease outbreaks is consistent with ethical requirements to promote good, be fair, reduce harms, and be evidence-informed in administering interventions. Each component of the goal is described below.

Prevent transmission and minimize illness and death

Death and disability will result from outbreak infection and because ongoing health threats to under-resourced communities—other infectious conditions, malnutrition, trauma, mental health issues, or inadequate health services—will likely be exacerbated when limited resources are diverted to support the response. Minimizing death and disability from both of these is a central goal of a response.

Support local ownership of the response

Severe outbreaks in lower-resource settings often bring an influx of responders from other regions, countries, and institutions. Their presence and resources, while helpful, may unwittingly eclipse or undermine the authority and expertise of local governments, institutions, community leaders and affected communities. Foreign responders who bring medical expertise, diagnostic and lab capability, medicines, or surveillance tools should recognize the potential for an unequal relationship and be deliberate in trying to ensure that local leaders play an equally strong role in co-directing, co-managing, and designing interventions for outbreak response. Those from affected areas can be expert partners to help reduce the likelihood of cultural and linguistic challenges and can increase the chance that containment messages are understood and voluntarily implemented.

Supporting local ownership requires identifying key formal and informal local leaders and stakeholders and understanding the dynamics between them. Responders should talk to people in different roles to determine whether self-appointed leaders are committed to the best interests of affected individuals, and be sensitive to any suggestions that might further marginalize certain ethnic, religious, tribal, gendered, or other local subgroups. Supporting local ownership also requires working with local communities to build their capacity and systems to better respond to current and future public health emergencies.

Disagreements and distress will likely occur at multiple levels; inclusive discussion and ultimately taking positions consistent with evidence may be important. Simultaneous commitments to evidence-based disease control and true partnership with community and civil society likely will facilitate the upholding of the other ethics principles of respect, fairness, and compassion; indeed, supporting local ownership of and throughout the response is a cross-cutting ethical obligation, relevant to all of the other ethical obligations described in this document.

Demonstrate respect, fairness, and compassion in interactions with individuals and communities

From initial engagement with individuals and communities, to implementation of containment, to care and treatment, and to recovery, response efforts must be carried out with respect, compassion, and fairness. The chaos and urgency precipitated by an outbreak can challenge the habit of recognizing the dignity and moral worth of others, including those very sick or fearful. Response efforts will be more effective and will build more trust if responders treat affected individuals and communities with compassion, fairness, and respect, and may provide responders with more pride in their efforts. The aim of this guidance is to apply these ethics principles, commitments, and responsibilities to specific areas of containment, including entering a community, isolation, quarantine and social distancing, or outbreak recovery.

Guiding Ethics Principles

The principle of **respect** requires never losing sight of and acting in ways that recognize the inherent moral worth of all individuals. Many ways we respect others are manifested in ordinary life, by keeping promises and confidences, respecting diversity of traditions and values, being honest and transparent, and treating others with dignity. These can be challenged during an outbreak. Perhaps most challenging to maintain is the obligation to respect the self-determination of others, particularly when containment policies threaten freedom of movement and association, bodily integrity, and livelihood.

Policies and programs should be designed to allow individuals as much control over their lives as possible, within the goals of preventing transmission and minimizing death and disability. For example, constraints on freedom of movement should be questioned to determine if a less restrictive approach could also protect others, and restrictions must be lifted as soon as the threat has passed. Respect requires acting in ways that recognize individuals' dignity, treat others with decency, are transparent with information, protect as possible the confidentiality of private information, and give try to understand and take account of the perspectives and histories of communities. Demonstrating respect means treating individuals equally regardless of ethnic or tribal origin, gender, sexual identity, age, job status, or religion. Respect also requires creating mechanisms of procedural justice by which those who disagree can raise objections, be heard, and have resolutions fairly made.

Justice requires implementing policies and programs fairly, ensuring equitable access to testing, care, treatment, and recovery resources, regardless of social status, ethnicity, or geography. Where some groups experience more burdens—for example, when some communities have their liberties or livelihoods restricted or response teams assume greater risk— strategies should be identified and implemented to fairly offset those burdens. Attention to justice also requires attention to social status and power, ensuring that policies and programs do not worsen existing patterns of social disadvantage. A fair response will strive to give voice to all groups within a population, often requiring the creation of mechanisms for genuine participation and influence.

Promoting good and preventing harm, together with justice, are often viewed as the moral foundations of public health. Promoting good for individuals and for communities are mutually reinforcing, sharing a response goal of preventing healthy people from becoming sick and helping sick people become as healthy as possible. Promoting health and well-being is attentive to physical and mental health needs and is undergirded by commitments to compassion for those who are sick, whether or not treatment is available. Preventing harm requires providing public health containment measures, but also anticipating and trying consciously to avoid further stigma to marginalized populations. Coordination with responders from other sectors such as transportation, education, public works, and labor, when possible, may help to minimize harms to social cohesion and economic viability. Promoting good and minimizing harm should provide useful mental anchors in the processes of making difficult decisions and implementing potentially controversial procedures during an outbreak response.

Annex 1 further specifies ethical responsibilities that follow from each of the above principles and provides examples of how they might be operationalized in an outbreak context.

Scope and Applicability of Guidance

This guidance is directed toward public health containment and response, including the planning, organization, decision-making, implementation, and management of disease containment and response strategies. This will likely include surveillance, community engagement, education, setting up treatment units, training on clinical care, treatment and prevention, active case finding, contact tracing, social distancing, isolation, and quarantine.

This guidance is directed primarily to population level interventions; it is not primarily directed at ethical dilemmas in clinical care and research.

Ethical dilemmas unique to clinical care and research (such as which treatments to provide, allocation of scarce treatments, access to experimental medicines, and whether to use placebos in research) are not directly addressed in this guidance. Other ethics guidance documents—including the WHO Guidance for Managing Ethical Issues in Infectious Disease Outbreaks (5), and others targeted to outbreak preparedness (6), clinical decision-making during outbreaks (7, 8), and research during outbreaks (9, 10)—focus more on these areas.

This guidance is particularly targeted to assist *managers* of the outbreak response and strategy, meaning those responsible for decision-making or oversight for multiple or particular aspects of the response. "Managers" may include:

- Officials and policy makers at local, regional and national government ministries
- Coordinating responders and team leaders from international organizations, non-governmental organizations, community-based organizations, and academic partner institutions
- Field level managers, technical leads, and other workers who will make decisions.

Inequalities, inequities, power differences and corruption are endemic within every country; relationships among and between countries, however, magnify and exacerbate these imbalances. Past practices of slavery and colonialism laid the groundwork for the racism, economic hegemony, and exclusionary trade policies that exist today. And continuing today, what has been described as global "structural violence" drives how current differences in wealth, health, and power constantly reinforce the dynamic of wealthier nations benefiting at the expense of less wealthy and less developed nations. This document acknowledges that history and the current reality. In this spirit, we underscore that the ethics principles raised in this document are not elastic and do not vary based on the position one holds, how much money one has, or where one lives.

There are many actions that can address the ethical issues in global politics and how they impact the health of the general public. This document, while cognizant of these central, contextual and historical factors, focuses ethics and outbreak response at a much more micro level. The guidance is specific to actions and interactions in the field and, while not designed to directly address the issues outlined above, it is designed to ensure that such issues are not a necessary feature that comes with operationalizing responses at the local level. That is, the intent of this document is to provide guidance to those responding to a disease outbreak so that everyone affected by the outbreak is treated with fairness, respect, and compassion.

Methods

This guidance is the product of an expert working group, which convened four times between November 2015 and September 2016. The working group consisted of 27 members from six countries (Canada, Liberia, Peru, Sierra Leone, Uganda, and the United States) with backgrounds in ethics, infectious disease, health systems strengthening, human rights, law, maternal health, HIV, TB, pediatrics, public health preparedness, mental health, epidemiology, and health communication.

To inform the expert working group's deliberations, project staff also conducted a) a systematic review of the literature on challenges of implementing containment measures in low- and middle-income countries (LMICs) and strategies for overcoming implementation challenges; b) in-depth interviews with 23 individuals involved in some aspect of a containment response for Ebola or other viral hemorrhagic fevers (VHFs) in LMICs, exploring ethics challenges encountered in their work and recommended or suggested courses of action; and c) six focus groups discussions (three in Liberia and three in Sierra Leone) with Ebola virus disease survivors, family members of those who died of Ebola, and health workers who participated in the containment response.

Findings from these three research projects (reported elsewhere), highlighted how the interplay of mounting a response to a severe and rapidly spreading disease in an economically and politically challenged social context can raise significant ethical challenges. Throughout the guidance that emerged, we have included quotations and anecdotes from this research to illustrate points through real-world examples. While our work was informed significantly by experiences with the 2014-16 West Africa Ebola outbreak, our goal was to use insights to craft guidance for outbreak response in LMICs more generally.

The working group discussed extensively which aspects of an outbreak response are most critical for guidance. Each chapter's key challenges, guidance points, and checklists were informed by the literature, interviews, and focus groups and then discussed, clarified, and supplemented by small and large group discussions among working group members. Members stressed the importance of also including ethics questions that remain unanswered. The entire document was sent for peer review to a group of professionals with expertise in outbreak response, infectious disease, community engagement, health communication, and ethics; project leads responded to these critically important reviews with an attempt to make the final document more clear and more relevant.

How This Document is Organized

This document is divided into eight chapters. Each chapter includes a summary of key challenges, key ethics considerations, and key recommendations, animated by examples from focus group discussions and interviews. Each chapter concludes with a checklist intended to be a practical, stand-alone document. Chapter topics are as follows:

1.   Preparing for and Initiating Public Health Response Activities with Local Communities
2.   Interacting with Local Communities During Public Health Containment
3.   Outbreak Communication and Messaging
4.   Special Considerations for Isolation, Quarantine and Social Distancing

5. Supporting and Protecting Outbreak Responders
6. Providing Care and Treatment during Outbreaks
7. Supporting Survivors
8. Outbreak Recovery

Chapter 1: Preparing for and Initiating Public Health Response Activities with Local Communities

Introduction

Outbreak response requires collaboration and coordination among outside and local responders, national and local government, other stakeholders and members of and leaders of affected communities. Outbreaks generally require responders to enter local communities to implement strategies such as active surveillance, case-finding, clinical care and treatment, and contact-tracing. While these often are essential in minimizing illness and death, *how* frontline workers enter communities can be as important as *what* they do. Frontline workers must approach individuals and communities respectfully, as partners in outbreak response. Workers will benefit from at least some awareness of communities' political and cultural histories; this may also help avoid some instances of fear, denial, resistance, misunderstanding, or outright hostility (11). Those in decision-making positions help to guide an ethical response. Early, intentional, and inclusive engagement with stakeholders—especially those impacted by containment measures—will streamline communication and reduce conflicts; response actions driven by the needs and voices (demands) of the community will often pay off in terms of local acceptance, time, and trust. The guidance in this chapter builds on previous guidance for engaging communities in outbreak control (12), biomedical research (13, 14), and HIV prevention and treatment (15).

Key Contextual Considerations
- Political history (e.g., colonization, civil conflict, tribal differences, pre-existing trauma) might influence community perception of national and foreign outbreak response teams, the government, and other communities or tribes in the region.   - Response workers might speak a different language or have different cultural norms than affected communities.   - Communities often have an existing internal leadership structure for making decision about matters affecting the community.   - Within all communities, there will be some individuals and groups who are more disadvantaged than others, and for whom containment measures might create a disproportionate burden.

Key Ethics Considerations
A respectful response is informed by engagement of local and/or traditional leadership prior to entering communities and partnering, when possible, as allies who can facilitate containment work. It is important to understand any ethnic, religious, tribal or other tensions within communities before developing outreach strategies.   - Treating communities with **respect** and recognizing their dignity requires trying to understand local norms and traditions—often through engagement of local leaders, local colleagues, or others who have worked in these communities—to jointly determine which approaches will be most effective while not undermining, offending, or insulting individuals

and communities. Responders should be attentive to local norms that might devalue minorities, women, members of certain religious groups or others.

- **Justice** requires identifying within communities who is most disadvantaged or excluded, and how to reduce the likelihood that containment activities will further harm these populations by lack of access, disproportionate stigma, loss of income, or communicating in a language they do not understand.
- To **promote good and protect from harm**, response teams should identify the best available evidence to inform containment approaches.

1.1. Reach out to local leaders to coordinate efforts and gain local insights.

Foreign managers and responders should make efforts early on to learn about the national and community context, including the political history, religions, cultural norms, and actors with and without power and influence in the area. Early identification of and continual consultations with key informants enables a more effective and respectful working relationship with local stakeholders and communities, especially in identifying marginalized or particularly vulnerable people.

As early as possible, responders should identify and aim to work with local health and other authorities, other stakeholders, and key NGOs. A threat to efficient response is having multiple actors react, with good intention, in entirely uncoordinated ways. The goal instead is to identify local leaders, coordinate outreach and response at the community level, mechanisms are in place for regular information sharing, and the needs of disadvantaged groups are considered in designing strategies.

Special considerations needed when working in areas of conflict, authoritarian rule, or weak governance:

Outbreaks that occur in areas of conflict, authoritarian or corrupt rule, or weak governance might limit the extent to which working with national government will further the goal of containing the outbreak. Those responding to outbreaks will need to make careful judgments about whether working with government officials will enhance the legitimacy of the response, protect the interests of those affected, and/or facilitate coordination, as well as how collaboration with government officials will affect post-outbreak governance. Even when national leadership is ineffective, corrupt or weak, regional health or local community leaders may emerge. Partnering with these leaders can help to reach communities. In other cases, NGOs with standing in the community, whether providing health or other services, can be valuable allies.

In some cases, a history of recent conflict might exacerbate tensions when entering communities. In these cases, it is essential to reach all groups while ensuring that outreach to one group is not perceived as a sign of taking sides.

Communities generally include subgroups who are worse off, and outbreaks typically are most severe where the most disadvantaged populations live: in conditions with poor sanitation, with the closest living quarters, with little access to primary health services, and poor transportation infrastructure to access resources. Active public health response (case-finding, contact tracing, surveillance) can help respond to the needs of the worst off, and yet awareness of the particular challenges of those most disadvantaged must be kept in mind throughout the response. Implementing response activities equitably, including prioritizing communities that may be harder to reach or are at heightened risk of violence (5), is essential

Biomedical and cultural claims of causality helped to obscure the role of human rights failings in the genesis of infectious disease outbreaks in West Africa:

From the early 20th century smallpox and influenza outbreaks to the 21st century Ebola outbreak, an imbalance of power and influence among nations is embodied by outbreaks of lethal diseases such as viral hemorrhagic diseases in West Africa, resulting in hundreds of thousands of preventable deaths. Then as now, biomedical and culturally-rooted claims of causality contribute to obscuring the role of human rights failings (e.g., colonial legacies, structural adjustment, exploitative mining companies, enabled civil war, rural poverty, and a lack of quality health care) in the genesis of the recent Ebola outbreak (3).

to mitigate further disadvantage and to get timely information about emerging cases. Infectious diseases may be more virulent in particular age groups, and certain subgroups may be more vulnerable, requiring specialized care or protections. Further, some individuals whose livelihoods may be associated with the outbreak (taxi drivers; nurses) may be stigmatized, and others (e.g., market vendors; restaurant workers) may lose business during an outbreak due to social distancing or illness.

1.2. Identify and synthesize the best available evidence.

Using the best available data to inform response approaches is ethically required to assure the integrity of the response and to increase the likelihood of success. Existing evidence on strategies that do and do not work should be widely disseminated across response teams, and new data collection, including rapid assessments and interim evaluations, should be ongoing, shared, and coordinated. Knowledge related to hotspots of transmission, community attitudes and practices, epidemiology of the infectious agent, the effectiveness of specific strategies, and the availability of resources will be constantly changing. This should be anticipated and strategies identified for adapting containment approaches in response to emerging data. To the extent that data use and ownership agreements can be

> **Challenges in data collection and transparency include:**
>
> - Data may expose corruption or incorrect/outdated health care practices.
> - Redundant data collection may be needed by multiple international organizations for their own funding justifications.
> - International partners are simultaneously engaging in research while contributing to disease control.

negotiated in advance, or use of a model agreement that is designed to maximize transparency and sharing of data, the less time will be spent working out these potentially time-consuming details.

