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Community Engagement in the International Emergency Response to Ebola, 2014-2016

by

Daniel William Martin

B.A., Goshen College

MSPH, Loma Linda University

A Dissertation Submitted to the Graduate Faculty
Of Georgia State University in Partial Fulfillment
of the
Requirements for the Degree

DOCTOR OF PUBLIC HEALTH

ATLANTA, GEORGIA
30303

Approval Page

COMMUNITY ENGAGEMENT IN THE INTERNATIONAL EMERGENCY RESPONSE TO EBOLA, 2014-2016

by

Daniel William Martin

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My Dissertation Committee:

- Dr. Sarah McCool (committee chair, faculty advisor) was, if anything, more excited even than I about the topic and findings of this work. From our first meeting when she interviewed me for entry into the DrPH program at Georgia State, through an independent-study introduction to anthropologic methods, and finally to the long process of this work, Sarah has been a brilliant guide and constant encourager of my efforts.
- Dr. Carlos Pavao brought rigor to the qualitative analysis in this work. While I didn't always welcome his suggestions at the time (sorry, Carlos!), I can say without reservation that his guidance strengthened my data and analysis. Any errors that remain are my own, but such quality as exists, is thanks in no small part to Carlos' guidance.
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Delphi panelists

The ethics of a Delphi study preclude my naming my panelists publicly, although several of them are also cited in published material elsewhere in this work. Nevertheless, their insights were invaluable, and I thank them for their kindness in participating in this study.

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My doctoral studies were supported by CDC¹ through a program for federal employees called Long-Term Education (LTE). I will likely never know how many people influenced my selection for LTE, but I do know that it could not have happened without the support and encouragement of my branch chief Dr. Olga Henao, and branch deputy Sarah Hedges. I know of several supporters throughout the Center for Global Health only through rumor and so will not name them publicly, but they all have my gratitude.

* * *

And finally, my wife of more than three decades, Janine Martin has been my anchor throughout the storms of my life, not least those of the past three years. Thank you, my love, for your patience, your encouragement, and your enthusiasm during this whole endeavor!

¹ The findings/conclusions in this document are the author's own, and do not represent the views of the Centers for Disease Control and Prevention

Author's Statement Page

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____Daniel William Martin_____

Signature of Author

A handwritten signature in black ink that reads "Daniel W. Martin". The signature is written in a cursive style with a long horizontal flourish extending to the right.

Abstract

COMMUNITY ENGAGEMENT IN THE INTERNATIONAL EMERGENCY RESPONSE TO EBOLA, 2014-2016

by

Daniel William Martin

February 24, 2023

An unsafe and illegal burial conducted in Port Loko, Sierra Leone during the Ebola epidemic of 2014-2016 exposed competing risk perspectives between emergency responders and the affected community, and called into question community engagement (CE) efforts in the response – particularly regarding strict, but culturally-problematic burial protocols. This work interrogates the effectiveness of CE through development of a novel, two-dimensional metric. The first dimension builds on the work of Davidson (1998) and others to parse CE efforts into four distinct domains: Information Provision, Consultation, Participation, and Community Empowerment. The second dimension builds on the work of Arnstein (1969) and others to create a semi-quantitative scale which assigns an Empowerment Score from zero to two, assessing the degree to which community feedback leads to material changes in interventions in each domain.

The Empowerment Score methodology was applied to analyze CE efforts reported in literature and in the CE standards of international response organizations. The methodology was then used in a modified Delphi survey of responders and anthropologists with experience in the Ebola response in Sierra Leone, to characterize the successes and shortcomings of CE efforts, with a focus on burial of persons who had died of Ebola. Quantitative analysis of Delphi panelists' numeric scores, combined with qualitative analysis of their textual comments, revealed substantial disagreement between diverse experts regarding the appropriateness or success of CE efforts in the response. However, there was general agreement among the experts that future epidemic responses should take into account cultural concerns in the negotiation of burial protocols or other interventions that may collide with cultural values.

For future emergency responses, the incorporation of social scientists such as anthropologists into CE structures, as well as intentional involvement of community members in the planning and implementation of disease-control measures, is recommended. Additionally, the international emergency response community is called to a posture of humility, acknowledging that realities other than the medicalized and materialistic drive human behavior, including health-affecting behavior. Respectful engagement with risk as understood by a community, combined with a Harm Reduction philosophy to define interventions, may save more lives than biomedically pure, but coercive approaches.

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List of Abbreviations and Acronyms

AAP.....	Accountability to Affected Populations (or People)
AMCE	Assessment, Monitoring, and Community Engagement
C4D.....	Communication for Development
CBP	Community-based Participation
CBPR.....	Community-based Participatory Research
CBPS.....	Community-based Participatory Service
CDC.....	US Centers for Disease Control & Prevention
CE	Community Engagement
CERC.....	Crisis and Emergency Response Communication
CHS.....	Core Humanitarian Standards
CLEA	Community Led Ebola Action
COMBI.....	Communication for Behavioural Impact
COVID-19	Coronavirus Disease, 2019
DERC.....	District Ebola Response Center
DRC	Democratic Republic of the Congo
ECDC.....	European Centre for Disease Prevention and Control
ETU.....	Ebola treatment unit
EVD.....	Ebolavirus disease
FAQ	Frequently-asked questions (usually, a document containing questions and answers)
GCC	Graniteville Community Coalition
HR.....	Harm Reduction
IASC.....	Interagency Standing Committee, a multinational standards body
IFRC	International Foundation of Red Cross and Red Crescent Societies
KAP.....	Knowledge, attitudes, and practices; either the concept itself, or a survey designed to elucidate KAP in a population
MOH or MoH	Ministry of Health
MSF	Médecins Sans Frontières or Doctors Without Borders
NGO	Non-governmental organization
PPE	Personal protective equipment
RAP.....	Rapid Assessment Procedure
RCCE.....	Risk Communication and Community Engagement
RRA.....	Rapid Rural Appraisal (or Assessment)
SCDHEC	South Carolina Department of Health and Environmental Control
SDB, SDMB.....	Safe & Dignified Burial or Safe & Dignified Medical Burial
SMAC.....	Social Mobilization Action Consortium
SocMob	A casual shorthand for Social Mobilization in common use during the Ebola response
UN	United Nations
UNHCR	United Nations High Commissioner for Refugees
UNICEF	The United Nations children's agency
VHF.....	Viral hemorrhagic fever, a class of diseases which includes Ebola
WHO.....	World Health Organization

Chapter 1 – Introduction and Purpose

Introduction

In the fall of 2014, in the summer of 2015, and finally in early 2016, I served in Sierra Leone as a field epidemiologist with the Centers for Disease Control and Prevention (CDC) in response to the largest Ebola epidemic in history. Originating in Guinea in December of 2013 and ending in early 2016, the West Africa Ebola epidemic sickened over 28,000 known individuals in 10 nations, and resulted in more than 11,000 deaths (CDC, 2019a). Working with Sierra Leonean nationals and fellow responders from around the world, we implemented a variety of interventions to stop the transmission of Ebolavirus disease (EVD), including isolating and treating persons with EVD, contact tracing, quarantine and monitoring of potential EVD contacts, and the safe medical burial of the bodies of those who succumbed to EVD.

The response encountered a variety of challenges in implementing EVD control measures. While some were simply logistical, others resulted from people resisting response measures that impacted their personal liberties and social customs. Some such resistance may be inevitable; however, it is also possible that our approach as public health professionals and emergency responders compounded the problem.

The management of the bodies of persons who died from EVD provides a poignant case study in how the best intentions of the responder community may actually have exacerbated the very epidemic we were trying to end. Consider the following narrative case, told from two divergent perspectives:

Narrative Case – A burial gone “wrong” in Sierra Leone

Emergency Responders’ Perspective

It was around 7:30 one morning in early August, 2015. As usual, senior leadership had gathered in the Port Loko District Ebola Response Centre (DERC), a room that in normal times was a nursing classroom but had become the nerve center of the Ebola epidemic response for this Sierra Leonean district.

The Burial Team lead brought troubling news. He told of an elderly man who had died a couple days previously. At the time, his post-mortem Ebola test had not yet come back, so we² did not know if his death was due to Ebola. Following the national epidemic protocol, the burial team had been called and the corpse was given a safe and dignified burial, overseen by the deceased man’s pastor who prayed at the grave along with the family. Our colleague had learned through the pastor that the man’s adult sons had returned that night, dug up their father’s corpse, removed him from the body bag, washed and dressed him and re-buried him on top of the body bag in his own clothes.

By the middle of 2015, the West African Ebola epidemic already sickened well over twenty thousand people, and claimed nearly ten thousand lives across the three countries of Guinea, Liberia, and Sierra Leone. We in the public health response knew that if someone dies from Ebola, his or her body is highly infectious, and even touching the body without proper protection carries great risk for infection. In fact, touching or washing a dead body at a traditional funeral was known to significantly increase one’s risk of contracting Ebola (Brainard et al., 2016; Curran et al., 2016). Because of this, Sierra Leone had instituted national “by-laws” forbidding traditional funeral practices across the country. Anyone aware of a death

² I had recently returned to the United States, and was not present in Port Loko for these meetings; however, as I had only just left, I remained in regular contact with DERC leadership and actively participated in the email discussions and internal reports relating to this case.

in their community was required to notify the public health system. Once notified, authorities would dispatch a trained burial team to the home. Clad from head to toe in full Personal Protective Equipment – hooded gown, gloves, boots, mask, face shield – team members would swab the body and send the specimen to be tested for Ebolavirus. The team then would perform a “Safe and Dignified Burial:” they carefully placed the body in a sealed body bag, disinfected the bag with chlorine bleach, and buried the corpse. Family members, religious leaders, or others not associated with the burial team were not permitted to touch the body, although they could observe from a safe distance (Government of Sierra Leone, 2015).

When these men dug up and handled their father’s body, they were exposing themselves to terrible risk. Not only they, but their families as well, would have to be quarantined at home and observed for 21 days, to be monitored for any signs of Ebola disease. The quarantine would, of course, be released if the father’s test came back negative, but if it was positive, there was a high likelihood that one or more of the family would contract Ebola and perhaps die from it.

What, we wondered, could these men have been thinking? It wasn’t as though messages on Safe & Dignified Burial hadn’t already been spread far and wide across Sierra Leone. Repeatedly, we’d warned people of how risky – even deadly – it can be to touch a dead body. Didn’t they understand the risk? Didn’t they know they could be killing themselves? Why wouldn’t they listen to us?

Community Perspective

Dr. Lily Owusu-Darkwa, a medical anthropologist with the World Health Organization went out to the village and spoke with the men, and with others in the village (Owusu-Darkwa, 2015b). She returned with a very different story. Yes, the old man had died. Not, they asserted, from Ebola – the gentleman had been ill for the last three years. He passed his days in much pain, but not only in his body. He feared for his soul.

The deceased, the family, and the village elders all knew of the by-laws ... alien rules created by foreign doctors and enforced by their own government. They knew that everyone who dies must be buried in a strange plastic bag that covers the whole body. They had seen other bodies in those bags: it appeared to them as though the body was sweating inside. What’s more, the people who came to bury bodies were outsiders, unknown to the villagers. These outsiders came covered in strange white clothes – even their hands and faces were hidden. These strangers were well known to show little respect for either the dead themselves or for bereaved family members. Many of them don’t even believe in God!³

The family of the deceased were Christians, but Christian, Muslim, or traditional faith – all knew that the manner in which the family treats a corpse matters in the next life. Tradition dictates that the bereaved will wash the bodies of a loved one, dress them in their best clothes, and wrap them in a white cloth for burial. In this manner, all are assured that the ancestors will recognize the deceased and welcome them into their village in the life to come.

The deceased father knew this too. As he suffered and moved close to death, he called his sons to him, in the presence of the elders. From his deathbed he implored: “*Duya, me pikin dem, una nor make leh*

³ It is not uncommon for local communities to “view support for the biomedical model of the response to epidemics as allegiance to the selfish interests of industrialised countries, which have crushed or are in the process of crushing (or turning into folklore) local cultures, scorning indigenous sciences and ‘beliefs,’ and imposing an atheistic, or even diabolical, ideological order” (Epelboin et al., 2007, p. 28).

me bodi rotin na ebola dead bodi bag” (Owusu-Darkwa, 2015b, para. 2) (Promise me, my children, don’t let my body rot in that Ebola dead body bag).

His sons did the only thing they could. After the burial, the very same night, they returned to the grave. They dug up their father’s body, took him out of that horrible bag, washed and dressed him, and buried him again with proper respect.

When Owusu-Darkwa visited the village, the men had been arrested and beaten, and were being held in the village until their penalties could be determined. But it was clear that community sympathy lay with the men. Although the leaders seemed bound to enforce the by-laws, all reported their discomfort with the emergency burial protocols. Stories had been swirling all over Port Loko. Another village not far away had reported being haunted by the ghost of a powerful traditional healer who had died and been buried by the ‘Safe Burial’ team (Owusu-Darkwa, 2015a). The spirit, we heard, had been throwing rocks at villagers and terrorizing a nurse from the health center.

These outsiders obviously didn’t understand the risks. Why, the villagers wondered, won’t they listen to us?

Clashing Understandings

Two very different stories – two entirely different world views. And yet paradoxically both the Sierra Leonean villagers and the international disease responders were doing much the same thing. Each group was evaluating the risk to themselves and their fellows, and choosing actions they believed most likely to mitigate that risk.

From a biomedical view of Ebola, the danger of unsafe funeral practices had been documented well before the West African outbreak (Guimard et al., 1999; Hewlett & Amola, 2003; Khan et al., 1999; The International Commission, 1978). A single funeral in Moyamba, Sierra Leone during 2014 led to at least 36 more Ebola cases, 21 of whom were known to have touched the body at the funeral (Curran et al., 2016). The first entry of Ebola into Sierra Leone from Guinea had been confirmed to have taken place through participation in a funeral (Gire et al., 2014). The burial protocols were solidly grounded in biomedical science.

Ordinary people were not ignorant of the biological risks. A national knowledge, attitudes, and practices (KAP) survey in August of 2014 found that 85% of respondents knew that Ebola could “be prevented by avoiding funeral/burial involving contact with corpse” (Jalloh, Sengeh, et al., 2017, p. 5), and a similar survey conducted in Kambia district in August of 2015 found that number had increased to 96% (Jalloh, Bunnell, et al., 2017).⁴

In Sierra Leone, the risks of failing to follow traditional funeral practices were also common knowledge. “It is widely believed that the transition [of the deceased to the afterlife] should be facilitated by the surviving relatives through funeral and burial rituals. In the event that the deceased fails to attain the more elevated rank of ancestral spirit, it is believed that their spirit may return and punish the living relatives” (Manguvo & Mafuvadze, 2015, p. 2); a belief also reported among the Kissi in Guinea (Anoko, 2014b). Also in Guinea, the mandate to bury the Ebola dead in body bags was “interpreted as a strategy

⁴ Importantly, though, only 81% in this second survey agreed that they would accept touchless burial.

by the government to prevent the deceased's spirit from leaving the body, exposing Guineans to vengeance/'fossi' from beyond the grave" (Caremel et al., 2017, p. 68).⁵

A villager in the neighboring Bombali district summed up the situation: "An Ebola death is not nearly as bad as an Ebola burial. Only the body dies from Ebola, but an Ebola burial kills the spirit" (Goguen & Bolten, 2017, p. 435). Or as an administrator in Freetown put it, "the terror the living face from not carrying out the burial rituals is more than the fear of contracting Ebola from a corpse" (Blevins, Jalloh, et al., 2019, p. 381).

In addition to spiritual concerns, there were socioeconomic implications to violating local norms. "Without [traditional] funerals, orderly access to farm land for staple rice production—a key survival requirement for rural families—is seen to be at risk ... [and through traditional burial] lineage rights, land tenure, and inter-family and inter-village relations were maintained" (Richards et al., 2015, pp. 8–9). Richards further elaborates that depending on the status of dowry obligations that span many years, a husband's family may be obligated to transport the wife's corpse to her own family's village for burial. Importantly, Richards is clear that families in these circumstances were not ignorant of the risk of Ebola infection, they simply weighed it against other risks and obligations that took precedence.⁶

In short, both the decedent's family on the one hand, and the Ebola responders and government authorities on the other, were making decisions to control risk. However, their divergent worldviews defined 'risk' in substantially different terms. Across cultures, "the way people interpret risks and benefits may be influenced less by the details of scientific evidence than by social, political, and ethical concerns" (Nelkin, 2003, p. 2), as well as by their culture and personal experience (Oaks & Harthorn, 2003). The risk calculus described by various anthropologists in Sierra Leone tends to be quite holistic and "[does] not make the kind of separations between mind, emotion, spirit, society, and cosmology that European medicine has made in the past few centuries" (Jambai & MacCormack, 1996, p. 280). Thus, the strictly-biomedical risk of infection and physical death, while not at all unknown to Sierra Leonean villagers (Mokuwa & Richards, 2020), simply did not encompass all the risks they were weighing in deciding their actions. As DuBois et al. observed:

"The early instructions on so-called safe burial – rigid and unworkable – were, in that context, a textbook manual for unsafe burial that then had to be overcome by working with local religious and community leaders. The strictures of bio-medically safe burial jeopardised the lives and well-being of people in (at least) equal measure to the risks posed by picking up the virus" (DuBois et al., 2015, p. 31).

In the short term, the government and responders 'won' and the Western-dictated controls were enforced. However, just as Pellechia et al. (2015) observed in neighboring Liberia, "sustained by the idea that traditions were wrong and funerals were the main cause [of Ebola transmission], implementation [of burial protocols] ... crudely defined the transition from life to death as a simple biomedical passage of state, wiping out deep social links, and endangering the credibility of the measure

⁵ The traditions described here are only a sample ... depending upon the specific people group and region of the country a wide range of other practices and beliefs may pertain. For more detail see Grant (2014) in addition to the references cited in the text.

⁶ This case report is by no means the only time families determined that Western and government requirements were simply too egregious, and responded by hiding illness or conducting secret burials. "One young man in a village in eastern Sierra Leone, who had attended his mother as she died of EVD, viewed it as simply unforgivable not to clean and dress her body. She had given him life, and he saw himself as obliged to stand by her in death. So he performed the ritual alone and quietly buried her; he informed no one and accepted that he would probably become infected with EVD and die" (Mokuwa & Richards, 2020, p. 6).

itself” (Pellecchia et al., 2015, p. 10). As the case report above illustrates, it is possible that the failure of response and national authorities to take community concerns seriously undermined compliance with a key disease control measure, and may have cost lives as people hid their ill and buried their dead secretly, according to local custom.

Of course, the above story represents only a single incident. The frequency of unsafe burials was never clear. WHO situation report data suggest that although it was a significant problem in Guinea, only a few unsafe burials were reported in Sierra Leone (Wendelboe et al., 2018). Although Wilkinson & Fairhead support this claim, they caution that a public façade of compliance may have masked background opposition: “there is, perhaps, much resistance ‘latent’ in communities in Sierra Leone, where not all ‘compliance’ is compliance ... Incidents of open resistance became rare, but reports of ‘secret burials’ and of bodies being washed before burial teams were called suggests that ‘sensitization’ efforts were superficial” (Wilkinson & Fairhead, 2017, p. 23). It has been reported that families with the right connections and sufficient funds could arrange for secret burials despite regulation (Lipton, 2017), suggesting that evading the nationally-imposed system was often desired and not-infrequently achieved.

Wilkinson & Fairhead’s (2017) caveats resonate strongly with this author’s memory, as rumors of “unsafe” or “secret” burials were a staple of daily briefings in Port Loko during the summer of 2015. At least five unpublished reports⁷ were submitted in June and July of 2015 by a district-assigned WHO anthropologist to the Port Loko DERC. All five referenced unlawful burials and quarantine-avoidance and explore the families’ perspectives on why they did not follow Ebola directives. Whether the incidents referenced in these reports were included in WHO statistics is unknown.

Statement of Purpose

The hypothesis of this work is that the emergency Ebola response system, including both international responders and government authorities, did not adequately take into account the cultural and spiritual objections of the affected communities. By insisting on interventions that were biomedically sound but culturally unacceptable, we⁸ created a situation in which resistance was inevitable.

When that resistance arose, we responded either with campaigns to educate the community in their error, or with coercive enforcement, or both. We were not attuned to the possibility that community resistance was itself a feedback signal that might have informed changes in practice. Faced with our intransigence, some community members hid disease and death, likely leading to further Ebolavirus transmission and avoidable loss of life.

It is further hypothesized that, although a variety of efforts in the response used language of ‘community engagement,’ the intent and effect of those efforts was to unidirectionally convey information and requirements to communities in order to obtain their compliance – that in fact, the response failed truly to ‘engage’ affected communities.

The purpose of this work, therefore, is first to characterize and understand the success or failure of community-engagement efforts during the Sierra Leone outbreak. To this end, literature will be

⁷ Several of these reports have since been published informally on a blog website. See Owusu-Darkwa (2015, a-e).

⁸ The first-person “we” is used intentionally. I was an active member of the international response, and an appropriate spirit of reflexivity compels me to own the fact that I was party – even if indirectly – to its efforts, for better or worse.

interrogated concerning the 2014-2016 Ebola epidemic in West Africa from the perspectives of both emergency responders and anthropologists who observed or interacted with the response. Further understanding of community engagement in the response will be sought directly from responders and anthropologists through primary data gathering.

A second purpose of this work is to consider ways in which community engagement efforts in emergency response might be improved by drawing on the discipline of anthropology and the philosophy of Harm Reduction.

Chapter 2 – Literature Review

Search Methodology

The literature for this section was obtained through searches of PubMed, Google Scholar, and Medline, supplemented by the regular Google search engine. Key phrases used as search terms included "ebola response," "ebola anthropology," "emergency response and community engagement," "ebola community engagement," "rapid anthropologic assessment," and "emergency rapid assessment." The results of these searches were supplemented with policy and procedure documents downloaded from the websites of major international agencies who respond to public health emergencies, including the US CDC, the European CDC, the World Health Organization, UNICEF, and UNHCR. Additionally, grey literature consisting of unpublished documents the author encountered as an active participant in the 2014-2016 Ebola response, were included. As with any literature search, references cited in the works identified yielded additional documents, including historical books and articles. A final total of 238 distinct documents are cited in this work.

Community Engagement

Conceptual overview

It is axiomatic to state that those wishing to serve a community in crisis must seek to understand both the crisis and its potential solutions from the perspective of that community. The imperative of empowering communities to support their own health has been acknowledged for decades. Nearly a half-century ago, community health pioneer David Morley advocated for providing health services to a community "always on their terms," bringing together health facility staff and community leaders to set priorities and guide medical practice (Morley, 1975). The community health worker paradigm Morley and others advocated has been criticized for paying "little regard ... to whether communities were interested in participating ..." (Espino et al., 2004, p. 1) and further for exacerbating inequality by shifting the burden of supporting health from governments to the poor themselves. Morley's own later work does seem to exhibit a unidirectional, expert-to-laity notion of community mobilization (Morley, 1999). Nevertheless, some contemporary community health worker programs such as the Jamkhed Project in India have been credited for significant beneficial impact and material participation by the affected communities (Arole, 1988; Perry & Rohde, 2019).

Often, however, the mandate for community engagement has been framed as an effort to help communities understand Western medicine & science (Alexander et al., 2015); a process in which "experts attempt to persuade others to take protective actions or to refrain from taking needless actions" (B. Reynolds, 2011, p. 207). "Indeed, reified culture is reconfigured into a 'risk factor'" (Jones, 2011, p. 1). Much less priority has been placed on Western health experts learning to understand the cultures in which they work. Rarely does a community have significant voice or agency (Wallerstein et al., 2019) in health interventions; in fact, "typically, programme managers identify effective control measures first, and then explore community participation issues" (Espino et al., 2004, p. 30).

A case study from Sierra Leone in 1996 highlighted the success of a long-term health intervention performed in partnership between Western-trained health professionals and a community's own respected authorities (Jambai & MacCormack, 1996). The rich field of participatory research (e.g., Abma et al., 2017; Airhihenbuwa & Liburd, 2006) is replete with evidence that when marginalized people are invited to the table to guide the definition of their own needs, substantial progress can be achieved.

The concept of community involvement in the context of a life-and-death emergency is far murkier. In an epidemic with potential global consequences, the principles of indigenous priority setting championed by a participatory research framework (Abma et al., 2017; Airhihenbuwa & Liburd, 2006; Wallerstein & Duran, 2006), or by community-directed development paradigms (IFRC, 2017; Minkler & Wallerstein, 2005) can only go so far. Although a local community may indeed prioritize the interruption of an epidemic, it is not at all assured that they will do so.⁹ For this reason, it is perhaps inevitable that the community organizer's ideal that an effort "begins with the community's felt needs rather than a personal or agency-dictated agenda" (Minkler & Wallerstein, 2005, p. 27) will collide with the exigencies of controlling an epidemic with potential global impact. Ultimately, the priorities of an infectious disease emergency response are and will remain externally imposed for the simple reason that the emergency threatens far more people than just those in the community where disease transmission began.

This reality does not obviate the community engagement imperative. As Minkler & Wallerstein (2005) observed, "even professionals who are helping to mobilize a community around a predetermined health or social problem ... can effectively apply many of the core principles and approaches of community organization and community building practice" (Minkler & Wallerstein, 2005, p. 44). The "Community Based Participatory Service" (Svendsen et al., 2010, p. 78) paradigm implemented following an environmental disaster in Graniteville, South Carolina may be instructive. Svendsen et al. were approached by community members in the immediate aftermath of a mass-casualty chlorine gas release; the resulting multi-year partnership between health experts and community representatives is a model of community trust and cooperation.

Definition of Terms

Many of the references cited below speak of 'community engagement' or 'social mobilization.' Frequently the terms are used interchangeably and without formal definition (e.g., Abramowitz, 2016; Gillespie et al., 2016), although Abramowitz' work implies a continuum in which social mobilization can involve unidirectional communication while community engagement requires involvement and dialogue. Sometimes, either term is used to refer to a two-way process of communication between responders/authorities and community members; at others, despite participatory language, a close examination of the activities described reveals an expectation that the community should simply accept and implement externally-defined knowledge.

For purposes of this work, except when directly quoting others, the term 'community engagement' is used to refer to any process or activity implemented with the intention of involving community members in disease-control efforts. In contrast, 'social mobilization' is used to describe specific activities, personnel, and institutional structure (largely, but not necessarily exclusively, in the health communication domain) within an emergency response, intended to achieve the support or implementation of predefined objectives in communities.¹⁰

⁹ One "international NGO executive" reported that Ebola was only "the 18th-ranked disease in terms of the country's mortality rate" (Caremel et al., 2017, p. 78) in Guinea. See also (UNHCR, 2015b, p. 3).

¹⁰ The term 'Risk Communication and Community Engagement (RCCE)' appears in more recent publications (e.g. (Corbin et al., 2021) and is now the term of choice in the documents of many UN agencies; however it was not commonly used during the Ebola epidemic and therefore is not used in this work. Given the one-way, top-down definition of risk communication used in RCCE documents (e.g. Dickmann et al., 2016), the conflation of the two concepts may be unhelpful in furthering the objective of obtaining input *from* communities.