Summary Results from WHO Stakeholder Consultation on Data Sharing Norms in Public Health Emergencies [6]

- Leading stakeholders from around the world convened at a WHO consultation in September 2015, where they affirmed that timely and transparent sharing of data and results during public health emergencies must become the global norm.
- Representatives from major biomedical journals who attended the meeting agreed that public disclosure of information relevant to public health emergencies should not be delayed by publication timelines and that early disclosure should not and will not prejudice later journal publication.
- Researchers should be responsible for the accuracy of shared preliminary results, ensuring that they have been subjected to sufficient quality control before public dissemination.
- Opting in to data sharing should be the default practice, and the onus should be placed on data generators and stewards at the local, national, and international level to explain any decision to opt out from sharing data and results during public health emergencies.
- Incentives for sharing data should be created and tailored for each type of data generator and steward.
- Data management and analysis expertise should be enhanced in low-income settings.

1.3. Identify and acknowledge local practices that may need to be modified due to transmission risks.

Individuals from and familiar with the local context can help response teams recognize local beliefs, values, norms, or practices that might contribute to transmission. These may include ways of preparing food, touching as a means of greeting others, wedding rituals that include touching and washing, healing rituals, and burial rites. The challenge will be to identify respectful lower risk ways to sustain the goal or spirit of local norms while minimizing disease transmission. Where local practices are changed, it should be made clear why, and that the change is temporary. Altering norms requires first acknowledging that they are valued, and then respectfully finding ways to modify, adapt, or temporarily suspend them until the outbreak is contained.

Negotiating Safe and Dignified Burials in West Africa

During the West African Ebola outbreak, safe burial of victims was extremely challenging, as traditional burial practices, such as washing bodies, led to high levels of transmission. Yet failing to engage in traditional practices was considered extremely disrespectful to the dead and distressing for family members.

Interim guidance was developed to help burial teams conduct safe burials in a way that recognized the dignity of sick individuals and their families, minimized risk of transmission, and allowed some traditional practices to be carried out in a modified way. Burial teams would spray the body and surrounding area with a concentrated chlorine solution, then place the body in a body bag and, in rural areas, transport the bag to the grave, or in urban areas, a truck for transport. In order to gain the trust of the community in the burial process, the burial teams arrived at the community in normal clothes (not suited up in PPE), and engaged with family members of the deceased as part of the case investigation. After engaging the family and community, they would invite the family to be present for the burial at a safe distance. Thus the burial process was "negotiated" in a way that both minimized risks of transmitting disease and was respectful of local practices. When possible, including components of valued practices in a response, while suspending those that contribute most directly to transmission, may demonstrate respect for individuals and their values while also improving the effectiveness of the containment response.

Working with Traditional Healers in Sierra Leone

During the Ebola outbreak in Sierra Leone, an NGO consortium recognized that traditional healing practices were posing disease risks. There were many opinions about how best to engage traditional healers and get them to refrain from touching ill patients, which would effectively be asking them to forego their livelihood. While some suggested incentivizing traditional healers to refer patients to the formal healthcare system, others feared that doing so would result in excessive referrals, that sick people might be sent to traditional healers before being referred to treatment centers, and that it would not be fair to incentivize traditional healers and not others, such as religious leaders, who had been referring sick people to ETUs voluntarily.

The NGO consortium worked with the Sierra Leone Indigenous Healers Union to devise a solution that gave traditional healers the responsibility of talking about Ebola with other traditional healers. Using previous research about how people want to receive information, they made a deliberate decision not to have healers be mobilizers talking to the general population, but instead to talk with other traditional healers through a "bush-to-bush campaign." Healers went from healing shrine to healing shrine in very rural areas to see if people were still being treated there and to then convey information to their supervisors. In this way, traditional healers worked through their own structures to retain ownership and responsibility for the campaign. In return, the NGO consortium compensated traditional healers for their transportation and developed materials to promote the contribution of traditional healers to combatting Ebola to improve their reputation in the community.

1.4. Identify community leaders and local community groups to accompany or "host" response teams not from the affected community.

Members of an affected community should both lead and be members of outbreak response teams. Response workers not from a local community should engage local chiefs, directors of civil society and religious organizations, and local government officials, and work with them to identify appropriate strategies to engage communities, including traditional healers, about containment activities. This not only demonstrates respect, but may also be reassuring to community members that a familiar figure has approved of the outside responders. Interaction with local community leadership can also enhance the effectiveness of containment efforts by helping ensure that information is conveyed with language and approaches most appropriate to the setting. A local host also can be critically important to the safety of the response team by preventing possible violence and aggression towards response workers.

"If you go to the district and do not talk to the Paramount Chief and do not talk to the traditional leader, then who will be your host? This was the first mistake that was happening here. The people would enter to the terrain, they do not deal with the stakeholder in the terrain- in the district or in the community. They would deal with the people who they choose… if you deal with people who do not have control over anything, then of course you will go, and you will see less result."

Paramount Chief, Liberia

Focusing only on those with formal leadership titles may further entrench local despots, or give rise to profiteers' groups with no true ties to those they claim to represent. Communicating with local individuals and with groups who advocate for women, persons with disabilities, elders, minority tribal groups or other marginalized groups is essential as is asking questions about who gets things done or to whom individuals turn for help.

How to Identify Authentic Local Leaders

Multiple scholars and practitioners of community engagement suggest identifying community level leaders by asking the following questions [2, 8, 9]:

- Who do people go to here for advice or help?
- When the community had a problem in the past, who came together to help solve it?
- Who gets things done?
- Who are some other respected community leaders? If no women are mentioned, ask which women have the trust and respect of the community and/or of other women.
- Whose voices are the most influential in decision making?

Asking these or related questions to a variety of stakeholders and seeking redundancy of responses can help identify authentic representatives or leaders who might be key allies in working with communities and understanding their interests.

Collaborating with Evangelical Leaders to Prevent an Outbreak while Continuing with Traditional New Year's Eve Services

During the West African Ebola Outbreak, after months of a state of emergency limiting mass gatherings, the President of Liberia pronounced that New Year's Eve church services would be held. Members of the response teams were uneasy with the potential risks of transmission. To attempt to mitigate this risk, the head of Social Mobilization, himself a religious leader, called together the heads of the major evangelical organizations in the country and demonstrated how the religious practice of "laying on hands" had contributed to a local outbreak of Ebola. Armed with this information, these leaders and their organizations developed and disseminated messages about how to continue to honor religious practices without touching, emphasizing means of staying safe during the New Year's Eve services.

Checklist: Preparing for and Initiating Public Health Containment Activities with Local Communities

Conducting outreach activities is key to preventing new infections and minimizing death and disability caused by an outbreak. As previous experiences have shown, *how* frontline workers conduct this work can be as important as *what* they do.

☐ Learn about local history, customs, networks, and tensions.

☐ Identify **local values and traditions** that might contribute to transmission.

☐ Develop strategies to safely modify procedures that will **respect traditions and mitigate risk** of transmission.

☐ **Identify influential leaders** who can accompany you in the community, make introductions, and "host" the response team.

☐ Work with local leaders to **identify evidence-based strategies** and approaches to disease containment at the community level.

☐ **Engage with local leaders** to identify who in the community is least-well off or subject to discrimination and what might be needed to protect them.

☐ Coordinate with local community leaders to discuss what response teams are planning to do.

Chapter 2: Interacting with Local Communities During Public Health Containment

Introduction

This chapter provides considerations for *how* outbreak responders should interact with local communities where outbreaks are occurring. Workers engaged in health education, active surveillance, active case-finding, contact-tracing, ambulance driving, implementing quarantine measures, vaccination, provision of psychosocial support, hygiene and other community health measures provide the face of the response to affected communities. These frontline responders can, through their interactions, influence people's perception of the overall response. Interactions between responders and communities on the frontlines can exacerbate existing fear and suspicions of outsiders or they can mitigate fear and engender cooperation and trust. This guidance is designed to enhance cooperation by bringing considerations of respect, transparency, and fairness to responders' interactions. Infusing these considerations into the technical aspects of containment enhances the likelihood of effectively containing the outbreak.

Key Contextual Considerations
- During outbreak containment efforts, confusion, fear, and urgency can make it more likely that respect, transparency, fairness, and privacy might be overlooked or discounted by responders—especially for those who are perceived as vulnerable or powerless.   - During an outbreak, if urgency has resulted in little community outreach or mobilization, entering a community may be met with suspicion.   - Stigmatization of affected communities, households, and individuals might be a persistent challenge during containment efforts.   - Routine clinical practices might compromise privacy and confidentiality.
Key Ethics Considerations
- Continuing to practice every day acts of kindness upholds commitments to **respect** and dignity, and is necessary even in very trying, fearful circumstances.   - Outbreak response workers demonstrate **respect** by being transparent when explaining to community leaders, affected individuals, and households why containment activities are implemented, for how long, and who can be contacted for more information/questions.   - Affected communities are treated with **respect** when they are given the opportunity to provide feedback and inform response activities. Outbreak response workers in any role should be prepared to educate communities and communicate feedback to managers, especially as it concerns groups who are disadvantaged.   - Privacy and confidentiality should not be compromised during an outbreak. Even when it may require more time, outbreak response workers should emphasize confidentiality and take steps to protect privacy of affected individuals, households, and communities to **promote good and protect from harm**.   - Including psychosocial support workers on field-based teams can help minimize the potential for fear, stigma, and uncertainty, upholding commitments to **respect and compassion** during the implementation of containment activities.

2.1. Demonstrate respect through everyday acts of kindness, courtesy, and empathy.

Maintaining acts of courtesy and kindness during outbreaks treats communities and households with respect and can help build and maintain trust and understanding between response workers and affected communities. Taking time to greet people in a way that is locally respectful but also avoids transmission is important in response work. Making efforts to understand how an outbreak is affecting communities can help responders relate in a more respectful way, and help find collaborative solutions if communities seem resistant to follow containment activities.

> "…as soon as we arrived, we were given a bag that had a towel, new clothing, toothpaste and brush. We went and had a shower, because I vomited on the way to [name of facility], somebody died in the ambulance so they really received us well. We were encouraged to take our medications and a lot of encouragement. We played cards, Lulu, etc."
>
> Survivor, Sierra Leone

2.2. Promote transparency about when, why, how, and duration of containment activities.

Frontline workers are an important interface between those representing the response and affected communities. Respect requires performing containment work with transparency, meaning that responders must communicate what they are doing in words community members can understand, why they are doing it and for how long. Workers should provide basic information about the disease and how it is transmitted so that community members understand why disease-containment activities are being implemented. People who were infected, treated, and cured may be employed to help with the response and serve as role models and sources of hope for others.

2.3. Ensure outbreak response workers clearly distinguish their role and scope of authority.

Outbreak response managers should clearly communicate assigned roles and responsibilities to both foreign and local responders (5) in order to improve coordination and avoid duplication when a range of clinicians, community health workers, and volunteers are involved in the response. Communication of one's role to communities is also essential. In circumstances where frontline public health responders (e.g., educators, surveillance workers) enter a community with a military

Stakeholders working together: Role reversal exercises in Guatemala

During the 2009 H1N1 outbreak in Guatemala, outbreak responders routinely met with local stakeholders including members of the media, societies, and the Ministry of Health. Role-playing exercises were facilitated between responders and stakeholders in which participants were paired and took turns assuming the other's role for the outbreak response. The exercises helped everyone better understand and appreciate the various roles played by members of the groups.

escort, they should communicate that they are there only to help respond urgently to the outbreak and are not there in a military or law enforcement capacity (16).

2.4.   Provide resources and information to act.

Treating communities with respect requires that frontline workers provide information to individuals, households, and community leaders needed to protect themselves. For example, if a CHW's responsibilities include distributing bleach, buckets, and gloves to households where an Ebola outbreak is occurring, workers should also assess if water is easily accessible, communicate what dilution of bleach should be used, how, when and where it should be used, when gloves should be worn, and what other precautions members of the household can take to protect themselves.

"My own challenge in my community was going around telling the people about hand washing. Most of them will say that you came to tell me about washing my hands, but where is the bucket you brought?"

Health worker, Liberia

Responders to outbreaks in low-income settings will likely encounter situations where it is not possible to provide resources to all who need them. It may be necessary to prioritize resources initially to groups that are at highest risk while taking steps to expand access for others to all relevant resources. In the interim, engage the community and share information about the situation to encourage community leaders to propose solutions, and continue to share information about any practices that will minimize risk of spread, even without resources.

2.5.   Respect privacy and confidentiality before, during, and after conducting frontline containment activities.

Routine clinical practices may compromise privacy and confidentiality regarding who is or is not infected. Confidentiality can be protected by sharing only the names of contacts and suspected contacts on a need-to-know basis and not recording contact information in easily-accessible documents. It may be important to develop outreach strategies that help protect confidentiality, such as visiting *all* households, not only those of suspected cases, to avoid causing suspicion. Taking time to adequately protect confidentiality might be perceived as an unnecessary delay in information sharing during an outbreak, yet implementing strategies that minimize breaches of confidentiality and the perpetuation of rumors will likely facilitate the response in the longer term. As needed, share the importance of and ways to practice confidentiality with colleagues, government ministries, community-based organizations, healthcare and field workers, and media.

2.6.   Include psychosocial support for all involved in the response.

Outbreaks will predictably induce fear, uncertainty, panic, denial, emotional trauma, and migration to other communities. Outbreak response teams entering communities are likely to encounter individuals who have recently experienced or are currently experiencing some form of psychosocial stress. Experiences with previous Ebola outbreaks suggest that interactions between teams of outreach workers and local communities can be enhanced when psychosocial support workers and, if possible, survivors are included as

part of the team (16-19). Including individuals who know what affected communities are experiencing and who are trained to handle distress and fear can mitigate negative responses to outreach teams and minimize harms of psychological stress for both community members and health workers.

2.7. Support two-way communication and feedback between managers and affected communities.

Frontline workers serve an important role in *listening* to communities and providing feedback about what is and is not working, what questions communities have, and how communities perceive the response. Responders should proactively solicit feedback from community members and in turn convey what they learn from individuals and households to response managers; managers should be prepared to adjust or change frontline containment activities and messaging as necessary.

Traditional communities will not necessarily welcome newcomers without the permission of the Chief/community

"We had very capable autonomous managers at local levels to really sort out a lot of the very complicated material gaps in the response so that, for instance, when there was a report that there was a funeral and a bunch of people washed the body, rather than just saying, "We need to deploy more educators on why that shouldn't happen," we could have these community health workers explain, "Well, actually, they called for a burial team to pick up the body and the burial team didn't come for 48 hours and so they were deciding what to do and they ended up washing the body because it just seemed so disrespectful." We could then use that information to advocate for faster burial teams. So there's this very interesting feedback loop that came out of this approach that I think was very helpful at trying to figure out what actually was going on in communities…"

NGO Worker, Sierra Leone

leader or the endorsement of a trusted opinion leader. By creating an open and interactive dialogue with community leadership, local techniques for containment can be identified and encouraged. For example, it was through these interactive sessions during the Ebola outbreak in Liberia that an international NGO determined that the burial teams working in Muslim communities had to be comprised of Muslims, so that bodies would not be touched by non-Muslims. The creation of Muslim burial teams greatly reduced resistance to body collection in these communities.

2.8. Support resolutions between responders as conflicts arise.

Disagreements might arise between national and local authorities, external public health authorities and local experts, or local authorities and community groups. Expect that there will be disagreements and distress at multiple levels of the response. Factual and moral disagreements are common. While it is best to facilitate a discussion between groups holding divergent views, there are times when responders should take a side. Transparent communication by a trusted source about what is known and unknown can help mitigate factual disagreements. For factual disagreements, the known and agreed-upon evidence should be available and weighed by all sides. For moral disagreements, there may not be a factually 'correct' response, but managers should get as much local input as practical, and attempt to settle the issue as democratically as possible. If consensus (which may be based on tribal identity, resource allocation, the scale of containment measures or any number of other sensitive or power-based issues) isn't possible, managers need to try to understand the

basis of the disagreement and what makes the most sense in terms of disease containment in order to keep work moving. When disagreements are moral in character response managers should try to provide equal access to information to all parties.

Checklist: Interacting with Local Communities During Public Health Containment Activities

Workers involved in health education, surveillance, case-finding, contact-tracing, ambulance driving, and other community health measures become the face of an outbreak response to affected communities. Through interactions with community members, these frontline responders can influence people's perception of the overall response.

☐ Go with local leaders into communities to understand how to appropriately **demonstrate respect**.

☐ Establish a **local task force or other formal mechanism** for community members to regularly communicate with local, national, and foreign leaders in a decision-making role.

☐ **Inform communities** about when, why, how, and for how long containment activities will be implemented.

☐ **Communicate the team's role, scope and limit of** their authority with local leaders and community members.

☐ **Provide actionable information** about the steps community members should take to protect themselves.

☐ Develop a strategy that **protects confidentiality**.

☐ Include **psychosocial support** workers on the response team.

☐ **Listen to community members' concerns** and make notes to inform decision-makers of on-the-ground challenges.

☐ Use short fact sheets to **regularly update the local media** on disease transmission, prevention and where to go for care and treatment (if available).

Chapter 3: Outbreak Communication and Messaging

Introduction

Communication campaigns are critical to outbreak containment; they can foster broad adoption of infection prevention and control practices, encourage health-seeking behavior, and keep the public informed of new information and evidence as it becomes available. Establishing an informative, trustworthy dialogue with the public can enhance the likelihood that messages will be well-received and acted upon by individuals and communities. This chapter discusses considerations for planning and implementing communication campaigns and messaging in these contexts.

Key Contextual Considerations
• Communication infrastructure might limit the ability to reach rural populations.   • There may be many local languages and dialects spoken in affected communities.   • Limited trust in government, outside experts, and/or Western institutions can undermine the credibility of messages from these sources.   • Local norms can have significant influence on the interpretation and acceptability of messages.   • Local media may not be fully informed or may want to sensationalize events
Key Ethics Considerations
• **Promoting good and avoiding harm** requires providing actionable information, based on emerging surveillance and facts, about how individuals and communities can protect themselves.   • **Justice** requires making efforts to reach all at-risk communities in a language, level, and format they will understand. This includes bridging infrastructure gaps and targeting age-appropriate and literacy-appropriate messages, using appealing and helpful formats and modalities.   • **Respect** can be enhanced by engaging local spokespersons and representatives of target populations to help ensure that messages and outreach strategies are in alignment with local norms and are perceived as trustworthy.   • Wherever possible, communications should be pilot-tested, to ensure they are **respectful**, do not exacerbate stigma or shame, and are understood as intended, **to promote good and reduce harm**.

General Resources for Communication Campaigns and Messaging during Outbreaks

This chapter draws from two widely referenced sources: the WHO Outbreak Communication Guidelines (20), and the Crisis and Emergency Risk Communication Guidelines of the Centers for Disease Control and Prevention (CDC) (21). This guidance further endorses the good practices of risk communication developed by WHO specifically for individual-level risk communication with Ebola outbreak survivors (22). These recommendations are reiterated and further specified below to uphold commitments to local ownership and to demonstrate ways of acting with fairness, respect, and compassion throughout campaigns. Key recommendations from these documents include:

> "[NGO] supported local leaders to talk to the people in their own languages. Before that, people were not taking anything into consideration. Health workers were dying. Traditional healers were dying because the prevention was not [working] … *Don't touch one another. Don't eat with someone*…But these things were to be explained to people in their own language…People responded to their own leadership. People respect their own leader. And these messages were taken from their own traditional leadership. That's how we were able to conquer Ebola."
>
> Paramount Chief, Liberia

a. Communication campaigns should include mechanisms to *listen* to the public; learn about public attitudes, fears, and beliefs about outbreaks; and collaborate with those directly affected when developing messages and materials.

b. Teams should gather feedback about draft communication messages, and make improvements.

c. Communication campaigns should be transparent, honest and describe any limits on what will be disclosed.

d. Communication campaigns should identify the channels of communication, which messages will be communicated, where, and why.

e. Communication should start as early in an outbreak as possible, acknowledging uncertainties, emphasizing what is known, and emphasizing that information may change as the outbreak progresses and new information is learned.

f. Messages should avoid fear-mongering as well as over-reassurance, focusing on providing actionable information for communities at risk to protect themselves and their families.

g. Communication campaigns should gather information to understand how affected individuals and their families perceive their risk of infection and identify their main concerns. These concerns should be elicited as part of a conversation, before giving advice or instructions, and provide opportunities for community members to ask questions.

h. Responders should work with community-level health workers, local media, volunteers and other groups and adapt advice as needed (e.g., content, language, modes of delivery).

3.1. Design communication campaigns so messages reach all individuals and communities at risk, in a language and format they can understand.

Rather than acting independently, managers should work with *key community contacts* to ensure messages are communicated in locally appropriate ways—with the right spokespersons, using the right words, and

through the right formal and informal channels—to improve relevance, understanding, and impact. In settings where formal government structures and authority figures have a reputation for being unfair or disrespectful to many communities, identifying alternative means of communication is especially important. To ensure clarity of message delivery, establish a protocol in which only one voice is authorized to speak for the organization. Know who on the response team is authorized to speak to the media. Prepare statements ahead of time.

Rural populations might be particularly vulnerable to exclusion from public health messages—and thus at greater risk of infection spread or care delays—due to limited communications infrastructure and local language differences. Deliberate efforts to extend messaging campaigns into hard-to-reach areas in local languages and locally relevant formats for subpopulations who might be at risk are necessary to uphold commitments to justice and avoid further disadvantaging these communities.

3.2. Identify mechanisms to create appropriate messages.

Outbreak related messages must be culturally appropriate and understandable. It is incumbent upon response workers to understand what individuals and communities believe about the disease, their fears, their questions, and how messages are being understood in order to craft what and how information should be provided or corrected. Messages to be widely disseminated should be pilot tested, and there should be mechanisms to get feedback from those in the targeted community. Abridged Knowledge, Attitude, and Practice surveys, rapid assessments, active listening by managers and staff, and use of creative strategies to share information often contribute to an effective response strategy. Radio call-in shows, street theatre, educational sessions in clinic waiting rooms, church gatherings, and town hall meetings present opportunities to hear what people are thinking and experiencing.

Acknowledging and quickly addressing concerns of local communities with evidence-based information is critical, especially if what individuals understand is inconsistent with best evidence. Those in charge of the response should keep in mind that an ethically sound and effective response will be facilitated by making efforts to appropriately allay fears, to be transparent about what is happening, to provide actionable prevention measures, to ask for volunteers if needed, and to let communities know when and where care and treatment measures are being provided. The content of these interactions with the affected community will provide further guidance on what additional or modified messages should be generated from outbreak responders.

3.3. Ensure messages are honest, transparent, evidence-based, actionable, and regularly updated.

"They said it does not have cure, so it's only with the grace of God that you will go [to the treatment facility] and come back. I never had the confidence that I will ever live again."

– Ebola survivor, Liberia

Timely, accurate communication during outbreaks is often challenged by high levels of uncertainty. Messages should be clear (23), informed by evidence, and regularly updated as more data becomes available. It is important to emphasize early in the outbreak response efforts that information may change with increased evidence-based knowledge.

Provide specific, *actionable* information about what individuals can do to protect themselves and their family members. This both reduces harm and also demonstrates respect by empowering individuals to have some control over their well-being. It is particularly important in low-income settings, responding to a widespread outbreak such that individuals may need to be more self-reliant in containing the spread of disease.

How can messages reflect commitments to honesty, transparency, and learning while still projecting competency and control?

"I chose to begin each daily briefing with a message, 'This is what we know…' By emphasizing what we know, even as new evidence became available and changes were made, I was able to create a consistent tone, remain honest and transparent about the situation and allow the messages to adapt as new information was learned…"

Ministry of Health Official, Liberia

Do not disseminate action messages that are not actionable:

There are times when messages are delivered to communities with no means to act on them, particularly early in an outbreak. During the 2014-2016 Ebola outbreak, people were instructed to call a hotline to have a burial team bury their loved one(s). Community members would call the hotline, and after waiting for three to four days for the team to come, they buried the deceased themselves. During the Zika outbreak, women were told to not get pregnant, but in many affected countries condoms were unavailable. Typically, these situations are ameliorated within a short period, but communication campaigns should be sensitive to the realities on the ground.

3.4. Ensure that messages do not perpetuate stigma or single out groups unfairly.

Outbreaks often lead to stigmatization of those thought most likely to transmit disease. Accurate information must be provided on how to reduce one's risk of infection while caring for individuals who appear sick. Messages should refrain, however, to the extent possible, from singling out subgroups as high-risk, or attributing disease to bad choices or to people from a certain region, class, tribe, or religion. To minimize stigma, emphasize the facts relevant to the cause of disease and to risky behaviors and correct misinformation about modes of transmission or subpopulations. For more strategies to combat stigma and

discrimination, see the [CDC Crisis and Emergency Risk Community Checklist for Inhibiting and Countering Stigmatization](24). Using fear in communication campaigns can heighten anxiety, misinformation and stigma (25), whereas expressions of empathy acknowledge individuals' fears while not feeding into them. National and community leaders can allay fears by making a 'media event' of getting tested, visiting those who are sick, and showing how they personally are operationalizing prevention measures such as hand washing, wearing a mask or gloves per recommendations, advising friends, avoiding crowds, or other measures.

3.5. Pilot test messages before broadcast, even in urgent situations.

Pilot testing is recommended for all health messaging and communication campaigns, yet shortcut strategies might be needed in the urgency of an outbreak. Even when a manager has little time to respond, running a message by local colleagues or local stakeholders who best resemble the target audience will provide useful information to better tailor the message. Failure to pilot test can result in messages that are misunderstood, inconsistent with local norms, or use confusing or potentially offensive words, leading to ineffective or even counterproductive messages.

How to Avoid Fear-Mongering when Messages Can Indeed Be Frightening

The Centers for Disease Control and Prevention's [Crisis and Emergency Risk Communication](#) tips offer some simple strategies for effective communication to populations that are rightfully afraid. These include:

- Using expressions of empathy
- Displaying honesty
- Telling the truth and focusing on what you know
- Giving people things to do
- Using positive terms
- Refuting negatives without repeating them
- Refraining from over-assurance

For the full list of tips, see: https://emergency.cdc.gov/ cerc/resources/pdf/basic_cerc_zcard.pdf

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3.6. Listen to and counteract rumors through frequent messaging.

Rumors can perpetuate fear and stigma. During the Ebola response in Liberia, there were rumors that ETUs and hospitals were removing organs and sending them to the West, that the United States brought Ebola, that Ebola came from the ETUs, and that people should bathe in salt water. During the 2003 SARS epidemic in China, many rumors circulated, including one that held firecrackers would keep the "evil SARS spirit" away (26). Rumors can be identified by observing social media posts and by asking community members why they think the outbreak is happening, what they think about the response strategies, and what people are saying about the response efforts. Managers should regularly ask frontline workers what they are hearing.

Counteract rumors frequently and in repetition, for example through daily briefings and updates of what is known and unknown throughout the response. To the extent that rumors bear some truth, they should be acknowledged with empathy and through transparent messaging.

Checklist: Communication and Messaging

Communication campaigns are critical to outbreak containment: they can encourage adoption of health-seeking behavior and infection prevention and control practices, and keep the public informed of new information as it becomes available. Establishing a trustworthy dialogue with the public can help ensure that individuals will receive and act on messages.

- ☐ Develop and pre-test **messages and communication platforms**.
- ☐ **Review messages** to ensure they do not unfairly single out specific populations or groups, especially those who might be social marginalized. Talk about specific behaviors, not specific people.
- ☐ Develop and continue **anti-stigma campaigns** throughout the outbreak and recovery.
- ☐ Coordinate with local leadership to ensure that messages reach **rural communities**, and are communicated in **local languages** and **user-friendly formats**.
- ☐ Hold regular **feedback sessions** with field workers to hear about how communication campaigns are going.
- ☐ **Pilot test messages**, even informally, for local understandability and acceptability.
- ☐ Provide **local media** with text or bullet points at the outset and as the response continues.

Chapter 4: Special Considerations for Isolation, Quarantine and Social Distancing

Introduction

Isolation, quarantine, and social distancing are very effective public health containment measures intended to reduce the spread of highly infectious diseases by minimizing the possibility of transmission between infected and non-infected persons. ***Isolation*** refers to separating people who are sick with a contagious disease from people who are not sick to protect uninfected people from exposure to the illness. ***Quarantine*** separates and restricts the movement of an individual who may have been exposed to a contagious disease, but shows no symptoms. The goal is to more closely observe the exposed person to see if he or she becomes sick to avoid spread to others. ***Social distancing*** primarily refers to community-level efforts to restrict when and where people gather together to prevent or slow the spread of a contagious disease, such as closing schools, shortening market days, or postponing church events or festivals. The term can also refer to *personal distancing* directives that establish a minimum distance between individuals.

Isolation, quarantine, and social distancing should be considered only in very specific circumstances, where diseases have high mortality or morbidity and spread relatively easily, usually through air, by touch[1] (27) or through fecal-oral routes. The duration of quarantine will vary depending upon the disease. For diseases with long periods of pre-symptomatic transmission, it becomes increasingly difficult to identify and maintain restrictions for what are likely numerous exposed contacts. Conversely, diseases with short pre-symptomatic periods allow little time to identify contacts before exposed individuals become sick and transmit disease (28). Once the decision to implement a restrictive measure is made, a further decision is whether it should be mandatory or voluntary. There is robust literature on the ethics of implementing these liberty-limiting measures, particularly for isolation and quarantine (29-35). These documents outline conditions that must be met if containment measures are to be implemented, including the provision of adequate food and water, ensuring safe and humane conditions for those confined, identifying mechanisms to care for dependents, and establishing fair procedures for making decisions about affected individuals and households.

In low-income settings, implementing these measures is especially challenging. For example, the ability to provide an individual's basic needs while confined might be compromised. However, in some cases, confinement through isolation or quarantine might lead to greater access to necessities and medical care than persons might otherwise receive. Even when basic needs are being adequately met, those implementing a response should be sensitive to whether the ethically required provision of food to those being isolated creates resentment among community members who do not receive these benefits. While such tensions in no way eliminate the responsibility to care for those whose movements are restricted, local input on what should fairly be provided, as well as how to explain why these provisions are being made available, is important. Enforcement of isolation, quarantine, or social distancing directives are sometimes delegated to

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[1] For example, in the United States, the authority of the Centers for Disease Control and Prevention to enforce isolation and quarantine is limited to only certain diseases, including infectious tuberculosis, plague, smallpox, yellow fever, VHFs, severe acute respiratory syndromes, and pandemic influenza.

the military in areas with limited personnel or logistics capacity, potentially undermining what is often already a fragile trust between citizens and government. However, in countries where the military has the capacity to support containment efforts, they can be an asset to the response. Liberty-restricting measures should be based on the best available evidence and never used when a less restrictive approach would be equally effective. Public health officials should clearly communicate the rationale for restrictive measures, acknowledge uncertainty when it exists, and revise directives as new information becomes available (5, 9).

This chapter first summarizes existing ethics guidance related to decisions to implement isolation, quarantine, and social distancing, and then offers additional recommendations to reinforce and further contextualize recommendations for low-income settings.

Key Contextual Considerations
- Background levels of poverty and economic vulnerability can increase the harms of isolation, quarantine, and social distancing, further disadvantaging poor, marginalized populations.   - Resource scarcity can undermine the ability to provide basic material needs to individuals and households restricted by isolation, quarantine, or social distancing directives.   - Post-conflict settings may be quick to revert to military involvement, and a sense of heightened risk among the population may exacerbate power, tribal, land, or other rivalries that were overt during the conflict. Settings with post-conflict histories might be overly quick to revert to military involvement; attention to evidence and whether interventions will be effective and justifiable will be particularly critical.   - There may be a lack of trust between those who are marginalized and those providing care.