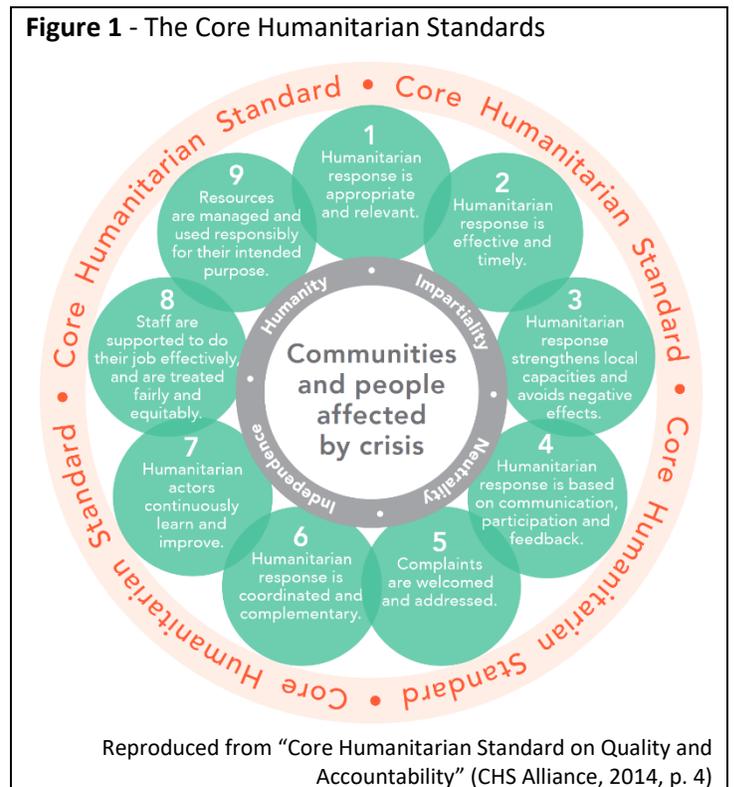
International Standards of Community Engagement and Social Mobilization

International agencies' standards for emergency response reflect philosophic agreement with a community engagement imperative. Under the auspices of the United Nations, the Inter-Agency Standing Committee (IASC) in 2011 undertook a review of weaknesses and inefficiencies encountered during the international response to major floods in Pakistan and the earthquake in Haiti the previous year (IASC, 2011), and developed the Transformative Agenda (IASC, n.d.) for humanitarian emergencies. The Transformative Agenda spotlighted reforms to international response in three major domains of leadership, coordination, and accountability.

A parallel effort involving many of the same international players resulted in the Core Humanitarian Standards (CHS), summarized in **Figure 1** (CHS Alliance, 2014, p. 4). The commitment in Standard 4 to “communication, participation, and feedback,” along with that of Standard 3 to “avoid negative effects” have particular bearing on the sort of community engagement being discussed in this work – acknowledging, of course, that negative effects to the community can only be recognized if community feedback mechanisms (such as Standard 5: “Complaints are welcomed and addressed”) function effectively.

The Transformative Agenda's ‘accountability’ domain was expanded into the Accountability to Affected Populations (AAP) Operational Framework (IASC, 2013a). Although the AAP Framework addresses numerous issues, among its objectives are to involve affected populations in needs assessment (Objective 4) and implementation (Objective 6) of any intervention, and to maintain effective mechanisms both to provide information to, and solicit feedback from, affected populations (Objective 2). These priorities are emphasized in more-recent AAP documents which call for “people-centred approaches that enable women, girls, boys, men, including the most marginalised and at-risk people among affected communities, to participate in and play an active role in decisions that will impact their lives, well-being, dignity and protection” (IASC, 2017, p. 2).

The AAP framework's commitments appear to focus solely upon feedback of the sort which might occur if community members deliberately approach response leaders with their concerns. A key indicator under AAP Objective 2 is that “Affected populations have opportunity to register complaints, provide feedback and to get a response” (IASC, 2017, p. 2). In epidemiologic terms, this sort of feedback mechanism could be characterized as passive surveillance – that is, response personnel passively await community members' expressions of concern. AAP documents do not describe active surveillance, in which the monitoring system would intentionally seek feedback from key informants. Nor does the communication-centric approach to monitoring



consider the possibility that ‘noncompliant’¹¹ behavior might itself be a form of feedback that should trigger inquiry.

According to international norms, the humanitarian response to health emergencies is coordinated by the World Health Organization (WHO) under its Emergency Response Framework (WHO, 2013). The multitude of national and international agencies who contribute to the health component of a response are coordinated under the Global Health Cluster, of which WHO is the lead agency (WHO, 2020). In a WHO document on social mobilization in public health emergencies, the organization made the case for community engagement in an epidemic context well before the West Africa Ebola epidemic:

“Epidemics cannot be managed by technological interventions alone. Experiences from previous outbreaks have shown a rather paternalistic view of how to affect human behaviour mainly through providing instruction. We have since come to realize that community understanding of diseases and their spread is complex, context dependent, and culturally mediated. Therefore, a one-size-fits-all response is not enough. There needs to be an understanding of how a community understands disease before developing effective strategies intended to affect behaviour” (WHO, 2010, p. 6).

WHO grounded its community engagement strategies in the “Centrality of Protection” principle (IASC, 2013b), and affirmed a mandate to “prioritize safety and dignity, and avoid causing harm: prevent and minimize as much as possible any unintended negative effects of your intervention that can increase people’s vulnerability to both physical and psychosocial risks,” and further to “set up appropriate mechanisms through which affected populations can measure the adequacy of interventions, and address concerns and complaints” (WHO, 2020, p. 19).

WHO’s Social Mobilization guide states that communities should be involved in “shaping the intervention” and be allowed to “trade off the benefits and burdens of engagement” (WHO, 2010, p. 6). Similarly, WHO’s Communication for Behavioural Impact (COMBI) manual highlights the responsibility of social mobilization for “monitoring ... from the perspective of affected communities in order to provide feedback to ... response staff” (WHO, 2012, p. 17). The COMBI manual considers burial interventions directly, recognizing that they should “be addressed, and ways of humanizing the ceremonies but still making them safe should be negotiated with family members, religious leaders and community members” (WHO, 2012, p. 36).

Likewise, UNICEF Communication for Development (C4D) guidelines describe the importance of helping communities to materially impact interventions, including “continuous feedback on the quality, availability, accessibility and acceptability of services” (UNICEF, 2020, p. 6). Consistent with good development and anthropological practice, the C4D standards state in Integration Standard 13.3, that community engagement is an essential element of all pillars/clusters of a response (UNICEF, 2020, p. 28).

UNICEF C4D Standard 4 calls for “bidirectional communication and feedback between communities and power-holders ... structured to ... include information on what is working in the project, what ideas communities have for improvements and project adjustments, current knowledge, attitudes and

¹¹ The term ‘noncompliant’ may imply the very top-down attitudes critiqued throughout this document. It is used deliberately in this context to highlight a generally-accepted term of art within the public health community – one that itself needs to be examined. It is this author’s contention that ‘noncompliant’ behavior must be recognized as a signal to reexamine interventions and their sociocultural impact, not merely as an indication that education or force may be necessary.

practices and reporting of rumours” (UNICEF, 2020, p. 52). As with AAP above, where the standards may fall short is in the area of unspoken communication – passive resistance of the sort Wilkinson and Fairhead (2017) described in the Ebola epidemic. Absent a recognition that ‘noncompliance’ itself may be a form of communication, it is unclear how community violations of Ebola burial policy might have triggered feedback to those who enforced or defined the policy.

Community Engagement on “Safe and Dignified Burial” during the 2014-2016 Ebola Response

As was described in Chapter 1, the biological risk of Ebola transmission as a result of traditional burial practices such as washing, touching and kissing the body has been known since the first reported outbreaks. Recommendations for aseptic burial are therefore a logical intervention, and in fact they have been part of Ebola control efforts since at least 1995 (Dowell et al., 1999; Guimard et al., 1999; Heymann, 2015), and were publicized in an interim guidance document from the World Health Organization in late 2014 (WHO, 2017b). In Sierra Leone, the national government codified safe burial practices into a *Standard Operating Procedure for Safe, Dignified Medical Burials* (Government of Sierra Leone, 2015) which mandated aseptic burial by trained technicians for all deaths, regardless of cause.¹² Among other provisions, burial technicians were only to handle a body while wearing full personal protective equipment (PPE), disinfect the body and surrounding area by spraying with chlorine bleach, and encapsulate the body in a sealable polyethylene body bag before transporting for burial. Only extremely limited, non-contact participation by family members or clergy was permitted (additional detail on this is provided in a later paragraph).

That there might be substantial resistance to aseptic burial requirements was no surprise; as far back as an outbreak in Kikwit, Zaire (now Democratic Republic of the Congo) in 1995, it was reported that family members forcibly removed the corpse of a deceased Ebola patient rather than permit them to be buried according to biomedical protocol (Guimard et al., 1999; Khan et al., 1999). In neighboring Liberia, where cremation was required early in the epidemic, bribing officials to evade official body removal was reported (Manguvo & Mafuvadze, 2015; Pellecchia et al., 2015), and this author personally recalls rumors of a similar informal market in Sierra Leone for ‘burial certificates’ to permit a normal funeral, which might include falsified reports of a negative Ebola test. Such certificates have been reported by others as well (Goguen & Bolten, 2017).

Aware of potential opposition, questions about both knowledge and practice related to funerals were incorporated into at least two Knowledge, Attitudes & Practices (KAP) surveys conducted in Sierra Leone (Jalloh, Bunnell, et al., 2017; Jalloh, Sengeh, et al., 2017). Observational studies of the conduct of burial teams (Nielsen et al., 2015), focus groups (Lee-Kwan et al., 2017) and in-depth community workshop sessions (Pedi, 2014) were held in the summer/fall of 2014. Two of these study efforts found that community members felt burials up to the time of the survey had been disrespectful to the deceased and their families. In some cases, respondents reported that multiple bodies were transported in untagged body bags, and even buried two or more to a grave. Family members had been excluded from the cemetery at burial, and religious practices had been curtailed or prevented (Lee-Kwan et al., 2017; Nielsen et al., 2015). Out of these findings, the Safe and Dignified Burial (SDB) protocol for Sierra Leone was adapted to include allowing for a pastor or imam to officiate at a burial, accompanied by not more

¹² The stated rationale for the all-cause mandate was to avoid delays that might be introduced by waiting for confirmatory Ebola tests.

than ten family members (Government of Sierra Leone, 2015). Additionally, the need for a social mobilization component to coordinate between family and burial teams was identified (Pedi, 2014).

These early community engagement efforts have largely been represented by the response community as successes: “achieving broad acceptance” (Lee-Kwan et al., 2017, p. 29), implementing “considerable improvements” (Nielsen et al., 2015, p. 27) that ultimately “met community needs for culturally acceptable mourning, thus reducing resistance to safe burials” (Frieden & Damon, 2015, p. 1898).

Particularly in view of the case described in Chapter 1, it is notable that the spiritual concerns that were identified in Lee-Kwan (2017) and Nielsen (2015) “acknowledged only Christian and Islamic traditions” (Blevins, Jalloh, et al., 2019; Martineau et al., 2017; Park, 2020) and do not appear to have meaningfully considered African traditional practices. A similar bias – considering Christian and Islamic concerns but overlooking traditional beliefs – was observed by anthropologists in an after-action study of an Ebola outbreak in Uganda (de Vries et al., 2016).¹³ Objections based in traditional beliefs, such as those highlighted by Owusu-Darkwa (2015b) – to the body bag itself, and to the notion of community outsiders handling the intimate processes of death and burial – appear not to figure in either the Lee-Kwan (2017) or Nielsen (2015) reports. This oversight may be due to the limited sample size upon which Nielsen et al. (2015) base their community-specific observations,¹⁴ although regional differences in community concerns (Alexander et al., 2015; Manguvo & Mafuvadze, 2015) may also have been a factor.

It is also possible that the approach of the study teams precluded respondents’ expression of dissenting opinion. The core elements of medical burial appear to have been presented as non-negotiable – they are simply stated as requirements in one study (Nielsen et al., 2015), and a principal recommendation for follow-up is “sensitiz[ing] the community with updated information on safe, dignified medical burial practices” (Lee-Kwan et al., 2017, p. 28) in another. The express intention of social mobilization efforts was framed around obtaining community acceptance of medical burials (Pedi, 2014; Pedi et al., 2017). Success was measured in part by a decrease in “the proportion of respondents objecting to SDMB [‘Safe and Dignified Medical Burial’] for a deceased family member” (Pedi et al., 2017, p. 39). Even as they acknowledged the need to move from a paradigm of one-way communication to a dialectic approach, their emphasis was on “adapting of messages” (Pedi et al., 2017, p. 43) not on the possibility that externally-imposed processes such as SDMB might require further modification.

In fairness, the social mobilization actors were operating in a response environment in which interventions were not amenable to challenge. “To health authorities, the solution was simple. With so much at stake, science eclipses religion: Risky rituals must end” (Maxmen, 2015, para. 13). The Western responders’ focus on biosafety – by implication if not overtly – presumed that traditional practices were “backward or barbaric” (Mokuwa & Richards, 2020, p. 6). Although some anthropologists were engaged in attempts at community engagement, even some of these engagement efforts considered local culture “an inconvenient and backwards obstacle” (Lipton, 2017, p. 804) to successful disease control.

¹³ Assumptions that even Christian or Muslim beliefs/practices are monolithic may ignore important local cultural nuances. A 5-country study on mortality surveillance found more variability in acceptance of autopsy methods between same-religion persons in different countries, than they did between Muslims and Christians in the same country (Blevins, O’Mara Sage, et al., 2019).

¹⁴ Nielsen et al. (2015) primarily conducted observations of burial teams. Only fifteen families/individuals were interviewed in the community. Lee-Kwan et al. (2017) conducted focus groups in only one of Sierra Leone’s fourteen districts.

Operating under a “‘deficit mentality’ which sees communities as a bundle of pathologies” (Marais et al., 2016, p. 444) and “relegates behaviors related to culture as unhealthy and behaviors to be overcome” (Airhihenbuwa & Liburd, 2006, p. 491), the response structure tasked social mobilizers with changing burial practices and educating the community (Frieden et al., 2014). Official Sierra Leonean government documents defined ‘Family Engagement’ as “help[ing] the family understand why some practices cannot be done because they place the family or others at risk for exposure” (Government of Sierra Leone, 2015, p. 4).

In this context, it is probable that community informants did not feel free to express any objections they may have harbored, to ‘Safe and Dignified Burial.’ As one anthropological team observed, “... they have been ‘sensitized’ to keep their real thoughts on the matter to themselves. Acceptance of Ebola control measures, despite their continued anti-sociality, may represent a similar tendency for playing along in public, and concealing discontent beneath” (Wilkinson & Fairhead, 2017, p. 22). Further, the manner in which community input was solicited – largely focus groups – may also have biased the answers in that individual group members might not have felt free to openly express dissenting opinions. Such a pattern has been documented elsewhere: “social psychology studies [have] demonstrated that group decisions are not simply individual decisions writ large; asked the same question, individuals questioned separately will give one set of answers, while the same individuals aggregated into groups will give different ones” (Feierman et al., 2010, p. 125).

More important, however, than the initial failure to recognize community objections, is the fact that no feedback loop existed to raise these objections to response leadership and reexamine intervention strategies. For example, the second KAP survey in August 2015 (Jalloh, Bunnell, et al., 2017) found that a substantial minority (about 19%) of the study population reported that they continued to be unwilling to accept safe burial protocols.¹⁵ The authors’ conclusion was that “These findings point to the need for community-level data on KAP during an outbreak *in order to develop more tailored risk communication strategies* as part of future outbreak control for Ebola as well as other endemic and emerging health threats” (Jalloh, Bunnell, et al., 2017, p. 5, emphasis added). Similarly, Wilkinson et al. (2017) observed, after a different ‘community meeting’ around an unsafe burial event, that “Follow up ... revealed no further activity or details except that from that point on it was treated as a police matter” (Wilkinson et al., 2017, p. 6). Neither report suggests that the evidence of resistance to safe burials might have indicated a need to revisit the policy. To phrase it more bluntly, it seems no one seriously asked the question “whose ways have to be amended?” (Leach, 2008, p. 3).

Where community feedback was solicited, it appears that important signals may have been missed. A group of social-mobilization actors in Sierra Leone created a Community Led Ebola Action (CLEA) initiative to train social mobilizers in-country and help them better to engage their communities (Bedson et al., 2020). CLEA focused heavily on two-way communication and encouraged social mobilizers to engage in a variety of roleplay and community feedback activities. CLEA seems to have constrained itself to the predefined safe burial protocol, to the extent that the number of safe burials vs. community-conducted burials was a key success indicator. Since the CLEA data indicated “100% safe”

¹⁵ The statistic is reported positively, as 81% acceptance. Due to possible positive reporting bias, the actual proportion of respondents unwilling to accept medical burial may have been higher.

burials (Bedson et al., 2020) in Port Loko during the time of the Chapter 1 case, it is clear that such community feedback as was gathered did not fully capture local behavior.¹⁶

Ultimately, social mobilization efforts in Sierra Leone failed on two levels. First, from a theoretical perspective, resistance to the prescribed burial standard was characterized strictly as indicative of a knowledge deficit on the part of the community: Marais et al. (2016) observed this directly, but it is also evident in the conclusions of Nielsen et al. (2015) and Lee-Kwan et al. (2017) in which further community education and/or refined messaging are identified as the sole solution to community objections.¹⁷

The knowledge deficit model – the assumption that resistance to a health intervention “can be countered by supplying probabilistic information about [the intervention’s] risks and benefits” (Dubé et al., 2013, p. 1767) – has been repeatedly criticized in social science literature as overly reductive of human motivation and behavior (Burgess, 1997; Dubé et al., 2013; Koutroulis, 2000; Leach & Fairhead, 2007; Marais et al., 2016), and further shifting culpability for undesired behaviors entirely onto the lay public (Leach & Fairhead, 2007).¹⁸ Speaking in the context of outreaches to reduce the use of illicit drugs, Burgess (1997) emphasized that differing value systems can be as important as differences in knowledge in influencing behavior. What is more, focusing strictly on a community’s lack of knowledge or trust in biomedical authority “misses opportunities to identify mismatches between people’s framings, and those of the institutions involved with science or governance” (Leach & Fairhead, 2007, p. 4). Acknowledging these mismatches invites epistemic humility for emergency responders and response institutions: perhaps the response operated under a knowledge deficit of its own.

The second failure of social mobilization efforts in the Ebola response was that, regardless of what success may have been achieved in ‘sensitizing’ communities to accept medical burial, the dissent that remained was misinterpreted. When resistance to the burial policy was reported, it was framed strictly as a question of (non)compliance, to be met with either education (Jalloh, Bunnell, et al., 2017) or coercion (Wilkinson et al., 2017). Response leadership failed to recognize ‘unsafe burials’ as a signal to possibly reexamine the intervention itself.

¹⁶ Bedson & colleagues acknowledge the possibility of positive reporting bias by self-reporting social mobilizers in the ‘Limitations’ portion of their paper.

¹⁷ As Bardosh et al. (2020) observe, “risk communication and behaviour theories used in epidemic response are outdated and in need of reassessment, although they continue to dominate response strategies and research” (Bardosh et al., 2020, p. 11).

¹⁸ “As Wynne (2005) and others have argued, deficit models, by, projecting ‘the problem’ onto the public, conveniently shore up scientific institutions and their perspectives as unproblematic, requiring no interrogation or adjustment” (quoted in Leach & Fairhead, 2007, p. 36).

Anthropology

Ebola in the Anthropological Literature

It has been shown in the previous section that the emergency response to the Ebola crisis failed to adequately comprehend and address community resistance to its interventions. One important element of this failure was a lack of understanding that at least some residents of affected communities calculated personal and collective risk in drastically different terms than those which the response presumed. Had response authorities fully engaged the expertise and experience of anthropologists and other social scientists, this void in understanding might have been recognized and addressed, perhaps minimizing the alienation of ‘resistant’ populations.

Engaging anthropologists with established relationships and prior ethnography in the region might, for example, have prepared the response community in the knowledge of a history of localized resistance to prior epidemic control measures (Wilkinson & Fairhead, 2017, p. 20). It also might have shown that traditional healers have a history of accepting training to modify their practices, if engaged in a mutually-respectful manner (Jambai & MacCormack, 1996).

The anthropological lens can be instructive to reflexivity. “Rather than an instrument of public health, [anthropology] can also be a mirror on the practice of public health” (Stellmach et al., 2018, p. 5). In this vein, anthropology suggests the uncomfortable possibility that public health as a discipline has never fully escaped its Occidentalist notions of superiority – notions rooted in anthropological as well as biomedical history (Greene et al., 2019; Hanna & Kleinman, 2019). Ebola control measures – especially in the social mobilization arena – undoubtedly sprang to some degree from an attitude Adams (2010) summarizes well:

“Interventions are promoted based on the assumption that if morbidity’s causes can be known scientifically, they can be prevented and even eradicated with the proper medical interventions. If villagers continue to see disease in a non-scientific, nonsensical way—that is, as a result of spirit attack, evil eye, loss of soul—then health will never be achieved. Ignorance is the real cause of disease ...” (Adams, 2010, p. 44).

Several anthropologists have critiqued elements of the West Africa Ebola response in similar terms to those discussed in the previous section. Bolten & Shepler (2017) describe their frustration, and that of their colleagues who had extensive experience in the three affected countries, “when it became clear that elements of the response were at best culturally insensitive and at worst wrong-headedly biomedical or even militaristic ...” (Bolten & Shepler, 2017, p. 349). They further observe that some response efforts “failed to halt the disease’s spread *precisely* because of the omission of the importance of working within and through local social practices and disease models” (Bolten & Shepler, 2017, p. 354, emphasis in original). This shortcoming was further detailed by Fairhead (2014), who, very early in the response, described in detail how interventions such as personnel in full PPE, or requirements to curtail social behavior, played directly into local constructions of sorcery.

The coercive and even militarized manner in which disease control interventions were enforced is a repeated point of critique (Benton, 2014; Bolten & Shepler, 2017; Parker et al., 2019; Pellicchia et al.,

2015; Stellmach et al., 2018).¹⁹ Several authors note that the heavy-handed implementation of quarantine, burial, and other requirements played into colonial (Wilkinson & Fairhead, 2017), national (Carmel et al., 2017), and local (Goguen & Bolten, 2017) political history which exacerbated resistance by those who perceived themselves to be on the weaker end of power dynamics.

In the face of their real-time witnessing of cultural violations in the context of the Ebola response, a group of anthropologists with deep ties to Guinea, Liberia, and Sierra Leone felt compelled to act, resulting in the creation in September, 2014 of the Ebola Response Anthropology Platform (Bolten & Shepler, 2017; Martineau et al., 2017) and similar efforts. Usually careful to maintain some academic distance, several anthropologists felt compelled to intervene based upon relationships in the region that had been years in the making; one reported that not only did she and her colleagues seek to insert themselves into response and policy, she also personally sent food relief supplies to her Sierra Leonean colleagues (Bolten & Shepler, 2017).

The efficacy of anthropologists' participation in the response appears to be a topic of some dispute. A celebrated case where an anthropologist negotiated the safe burial of a pregnant woman who had died in Guinea without the normal requirement that the fetus be removed and buried separately (Anoko, 2014b; Fairhead, 2014) also may have reinforced Westerners' otherization of local custom (Moran, 2017).²⁰ While glad to have been at the table, another remarked on "the instrumentalized, 'community engagement' and 'culture broker' roles of anthropologists" (Martineau et al., 2017) which may have compartmentalized their contributions "merely as a way to overcome culture barriers" (Jones, 2011, p. 2). While anthropologists directly contributed insight to WHO's 'Safe and Dignified Burial' protocols as well as the Sierra Leonean protocol (Lee-Kwan et al., 2017; Mokuwa & Richards, 2020; Nielsen et al., 2015), at other times they found their insights "silenced ... on both technical and moral grounds" (Martineau et al., 2017, p. 486). Bolten & Shepler (2017) point out the fact that even the anthropological experts who were heard were disproportionately expatriates, often to the exclusion of African scholars.

Several have remarked on the incongruity of finding themselves at the policy table instead of critiquing it from an external position (Bolten & Shepler, 2017; Martineau et al., 2017; Moran, 2017), and described how their engagement with the response led to unexpected observations of the culture and expectations of the responders as a community in their own right (Martineau et al., 2017). To their credit, Martineau et al. grant that anthropologists, as well as public health professionals, had their own "disciplinary and methodological blind spots" (Martineau et al., 2017, p. 490). Nevertheless, at its best, "by the conclusion of the Ebola response, the term 'anthropological' had come to signify something much more powerful within the response. For Ebola response workers, 'anthropology' signified an ethical location of radical alliance with local populations, global health justice, long-term commitment to health systems, and human rights as well as of opposition to violence, coercion, and passive or active abuse by powerful institutions" (Abramowitz, 2016, p. 436).

¹⁹ One pre-outbreak WHO document explicitly lists among the roles for anthropologists in an Ebola or Marburg outbreak "finding a balance between the authoritarian enforcement of sanitary measures and empathic approaches" (Epelboin et al., 2014, p. 78). The literature contains little evidence the latter 'empathic' approach was employed in the 2014-2016 epidemic.

²⁰ See also Leach (2008, p. 15).

Key concepts highlighted by anthropologists observing the Ebola response

Beyond the general participation and critique of the response already discussed, anthropologic literature on the 2014-2016 Ebola response contains insights in several topics that merit closer examination. Three such topics are examined below: understanding of what is meant by the term ‘community;’ exploring ways in which local practices within a community may be enablers, not only barriers, to disease control; and insights around burial traditions and practices.

Defining ‘community’

The broad agreement that successful emergency intervention requires engagement with communities has already been highlighted in this chapter. “Yet, for all the reports extolling the virtue of ‘community engagement’ and ‘community-based’, ‘community-centred’ or ‘community-led’ programmes, there has been less attention paid to what that might entail, and little reflection on the nature of ‘communities’ as locally understood and experienced” (Wilkinson et al., 2017, p. 2). Wilkinson et al. note that the literature of anthropology has deconstructed and debated the idea and mythos of ‘community’ for years, and resoundingly dismissed the idea that community is strictly, or even mostly, a geographic construct. However, the public health community²¹ – especially in epidemiology – tends to use the term either to describe “a group of people vulnerable to infection” (Espino et al., 2004, p. 9) or, in the case of health promotion, as the target for ‘engagement’ as described in the previous section.

Misconstrual of the bounds or composition of a community can overlook vital nuance within a local geographic setting, and “externally—or rapidly and naively—generated conceptions of communities, which fail to identify locally recognized sources of legitimacy, authority and influence, can have grave consequences” (Wilkinson et al., 2017, p. 4). This author personally witnessed an example of these consequences in Port Loko, when the response’s perceived association with one local political leader led to a rival’s refusal to permit members of his extended family to be taken to an Ebola treatment center – potentially resulting in the exposure, illness, and death of several people. A similar situation was reported by ethnographers in a different part of Sierra Leone (Goguen & Bolten, 2017).