Key Ethics Considerations
- Isolation, quarantine, and social distancing are highly effective strategies at preventing transmission however they will be less effective when material needs cannot be provided; decisions of whether to implement such measures should balance the expected benefit with consideration of social factors influencing effective enforcement.   **Promoting good and protecting from harm** requires that isolation, quarantine, and social distancing directives be accompanied by robust surveillance systems, including valid diagnostic and contact-tracing capabilities, to identify sick persons quickly and accurately.   - Those responsible for enforcing isolation, quarantine, and social distancing directives should uphold commitments to **respect** by recognizing the basic human dignity of everyone, especially when restrictions on movement, loss of autonomy, or severe illness can lead to feelings of disempowerment and despair.   - Understanding when a restrictive measure should be *lifted* is just as important ethically, as determining when it should be implemented. Transparent communications should describe in advance the circumstances in which it will be lifted, assuring the public that restrictions are not sustained beyond when they provide important public health benefit.

Review of Existing Guidance

Ethics guidance related to isolation, quarantine, and social distancing exists in the context of control of SARS, pandemic flu, tuberculosis and other highly infectious outbreaks (36, 37). The key components of existing

guidance are repeated here, recommending that enforced isolation, quarantine, and social distancing should occur only when:

a) There is strong epidemiologic evidence for an expected public health benefit;
b) Legitimate legal authority is trained on how to respectfully enforce these conditions;
c) The magnitude of expected benefit outweighs the infringement on rights and liberties that will occur;
d) There is no feasible alternative, less restrictive approach that would similarly protect the public from risk of infection;
e) The basic material needs of those undergoing isolation, quarantine, or social distancing are met subject to available resources;
f) Protections from loss of jobs or income are available or appropriate compensation provided;
g) Protecting the health information and bodily privacy of affected individuals and households is prioritized to minimize stigmatization; and
h) There are mechanisms for affected households to appeal quarantine and isolation directives.

The considerations below are intended to reinforce and contextualize the above guidance for settings where system and resource constraints might undermine the fulfillment of the above conditions.

4.1. Implement isolation, quarantine, and social distancing only when there is a strong epidemiologic reason to expect significant public health benefits and when no less restrictive approach would achieve the same benefit.

Restrictive measures can be very useful strategies to prevent disease transmission, especially when transmission is not understood or treatment measures are lacking. The use of quarantine and isolation needs to balance the restrictive measure with the risk of transmission, the vulnerability of the population at risk, and the severity of the infection. If the risk to the population is significant and there are no other prevention measures, the strategy can be lifesaving. However, uncertainty, fear and panic can lead to inappropriate use of restrictive measures (38).

Isolation and quarantine should be considered when there is a strong epidemiologic reason to believe they will contribute to interrupting the spread of disease. Restrictive measures can be helpful in preventing further harm, and additional considerations should always be considered, such as how a person being isolated will have access to food, water, and communication with loved ones. Restrictive measures should not be conflated with, nor are they a substitute for, treatment. Isolating someone in an ETU and providing comfort measures should not be equated to providing treatment if no treatment is available, but isolation may prevent others from getting the disease when there is no therapy.

When isolation and/or quarantine is necessary, those isolated or quarantined should be offered a choice of isolation/quarantine at home or in a separate holding facility if reasonable given what is known about the infecting agent, its transmission and the associated consequences of infection; for many, home isolation will feel less restrictive than isolation elsewhere. Even for social distancing, it may be less restrictive to close certain establishments (e.g., schools) than others (e.g., markets). Transmission networks should be considered in deciding when and if to close establishments (39). Considerations of closure or limiting the

amount of time a store is open should take into account what services the community can't do without (i.e. a clothing store might close whereas a grocery store stays open). There also may be strategies to reduce social contact without closing businesses, such as staggered market hours, fewer market trips per household per week, messaging to limit physical touch, or delivery schemes.

4.2. Ensure there is timely, reliable access to basic material and communication needs for individuals and/or households subject to either isolation or quarantine.

Whether or not to quarantine or isolate must include consideration of whether food, water and other basic needs are available for those quarantined or isolated. [2] Those with authority to enforce isolation or quarantine are responsible for ensuring this happens either directly or through managing alternative providers. When resources are not available to meet basic needs, they must create a plan for immediate resource delivery and distribution to justify initiating isolation or quarantine.

Personal hygiene products as well as regularly offering to call family, send messages, or help with other means of communication with family and friends also should be provided. If there is no reasonable expectation that basic material needs can be provided, isolation and quarantine are unlikely to be successful in limiting movement as

What are "basic needs" for those asked to submit to quarantine?

Required immediately:
- ✓ Food sufficient for length of quarantine
- ✓ Water sufficient for drinking, bathing, washing clothes/dishes, and cooking
- ✓ Mechanisms to communicate with loved ones
- ✓ Essential medications to treat existing and underlying conditions
- ✓ Access to care if/when symptoms develop
- ✓ A source of light

Required as soon as feasible:
- ✓ Items upon which individuals are physiologically dependent (e.g., caffeine or tobacco products)
- ✓ Psychosocial or mental health support

What if the entire community does not have regular access to food, water, and material needs?

In many LMICs, inadequate access to food, water, electricity and other basic material needs may exist as a normal background condition in communities. However, the status quo does not make it acceptable to fail to provide basic material needs to those whose movements have been restricted. Providing these supports only to individuals and households subject to isolation, quarantine, or social distancing may create an inequity within communities that can undermine the effectiveness of these measures and result in communities breaking restrictions to share, sell, or otherwise access materials or exchange them with others. Further, it may create an incentive to report oneself as a contact or suspected case to access materials. Decision-makers, in consultation with trusted local informants, should consider in advance how best to handle the challenge of meeting the basic needs of those subject to isolation, quarantine, or social distancing in a background of scarcity.

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[2] For additional guidance on minimum standards in humanitarian response, see "The Sphere Handbook" at: http://www.spherehandbook.org/

affected persons might breach their isolation or quarantine to obtain them, and restrictions should not be considered. Alternative strategies that make allowances for individuals to buy or trade food, obtain water, and meet other basic needs should be considered; family members can either bring those items personally, pay for them ahead of time or, as they did during the Ebola outbreak, communities can organize to collectively provide meals to those who are in isolation or quarantine along with alternative strategies such as social distancing to limit transmission.

4.3. Implement isolation, quarantine, and/or social distancing only when they can be done fairly and in ways that minimize stigma.

Upholding a commitment to justice requires treating like cases similarly, yet ensuring equitable implementation of unpopular policies can be challenging. In most environments, there are political or social norms that allow wealthier or more politically connected individuals to "buy" themselves out of or otherwise get exceptions to mandatory policies. Inequitable implementation, or the appearance of it, is not only unfair, but also can undermine the effectiveness and legitimacy of the response, limiting communities' willingness to comply with public health measures more broadly. Equitable enforcement requires sufficient resources and workers with technical capacity to conduct measures like isolation or quarantine without unfairly burdening households inequitably. If workers are in short supply, local civic and religious leaders may be willing to recruit volunteers who can be trained to help.

"...there was just such an absence of a real public health system and people who were experienced in organizing the type of contact tracing that's needed to do effective quarantining that it seemed somewhat whimsical who was getting quarantined and who wasn't."

NGO worker in Sierra Leone

Prior to implementing quarantine or enforced isolation, outbreak response managers should identify the least advantaged groups in a population and consider how restrictive measures would affect them. While *everyone* subject to isolation or quarantine should have basic needs met and be protected from economic loss, some households will require greater support than others. When resources are scarce, more support will be needed for those who are least well-off, and who have fewer support systems to protect them from being further disadvantaged.

Those subject to restrictions might be stigmatized by others in their community. Information on who is isolated or quarantined can travel quickly by word of mouth or through social media. Responders must keep information confidential but also be aware that community members are often tempted to post on social media. Public messaging should continue to underscore why respecting individuals and their privacy is important. Efforts to enforce a quarantine with signage or other visible markings should be as unobtrusive as possible to achieve the desired goal while not drawing unnecessary and stigmatizing attention to individuals, families, and communities. When isolation, quarantine or social distancing are in place, altered standards of care may be appropriate (e.g., taking temperatures remotely or changing frequency of prenatal or well-child visits). Any workers deployed to enforce the quarantine or to deliver material support should be respectful and avoid any behaviors that contribute to stigma of households and individuals.

Additional strategies to minimize or reduce stigma include quickly responding to and correcting rumors, implementing measures equitably, and making deliberate efforts to communicate—through mass media, individual communication, or other means—the public health rationale for restrictions and when they will be lifted.

Limiting freedom of movement can be particularly harmful for certain populations. Households with children may require access to age-appropriate foods; those who are pregnant, elderly, have a chronic condition, or live with mental illness might need to travel to access services or receive home-based care. Attention to the needs of each household is essential. Previous crises have shown that women and children might be at increased risk for sexual violence while quarantined, particularly when schools are closed as a measure of social distancing (40).

"When we do not have systems in place it is extremely difficult… So while we are pushing quarantine, there were not enough food supplies, or people were struggling in there with lack of water, or economically because their farms had not been going. It became very difficult, especially for people who were not high-risk contacts - for people were just happened to be in the community and that community became quarantined… you start questioning the ethical aspects around whether it makes sense to quarantine everybody or not."

NGO worker in Sierra Leone

4.4.   Show everyday respect and common courtesy to individuals or households subject to isolation or quarantine.

Response workers should enter households only when invited and be mindful of local traditions upon entering. For those isolated in their homes, a caregiver should be designated, equipped with basic resources, and shown how to verbally express caring and compassion to those who are isolated with phrases like "I know this is frightening, but please remember it won't last forever"; "You are doing very well so far;" "It's extremely difficult to stay isolated like this"; and "You are not alone." Caregivers should be shown how to safely care for and clean up after those who are ill. Responders also are responsible for respecting the self-determination of individuals by ensuring continued access to practices or provisions that individuals or communities identify as central to their identity or sense of self, such as providing food that meets specific dietary traditions or ensuring people can pray the way they like.

Public messaging should clearly and consistently explain why isolation, quarantine, and/or social distancing will be implemented, what households will be asked to do, and what supports will be provided. Messaging should further encourage communities to support affected households, and media must be cautioned on the public health harms of and need to avoid sensationalism. At the community level, fieldworkers approaching households to implement restrictive measures should explain why restrictions are being implemented, how household members' freedom of movement will be limited, for how long, and what material and social supports they will be given. It may be helpful to give households in isolation or quarantine a written, official document that describes or illustrates the restrictive

> **What if there is no space to effectively isolate a confirmed or suspected case?**
>
> In many low-income settings, there is limited space to follow through with an isolation directive. Isolation facilities might be full or non-existent; common dwellings may only have a single room, making it impossible to separate sick individuals from others within the home. In such situations, individuals and households should not be left to manage on their own. Basic hygiene kits and evidence-based information on infection prevention and control practices should be provided to minimize risks to other household members and to avoid undermining the dignity of those who have no alternative means of caring for loved ones.
>
> Supporting such efforts should not be offered as a substitute for access to high-quality isolation and treatment facilities when they become available, but rather as a stop-gap measure to reduce potential harms until alternative arrangements become available.

measures in simple terms, in the spoken language of the household. Where possible, it is also appropriate to provide households with mechanisms through which they can provide feedback, concerns, and requests to those with decision-making authority either through regular home visits, having a central place to post concerns, periodic meetings, or designation of a specific person to relay concerns to those running the local response.

4.5. Implement restrictive measures with local community support, enforced by authorized personnel.

Involving local community leaders or representatives in the decision to implement isolation, quarantine, or social distancing measures is essential, as is involving them in the development of specific implementation strategies. Community task forces may be able to play an important role. In Monrovia, Liberia, communities were willing to take a central role in managing the health and safety of quarantined families in the 2014-16 Ebola outbreak through the provision of food and medical supplies, illness surveillance and oversight, reporting, and communication campaigns (41).

When isolation, quarantine, and/or social distancing are being considered, authorized personnel must be identified to enforce restrictive measures. In most settings, this will be an individual from national or local government where the outbreak is occurring (see box). International NGOs or other emergency response organizations do not have the authority to enforce restrictions on the movement of citizens of another country, although they may recommend personal distancing or more informal isolation measures within communities or households.

Should the military be used to enforce a mandatory quarantine?

During the 2014-2016 Ebola outbreak, community members and HCWs had mixed reactions to military deployment enforcing household quarantines and road blocks monitoring movement in and out of cities.

Local governments considering military involvement should, in conjunction with local leaders, consider the following questions:

- How will military use be received by communities?
- How will it be made clear that deployment is to support public health protection and not otherwise to demonstrate use of force?
- Who else might fill these roles and how effective would they be? How would they be received by communities?

4.6. Monitor the effectiveness and acceptability of restrictive measures.

A plan for ongoing monitoring must be in place, to measure the effectiveness of restrictive measures in preventing new cases, and to verify that commitments of material support and responsiveness have been upheld. Quarantine and isolation monitoring plans should include regular "check-ins" with affected households to track public health effectiveness and psychosocial well-being. Managers and decision-makers should regularly seek the input of field workers who will have on the ground, relevant information.

4.7. Special considerations for community quarantine.

Community quarantine refers to restricting movement of a geographically defined group of people where it is suspected that multiple members of the community have been exposed to an infectious illness, with the goal of avoiding spread to others outside of the community. Use of community quarantine should be very rare.

Before implementing a community quarantine, managers must ensure that emerging data suggests it would be effective. Community quarantines are more likely to be successful when self-imposed by the community and basic needs can be met. Responders should ensure that there are sufficient protections for low-risk contacts within the community to keep themselves safe, and identify community leaders who can transmit information about why the quarantine is being implemented, how to obtain resources, and when measures will be lifted.

Checklists: Special Considerations for Isolation, Quarantine and Social Distancing

Isolation, quarantine, and social distancing are public health containment measures designed to reduce the spread of highly infectious diseases. ***Isolation*** refers to separating people infected with a contagious disease from uninfected populations. ***Quarantine*** refers to separating and restricting the movement of those who may have been exposed to a contagious disease but are not known to be sick. ***Social and personal distancing*** refers to community-level efforts to restrict when and where people gather, and establish a minimum distance between individuals. Examples include closing schools, shortening market days, or postponing church events or planned festivals.

Determining whether to issue an isolation, quarantine or social distancing directive[1]

	Isolation	Quarantine	Social Distancing
Disease causes severe illness or has a high risk of death	☐	☐	☐
Disease is relatively easily transmitted by touch, air, or fecal-oral route	☐	☐	☐
Response workers are prepared to minimize and mitigate stigma	☐	☐	☐
There is a legitimate authority trained to enforce the directives equitably	☐	☐	☐
The burden of the restrictive measure will be distributed equitably within and among communities	☐	☐	☐
Alternative, less restrictive measures would be insufficient to limit transmission	☐	☐	☐
There is a relatively short period of pre-symptomatic transmission	☐	☐	
Timely, adequate levels of food, water, and basic material supplies can be provided to individuals and households	☐	☐	
Effects of restrictive measures on material resources and income can be compensated	☐	☐	
Disease has clearly detectible symptoms of infection	☐		
Closure of proposed public space will result in minimizing gatherings of people, rather than cause individuals to gather in alternate places			☐
Benchmarks for re-opening public spaces and ending social distancing measures are identified			☐

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[1] Checklist items informed by the Checklists developed at the Bellagio Meeting for Social Justice and Influenza, available at: http://www.bioethicsinstitute.org/research/global-bioethics/flu-pandemic-the-bellagio-meeting

Considerations for implementing an isolation directive. [1]

☐ **Secure the permission of local leaders** and community representatives before implementing isolation measures.

☐ Ensure that local leaders and community representatives understand **why** the directive is being put in place and **when** or under what circumstances it will be lifted.

☐ Identify ways to appropriately **demonstrate respect and compassion.**

☐ **Confirm identified households** as ones in which a person who is a suspected or confirmed case is residing.

☐ **Identify and acknowledge local customs**, norms, or traditions that might affect the implementation of isolation.

☐ Identify who in the community is least-well off, **how isolation will affect them**, and what additional protections may be needed.

Before leaving a household subject to isolation

☐ **Offer the option** of being isolated in a treatment/isolation facility, if there are any.

☐ Coordinate with local leaders and authorities to make sure individuals will **immediately receive basic material needs**.