In addition to misunderstanding the bounds of a community, outsiders may falsely assume homogeneity in the communities engaged (Espino et al., 2004; Wilkinson et al., 2017). Engagement strategies should start from the “premise that community groups are heterogeneous and that the diversity of opinions and sociocultural perspectives” (Anoko et al., 2020) must be considered. Community members may differ substantially in their acceptance of external interventions, and in fact dominant voices within a community may well discount or suppress dissenting opinions or actions (de Vries et al., 2016). Only by identifying trusted interlocutors among those minorities may important barriers be identified.

Anoko (2014), in particular, observed this failing when she conducted listening sessions in a group of villages in Sierra Leone to gather a list of community members that people said they trusted to represent their interests. She later compared the list she compiled to a list of ‘stakeholders’ with whom health partners were working, and found zero overlap between the two (Wilkinson et al., 2017). The response partners “had identified ‘community leaders’ ... either through self-identification or assumed from their professional, civic or political associations” (Anoko, 2014a, p. 7). In contrast, people told Anoko they trusted “traditional practitioners, heads of the sacred forests, religious leaders (Christians

²¹ The irony of using the same word to describe a professional sphere is hereby acknowledged.

and Muslims), circumcisers, village birth attendants, hunters, youth ... returned migrants from the city ... and the elders” (Anoko, 2014a, p. 7).

Anoko (2014a) further found that identifying diverse, non-authoritative community members provided a window into community opposition that putative ‘leaders’ either did not understand or simply ignored.²² Elderly men and women, youth, and low-status street vendors at times “proved to be leaders against the Epidemic [*sic*] response measures with a power to mobilize that even exceeded those of religious and traditional leaders, and to everyone’s surprise” (Anoko, 2014a, p. 8).²³ One of the lead organizations in Sierra Leone’s Social Mobilization Action Council similarly recognized the power of market women and ‘okada’ (motorcycle taxi) riders both as informants and influencers (M. Jalloh, personal communication, 2015).

Enablers as well as barriers

In addition to potentially misidentifying communities or their leaders, ill-defined understanding of community may unfairly presuppose that communities will only be problematic. This presupposition can take at least two forms: on the one hand, there is a sense that everything is disordered till responders arrive – “that a panic-stricken public, blinded by self-preservation, will constitute a secondary disaster for authorities to manage” (Schoch-Spana et al., 2007, p. 8). Particularly early in the Ebola response, humanitarian agencies operated on a “widespread perception [that] local cultural traditions, practices, and resistance” (Abramowitz et al., 2017, p. 60) would block response efforts.

On the other hand, the assumption can be that whatever communities are already doing is necessarily harmful: “Many sociocultural studies tend to focus only on how local beliefs and practices amplify the disease (e.g., how traditional burial practices contribute to disease transmission); little attention is given to how local peoples’ beliefs and practices might contribute to control efforts” (Hewlett & Amola, 2003, p. 1246).

Both presuppositions – of community opposition and community incapacity – overlooked the simple fact that people were responding to Ebolavirus disease in the context of their own lived experiences, striving “to take care of their fellow human beings and to diagnose and explain within their own cultural framework” (de Vries et al., 2016, p. 10). The “epistemic injustice” (Abma et al., 2017, p. 492) of dismissing community knowledge in favor of putatively superior Western understanding can lead to a “negation of [the] community” (Caremel et al., 2017, p. 74) – that is, dismissing the possibility that a community has any wisdom to offer in the service of their own defense.²⁴ In the Ebola response, this negation was reflected in part by who was hired or otherwise assigned to perform key public health tasks: “Local/community players were replaced by NGO workers, and other ‘projects’ evolved ... in which traditional players became at best auxiliaries and at worst, as was most often the case, illegitimate” (Caremel et al., 2017, p. 75).²⁵

²² See also Anoko’s more recent application of lessons learned during Ebola to COVID-19 and other pandemics (Anoko et al., 2020, p. 2).

²³ See also the discussion of “cadets sociaux” (Le Marcis et al., 2019, p. 24), that is, younger, junior, or otherwise powerless members of society who nevertheless wield important social influence.

²⁴ Caremel et al. also note that such negation of the community is rather paradoxical since the very same community is then supposed to be ‘mobilized’ to control disease according to outsiders’ guidance.

²⁵ This was not always the case. See the reports of local workers hired as highlighted in the Delphi survey in Chapter 4.

A direct challenge to these presuppositions is the initiative of communities themselves in Sierra Leone. Well before outside responders arrived, some villages or chiefdoms exercised considerable initiative to control Ebola among their members, informed by their own observations as well as by publicly-available guidance. One case study reports on a local chief imposing movement controls and even quarantine between villages (Goguen & Bolten, 2017). Another describes extensive, evidence-informed measures taken by a village that felt isolated from national assistance; measures that included designated caregivers to minimize community exposure, isolation and rehydration to treat ill members, and locally-constituted burial teams who improvised their own PPE (Parker et al., 2019).

Spiritual beliefs were also found at times to readily support outbreak-control measures. The support of Muslim and Christian leaders who developed key messages (particularly on sanitation and burial) based upon their scriptures and religious teachings has been widely reported and rightly celebrated (Bedson et al., 2020; Lee-Kwan et al., 2017; Lyons et al., 2021; Nielsen et al., 2015). Less public recognition has been granted to those beliefs within indigenous traditions that similarly supported public health concepts. For example, the Kissi of the forest region near the intersection of the Guinea, Liberia and Sierra Leone borders, hold that “one should purify and replace the furniture, clothing, and provisions that are in the room where a death occurred; a custom that could be seen to dovetail with disinfecting houses after a death” (Fairhead, 2014, p. 4). Similarly, Hewlett and Amola (2003) documented that among the Acholi of Uganda, if a disease is recognized as “a killer epidemic (*gemo*) ... burial practices change. The body is not touched and is buried outside or at the edge of the village. The designated caregiver, someone who has survived the outbreak or an older woman, is responsible for washing and preparing the body for burial” (Hewlett & Amola, 2003, p. 1244). Analogous infection control beliefs have been documented in the Republic of the Congo (Hewlett et al., 2005).

Not only can spiritual or traditional beliefs sometimes support outbreak control, even potentially problematic practices rooted in spirituality are not immutable, particularly if concerns related to them are approached respectfully through those leaders who mediate that spirituality within a community. A sterling example of this fact dates back to the colonial period in Sierra Leone, when Dr. Milton Margai²⁶ established a training program within the Sande women’s secret society, to train initiates in hygiene and to provide limited obstetric training to Sande midwives (Jambai & MacCormack, 1996; Margai, 1948). Among other interventions, Margai and his successor, Sister Omita Samai, persuaded Sande leaders to incorporate tetanus toxoid immunization into the traditional ‘washing’ initiation rituals for pubescent girls (Jambai & MacCormack, 1996).

A more-proximate example already referred to in the previous section was a situation in Guinea during the Ebola outbreak. In 2014, a pregnant woman had died of Ebola, and according to local tradition, it was necessary to remove her fetus and bury it separately from the mother. Recognizing that the process of removing the fetus would be biologically risky to those involved, local authorities forbade it, leading to a standoff between the community and the burial team. Anthropologist Julienne Anoko mediated an agreement between the parties and obtained approval from local elders for a reparation ritual to cure the ‘fault’ caused by burying the woman and fetus together (Fairhead, 2014; Moran, 2017). Nor was this example unprecedented: during the Sierra Leonean civil war, as many victims fell in battle

²⁶ Later, Sir Milton Margai, the first Prime Minister of independent Sierra Leone.

and their bodies were never found, traditional funeral practices were adapted to appropriately honor the dead absent a physical corpse to bury (Martineau et al., 2017).

Obviously, the specific cultural enablers or barriers will vary both with geography and time, and successful mediation of barriers is by no means assured. The Guinean example above is remarkable in part because the personalized, on-the-ground negotiation it entailed was not broadly repeated (Moran, 2017), whether for logistical or prejudicial reasons, and “the grievances and customs of the population often continue[d] to be forgotten” (Anoko, 2014a, p. 18). The fact remains that, if indigenous cultural authorities are approached with deference, seemingly-intractable barriers can at times be bridged.

Burial-Specific Observations

Although anthropologists provided important insights on burial customs in the three countries most affected by Ebola, these insights did not always translate successfully to improved practice. Part of this failure may have been due to the Occidental bias previously mentioned.

Moran (2017) suggests that the otherization of West African funerary practices too-readily dismissed universal emotional realities of mourning: “... committing an unwashed body to the grave can be understood as a violation of every normal definition of human dignity, entirely omitting the specific burial requirements of Islam, Christianity, or any other formal religion” (Moran, 2017, p. 413). The exoticization of West African practice missed the fact that bereavement and mourning often include practices that span far more than a simple dichotomy of ‘primitive’ belief over against ‘scientific’ knowledge (Moran, 2017). “Although anthropologists brought a more nuanced and historically grounded understanding of ‘ritual’ to the conversation, they too acted as though finding alternative, epidemiologically ‘safe’ practices would fully appease distraught communities” (Moran, 2017, p. 403). The previously-described incident with the burial of the pregnant woman in Guinea may have “... further reinforced the distance between ‘traditional’ and superstitious African villagers and the ‘rational’ scientists attempting to save them from themselves” (Moran, 2017, p. 405).

Anthropologists in the Ebola Response Anthropology Platform were directly involved in the creation of WHO’s burial guidelines (Martineau et al., 2017; WHO, 2017b), which in turn influenced Sierra Leone’s own burial standards. “The WHO and others certainly claimed authority to determine what did and did not constitute a ‘medical’ or ‘safe’ burial, namely one free from risk of viral transmission, but turned to anthropology to shed light on what constituted a ‘dignified’ burial (as such burials came to be labeled within the formal response)” (Martineau et al., 2017, p. 486).

Martineau et al. (2017) acknowledge the limitations of the policy itself – which attempted to accommodate certain Christian and Muslim practices but not indigenous spiritual traditions. They also note that not all of their recommendations were implemented. For example, their “suggestion for a radical decentralization of the formal burial response—namely, to train locals to carry out burials, so that centrally recruited ‘strangers’ or people from inappropriate ages or gender did not bury people—did not happen until much later, and even then, only partially” (Martineau et al., 2017, p. 482).²⁷

At least one anthropological team provided the very sort of warning that the response ideally should have received and heeded. Following a 2014 study published only a few months before the events of

²⁷ Martineau et al. (2017) qualify this statement by suggesting that objections by response leadership to their suggestions tended to be largely logistical rather than merely dismissive.

Chapter 1, the study team warned in their supplementary text that “Burial is now safer, and more respectful, but it is not yet adequate to the needs of societal reproduction. Efforts at consultation with and engagement of local groups on this crucial issue must continue, or dangerous evasions will continue to be attempted” (Richards et al., 2015, S1, last full paragraph). Whether appropriate ears heard this warning, and what, if any, actions were considered, is not known.

Caveat

As the preceding section has shown, anthropologists – particularly those with long ethnographic history in West Africa – can and did bring valuable insights to the table with regard to the communities affected by Ebola and how the response did or did not engage them. However, as several of these anthropologists have themselves acknowledged, their involvement – necessary though it was – was not sufficient to remedy key cultural shortcomings of the response. Part of the reason may have been the inherent difficulty of applying what is typically a slow, methodical discipline to the context of a fast-moving crisis: Bolten & Shepler (2017) mention the impact of anthropologists’ “inability or unwillingness to make rapid-fire assessments from very little data, and issue practicable solutions that depend on parsing great clarity and simplicity from chaos” (Bolten & Shepler, 2017, p. 356). They further confront the reality that even within their own discipline, “local anthropologists and African scholars were overlooked” (Bolten & Shepler, 2017, p. 358) in favor of expatriates.

Further, the tendency of response leadership (and sometimes anthropologists themselves) to perceive the domain of anthropology as “interlocutors” and “health communicators” with a “need to retain a fidelity to global health campaign messages” (Abramowitz, 2016, p. 427) may have inappropriately constrained the sorts of input anthropologists otherwise might have offered to the response. This “instrumentalized” (Martineau et al., 2017, p. 487) involvement, while it may have helped to bring anthropologists to the table, may also have prejudiced the broader structure against receiving and acting upon critiques of response behavior and policy.

With regard to community engagement as discussed in the previous section, some anthropologists’ descriptions of their own roles seemed to overlook the possibility of materially adapting public health interventions imposed on communities (see for example Epelboin et al., 2014, p. 80). To be fair, the same work points out that “When their [anthropologists’] observations compel them to question the methods and management of resources engaged in epidemic control operations, even to reveal dysfunction of national and/or international institutions, their views are often not welcomed” (Epelboin et al., 2014, pp. 81–82).

Anthropologists were directly involved in the Sierra Leonean Government’s adaptation of ‘safe and dignified burials’ to address local objections (Manguvo & Mafuvadze, 2015; Moran, 2017), but the changes that were effected only went so far, and significant objections remained in some communities. Despite these possible limitations, the discipline of anthropology can offer important insights, both into how humanitarian agencies frame emergency response, and how better to engage with affected communities. Later portions of this work will consider how such insights might better be incorporated into emergency protocols and structures.