☐ Coordinate with local leaders and authorities to make sure individuals **receive items upon which they are physiologically dependent**, psychosocial or mental health support, and protections from loss of jobs or income as soon as feasible.

☐ Explain to the individual and/or household **why the directive was implemented** and when it will end.

☐ Assess whether there is a **designated person** who will care for the isolated individual.

☐ Provide the designated caregiver with **basic hygiene equipment** and personal protective equipment, if available.

☐ Provide the designated caregiver with **training** on how to effectively use PPE and/or hygiene supplies.

☐ Discuss means of **demonstrating care and compassion verbally**, with limited touch, with the caregiver.

☐ Give the individual and/or household an **opportunity to ask questions** and raise concerns.

☐ Provide the individual and/or household with **contact information** for a person to call if they have questions or concerns.

☐ Coordinate with local leaders and the authorities to **arrange follow-up visits** to the individual/household to assess health status and provide psychosocial support.

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[1] Checklist items informed by the Checklists developed at the Bellagio Meeting for Social Justice and Influenza, available at: http://www.bioethicsinstitute.org/research/global-bioethics/flu-pandemic-the-bellagio-meeting

Before entering a community

- ☐ **Secure the permission of local leaders** and community representatives before implementing a quarantine.
- ☐ Ensure that local leaders and community representatives understand **why** the quarantine is being put in place and **when** or under what circumstances it will be lifted.
- ☐ Discuss with local leaders and community representatives **why** the directive is being put in place and **when** or under what circumstances it will be lifted.
- ☐ Identify ways to appropriately **demonstrate respect and compassion.**
- ☐ **Confirm identified households** as having contact with a suspected or confirmed case.
- ☐ **Identify and acknowledge local customs**, norms, or traditions that might affect the implementation of the directive.
- ☐ Identify who in the community is least-well off, **how quarantine will affect them**, and what additional protections may be needed.

Before leaving a household subject to quarantine

- ☐ **Offer the option** of being isolated in a treatment/isolation facility, if there are any.
- ☐ Coordinate with local leaders and authorities to make sure individuals will **immediately receive basic material needs**.
- ☐ Coordinate with local leaders and authorities to make sure individuals **receive items upon which they are physiologically dependent**, psychosocial or mental health support, and protections from loss of jobs or income as soon as feasible.
- ☐ Explain to the individual and/or household **why the directive was implemented** and when it will end.
- ☐ Give the individual and/or household an **opportunity to ask questions** and raise concerns.
- ☐ Provide the individual and/or household with **contact information** for a person to call if they have questions or concerns.
- ☐ Coordinate with local leaders and the authorities to **arrange follow-up visits** to the individual/household to assess health status and provide psychosocial support.

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[1] Checklist items informed by the Checklists developed at the Bellagio Meeting for Social Justice and Influenza, available at: http://www.bioethicsinstitute.org/research/global-bioethics/flu-pandemic-the-bellagio-meeting

Considerations for implementing a social distancing directive. [1]

- ☐ **Secure the permission of local leaders** and community representatives before implementing a social distancing directive.

- ☐ Ensure that local leaders and community representatives understand **why** social distancing is being put in place and **when** or under what circumstances it will be lifted.

- ☐ Identify ways to appropriately **demonstrate respect and compassion.**

- ☐ **Identify and acknowledge local customs**, norms, or traditions that might affect the implementation of the directive.

Before leaving a household subject to social distancing

- ☐ Explain to the individual and/or household **why** the directive was implemented and **when** it will end.

- ☐ Give the individual and/or household an **opportunity to ask questions** and raise concerns.

- ☐ Provide the individual and/or household with **contact information** for a person to call if they have questions or concerns.

- ☐ Coordinate with local leaders and the authorities to **arrange follow-up visits** to the individual/household to assess health status and provide psychosocial support.

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[1] Checklist items informed by the Checklists developed at the Bellagio Meeting for Social Justice and Influenza, available at: http://www.bioethicsinstitute.org/research/global-bioethics/flu-pandemic-the-bellagio-meeting

Chapter 5: Supporting and Protecting Outbreak Responders

Introduction

An adequate, capable workforce is essential for preventing new infections, minimizing death and disability, and addressing other health concerns in a community during an outbreak. Questions of appropriate risk levels to undertake, fair compensation, and rights of healthcare workers (HCWs) are central ethics concerns in containing outbreaks. These ethics questions become more pronounced where resources are severely limited and where health systems do not have basic protective equipment. All workers are entitled to a fair wage, but in many low-income settings, the right of healthcare workers to a fair wage is not consistently fulfilled under ordinary circumstances. Worker strikes in response to unpaid wages are not uncommon; community health workers (CHWs) are not universally paid, and existing wages might not be considered by many to be fair wages. This chapter offers considerations relevant to supporting and protecting outbreak response worker. These considerations should be reinforced with infection prevention and control practices, including sufficient personal protective equipment (PPE) and logistics help.

Protecting Health Workers in Liberia During the 2014-2016 Ebola Outbreak

"A lot of them were never equipped appropriately, whether they be Community Health Workers or ones in the clinic…where that epidemic was happening in [town], the very same day, the gloves in the maternity clinic ran out…so what they did is, they would actually re-use them. They'd take the gloves, put them on the top of the roof, and wait for the rain to come after delivering a baby in the maternity center…. you could say, well that's a systems-level issue, it's a financing issue— and it's all of those— but it's also a 'rights of healthcare providers' issue, especially when in fact it's those workers that have to take the greatest risk."

NGO worker, Liberia

Key Contextual Challenges
• Shortages of HCWs require recruitment and training of additional workforce members and greater reliance on foreign response groups.
• Lack of availability of PPE, particularly early in an outbreak, creates high-risk conditions and fewer means of reducing infection risk.
• Few workers have been trained in infection prevention and control, the care and treatment of those who are contagious, psychosocial skills, and other relevant skills.
• Robust systems do not exist to pay workers in a fair, consistent, and timely manner.
• High levels of poverty and or solidarity to one's community might increase willingness to engage in high-risk work even without adequate training, protective equipment, and psychosocial support.
Key Ethics Considerations

- **Respect** requires acknowledging and expressing appreciation for responders' willingness to undertake challenging, stressful, and often risky work.
- The duty to **protect from harm** requires that outbreak responders are prepared with training and proper protective equipment. Risks should always be minimized to the extent possible. Only then can one consider what level of risk is acceptable for responders. HCWs should have priority access to prevention and treatments when available.
- **Justice** heightens this priority to protect from harm because response workers accept heightened risks as part of their service. Reciprocal obligations of employers extend to all outbreak responders, whether formally trained in health professions, already on the payroll, or hired temporarily for the response.
- Hazard pay, danger pay, and incentive pay should be determined with commitments to minimize risks as much as possible as part of a **just** response. Managers should also consider how it will impact workers providing other basic services during outbreaks, sustainability of increases in pay, and to what extent they will support workers for whom salaries may be reduced after the outbreak subsides or for whom continuing employment is not possible.
- Outbreak responders might be subject to significant stigma during and post response, increasing the importance of psychosocial support and post-outbreak transitional support.

General Considerations

Multiple ethics guidance documents describe the reciprocal obligations of employers to healthcare workers in the contexts of pandemic influenza and tuberculosis (36, 37, 42). These generally justify the duty of doctors and nurses to provide care during outbreaks by noting the advanced training professionals receive and their commitments to professional codes of ethics (43-45). These same codes however, do not usually apply to community health workers or home visitors. There also is general agreement that these codified duties for professionals are not absolute, and there are many calls to clarify and codify the expectations of healthcare providers during outbreaks (46, 47).

When the key ethics considerations listed above have been addressed, it becomes reasonable to ask HCWs to provide care and, when available, treatment to those who are infectious, and the occupational risk is both minimized and acknowledged as part of the duty to provide care. Further, while the frequency of riskier procedures—such as drawing blood or inserting IVs (in the case of blood-borne diseases)—may be reduced, the duty remains to conduct risky procedures, but to do so safely. If obligations that help reduce risks are not met by employers and governments, and risks are high, HCWs may be justified in not providing care. They should have a robust mechanism to appeal to higher-level decision makers to request that they meet minimum obligations of protection, in terms of both training and equipment. The recommendations below offer additional guidance for what can and should be asked of outbreak responders, and required of governments and employers in such contexts.

5.1. Extend governments' and employers' reciprocal obligations to healthcare workers to all outbreak response workers at high risk for infection.

Outbreak response requires many types of workers to take on different roles in the response, including professional health workers as well as those not generally considered healthcare professionals, such as CHWs, ambulance drivers, contact-tracers, burial workers, and others. While these workers might not have

formal medical training, or be guided by a professional code of ethics, many will take on personal risk in their work out of solidarity with their community and a felt responsibility to help respond. The willing acceptance of risk requires reciprocal obligations to all workers, not only to professional health workers.[3] Outbreak responders should be prepared and enabled to be effective in the performance of their duties through training on infection prevention and control, disinfection practices, and standardized procedures for using PPE (2, 48-51).

5.2. Prioritize making working conditions for responders as safe as possible; only then can questions of hazard pay be considered.

While outbreaks create higher than usual levels of risk, money cannot substitute for protection from risk, even when outbreak response workers express willingness to work in risky environments. Managers have a responsibility to allocate protections such as PPE, additional training, and rest time to ensure that workers' risk of infection is reduced to the maximum extent possible.

Considerations for Setting Hazard Pay in Low-Income Settings

Hazard pay can be an appropriate mechanism to recognize health workers' acceptance of higher levels of risk. Yet, where background conditions are characterized by significant under or intermittent payment of workers, hazard pay may particularly be seen as undue inducement. The following considerations should inform the development of hazard pay policy in low-income settings:

- Hazard pay, regardless of its magnitude, never absolves the obligation to first minimize risks, whether through PPE, environmental protections, training, or other strategies before asking workers to respond.
- Hazard pay should not take the place of a fair, regular wage. In settings where previously employed workers may not be receiving a regular wage, hazard pay should not become a substitute.
- Hazard pay is in most cases a finite raise in pay limited to the duration of hazardous conditions. Outbreak response workers should return to a fair, regular wage when hazardous conditions subside, and should be informed in advance of when hazard pay rates will end and basic wages will resume.
- Determinations of the magnitude of hazard pay should consider the degree of difference between basic pay and hazard pay, how local public sector wages compare to those of workers in similar contexts, and wage differences between public sector workers and workers employed by NGOs. All organizations and institutions employing local response workers should harmonize their rates of hazard pay. The NGO Code of Conduct for Health Systems Strengthening offers further guidance on human resource practices for international NGOs with which hazard pay considerations should be consistent.

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[3] In the Ebola epidemic in 2014-16, preliminary data from WHO shows that of all infections in Sierra Leone, Liberia, and Guinea, approximately 33% of infections occurred in non-medical workers, including ambulance workers, pharmacy workers, laboratory workers, community health workers, trade workers and others. Full report available at: http://apps.who.int/iris/bitstream/10665/171823/1/WHO_EVD_SDS_REPORT_2015.1_eng.pdf?ua=1&ua=1

Risks emerge not only from the infection, but sometimes also from community reaction. Outbreak responders might be at risk of violence from individuals in disbelief, who fear the disease, or who are angry at what may seem an inadequate response (19, 52, 53). Managers should try to understand the historical context, including conflicts or trauma that could result in suspicion and distrust as well as constantly seeking feedback on current understanding of the disease and the response. As in every phase of response, managers should engage local leaders, community representatives, and religious leaders to participate in response activities to build trust between communities and HCWs (19, 41, 54, 55).

In addition to hazard pay, national human resources plans and workforce development partnerships should be explored by external agencies and the local government to transition temporary response workers into another livelihood. Temporary workers should be told that they will be hired for the duration of the outbreak only, and recognize their efforts as heroes of the response. In Sierra Leone, temporary workers were given certificates, three months of additional pay, and were honored guests at a celebration attended by the prime minister.

5.3. Prepare and support outbreak responders regarding the psychosocial challenges of participating in the response.

Emergency health situations, particularly those affecting large numbers of persons, provide psychological stressors as well as physical ones. Outbreak response workers will likely encounter situations where they have no capacity to provide the care that individuals need; they may feel they are providing less compassionate care by having to wear depersonalizing PPE; and they may be implementing distancing measures that they know pose psychological or material hardship to those affected. Indeed, psychological and moral distress will

"The men that were doing the cremation are facing serious trauma presently. Some are even progressing to mental illness. … Every time I go to bed and my mind run on that thing, it pains me so much. You give a job to somebody and the job affected that person and you can't really help…"

Health care worker, Liberia

likely be a hallmark of crisis response (56-58); some outbreak response workers will benefit from psychosocial and mental health support throughout and after the outbreak. Having clear rules and guidelines for responders may decrease the moral stress that they take on individually.

Response workers also may be vulnerable to stigma and the loss of social relationships with family, community members, and colleagues if they are perceived as transmitting disease. In previous Ebola outbreaks, HCWs were shunned by family members and their communities, and some were evicted from their homes (2, 59, 60). Psychosocial support from employers or other stakeholders for response workers not only demonstrates compassion, but is also a necessary reciprocal obligation (61). After the outbreak subsides, health sector employees deployed during the outbreak will likely return to their normal responsibilities, and should continue to have access to psychosocial support. Unemployed individuals who took temporary jobs as part of the response may not be retained after the outbreak is over, yet they may continue to experience psychosocial difficulties beyond their period of employment. These workers might be stigmatized due to their role in the response, making it difficult to find new employment. If the responder is from the local area, the local government or participating NGOs should provide or ensure psychosocial support; if the responder is foreign, their employer or home government should provide or facilitate support. Mental healthcare

especially during a time of acutely competing priorities, is a moral obligation and yet it will often fall to the bottom of the list; foreign entities participating in the local response should keep this consideration in mind.

5.4.   Prepare outbreak responders from international agencies for the reality that they will probably have access to more advanced care and support than their local counterparts.

Local workers experience an outbreak as members of their own community or country, while international responders leave their usually lower risk environments to assist with the response. A troubling consequence of the disparities between high- and low-income countries is that responders who work for international organizations or governments of high-income nations will likely have access to more advanced care and treatment options if they become ill than their local country counterparts. High-income countries ensuring adequate and reciprocal protections to their responders will highlight an obvious inequity. For example, international responders may have guarantees from their employers to be airlifted to world-class treatment facilities should they become ill, while local responders may have guaranteed treatment, but in facilities with fewer trained personnel and fewer resources. Both local and international workers should be prepared for this, recognize the tension and distress it can cause, and acknowledge the inequities as a stimulus for change. Honesty, openness, and transparency in dealing with this issue, if it arises, may ease some of the inherent tension and reinforce trust.

> **Do organizations have a responsibility to prohibit workers from taking on exceptional risk?**
>
> In some cases, health workers might feel compelled to take on extraordinary levels of risks, even in the absence of PPE. In the 2014-2016 Ebola outbreak, for example, some doctors were willing to provided needed care to high-risk Ebola patients, including performing high-risk pregnancy procedures with Ebola-infected women. While their actions might be seen as heroic, they may also be viewed as insufficiently safeguarding their responsibility to protect themselves, their coworkers, and their future patients from risk.
>
> *"I think there's an inclination with healthcare workers to take a little bit more risk when there's a baby involved …I've seen people take higher risks than they should have… And I think you have to have somebody at the helm who can say, "These are the rules, and we're not doing this, and if you bend the rules, you go home." And you have to have somebody who remains tough and does that or people are going to bend the rules, and they're going to get sick."*
>
> *– OB/GYN working in Sierra Leone*

"…those poor healthcare workers even if they weren't working in ETUs, how many of their friends and colleagues did they lose? There's just a whole lot of tension that's a very, very thin layer below the surface."

NGO worker in Liberia

5.5.   Special considerations for hiring survivors as outbreak response workers.

Survivors can play an important role in outbreak response efforts. Those who have survived extremely drug-resistant TB can serve as the best role models and teachers to those at-risk. During the 2014-16 Ebola

outbreak, survivors accompanied outreach teams to communities to demonstrate that survival and recovery were possible; they also facilitated communication between families and loved ones in ETUs. Because survivors of the 2014-2016 Ebola outbreak were believed to have some immunity to the virus, they sometimes filled direct support roles to patients in ETUs or individuals isolated in their homes that would be high risk for individuals with no immunity. Nonetheless, as a precaution, survivors should still receive the same level of infection control training as other workers. Further, they might experience psychological sequelae including being re-traumatized by returning to treatment settings. Organizations that hire survivors to participate in outbreak containment should consider what are appropriate roles for each survivor and consider how best to minimize physical, social, and psychological risks. Additionally, employers should be transparent in providing information on what is known and unknown about the outbreak.

Checklist: Supporting and Protecting Health Workers

Ensuring a capable workforce is key to preventing new infections, caring for those who are sick, minimizing death and disability, and addressing other health concerns during an outbreak. Workforce ethics questions regarding appropriate risk levels, fair compensation, and rights of healthcare workers (HCWs) are heightened where resources are severely limited and health systems lack basic protective equipment.

Setting Workforce Policy

☐ Identify existing policies at the local or national level that describe the **expectations of responders** during an outbreak, outlining both what responders are and are not expected to do.

☐ Identify **professional and ethics guidance documents** that describe the expectations of responders during an outbreak, outlining both what responders are and are not expected to do.

☐ Create **workforce policies** if none exist.

☐ Identify or propose policies describing **outbreak responder compensation** and what they can do if they do not receive timely payment.

☐ Identify or create policies that describe the **material and psychosocial support** for outbreak responders and their family in the event of disability or death.

Sending Responders to the Field

☐ **Weigh the individual risk** that outbreak responders will undertake against the likelihood that their proposed activities will contribute to outbreak containment.

☐ Provide outbreak responders with adequate **personal protective equipment (PPE) and training**.

    ☐ If PPE is unavailable, consider how to **minimize risks** through the use of alternative materials, length of exposure, compassionate conversation rather than touch, and environmental design or other strategies. In some outbreaks, masks and gloves alone may be sufficient.

☐ Inform outbreak response workers of which **tasks and risks** they are expected to take on, which are allowed but not required, and which are not allowed.

- ☐ Make **working conditions as safe** as possible and prioritize resources to improve working conditions as they become available.

- ☐ Set **hazard pay** at a level commensurate with risk and offer to all workers who encounter higher than usual risk.

- ☐ Provide **psychosocial support** for all outbreak responders.

- ☐ Provide **transitional support** for temporary outbreak responders, including community level education to minimize stigma, material support to minimize consequences of unemployment, and continued access to psychosocial support.

Chapter 6: Providing Care and Treatment during Outbreaks

Introduction

Providing care and, when available, treatment, is essential for minimizing suffering, death, and disability during an outbreak. Providing care and treatment is ethically required both because it brings relief to those who are sick and because it halts potential pathways of transmission. Yet to be valuable and desirable, care and treatment must be accessible to those affected, interventions must be evidence-based, and care approaches must be implemented in ways that demonstrate respect to patients and families. Particularly early in outbreaks, for example when facilities are crowded and under-resourced, or when it is not yet known which interventions are effective, there may be instances where receiving healthcare is not necessarily better than staying home, providing challenges regarding what messages to provide. In this chapter, we do *not* focus on bedside or clinical ethics challenges such as triage among patients or decisions about whether to use experimental treatments. Rather, we focus on how to incorporate care and treatment into public health containment, the ethical duties of care providers in terms of transparency and respect, and the ethics challenges that emerge when decisions must be made about whether to refer individuals to poorly equipped or understaffed care facilities. In addition, the demands of an outbreak response can threaten already strained health systems, resulting in the neglect of routine but critical health services and care.

Key Contextual Considerations
- Health facilities might be scarce, available only in urban settings with few local medical doctors.   - Health professionals might flee outbreak areas.   - Health facilities might have been sources of prior infectious outbreaks.   - There may be an influx of international responders.   - Poor roads and limited transportation infrastructure challenge the ability to get patients to health facilities as well as family members' ability to be near patients in such facilities.   - Rural, poor, and other marginalized groups will likely face heightened barriers to care related to income, transportation, language, inability to leave their jobs or care-giving responsibilities, or preferences for traditional care providers.   - Non-outbreak related services may be extremely limited.
Key Ethics Considerations

- Providing evidence-based care to patients and their families **promotes good and protects from harm**.
- **Protecting from harm** requires balancing and consideration of which non-outbreak care can be postponed and which should continue in balance with outbreak care.
- Upholding commitments to **respect** requires providing transparent and dignified care to patients and their families.
- **Justice** is upheld when special accommodations are made for the care of hard-to-reach populations, children, pregnant women, and those with mental or physical disabilities.
- A **respectful** response engages community leaders in decisions of how to prioritize resources for outbreak care.
- When possible, resources for outbreak-related care should be allocated to investments that will also provide long-term benefits to the community (i.e., that will improve local capacity to provide routine care or preparedness for future outbreaks).

General Guidance

Clinical guidelines detail the technical aspects of providing care and treatment during outbreaks, although they vary in the degree to which they discuss commitments to equity, transparency, and respect in care, ongoing communication between patients and families, and maintenance of essential services during outbreaks. Ethics guidance in this chapter draws from existing clinical guidance documents (62, 63).

6.1. Provide evidence-based care and treatment to patients and their families.

The best available information and evidence should drive public health practice. Surveillance systems that protect confidentiality, if they don't already exist, should be set up immediately to continually supply accurate, up-to-date data to inform decision-making. Ongoing monitoring (continual) and evaluations (one-off events) must be built into outreach and treatment systems in order to be able to continuously monitor response strategies; response leaders must be willing to act on new information and make changes.

6.2. Invest in strategies to improve equitable access to care and treatment if available.

In many areas of the globe, access to services is different in rural versus urban areas. High quality hospitals and health centers are often concentrated in areas rich in resources while inadequate transportation infrastructure and ambulance supply make access difficult for poor and rural populations. Outreach to more remote areas for surveillance and prevention should also be accompanied by commitments to create additional treatment facilities in these areas; a virtuous process can be implemented to integrate high quality, dignified and compassionate clinical care with public health response activities such as surveillance, contact tracing, testing, support, and reintegration of survivors.

Efforts must be made to bring care and treatment to those who are geographically isolated and difficult to reach. For example, rapid response teams with helicopters or mini-isolation and treatment centers have been used in some settings to reach more isolated populations. The construction of makeshift care and treatment facilities in more rural areas will introduce difficult questions regarding the complexity of care and treatment that can be provided. Altered standards of care may need to be considered, starting with an assessment to determine if a patient should remain at home, be moved out of the home, or go to a treatment center.

Community Care Centers

During the 2014-2016 Ebola outbreak, Community Care Centers (CCCs) were rapidly constructed or put into repurposed buildings to provide basic care and serve as a local holding center for sick individuals waiting for space in Ebola Treatment Centers (4). Local community leaders and chiefs participated in consultations about where to position CCCs, which were staffed by local workers. CCCs were equipped to provide oral rehydration, antibiotics, treatment for malaria (based on clinical presentation), and Ebola diagnostic testing. While less advanced than newly constructed ETUs, CCCs were an important stopgap measure, allowing greater access to care and timely transfer to ETUs when beds became available.

While CCCs proved helpful to many, others expressed concern that they heightened transmission risk, or conversely, that they represented that community's first access to care and would disappear after the outbreak. Clearly, there is a not one-size-fits-all answer for every community. In each case, the decisions should be made locally and driven by the latest available evidence.

6.3. Approach care with a commitment to transparency.

Improving the transparency of the entire prevention, care and treatment continuum enhances respect and reduces the uncertainty and fear that can dissuade individuals and families from seeking treatment or care. Explaining why an ambulance is being called, where it is taking a sick individual, and, to the extent possible, how long patients will be kept at facilities is essential. During the Ebola outbreak, for example, fear and resistance to care-seeking were mitigated by public displays showing the inside of an ambulance and explaining the procedures for cleaning an ambulance between stops. Input from community members on what people think and rumors that are circulating can help to direct what types of information should be shared or demonstrated.

Using literally transparent materials

Previous experiences with viral hemorrhagic fevers have shown community preferences for more transparent materials, from PPE to treatment facilities to body bags. For example, communities have expressed preferences for PPE that allows individuals to see the faces of healthcare workers, use of face shields rather than goggles, and use of body bags with windows. Constructing treatment and/or isolation facilities with transparent materials, half-walls, and safe spaces for visitors is also recommended (1, 2).

Ideally, treatment centers should be built in ways that facilitate families' ability to visit, see, or get regular information about a loved one, including using windows or other see-through materials in treatment units (if consistent with community preferences), allowing local leaders and members of the community to tour treatment centers, and sharing videos of what happens inside a treatment center. These measures may be

particularly important when children are in treatment centers, so parents can better understand where their children are and what is happening to them.

6.4. Prioritize communication and feedback between patients in treatment facilities and their families.

Information sharing is an important aspect of respectful care and treatment. Providing information to families about patients begins with entry into care. Whether a patient is brought in by an ambulance or walks into a heath facility, feedback mechanisms for families must be provided. Information sharing can be improved by taking a cell phone number of a contact for each admitted patient (or his/her family), creating space for visitors at treatment centers, or designating specific workers to maintain communication with family members. For example, during the 2014-2016 Ebola outbreak response in Liberia, ambulances distributed mobile phones with programmed numbers to next-of-kin so they could call and inquire about the status of a loved one. Mechanisms for patients to communicate with families who are not able to come to treatment centers must be identified. ETUs should contact family members to provide information on discharge preparation. In the case of death, safe and dignified burials and funeral rites should be arranged with family members or key contacts.

6.5. Balance outbreak care and treatment with other health needs.

Outbreaks in already strained systems can significantly interrupt the management of other infectious and or chronic diseases, of acute illness and injury, and of ongoing key preventive services such as childhood vaccination, prenatal care, and child and maternal health services (64, 65). Vaccination campaigns can often be made up after an outbreak is controlled through "mop-up" campaigns; however, in areas where substantial effort has been put into promoting childhood vaccination, suspending the campaign could have more negative consequences than conducting it. It will be important to work with local health and community leaders to balance providing care for persons ill with the outbreak infection and providing some essential care for other urgent health needs. Both ultimately will affect a population's sense of security.

What happens when healthy children accompany their parent to an ETU?

"...Everyone was afraid 'Well, if the mom is sick, then maybe the baby's sick,' which is a fair take. Literally what do you do with that baby, especially if they're still breastfeeding? There's no holding area for the children, so there are actually incidents of apparently healthy children being admitted to an ETU where everybody else was in full PPE. Now we've got an unprotected infant or child back there for no other reason than their parent was being admitted and there was nowhere for them to go."

Clinic worker, Liberia

6.6. Minimize psychological triggers of fear.

While responding to an outbreak, simultaneously and constantly considering ways to minimize the fear, urgency, and uncertainty during an outbreak will help minimize avoidable trauma. Communities affected by

> "For me the ambulance is still scary, especially when I hear the sound of the siren."
>
> Ebola Survivor, Sierra Leone

the 2014-2016 Ebola outbreak reported that ambulance sirens, seeing personal protective equipment (PPE) on responders, and the spraying of chlorine created fear. In some instances, there are alternative ways to implement response strategize that allay or minimize fears. For example, simply turning off the ambulance sirens or having workers refrain from donning PPE until after they have entered a community can humanize care and make it less traumatic (66). Even explaining in advance what one is doing and why can be helpful. Responders wearing PPE can be humanized by wearing a name tag with their photo.

6.7. Respect the privacy and protect confidentiality of those who are ill in all aspects of care.

Most outbreak infections carry some stigma. Protecting the privacy and confidentiality of affected persons to the greatest degree possible is essential, balanced thoughtfully with the need to notify specific responders, contact tracers, health care providers and specified family members. Communicating with families by phone, text, or messenger about where sick family members are taken is preferable to public postings of patient names outside treatment units. Windows and transparent materials may increase the risk of a breach of confidentiality, but may still be preferred to allow family members to visit patients.

Consider who needs access to patient information and for how long. To safeguard data, it may be necessary to have local and international staff sign confidentiality or privacy agreements. Individuals with access to patient identifiers and other confidential information should retain such access only on a need to know basis; plans and training should underscore discontinuing access to patient information beyond providers' period of duty on-site. Clinicians rotating in and out of health care facilities should not retain patient records on their personal computers.

6.8. Demonstrate respect and recognize dignity in the provision of care.

Attention to kindness during care is an important demonstration of respect. Providing clean clothes and hot food are challenging, but will help make patients feel more "human," particularly while in an unfamiliar and uncomfortable environment. Ensuring as much human interaction as is safely possible also recognizes human dignity. Allowing religious leaders, with sufficient PPE, to comfort patients, having cell phones for patients to talk to outside family, and hiring survivors to perform direct supportive tasks have been helpful in some

> "…the food they will wait till it is cold before bringing it because they were afraid to come near the holding center, sometimes they will bring it around midnight. I will not have appetite to eat when the food is cold…. I stayed for 6 days at the holding center without a shower, no change of clothes, but when we arrived in [new location], they gave me new clothing, I showered and changed my clothes and they brought me fresh food and I ate well. Then I realized I have come to a place where I can receive treatment, even the encouragement is better…"
>
> Ebola Survivor, Sierra Leone

contexts. These acts also can influence community members' perceptions of the quality of care, relevant to others' willingness to seek treatment or refer others.

> **What is the role of supportive care when the outcome cannot be affected?**
>
> Even when there is no known course of treatment, it is always possible to provide care. Even the presence of a compassionate person nearby can be helpful. Patients should never feel abandoned.

Checklist: Providing Care During Outbreaks

Providing care and treatment is ethically required both because it brings relief to those who are sick and because it halts potential pathways of transmission. For individuals to be willing to come for care, the care must be accessible, based on the best information, and respectful and dignified.

☐   Construct new healthcare facilities near where new infections are occurring to **create equitable access**.

☐   Include mechanisms to **facilitate personal communications between patients and loved ones** at treatment centers, e.g., using transparent materials, half-walls, windows, or adjacent visiting areas.

☐   **Show** community leaders and community and family members what care facilities, ambulances, and outbreak related equipment look like through tours, explanations, videos and photos.

☐   Consider what will make people fearful and **take steps to minimize sources of fear**, such as putting on personal protection equipment only after being seen without it.

☐   Make efforts to **"humanize" care** for patients, e.g., by writing names and posting providers' photos on PPE, constructing spaces for visitors to see patients, providing supportive counseling or prayer.

☐   Create policies that include a **confidential process** to communicate with families and loved ones about a patient's status.

☐   Put policies in place defining **patient information record keeping**, and ensure that temporary outbreak response workers do not retain patient information beyond deployment.

☐   Develop evidence-informed protocols for **care of vulnerable populations** who present with disease.

☐   Involve community leaders and stakeholders in planning for **continuing provision of essential services** during outbreak.

Chapter 7: Supporting Survivors

Introduction

Those who survive an infectious disease outbreak, or whose illness becomes manageably chronic, often experience significant disadvantage. Survivors might experience clinical sequelae, as has been documented for Ebola (67-69), Lassa fever (70), and polio (71), requiring ongoing clinical care and potential psychosocial stress or stigma. Physical and/or mental complications can contribute to an inability to work, or to sustain relationships or previous life activities. Stigma toward survivors might result in loss of relationships, employment discrimination and loss of housing. Illness and social distancing measures might have contributed to interrupted or lost education and livelihood.

This chapter addresses both short-term considerations for survivors after immediate discharge from treatment and longer-term considerations for supporting survivors and facilitating reintegration into their communities.

Key Contextual Considerations
- Survivors of infectious outbreaks might experience significant stigma.   - Stigma might extend to individuals who were associated with someone who was ill (e.g., family members, healthcare workers, and burial workers).   - Survivors' needs for medical, psychosocial and material support will occur in a context where many other populations also have need for similar types of support.
Key Ethics Considerations
- Treat survivors with **respect** and kindness, acknowledging their dignity in the face of the challenging situation they endured.   - Efforts to prepare communities for the return of survivors may be needed (e.g., coordinating with community/local leaders) to share facts and minimize stigma and further disadvantage.   **Promoting good and protecting from harm** requires enhancing the health and well-being of survivors.   **Justice requires trying to protect survivors, who already experienced hardship, from** becoming further disadvantaged. Allocating resources for follow-up clinical and mental health care, nutritional supports, job training and livelihood supports, as possible, will be helpful.   - Commitments to protect all disadvantaged individuals from further disadvantage may require providing support to family members of those who died or became disabled.   - Response workers should be aware that special privileges, payments, or free services for survivors may result in jealousy among those community members who were not infected, but who face the same daily financial difficulties and lack of quality health services that exist under normal conditions.