Chapter 3 – Methods

A World Health Organization (WHO) document stated a decade ago:

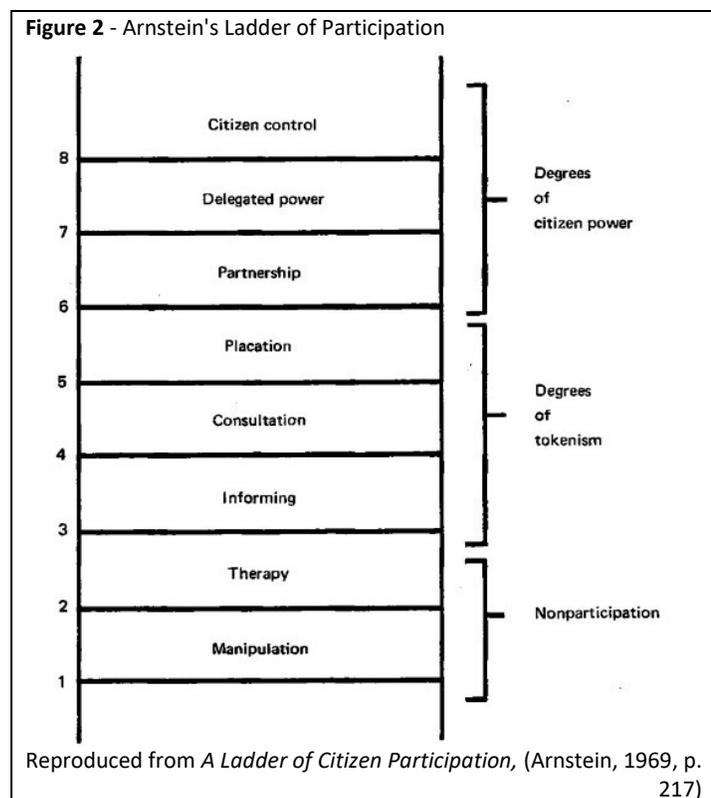
“Experts have come to realize that community understanding of diseases and their spread is complex, context-dependent and culturally mediated. Integration of participatory approaches into veterinary and public health responses are essential to look in the right places, ask the right questions and listen more effectively before making technical recommendations and implementing interventions” (WHO, 2012, p. vi).

As was shown in the literature review of agencies’ standards of community engagement in Chapter 2, there is broad acknowledgment among international response players that engaging with communities is imperative to effective intervention. However, the process of assessing engagement with a community is not at all straightforward. To the extent that the literature discussed in Chapter 2 assessed engagement, it was done in descriptive, qualitative language with no real metrics used to evaluate the strength or weakness of engagement efforts.

The following section describes a new methodology, developed for this work, to assess community engagement activities. In subsequent sections, this methodology is first applied to an analysis of community engagement efforts as described in literature, and second to select international agencies’ engagement strategies. Finally, the Empowerment Score methodology is used with a Modified Delphi survey of Ebola response experts to assess elements of the 2014-2016 Ebola response.

Development of an ‘Empowerment Score’ Metric to Assess Community Engagement

An often-overlooked variable in assessing community engagement is the extent to which (if at all) community voices have any power to determine or effect change in the situation around which engagement is being considered. In a harsh critique of 1960s United States urban redevelopment efforts, Arnstein (1969) observed that “There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process” (Arnstein, 1969, p. 216; see also discussions on power dynamics in De Weger et al., 2018; and Lang et al., 2013). Grounded in the axiom that “Citizen Participation is Citizen Power” (Arnstein, 1969, p. 216), Arnstein proposed eight levels of participation depending upon the extent to which power remained with an elite authority or was devolved to citizens themselves (**Figure 2**).



Following Arnstein (1969), Wilcox (1994a, 1994b) proposed a five-rung ladder that did not so much focus on power as it did on the extent to which a community is materially involved in development efforts that affect them. Whereas Arnstein was unequivocal that higher levels on the ladder, being more empowering of a community, were to be desired, Wilcox held that each of his five levels would be wholly appropriate for distinct situations: “I do not suggest any one stance is better than any other – it is rather a matter of ‘horses for courses’. Different levels are appropriate at different times to meet the expectations of different interests” (Wilcox, 1994a, p. 4).

Wilcox (Wilcox, 1994b) defined his five levels as:

- *Information*: merely telling people what is planned.
- *Consultation*: offering some options, listening to feedback, but not allowing new ideas.
- *Deciding together*: encouraging additional options and ideas, and providing opportunities for joint decision making.
- *Acting together*: not only do different interests decide together on what is best, they form a partnership to carry it out.
- *Supporting independent community interests*: local groups or organisations are offered funds, advice or other support to develop their own agendas within guidelines” (Wilcox, 1994b, p. 1).

The World Health Organization, in a 2002 document on participation in health and development, observed that “community participation is an umbrella term for many different practices. It is especially important to recognize different degrees or levels of participation” (WHO, 2002, p. 13). The WHO document further acknowledges that some community development initiatives present a “challenge ... to move up the ladder, finding new tools and techniques that promote active and genuine involvement, citizenship and empowerment rather than settling for the more passive processes of providing information and consultation” (WHO, 2002, p. 13). Nevertheless, echoing Wilcox (1994b), the WHO authors acknowledge that pragmatically, it is “not always possible or appropriate to aim for the top rung of the ladder” given local political and societal structures (WHO, 2002, p. 15).

Popay (2010) refined Wilcox’ (1994) ladder by tying the levels of participation Wilcox had described to the degree to which communities are empowered to participate in, and ultimately control efforts to improve their own health (Popay, 2010).²⁸

Arnstein’s (1969), Wilcox’ (1994), and Popay’s (2010) rubrics all describe a scale of empowerment; however, as linear scales they miss important nuance. It is entirely possible that a community may be highly empowered in specific elements of an emergency situation and yet fully excluded from others. Adding a second dimension to the Arnstein-Wilcox-Popay rubric may better elucidate this nuance.

As an exemplar of this second dimension, Davidson’s “Wheel of Participation” (Davidson, 1998) provides a frequently-cited model. Harking back to Arnstein’s (1969) ladder, Davidson suggested that the right level of participation could be visualized in four semi-independent ‘objectives’ for community involvement: Information, Consultation, Participation, and Empowerment. With Wilcox (1994b),

²⁸ Though none of them cite the works listed above, other variations of this participation spectrum can be found at (de Vries et al., 2020, p. 2; IAP2, 2018; McCloskey et al., 2011, p. 8).

Davidson held that his wheel “promot[ed] the appropriate level of community involvement to achieve clear objectives, without suggesting that the aim is always to climb to the top of the ladder” (Davidson, 1998, p. 1). Davidson did not describe any of these four objectives in detail, but suggested that each may be appropriately applied to different community-development efforts.

Davidson’s (1998) work is only a two-page brief, and other publications allude to Davidson’s wheel and the four major objectives without expanding upon them or discussing their implications, (e.g., Dooris & Heritage, 2013; WHO, 2002), although both of these publications mention that more than one objective may be reasonably applied to a specific situation – for example, it is possible to use both Information Provision and Consultation approaches in the same project. Barker et al. (2020) developed a taxonomy of community engagement based on Davidson’s wheel (as adapted by others) and applied it to an assessment of community engagement efforts by the Ebola response in Liberia (Barker et al., 2020). Barker et al. described Davidson’s ‘objectives’ as “four broad categories” (Barker et al., 2020, p. 418) of community engagement, and identified instances of all four in Liberia’s Ebola response. In this work, the term “domains” of engagement is considered to be a more helpful descriptor of the four objectives (Davidson) or categories (Barker). For the methodology developed herein, the following working definitions for each domain of engagement are used:

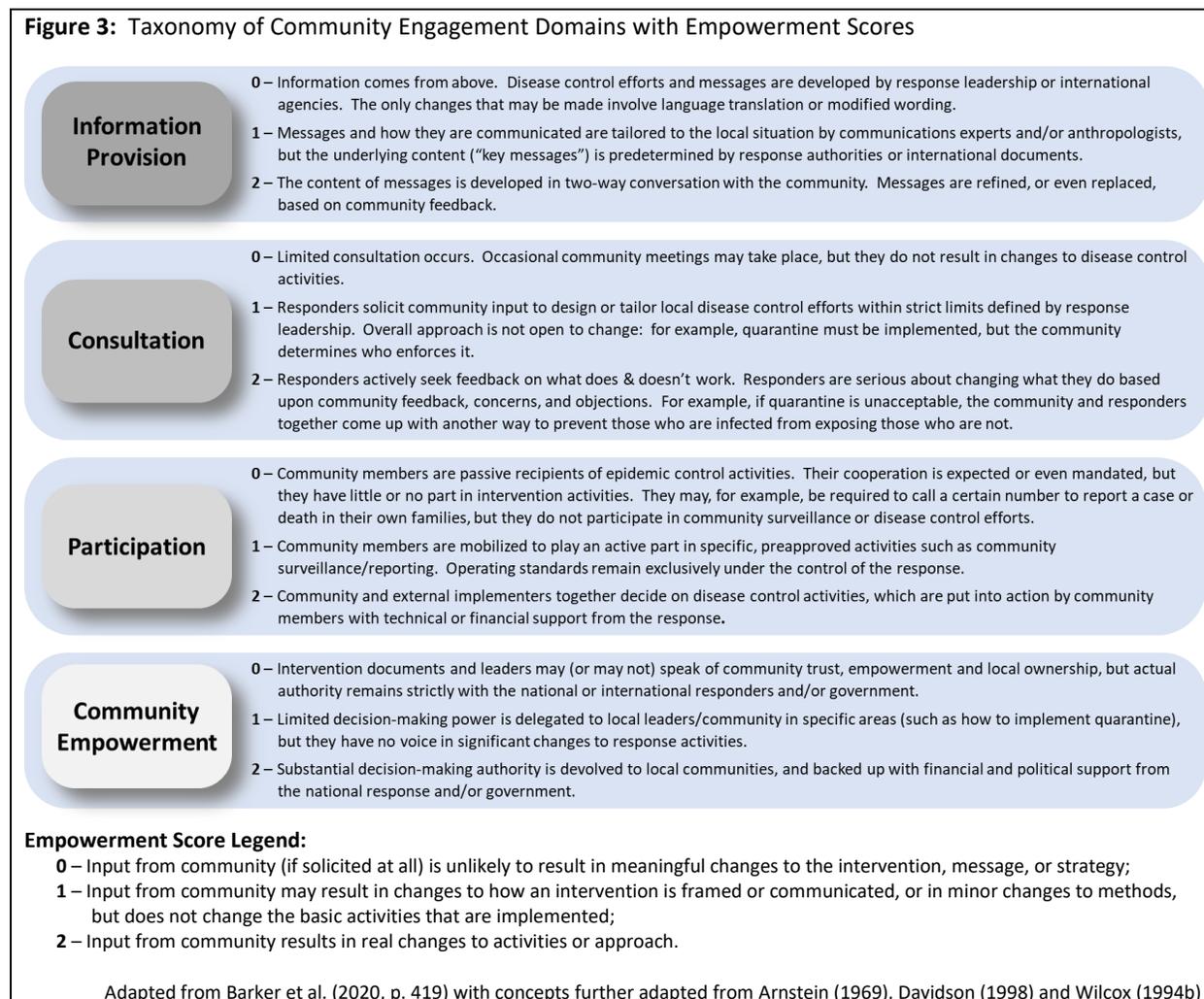
- **Information Provision** – describes any activity designed to communicate information about the epidemic or control efforts. This communication may take the form of information moving from responders to the community, from the community back to responders, or in both directions.
- **Consultation** – describes any effort made by responders to invite community feedback on the response. The difference between Information Provision and Consultation is the extent to which feedback from the community may be used to change actual activities or requirements that the response may expect of community members, as opposed to merely refining messages.
- **Participation** – describes the extent to which community members play an active part in the interventions in their community – that is, they actually *do something* (for example, contact notification or case reporting) as opposed to simply receiving what is done by the response.
- **Community Empowerment** – describes the extent to which community members *direct* what is done in their community to control the epidemic.

The assessment by Barker et al. (2020) was strictly descriptive in nature, and provided narrative examples of Ebola activities in each of the four domains of engagement. For the purposes of this work, the Barker et al. taxonomy has been adapted (**Figure 3**) to assign a discrete ‘Empowerment Score’²⁹ from zero to two based upon a pragmatic assessment of the degree to which community input may lead to systemic change, roughly (but not completely) following the levels of empowerment described by

²⁹ Note that the term ‘empowerment’ used here explicitly describes the community’s ability (power) to determine/modify approach and strategy. A common usage of the term in health promotion literature, for example to “empower individuals, families, and communities to adopt preventive and healthseeking behaviors” (Zikargae, 2020, p. 2807) is not what is here intended. Consistent with Arnstein’s (1969) ‘participation equals power’ maxim, in the context of this work, empowerment is meant to imply setting (or at least influencing) the agenda, not merely implementing an externally imposed one.

Davidson (1998) and Wilcox (1994a, 1994b).³⁰ In other words, activities relating to each domain in **Figure 3** are assigned an empowerment score according to the following broad definitions:

- 0** – Input from the community (if solicited at all) is unlikely to result in meaningful changes to the intervention, message, or strategy;
- 1** – Input from the community may result in changes to how an intervention is framed or communicated, or in minor changes to methods, but does not change the basic activities that are implemented;
- 2** – Input from community results in real changes to activities or approach.



Importantly, if an intervention is scored using the rubric in **Figure 3**, one should not assume that a higher numeric score for any domain necessarily represents a ‘better’ intervention – as previously mentioned, the appropriate level of empowerment in any given circumstance may not always be that described by a

³⁰ See also Section 5.3 “Community Engagement” (WHO, 2022, pp. 99–100 & 102) in the World Health Organization’s Global Health Security Joint External Evaluation (JEE) tool for further understanding of the levels of empowerment.

score of 2. In fact, given that not all interventions necessarily contain elements of each of the four domains, an individual domain may be scored 0, not because of any deficiency, but simply because that domain is not relevant in the circumstances. Further, the sum of scores across the four domains has no functional meaning and is not recommended. In an emergency response, for example, it is entirely possible that an approach could maximize empowerment in the domains of Information Provision and Consultation – with both scored at 2, with Participation appropriately scored either 1 or 2, depending on local circumstances. Given the external imperative of interrupting an epidemic, it is probable that little to no authority over major response priorities would be delegated (if a community could stop an epidemic on its own, an international response would be unnecessary) and so Community Empowerment would rightly remain scored at 0, or perhaps at 1.³¹

Reflecting on the case described in Chapter 1, the reader will recall that a key point of concern was the lack of change at the programmatic or strategic level in response to community objections to burial protocols during the Ebola epidemic in Sierra Leone. Obviously, in order for community feedback to have influenced such change, it would be necessary first of all for the response to be open to changing its practice, not merely its messaging. Such a willingness to change could be expressed through meaningful Consultation, through engaging the community as Participants, or through directly Empowering the community to drive burial practices (or some combination of the three), which would result in an Empowerment Score of 2 in at least one of these three domains. Information Provision alone, even with sufficient community involvement as to merit an Empowerment Score of 2, could not result in changed protocols, only in changed messaging about them.

Analysis of Emergency Response Reports and Guideline Documents

Application of the Empowerment Score Methodology to Literature

To apply the Community Empowerment Scores to assessments of community engagement efforts, a PubMed search³² on community engagement in emergency response was conducted on 2/15/2022. The search criteria were ((("community engagement"[All Fields] OR "social mobilization"[All Fields] OR RCCE[All Fields]) AND ("emergency response" [All Fields] OR "emergency preparedness" [All Fields]) AND (2000/01/01:2022/12/31[Date - Publication]))). The search yielded 43 articles. Planning documents, literature reviews, commentaries, and articles that did not describe community engagement activities/priorities in the context of an active response, were excluded, resulting in 8 articles for analysis.

Full-text review of the 8-article set characterized the community engagement efforts described in each article. Efforts were identified according to the four domains of Information Provision, Consultation, Participation, and Community Empowerment, and then scored from zero to two for each article according to the rubric shown in **Figure 3**. If an article did not contain references to one or more of the four domains, those domains were scored at zero.

³¹ Indeed, one might reasonably question whether community empowerment is plausible – or appropriate – in the context of externally-driven epidemic control efforts. The fact remains that this language was used in the context of social mobilization during the response, and appears in community engagement guidelines from international agencies. Accordingly, it is appropriate to interrogate whether it happened; that is, whether and to what extent communities were actually empowered.

³² This search was distinct from the literature search which formed the basis of Chapter 2, and was designed strictly to provide a document set for this illustrative analysis.

In some articles, there was a discrepancy between the level of empowerment promoted in the article's theoretical language, and that in evidence through the activities that were reported. In such instances, a divided score between "language" and "action" was assigned. If no such discrepancy existed, a single score was assigned for each domain.

Assessing International Agencies' Response Guidelines Using the Empowerment Score

Methodology

Having applied Empowerment Scores to assess specific disaster responses, the same Empowerment Score rubric was then applied to a selection of field manuals and guidelines published by various response agencies including the US Centers for Disease Control and Prevention (CDC), the European Centre for Disease Prevention and Control (ECDC), the International Foundation of Red Cross and Red Crescent Societies (IFRC), the UN High Commissioner for Refugees (UNHCR), UNICEF, and the World Health Organization (WHO). Policy documents for these agencies tend not to be indexed in the published literature, and were retrieved from each agency's respective website. The selection of documents is not comprehensive; rather, the author attempted to retrieve the latest documents from each agency which included content relevant to emergency response and/or community engagement, including policies on burial and dead body management when available.

A Modified-Delphi Survey of Ebola Response Experts

Purpose

As has been demonstrated in Chapter 2, literature surrounding the 2014-2016 Ebola response in Sierra Leone frequently refers to the concepts of 'community engagement' and 'empowerment,' but it is not clear that the terms are used uniformly across all documents. Furthermore, scholars and responders differ in their assessments as to whether communities were, in fact, appropriately or successfully engaged or empowered.

A survey of responders and scholars (collectively, 'panelists') was conducted, both to clarify important concepts in the definition of community engagement, and to compile expert opinion as to how those concepts were, or were not, put into practice in Sierra Leone. The survey was designed to explore both explicit community engagement strategies such as social mobilization, and the extent to which communities were engaged or empowered regarding Safe and Dignified Burial.

Since the literature includes both positive (e.g., Bedson et al., 2020) and critical (e.g., de Vries et al., 2016) assessments of community engagement in the Ebola response, it is reasonable to expect a similar divergence of opinion among the panelists as to how well communities were engaged/empowered. On the other hand, the frequency of 'empowerment' or 'ownership' language in the literature (see Chapter 4, especially **Figure 4** and **Table 1**) may predict considerable consensus about the need for such engagement. Given the possibility of both consensus and divergence in expert opinion, a methodology that can capture both is desirable. A modified Delphi technique (Hasson, 2000; McKenna, 1994) was selected, both for its strength in gauging consensus (Dalkey & Helmer-Hirschberg, 1962; Turoff & Linstone, 1975), and for its ability to aggregate a diversity of ideas and expert opinions (Niederberger & Spranger, 2020).

Developed first by RAND Corporation to obtain consensus from experts around nuclear defense strategy (Dalkey & Helmer-Hirschberg, 1962; Turoff & Linstone, 1975), the Delphi technique has since been used across a wide range of disciplines including futurism (Gordon & Helmer-Hirschberg, 1964), program

planning and needs/resource assessment (Hsu & Sandford, 2007) health and health care (Fletcher & Marchildon, 2014; Hasson, 2000; McKenna, 1994; Niederberger & Spranger, 2020). Although there is considerable variation in methodologic implementations of the Delphi technique, common elements include a relatively small panel size³³, purposively-selected panel participants, and an “iterative multistage” (Hasson, 2000, p. 1010) design of two to five rounds (Niederberger & Spranger, 2020), with the preference for two or three rounds among most researchers (Fletcher & Marchildon, 2014; Hasson, 2000; Niederberger & Spranger, 2020). The purpose of iterative rounds is for each successive round to build upon the results of the previous round, either to refine/expand expert opinions or to achieve consensus among the panelists.

Another key feature of the Delphi technique is that panel members’ identities are not revealed to other members (Dalkey & Helmer-Hirschberg, 1962; Turoff & Linstone, 1975). Maintaining within-panel anonymity is considered to be “more conducive to independent thought” (Dalkey & Helmer-Hirschberg, 1962) and to “mitigating the effects of power relationships among members” (Fletcher & Marchildon, 2014) to the extent that members represent different levels of authority.

This modified Delphi survey consisted of three rounds (described below), using a combination of online questionnaires and email communication. The conceptual framework for this study was the Community Engagement Taxonomy and Empowerment Scores described in **Figure 3**. Initial questions invited panelists to assess the degree to which emergency response community engagement activities functioned within the four domains of Information Provision, Consultation, Participation, and Community Empowerment. This structure was employed, not because each domain is necessarily appropriate to every emergency response, but rather because it grounds the analysis in a rubric that has been considered in other community engagement literature, including an assessment of Ebola-control activities in neighboring Liberia (Barker et al., 2020).

Methods

Expert Panel Selection

Panelists were selected using a purposive sample of individuals involved in various roles in the Sierra Leone Ebola response during the time of the case study described in Chapter 1. The goal was a panel size of eight to fifteen members (ultimately, seven completed all three rounds), with the understanding that final makeup of the panel depended upon the availability of those recruited. For purposes of this study, an ‘expert’ was defined as someone who either:

- Worked on the ground with the Ebola response in Sierra Leone. Individuals who had direct experience with response leadership, community engagement/social mobilization, or disease control fieldwork, were approached, with a preference to individuals whose service overlapped with the time period of the case study in Chapter 1.
- Published studies on the Ebola response in Sierra Leone, in particular burial policies and/or community engagement, or ethnography around these topics.

³³ A recent review of other reviews documented Delphi studies with as few as three to as many as 270 panelists, with the bulk of reviewed studies reporting under fifty. Numerous published studies have used panels of less than ten to twenty participants (Niederberger & Spranger, 2020).

In an effort to capture an appropriate range of insights, panel members were purposively recruited to achieve diversity in at least the following areas:

- Sierra Leonean nationals and Western Europeans/Americans;
- Male and female respondents;
- On-the-ground responders who worked with a variety of institutions, including the World Health Organization, the US Centers for Disease Control and Prevention, the British Department for International Development, and non-governmental organizations based both in Sierra Leone and Europe;
- Individuals who served at varying levels of authority within the response, from line-level to senior leadership; and
- African and Western anthropologists who studied and published on the response.

The questionnaires for all three Delphi rounds are presented in Appendix A. The questionnaires were administered from June 27-October 17, 2022 via an online survey tool (Qualtrics, hosted by Georgia State University). Responses for each questionnaire were downloaded in a comma-separated values (CSV) format, then split into a key file which retained all personal information about each respondent and was kept secured, and a second file containing only a generic identifier (e.g., “Respondent 1”) along with the response data. Only the anonymized data were shared with the author’s advisory committee; all data were kept secure in encrypted cloud storage with controlled access. This study was approved as Exempt Category 2 by the Institutional Review Board of Georgia State University, IRB number H22644, Reference number 370363.

Data Analysis

The results of defined-response questions were analyzed by producing simple frequency distributions using Microsoft Excel v. 2019. Comment-field responses, including any clarifying email text, were imported into NVivo v. 12 (QSR International Pty Ltd., 2020) for qualitative analysis. Following Fletcher & Marchildon (2014), coding strategy included a mixture of both deductive and inductive coding techniques. Deductive coding used codes created from preexisting concepts in Community Engagement and Safe & Dignified Burial, including the previously-described Community Engagement Taxonomy with its four domains. The code set was then enriched through a process of “inductive open coding” (Auerbach & Silverstein, 2003, as quoted in Fletcher & Marchildon, 2014, p. 10), whereby “any data that did not fit our deductive code list were placed into new codes” (Fletcher & Marchildon, 2014, p. 10). As new codes emerged, the texts were reviewed to identify where else within the text these same codes were either supported or, in some cases, contradicted (in which case two codes were created representing the positive and negative instances of the concept).

Once the qualitative data were coded, codes were organized into visual maps based upon Clarke’s (2005) Situational Analysis approach.³⁴ Clarke described the mapping phase of her approach as an effort “to descriptively lay out as best one can all the most important human and nonhuman elements in the

³⁴ Adele Clarke’s (2005) full Situational Analysis methodology engages with the Grounded Theory of Glaser & Strauss (1967) and “pushes [it] around the postmodern turn” by “address[ing] head-on the inconsistencies, irregularities, and downright messiness of the empirical world” (Clarke, 2005, p. 15). Clarke’s full methodology is designed for more in-depth ethnography than was intended in this work; nevertheless, her Situational Mapping techniques described above were useful in this analysis.

situation of concern of the research broadly conceived ... the questions are: Who and what are in this situation? Who and what matters in this situation? What elements 'make a difference' in this situation?" (Clarke, 2005, p. 87). Her technique involves starting with a 'messy' map in which are displayed "all the analytically pertinent human and nonhuman, material, and symbolic/discursive elements of a particular situation as framed by those in it and by the analyst" (Clarke, 2005, p. 87). From this 'messy' map, the researcher then builds an 'ordered' map by categorizing the coded data into major and constituent themes creating "new and different inductive categories and/or modifications" (Clarke, 2005, p. 89) as the data demand. Out of the 'ordered' situational map, the categorized themes were fed back into the NVivo codebook and textual data were recoded as appropriate to those themes.

Following the preliminary analysis of each Delphi round, themes which emerged from that round were used to create the questions for the following round. Second- and third-round questions were asked both to gauge the panel's consensus, and to clarify areas of disagreement, with identified themes.

Delphi Round 1

Round 1 questions were a combination of defined-category options such as Likert scales or multiple-choice categories. Each question also included a free-text comment box in which panelists were invited to provide nuance to their defined-category answers.

As described above, questions in this round were designed to apply the Community Engagement Taxonomy and associated Empowerment Scores delineated in **Figure 3**. Questions first invited panelists to consider the four domains of Information Provision, Consultation, Participation, and Community Empowerment, and give their assessment: first, whether each domain is appropriate in an emergency response setting; and second, the Empowerment Score each panelist would ascribe to the 2014-2016 Ebola response to describe the level of empowerment in each domain. Because significant community-assessment and -engagement activities were undertaken around December of 2014 (Lee-Kwan et al., 2017; Nielsen et al., 2015), panelists were asked to assign a distinct Empowerment Score to activities that occurred before December 31, 2014 and after January 1, 2015.

Further questions asked whether the four domains, if appropriate to the response at all, either were or should have been led by the Social Mobilization Pillar, which was the organizational unit of the response tasked with community engagement and communications. Additional questions asked whether community engagement efforts overall succeeded or failed, and specifically whether the Safe and Dignified Burial protocol succeeded or failed. Two questions solicited the panelists' assessment of knowledge deficit on the part of the community and responders, respectively. Finally, one question sought panelists' opinions as to whether resistance to burial protocols should have been addressed through stronger enforcement or protocol modification.

As previously mentioned, each question consisted of a defined-response element (multiple choice or Likert scale as appropriate), with a free-text comment box in which panelists were invited to explain or elaborate upon their answers. In a few instances, free-text answers in the Round 1 questionnaire were brief or unclear. Accordingly, before the free-text responses were analyzed, the author communicated by email with those panelists as needed to clarify any uncertainties and/or invite more detail on their responses.