General Guidance

There is relatively little ethics or policy guidance regarding support and care for outbreak survivors, despite well documented stigma, health complications, and poorer social outcomes for survivors of outbreaks of polio (71), smallpox, previous outbreaks of VHFs (48, 72), and pandemic flu (73, 74). Following the 2014-16 Ebola outbreak, the governments of Liberia and Sierra Leone drafted preliminary policy frameworks aimed at facilitating survivor reintegration into the community. WHO's Interim Guidance on Clinical Care for Survivors similarly highlights considerations for survivors before discharge from care (75). The guidance below builds on existing documents, emphasizing ethics commitments behind emerging frameworks and guidance.

7.1. Ensure survivors have access to clinical follow-up services.

For many diseases, recovery from acute illness is often followed by a period of chronic illness (e.g., paralysis following polio, post-Ebola syndrome), leaving survivors with chronic health conditions requiring ongoing care. Before discharging survivors, response workers should check if normal out-patient services have resumed, or if not, where survivors can go for follow-up care. The severity of an outbreak and the shortage of

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The WHO's Interim Guidance for Ebola Survivors highlights how communicating information about follow-up care requires trust and empathy, and should be offered in language that is easily understood. It offers the following Good Practices for Risk Communication for individuals in the role of communicating follow-up care to survivors:

1. **Try to understand how the Ebola survivor and their family perceive their health** status and identify their main concerns—stigma, inability to find employment, worries about transmitting the disease through sexual contact or from mother to baby, etc.

2. **Elicit these concerns as part of a conversation**, before giving advice or instructions. Provide opportunities, prompted or spontaneous, for them to ask questions.

3. **Use language that is appropriate** for the educational level of the survivor. Explain scientific terms and avoid using jargon; use the language of the survivor and their community.

4. **Use pictures and posters** to reinforce what you say and to provide another way to convey your messages and advice.

5. **Work with community health workers (CHWs)**, volunteers and other groups and adapt your advice as needed (e.g. content, language, modes of delivery).

6. **Engage community leaders**, religious figures and other trusted persons to help you get your messages across and to reinforce the advice given by clinical care personnel.

7. **Find ways to get feedback** on how survivors and their families perceive your communications and make regular improvements to the way you communicate risk.

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trained health care workers can easily disrupt routine service delivery. Outbreak response workers should provide survivors with as much information and assistance about accessing follow-up care as possible.

7.2. Refer survivors to ongoing social and psychological support.

Survivors of highly infectious, serious diseases will often face stigma, loss of loved ones, and dramatic changes in their lifestyle and livelihood opportunities. Survivors may require continued access to psychosocial support and counseling, as well as assistance finding jobs to reintegrate into their communities. Responders should treat survivors with respect, acknowledging their dignity in the face of the challenging situation they endured. In previous outbreaks of VHFs, survivors were involved in containment response, which provided employment, lessened stigma, and served as a way to give back to their communities (76-78).

7.3. If possible, replace property of survivors that may have been destroyed while receiving care or treatment.

Infection prevention and control practices can result in the destruction of potentially contaminated personal property such as mattresses, clothes, and phones, and community fears sometimes lead to the destruction of homes and other personal property. Fair treatment requires identifying or creating the means for survivors to replace needed items.

Country Approaches to Survivor Support and Reintegration

Several countries have developed policies to help survivors reintegrate following outbreaks.

Following the 2000-2001 Ebola outbreak in **Uganda**, the government issued all survivors 70,000 shillings (the equivalent of $40 USD) to compensate for lost personal effects.

During the 2014-2016 Ebola outbreak, **Liberia** developed a comprehensive policy framework for survivor support, which included the provision of free clinical care services, mental health and psychosocial support, social protections, economic support, educational support, legal protection, and ongoing efforts to fight stigma and discrimination. The framework called for the involvement of survivors in the design, monitoring, and implementation of survivor care and support programs; community engagement to aid in survivor reintegration; media engagement in fighting stigma and discrimination; data management efforts to ensure accurate, up-to-date registries of survivors and organizations that provided survivor support services; research and documentation of long-term health outcomes of Ebola survivors; and enhanced coordination between partners involved in survivor recovery.

A presidential mandate in **Sierra Leone** stated that all survivors of the 2014-2016 Ebola outbreak should receive free health care in government facilities and was funded by the Department for International Development (DFID) through 2017. An additional policy is being developed that, once passed in parliament, will ensure all survivors continue to receive free health care in government facilities.

7.4. Prepare communities for the return of survivors from isolation and care facilities.

To minimize the likelihood of survivors being shunned by their communities, it is important for local community leaders to be engaged in messaging and to create public announcements through radio or other media to prepare communities for the reintegration of survivors. This includes communicating accurate

information about the health and lack of risk presented by survivors and publicizing images of important or highly recognized figures hugging or shaking hands with survivors. Stigma and discrimination can be further mitigated when local CHWs work with local leaders to communicate survivors' lack of risk.

> "Sometimes, when the patient is treated and recovered, the ambulance can just drop the person without informing the family that the person is well now or showing the certificate to them."
>
> Health worker, Liberia

7.5. Collaboratively develop a plan for allocating and distributing material supports to survivors and affected communities.

Commitments to protecting survivors from further disadvantage require providing material support, as possible, in response to health needs and the loss of income, employment, social connections, and missed education Yet, in contexts of high poverty —or where communities were also harmed economically by the

> "…people were really desperate to be known as survivors even with the stigma and the shame that came with it because they wanted access to these financial benefits…"
>
> NGO worker in Sierra Leone

outbreak— providing benefits to survivors can create inequities between survivors and others who lived through the outbreak. Communities will need to wrestle with how they define "survivor," with options ranging from narrower definitions of those who tested positive for disease and survived, to those who were suspected of being ill and were taken for observation, to broader definitions including being a family member or neighbor of a survivor. All of these groups might have experienced stigma and further disadvantage following an outbreak.

Determining who ought to receive support, how much, and for how long involves careful reasoning about what fairness requires, particularly in accordance with local norms:

a) **Decisions about what support to provide, to whom, and for how long should be made inclusively,** with opportunity for survivors and other affected community members to provide input.
b) **Providing material benefits *only* to individuals who survived the disease should be justified in a way that others agree is fair**. For example, providing nutritional supplements to survivors, but not others in the community, may seem justifiable given the unique nutritional needs of someone recovering from a particular disease. However, it may also be reasonable to provide the same benefits to all experiencing a nutritional deficit. Such determinations need to take available resources into consideration. Other forms of support may include income generation and employment. In contexts where there are few additional resources available for anyone, limiting material support to survivors may be difficult to justify.
c) **Any provision of material support ought to be provided with transparency** about who is eligible, why they are eligible, what they will receive and for how long they will receive it. Non-infected members of the community should be treated with the same levels of kindness, respect, and transparency in decision-making as those who were ill.
d) **Material support should be withdrawn gradually** and with ample notice. Recipients of material support should be reminded at regular intervals about the length of time for which they will continue to receive such support.

Checklist: Supporting Survivors

Survivors of infectious diseases and people who develop chronic illnesses from an outbreak often experience significant disadvantage. Survivors (e.g., from Ebola, Lassa fever, TB) might experience clinical sequelae, requiring ongoing clinical care and potential psychosocial stress or stigma. Physical and/or mental complications can contribute to an inability to work, or to sustain relationships or previous life activities. Stigma toward survivors might result in employment discrimination and loss of housing. This checklist addresses both short-term and longer-term considerations for survivors, including facilitating reintegration of survivors into their communities.

Before Sending Survivors Home

☐ Research the availability of routine out-patient care services. Determine the nearest site where survivors can get follow-up care.

☐ Provide the survivor with **information** about recovery and how to get follow-up care.

☐ Coordinate with psychosocial support workers to ensure **follow-up with the survivor** to address grief, isolation, or other mental health concerns.

☐ If feasible, **replace** - or provide the means for survivors to replace - personal property destroyed during the emergency (e.g., clothes, mattress, and cell phone).

☐ Conduct **community outreach** efforts about survivors returning and their need for safety, reintegration, and health.

☐ Explain to survivors how to **access material supports**, and the type, amount and duration of support for which they qualify.

Developing Survivor Support Policy

☐ Work with survivors, families, community leaders and other representatives on the **survivor support policy**.

☐ Ensure policy provides a clear definition of **eligibility criteria** for support and duration of support.

☐ Put mechanisms in place to ensure supports are provided to **all who are eligible**.

Chapter 8: Outbreak Recovery

Introduction

The larger and more lethal the outbreak, the more profound its impact. The entire country may be affected when ports and businesses are closed, when trade and agriculture are disrupted, or when tourists, foreign investors, or international conferences cancel plans to travel to the country where the outbreak occurred. Lapses in basic health services during an outbreak create a care deficit from unmet needs, and the emotional trauma, economic hardship, and stigma for survivors and families might be long-lasting.

Outbreak response is often accompanied by an influx of resources, infrastructure, and worker training that is important, but generally is temporary. Policies and practices, updated systems for delivering services, and more trained personnel that emerged during the outbreak will need to be reviewed and ideally sustained after the outbreak is over. Treatment centers and related physical infrastructure constructed during the response will need to be repurposed or decommissioned. Outbreak response workers who received a fair wage for the first time will need to transition to a regular position of employment or be fairly and respectfully transitioned out of their role; basic services that were suspended during the outbreak should be reinitiated; schools and businesses will reopen. Recovery, then, like emergency response, must be deliberate in how it is handled.

Recovery is a lengthy process, with multiple stages over many years. The best long-term recovery is framed as preparedness and implemented through systems strengthening and policy change. While it is beyond the scope of this guidance to address these issues in depth, this chapter highlights some ethics considerations for the transition from active outbreak containment to robust outbreak recovery.

Key Contextual Considerations

- Pre-outbreak levels of responsiveness, accountability, and effectiveness of public institutions will influence the scope, scale and credibility of outbreak recovery efforts.
- Trade, business, tourist, and agricultural disruptions, school closures, lapses in basic health services, and illness and deaths in families might create serious economic hardship and emotional trauma among survivors and the communities in which they live.
- Usual government services such as police, fire, trash disposal, or transportation might remain limited for lengthy periods into the recovery process.
- At the same time, communities may have received an influx of resources and infrastructure that can be transformed into sustainable institutions.

Key Ethics Considerations

- To uphold commitments to reduce harm to communities, identify clear benchmarks for the reopening of schools, businesses, marketplaces and other public places that may have been closed during the outbreak.
- **To uphold justice,** address and ameliorate underlying inequities in care by using resources for crisis response in ways that are most likely to help develop infrastructure and/or trained,

> experienced personnel that will leave the community better off in handling future crises as well as basic, ongoing care.
> - To **uphold respect,** ensure that policies are in place and practices are modeled that continue to involve survivors and thank those who served in the response;
> - Relevant both to **promoting good and to justice**, there may be ways for the tragedy of an outbreak to be a stimulus for the implementation of systems-level public health change, including sustainable public health surveillance and response systems that engage with and build community capabilities through informed alliances.

Relevant Resources

Important resources exist for recovery after a disaster and preventing further disadvantage. One such resource, Management Sciences for Health, also highlights ethical considerations and provides a framework for Ebola recovery locally that includes attending to the needs of the most vulnerable and, with the participation of affected communities, developing plans to minimize long-term negative impacts (79).

The International Federation for Red Cross and Red Crescent Societies developed recovery plans specifically in the countries affected by the 2014-16 Ebola outbreak, highlighting the essential role played by local communities as partners and leaders of outbreak response (80). They call for a 'dignified recovery' in which governments and partners aim to integrate newly trained outbreak response workers into the community health workforce, keep the workforce engaged during outbreak recovery and embed community engagement into their response operations. They further call for donors to continue to support survivors and their communities in outbreak recovery. The considerations below are not put forth as a model recovery plan, but rather reinforce how ethics commitments can inform recovery efforts.

8.1. Consider long-term recovery goals and community perception of dismantling infrastructure built as part of response.

While it may be necessary to dismantle or decommission infrastructure that was constructed and designated for outbreak control, it will be helpful to maintain infrastructure that strengthened the health system. If the human and other resources to maintain helpful structures can be mounted, further harm will be averted and preparedness increased. Local stakeholders should be consulted when deciding when to close, dismantle, or discontinue response resources, and communities should be informed in advance.

It is important to identify benchmarks that indicate a sufficient level of safety and personnel to reopen public places. Some amount of containment infrastructure may be needed in the early phases of reopening, and responders should be prepared for an outbreak to happen again.

Issues of resource allocation during outbreak recovery:

Infectious disease control generates public goods, and major outbreaks readily get the attention of countries and international donors. During the recovery phase, a resource allocation problem may exist if the government of an affected country either refuses or is reluctant to allocate domestic resources to core public health functions and institutions. Such behavior would no longer be out of ignorance because the consequences of the previous reluctance to fully invest in the health system should be known. This is a problem at the interface between the country and global levels: an expectation that richer countries will pay for health systems strengthening because they do not want to risk exposure to outbreaks that might originate from the same country.

8.2. Find ways to respectfully recognize and remember lost loved ones.

Infectious outbreaks of serious illnesses are traumatic events; loss of life on a large scale has long-lasting social consequences. Finding ways to honor those who died through memorials and public days of remembrance should be considered part of recovery and social healing. It is especially important to recognize HCWs who lost their lives in duty. Incorporate culturally appropriate ways to acknowledge those who have died, and ways to reintroduce joy and normalcy, into the recovery process.

In Liberia, August through October are traumatizing months for survivors because many loved ones were lost during these months. As part of the recovery process, group counseling was organized during these months in the subsequent year to help survivors and their communities deal with their grief and loss.

8.3. Apply lessons learned during the outbreak to local preparedness planning.

Containing an infectious disease outbreak offers the best opportunity to learn which strategies are effective versus ineffective in one's own environment. A commitment to ongoing learning requires that the course-corrections and innovations that occur during outbreak containment are documented and disseminated in ways that will inform preparedness for future outbreaks and enable others to benefit. Publishing lessons learned, creating platforms to store mobile applications that enhance contract-tracing and surveillance, investing in community networks and systems, and sharing good practices are essential to fulfilling a responsibility for ongoing learning and facilitating evidence-based practice. Further, reviewing best practices and lessons learned, as well as rehearsing key processes and simulations with personnel during non-outbreak times, can help with response effectiveness in future outbreaks. Advance preparation such as "tabletop exercises" as a routine part of physical and mental health service management is key to mounting an effective response to future health crises. Risk is typically managed by specific hazard in health systems, but

an argument can also be made for capacity building to manage all hazards. The [Pandemic Influenza Risk Management WHO Interim Guidance](#) served as a model for all-hazards guidance and included a series of emergency risk management principles for health (see box) (81). These principles apply to response and recovery efforts.

While an all-hazards approach is a good starting point, pandemic preparedness and response protocol should be adaptable and responsive to particular infectious disease characteristics (82).

The Pandemic Influenza Risk Management WHO Interim Guidance provided the following emergency risk management principles for heath:

- Comprehensive risk management: A focus on assessment and management of risks of emergencies rather than events.
- All-hazards approach: Use, development and strengthening of elements and systems that are common to the management of risks of emergencies from all sources.
- Multisectoral approach: Recognition that all elements of government, business and civil society have capacities relevant to emergency risk management for health.
- Multidisciplinary approach: Recognition of the roles of many disciplines in health required to manage the health risks of emergencies through risk assessment, mitigation, prevention, preparedness, response, recovery and capacity strengthening.
- Community resilience: Utilization of capacities at the community level for risk assessment, reporting, providing basic services, risk communication for disease prevention and long-term community care and rehabilitation.
- Sustainable development: Recognition that development of country and community capacities in health and other sectors requires a long-term approach to protect health and build resilience.
- Ethical basis: Consideration of ethical principles throughout health emergency risk management activities.

8.4. Develop a multidimensional recovery plan in partnership with local leaders.

Social disadvantage and inequalities are likely to surface and even be exacerbated during outbreaks of a lethal disease. Minimizing the extent to which outbreaks compound disadvantage requires significant and deliberate investments in recovery across multiple sectors, including education, workforce training, economic development, and health and social services. Address and ameliorate underlying inequities in care using resources for outbreak response in ways that are most likely to develop infrastructure that will leave the community better off in responding to ongoing care and future crises. Develop a survivors' policy (see Chapter 7) to outline what will be provided to address clinical and psychosocial needs of the clinical survivors as well as the orphans, families and communities affected. Take care to minimize the chance that the recovery plan pits survivors against others in their communities.

8.5. Leverage the systems built during the outbreak response to advocate for broader systems strengthening initiatives.

During normal times, it is often hard for ministries of health to secure funds for public health functions, and large-scale outbreaks in low-income settings can have devastating consequences. While it is not possible to build a durable, functioning health system during a crisis, attention is often concentrated on what can happen when critical public health functions are missing, creating a space for policy and resource allocation decisions that would have remained otherwise difficult. In this way, an outbreak may be leveraged, and the partners and resources mobilized during the response can develop alliances to inform policy and influence systems-level change. These changes are best led by local analysts and policy advisors with support from external parties to create sustainable public health surveillance and response systems that engage with and build community capabilities.

In the 2014-2016 Ebola outbreak, for example, thousands of community members were trained as community mobilizers, community educators, supportive caregivers, and surveillance workers. Following the 2014-16 Ebola outbreak in Liberia, the Liberian government launched a National Community Health Worker Plan to improve access to primary care in rural areas, addressing deficits in primary health that may have occurred during the outbreak and better preparing for future outbreaks (83). Looking for opportunities to advocate for initiatives that create more just conditions both in non-outbreak and in future outbreaks periods, such as improving access to primary care, strengthening the workforce, building laboratory and supply chain capacity, providing additional education and training, and creating additional systems of physical health, mental health, and social service structures can be invaluable in reducing disadvantage and increasing outbreak preparedness.

Checklist: Outbreak Recovery

The larger the outbreak and the more lethal the disease, the more profound its impact. Recovery is a lengthy process, with multiple stages over many years. Long-term recovery is best characterized as preparedness through systems strengthening and policy change. This checklist highlights some ethics considerations for the transition from active outbreak containment to robust outbreak recovery.

- ☐ Follow the **benchmarks for reopening** businesses, schools, market places and other public places that were closed during the outbreak.

- ☐ Consider community **perceptions and impact** when planning to dismantle or decommission infrastructure built as part of the response.

- ☐ Identify respectful ways to **recognize and remember** lost loved ones through community outreach and public events.

- ☐ Document **lessons learned** during the outbreak.

- ☐ Identify ways to **invest in multiple sectors** including education, workforce training, economic development, health and social services in the recovery plan.

- ☐ Consider broader **health systems strengthening** initiatives in the recovery plan.

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Annex 1. Ethical Responsibilities

Principle	Responsibility	Description	Examples
Justice	**Distribute benefits and burdens equitably**	The ethical principle of justice requires policies and programs to be implemented fairly and equitably. For example, those in positions of power or privilege should not be exempted from containment strategies applied to others of similar health status or risk.	• Ensuring uniform enforcement of containment policy across the population affected (e.g. mandatory safe and effective burials or cremation) • Monitoring response measures, especially isolation, quarantine and social distancing directives, to ensure they are enforced based on equivalent infection risk rather than power or position. During the Ebola response in Sierra Leone, an NGO worker reported that quarantine was not equitably enforced due to an absence of a strong public health system. • Developing policies that recognize that *how* measures are implemented may differ across communities, but that all measures should share the same goals and respect ethical commitments in consistent ways (e.g. resolving in similar ways the tension between liberty and the common good)
	Protect disadvantaged groups from further disadvantage	Protecting disadvantaged groups from further economic, educational, social, and health disadvantage and promoting the well-being of the least well-off are core commitments of public health, supported by the ethical principle of justice. Being attentive to and avoiding exacerbations of patterns of social disadvantage can prevent further disadvantage to vulnerable and marginalized populations. In fact, responding to an urgent crisis sometimes presents unique opportunities to address underlying inequities even in small ways.	• Supporting newly trained workforce in more permanent positions • Working with trustworthy sources who can identify which groups within a community are least well-off in terms of power, wealth, and social standing to inform how the containment response might exacerbate marginalization or vulnerabilities • Ensuring that other health services (e.g. malaria, typhoid, maternal health, childhood vaccinations) either are not suspended or, if they are suspended, with deliberation about how they will be resumed. Additional community-based clinics can be opened or CHWs can be supported to provide point-of-care testing and services. • When feasible, providing compensation for travel costs to treatment centers, lost income and/or assets resulting from isolation, quarantine or social distancing

			• Considering long-term recovery goals and community perception of dismantling infrastructure built as part of the response
	Protect and care for response workers who accept heightened risks as part of their service	Justice not only requires treating individuals and communities in outbreak regions fairly but also requires the fair treatment of those who agree to serve as response workers. Response workers often take on additional risks, longer hours, and increased stress compared to their previous employment. Those who serve must be provided with protective equipment and training if they will have direct contact with infected persons; response workers should be given priority care and treatment if they become infected, or mental health intervention as needed.	• Prioritizing outbreak response workers at highest risk for access to and receipt of PPE, training, prophylaxis if available, and treatment if necessary and available • Compensating healthcare workers at a reasonable increase versus base pay • Compensating families of response workers who die because of their work • Ensuring mental health providers are identified and available as needed to support response workers
Respect	**Treat individuals with respect and recognize their dignity**	Outbreaks can place affected individuals in situations of dependence and reliance on others, away from their homes, families, and familiar routines, often leaving them feeling isolated or scared. Ensuring that the inherent dignity of individuals experiencing outbreaks is recognized can uphold a foundational commitment to respect. Commitments to treat people with respect are further upheld by maintaining acts of courtesy and showing compassion during outbreaks. Communities also deserve to be treated with respect, which may include acknowledging the leadership and decision-making processes within communities and approaching leaders with deference and respect.	• Following customary norms of respectful interaction and courtesy, which may include beginning interactions with greetings, using appropriate titles, refraining from shouting, and showing special acknowledgment for older members of a community • Refraining from disclosing names and locations of people who contract disease and their families with neighbors or in the public media • Informing family members of the status of loved ones after they have been moved for testing, treatment or quarantine • Referring to people suffering from or who have died from disease as "patients" or "loved ones" rather than "cases" or "bodies"
	Practice honesty, transparency, and accountability in	Being transparent demonstrates respect; it also should result in better outcomes by increasing public trust, increasing awareness of which behaviors are safe vs. risky, building confidence in the rationale for restrictive measures or altered standards of care, and facilitating feedback about how measures are implemented (84). It is especially important for those in leadership positions at both national and	• Ensuring messages are as accurate as possible, reflecting uncertainty, and mitigating stigma and discrimination (9) • In Monrovia, chalkboards and large bulletin boards were a popular way for people to receive information on the Ebola outbreak and helped to create means of communication that were accessible to wider groups of individuals.

	communication and interactions[4]	community levels to practice transparency as messages evolve. Outbreak containment requires sharing unfolding information and, as needed, revising containment approaches. Honesty about rationales for adopting specific policies should contribute to public understanding, cooperation, and trust. Accountability requires honoring the promises and commitments made to affected individuals, communities, and other response workers; it also requires provision of a reasonable explanation if previous commitments cannot be met.	- During the Ebola outbreak in Nigeria, the minister of health worked closely with the minister of information to provide wide coverage of health communication on all media channels in the country on a nearly daily basis. Social media was also used extensively, especially the hashtag #EbolaAlert on Twitter to communicate health messages. The public was informed that only communication from the minister or other government-approved channels should be considered authentic, which helped to build confidence in the response.
	Respect self-determination	Response containment can limit individual movement, decision making, and behavior. These restrictions limit self-determination and should be imposed only when necessary, and in the least restrictive ways possible, to achieve stated public health goals. Respect for self-determination also recognizes that one's sense of self can be better maintained if people are able to continue practices that are particularly meaningful to them or if they are able to access particularly meaningful objects or provisions, even when their movements are constrained.	- Using less restrictive measures for diseases transmissible by contact with bodily fluids than those transmitted through casual contact - Providing religious or culturally preferred food to an individual undergoing isolation or quarantine - Ensuring people can pray the way they like (e.g., ability to take communion even in isolation)
	Incorporate local knowledge and recognize cultural norms	Actors engaging in containment activities—particularly response workers from outside the country or region—should try to understand and act in ways consistent with local culture, beliefs, and patterns of caretaking and health-seeking behavior. Public health messages should be mindful of local norms to ensure messages are respectful and acceptable, are disseminated through trustworthy forums, and are	In Liberia, religious tradition was respected when the heads of major evangelical organizations met to demonstrate how the practice of "laying on hands" had contributed to the local outbreak of Ebola. Religious organizations were then in the lead as messages on how to keep safe during New Year's services were developed and disseminated.

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[4] This responsibility has also been framed as the ethical value of openness by the National Ethics Advisory Committee in Wellington, New Zealand. Openness includes: "Letting others know what decisions need to be made, how they will be made and on what basis they will be made; letting others know what decisions have been made and why; letting others know what will come next; and being seen to be fair."

		able to reconcile any conflicts between public health recommendations and local practices. Local knowledge can help to identify those at disproportionate risk in an outbreak, e.g., those who hunt, those who prepare food, those who care for ill persons.	• In Sierra Leone, the social mobilization pillar engaged traditional healers through an association representing thousands of members and partnered with them to persuade community members to report cases, seek care, and take preventive measures.
	Provide mechanisms through which the public can raise objections	A fair process approach, also framed as due process or procedural justice (5), requires mechanisms to raise objections. While those in leadership positions must act swiftly and confidently, it is important to ensure that there are avenues through which the public can raise concerns, and that they are acknowledged and responded to by those in positions of authority. Acknowledgement of objections and, when appropriate, changes in policy in response demonstrates respect and a commitment to fair process.	• Holding town halls or public forums in which policy decisions are explained to the public by those in authority, and at which community members have opportunity to voice concerns • Communicating openly about any changes made in response to concerns raised
	Support a locally-led response	Supporting a locally-led response stems from a commitment to respect the self-determination of affected countries and communities, to recognize the expertise and capacity of local actors, and to support and strengthen existing country capacities. These result in a commitment to, as possible, refrain from interfering with the leadership and responsibilities of local authorities and institutions. Responders from outside the local health system should strive to determine how best to support and strengthen the local system and its leadership in mounting the response, through efforts such as coordination of responders from outside of the locality or providing technical expertise. Acting with humility—particularly if one is an outsider—demonstrates respect for communities and their experiences. Humility is meant to communicate an acknowledgement of local, existing expertise, and consideration of ways in which one's own expertise and capacity can contribute, in	• Engaging in dialogue with local and national stakeholders to understand the other actors with whom one should be interacting • Acknowledging any existing power imbalances between international and local actors and making deliberate efforts to support a locally-led response • PSI's "Listen, Learn, and Act" methodology was used during the Ebola response; after listening to the experiences of community members (their stories, hopes, fears, rumors, etc.), facilitators would provide approved health messages and prompt the community to take actions to prevent Ebola (85). • In Liberia, EVD task forces were established in communities, and communities were given the responsibility to conduct vigorous surveillance on sick people entering their towns and villages.

		collaboration with and some degree of deference to, those who are directing the response.	
	Foster inclusion of and engagement with community and other key stakeholders	Decision-makers responsible for leading the containment response should prioritize the involvement of multiple stakeholders who bring expertise, beginning with local authorities and leaders (e.g. government ministries, grassroots NGOs and/or advocacy groups, community leaders). Consistent efforts should be made to encourage participation, input, and feedback from a variety of stakeholders, including community and religious leaders, community representatives, and members of the community less commonly engaged in decision making (e.g. advocacy groups for marginalized or politically weak populations) and international organizations or governments with previous experience containing outbreaks.	• Committing resources to social mobilization, community engagement, and coordination activities from the beginning of the response • Making efforts to seek out perspectives that might be otherwise overlooked (e.g. women, persons with low literacy, social sectors other than religious groups or commonly sought out community voices) • Including survivors and local community members in outreach teams or other aspects of response
Promoting good and protecting from harm	**Enhance health and well-being**	Those who are sick should be given therapeutic, compassionate, and supportive care, as applicable, and care mechanisms should be identified for those with acute health needs unrelated to the outbreak. Individuals should be given the "best supportive care sustainably available in the community" (10). Essential health services should be maintained and strengthened during the crisis response (86). Attention to community-level social cohesion and the provision of mental health services are critical in improving well-being during an outbreak.	• In Nigeria, the virology laboratory at Lagos University Teaching Hospital tested the sample of the first person with Ebola. As more cases were recorded, other treatment sites sent their samples to the same laboratory. To improve triage and response times, the government established additional testing sites and educated treatment sites on the most appropriate labs to send their samples for testing. • In Sierra Leone during the 2014-2016 Ebola outbreak, psychosocial support (hotline services, breathing exercises and other relaxation techniques, and counseling) was provided by trauma specialists to burial teams and other service providers.
	Preventing harm from the infection	Providing education, social and behavior change communication, and protective interventions to keep healthy people from becoming infected helps to protect against harm. Public health has many containment strategies designed to protect individuals	• In Zika-endemic areas, door-to-door campaigns provided both social and behavior change communication on reducing sources of standing water and repellent at no cost to women of reproductive age.

		from harm, including education, contact tracing, social distancing, isolation, and quarantine; the least restrictive effective measures should be implemented, acknowledging that several strategies may need to be combined. Protecting individuals from harm serves to protect communities from harm.	• Providing support to survivors returning to their communities to ease the transition (e.g. accompany, provide travel resources, assist in developing a plan to reintegrate)
	Minimize harms of response	Response teams will often be entering unfamiliar communities, and may introduce interventions that either invade others' privacy or restrict the movements of others. Minimizing harm is a widely accepted ethical responsibility of public health. The harms of interventions can be minimized by partnering with local, trusted groups, relying on surveillance data to lift intrusive measures as soon as possible, maintaining confidentiality throughout one's work, implementing anti-stigma campaigns, and providing material supports to those restricted.	• Maintaining confidentiality when conducting contact tracing (e.g. do not show photos of sick individuals) • Providing food, water, and means of communication for those subject to restrictive measures • Putting transparent "windows" into healthcare facilities so that family members can see their loved one • Involving Ebola survivors, no longer susceptible, in household and community response • Involving social mobilizers, already in communities, to spread messages including of others planning to enter a community (e.g., to conduct contact tracing) to minimize misunderstanding and anxiety
	Support data-driven public health practice throughout a response	The best possible evidence should drive public health practice. Relying on data makes the response more effective and more efficient, targeting areas in greatest need of help with interventions with the best chance of effectiveness. Response workers should implement confidential surveillance systems early in an outbreak and use surveillance data to guide which interventions are needed where and how response strategies are working. Interventions or treatments should be as evidence-informed as possible given the uncertainty associated with new outbreaks, and ongoing evaluations/learning should be built into outreach and treatment plans. Those leading the response must be willing to act on new information and change programs during a response. If evidence suggests that interventions are not effective, or not effective beyond a certain period, they should be stopped. As such, response professionals may need to	• Conducting rapid assessments to gather data on local practices and norms, if none exists and including relevant social science/communication experts to draw on evidence regarding what makes communication strategies more effective • Understanding existing data systems and engaging in additional data collection that is complementary to existing efforts and meets unmet needs of local systems. • Ensuring that data collection efforts do not interfere with timely provision of appropriate care to patients

		provide a check on political leaders who can be tempted to pursue ineffective and counterproductive strategies to be seen as doing something "aggressive" to counter the threat. Actors should make efforts, as possible, not only to collect and confidentially maintain data to monitor effectiveness of efforts but also to compare success across efforts and communities.	