Delphi Round 2

The major themes that emerged from analysis of the first Delphi round provided the basis for the second round. For each Round 2 question, panelists were presented with a histogram showing the distribution of panelists' responses to the Round 1 defined-response questions, along with key quotes from panelists' comments illustrating the range of opinions expressed. Panelists were then invited, in consideration of their fellow panelists' opinions, to reassess their Empowerment Scores for each domain. Since two of seven panelists did not feel they could answer for the early part of the response, and another took issue with the date dividing early and later, Round 2 only asked about the response overall and about the appropriate level of empowerment for a hypothetical future response.

For the Likert-scale questions from Round 1, panelists were presented with a 1-2 sentence summary of the theme(s) which emerged from that question, and asked once again to rate their agreement or disagreement with each summary on a 5-point Likert scale. As in Round 1, panelists were invited to provide any other comments they deemed relevant for each question.

As in Round 1, Round 2 was analyzed using the same combination of frequency histograms for defined-option answers, and qualitative analysis of major themes for free-text answers. As with the first round, if any text answers were unclear or required amplification, email questions would have been sent to each panelist to seek clarification or expansion of her/his thoughts (this did not actually occur in Round 2). Free-text answers in Round 2 were appended to the qualitative NVivo database from Round 1 and coded according to the existing codebook. As in Round 1, as additional topics emerged from Round 2, new codes were added inductively and then the entire text was re-scanned for appropriate application of those new codes.

Delphi Round 3

The purpose of the third Delphi round was (1) to measure the panel's consensus, or lack thereof, regarding the Empowerment Scores from Round 2; and (2) obtain final clarification on two issues where the emerging theme remained unclear. These issues were offered as short-paragraph descriptions, and panelists were asked to rate their agreement or disagreement with the issue as stated using a 5-point Likert scale. Unlike the first two rounds, panelists were offered only one opportunity for free-text comments in Round 3.

Results from Round Three were summarized quantitatively as with the prior two rounds, and two comments received were added to the qualitative data for final coding.

Chapter 4 – Data Analysis and Results

Analysis of Emergency Response Reports and Guideline Documents

Analyzing Community Engagement in the Literature

The PubMed search described in Chapter 3 yielded 43 articles. Planning documents, literature reviews, commentaries, and articles that did not report community engagement activities/priorities in the context of an active response, were excluded, resulting in 8 articles for analysis. A brief synopsis of each article with a rationale for its scoring appears below, followed by a summary of these data.

Document Scoring

In each of the following descriptions, interventions reported are assigned an Empowerment Score according to the activities described, using the definitions for each score presented in **Figure 3**.³⁵ If any domain is not described in an article, it is scored at 0, not because the intervention was necessarily deficient, but simply because no empowerment in that domain is reported. As set forth in Methods above, where there was a discrepancy between the level of empowerment promoted in the article’s theoretical language, and that in evidence through the activities that are reported, a divided score between “language” and “action” is reported below. If no such discrepancy was found, a single score is reported for each domain. The 8 articles analyzed are described in the following paragraphs:

Abara et al. (2014) report on the public health response to a chlorine-gas leak disaster in Graniteville, SC which resulted in mass evacuations, illness and death. Emergency responders consisted of a coalition of state health department and university representatives as well as local health and emergency officials. The responding team used a “community-based participatory service (CBPS) approach” (Abara et al., 2014, p. 5688) to ensure community interests were included in all aspects of the response, and “with assistance from SCDHEC,³⁶ voluntary local leaders eventually came together to form the Graniteville Community Coalition (GCC)” (Abara et al., 2014, p. 5689). Scoring:

- **Information Provision:** Community leaders expressed concern that they were not receiving the information they most needed, particularly with regard to potential long-term outcomes from chlorine exposure. In response, authorities created a fact sheet answering community questions, and instigated a long-term monitoring registry to address their health concerns. This effort is scored a 2 for Information Provision.
- **Consultation:** The article describes “a series of town hall public meetings and training workshops where its staff would meet with community members, and address their questions and issues” (Abara et al., 2014, p. 5689). The result was that “the next steps for the recovery of Graniteville were made collaboratively between SCDHEC and GCC” (Abara et al., 2014, p. 5689). A follow-on “research agenda was driven by the concerns of residents” (Abara et al., 2014, p. 5691) as well. Because these consultations drove material aspects of the recovery strategy, this effort is also scored at 2.
- **Participation:** The community tracking registry, though implemented by SCDHEC, used community members to recruit voluntary participation in the registry. Additionally, an

³⁵ The reader may find it helpful to print a copy of **Figure 3** and refer to it while reading the following sections.

³⁶ South Carolina Department of Health and Environmental Control.

established local clinic was engaged to do health screening and monitoring, and screening efforts were staffed with a combination of community volunteers and contractors. As long-term research efforts were undertaken, “the GCC was intricately involved in the grant submission and grant writing process” (Abara et al., 2014, p. 5691). The extent of community-volunteer involvement in these activities results in a score of 2.

- **Community Empowerment:** The fact that community concerns resulted in the implementation of follow-on monitoring and research activities, as well as driving specific health research questions, merits a score of 2 for community empowerment.

Ali et al. (2017) describe a project by which Médecins Sans Frontières (MSF) provided kits containing tools and materials to repair roofs and boats to communities in the Philippines following Typhoon Haiyan. Community engagement consisted of delegating to leaders in affected communities, the responsibility for distributing kit contents as they saw fit. This article does not suggest that any Information Provision or Consultation efforts were intended or attempted, so both are scored at 0.

- **Participation:** Once MSF provided the kits to communities, “the distribution in the community was implemented by the community and led by community leaders represented by a community council” (Ali et al., 2017, p. 286). All repair efforts were done entirely by community members, either individually or collectively. Accordingly, Participation is scored at 2.
- **Community Empowerment:** MSF’s intention was to “empower the community from the start and leave the distribution process to the local decision-makers” (Ali et al., 2017, p. 288). However, the parameters of the intervention – in this case, the composition of the repair kits – were previously fixed by MSF and no feedback was obtained until an after-action study which is reported in this article. Since even community leaders had no power to substantially change the intervention, Community Empowerment is scored at 1.

Bedson et al. (2020) describe the Community-Led Ebola Action (CLEA) approach implemented by the Social Mobilization Action Consortium (SMAC) in Sierra Leone during the 2014-2016 Ebola epidemic. CLEA was an effort implemented by SMAC-trained social mobilizers recruited from local communities, to educate communities on various Ebola prevention strategies and motivate them to implement desired actions.

- **Information Provision:** The educational aspects of CLEA were conducted using a highly interactive combination of discussions and roleplaying activities, and “implementation of CLEA was regularly adjusted in response to findings of knowledge, attitudes, and practices assessments” (Bedson et al., 2020, p. 3). Their use of “an interactive and iterative community facilitation approach (Bedson et al., 2020, pp. 3–4) warrants an Information Provision score of 2.
- **Consultation:** Among other purposes, the stated focus of CLEA “not only on supporting and encouraging Ebola-safe behaviour, but also providing a reliable communications infrastructure for directly linking large numbers of communities, via mobilisers and SMAC staff, with response authorities” (Bedson et al., 2020, p. 4) would warrant a score of 2 for Consultation. However, the authors acknowledge that in this and more-recent Ebola outbreaks, “information collection remains largely unpaired with measurable operational changes or action” (Bedson et al., 2020,

p. 10). As no successful feedback leading to changes in the response approach are described, this article is scored at 2 for the language of consultation and 1 for action.

- **Participation:** The broad attempt of CLEA was to “to create a sense of urgency, a desire to act and local ownership ... [and] emphasized *community* identification of priority actions for action plans” (Bedson et al., 2020, p. 4, emphasis in original). This language suggests an Empowerment Score of 2 for Participation. However, detailed description of CLEA events shows that community members were encouraged to engage in “actions covering focus areas such as burials, reporting symptoms/deaths, reintegration of survivors and child protection” (Bedson et al., 2020, p. 4). Further, success was measured by “metrics such as the total number of suspected Ebola cases, number of cases referred to a health facility/health alerts within 24 hours of symptom onset, number of survivors, number of suspected deaths, number of safe burials, number of burials conducted by the community and the time elapsed since last suspected case” (Bedson et al., 2020, p. 4), all of which suggest that community action was only countenanced along previously-prescribed pathways; hence, these interventions warrant an Empowerment Score of 1 for the actions reported.
- **Community Empowerment:** The stated intent of the CLEA approach was that “Communities feel empowered to protect themselves using local resources” (Bedson et al., 2020, p. 3, Table 1). This language suggests that empowerment at a level 2 score was intended. However, the interventions described state that community members were encouraged under CLEA to develop local disease mitigation and enforcement activities such as “bylaws (such as restricting entrance to, and exit from, a community)” (Bedson et al., 2020, p. 4), and as previously noted, success was measured by implementation of nationally-dictated measures. As there is no report that communities had any influence on decisions or standards affecting these measures, the accurate ‘action’ Empowerment Score for these activities is 1.

Brewer et al. (2020) report on an effort to build COVID-19 preparedness into an existing community-based participatory research (CBPR) network of African-American churches working with Mayo Clinic in Minnesota. This project was an Information Provision effort with some Consultation in its development. No claims of Participation or Community Empowerment are made in the article, so these domains are scored at 0.

- **Information Provision:** The authors describe an effort designed largely around the dissemination of predetermined emergency preparedness materials designed by the US CDC, the American Red Cross, and others. Although the Task Force includes community members: “a clergy leader ... a financial advisor ... and a community health worker” (Brewer et al., 2020, p. 2), the only dialog with the larger community that is described consisted of interactions on a Facebook page. Since “the Task Force also created culturally tailored educational resources” (Brewer et al., 2020, p. 3) these activities receive an Empowerment Score of 1.
- **Consultation:** There is a consultative element implied in the needs assessment conducted among the leaders of participating churches at the beginning of the reported activities. In that assessment, church leaders expressed needs for “financial support, food and utilities, and COVID-19 health information” (Brewer et al., 2020, p. 1). The implemented strategy consisted solely of the sharing of informational documents and Facebook messages (i.e., Information

Provision). Since the needs assessment implied a desire for community input, this article is scored 1 for the language of empowerment. However, since the community's expressed needs beyond information appear not to have been addressed, the article is scored 0 for Consultation action.

de Vries et al. (2016) is an anthropologic investigation of the previously-claimed success of social mobilization in a 2012 outbreak of Ebola in DRC. The authors comment upon (indeed, criticize) the manner in which an international agency implemented social mobilization efforts in this outbreak. Although the overall response in this outbreak (as in any) is multifaceted, the intervention analyzed by de Vries and colleagues was strictly focused on mobilization in the Information Provision domain. Since Consultation, Participation and Community Empowerment are not in the scope of this article, all three of these domains are scored at 0 (recognizing these scores may not characterize the whole response, merely the part covered by de Vries et al.).

- **Information Provision:** The agency who implemented social mobilization activities in this DRC outbreak “enlisted and trained local volunteers and local community health workers (VHTs) to provide psychosocial support and built community trust and confidence” (de Vries et al., 2016, p. 3). This team of volunteers aimed to “to strengthen the community component which delivered the ‘actual definition by the health system of the problem’” (de Vries et al., 2016, p. 5) over and against the witchcraft explanation extant in the community. The agency’s stated intention to provide “‘culturally acceptable’ interventions” (Thorimar, SB as quoted in de Vries et al., 2016, p. 8) would suggest an Empowerment Score of 1 for Information Provision, so this is the score given for the language of the intervention. In practice, however, a community member told de Vries’ team that “We attended those sensitization sessions through the barrel of a gun. Before the government used force, people would come to the sensitization sessions, argue with the health workers and disrupt their sessions. But when the guns came in they had to sit and listen” (de Vries et al., 2016, p. 7). This coercive reality, showing little if any willingness to alter message or approach, results in an action Empowerment Score of 0.

Earle-Richardson et al. (2021) also report on the response to an Ebola outbreak in DRC, this one in 2018-2020. The authors’ “Mixed methods approach for monitoring community perceptions” (Earle-Richardson et al., 2021, title) comprised a combination of Information Provision and Consultation activities. No Participation or Community Empowerment activities are discussed, so these two domains are scored at 0.

In the reported social mobilization effort, teams of two volunteers went out to villages to hold “an informal conversation about Ebola, sharing basic facts about the disease, treatment, and prevention and answering any questions. While one volunteer led the conversation, the other took notes, writing down anything anyone said related to Ebola that was a question; a statement of rumor, experience, or belief; a suggestion; or an expression of appreciation” (Earle-Richardson et al., 2021, p. 334). All feedback written down in this manner was taken back to the office and qualitatively analyzed to identify information needs, issues requiring further attention, and feedback to response authorities.

- **Information Provision:** Where issues identified by the monitoring team were identified, “leaders used weekly data summaries to facilitate discussions and reinforce volunteer Ebola knowledge” (Earle-Richardson et al., 2021, p. 337). These reports were used to develop

frequently-asked questions (FAQ) documents which were disseminated through a WhatsApp group to community teams, and shared through local radio and print media. Because the authors report developing new messages and changing existing ones in response to community feedback, this article is scored a 2 for Information Provision.

- **Consultation:** The authors report that “A compilation of available field reports documented more than 25 different response actions to which community feedback contributed” (Earle-Richardson et al., 2021, p. 339). Among changes they reported besides modified messaging, were modifying the burial protocol to use transparent body bags (allowing family members to see the bag indeed contained their loved one) and expanding eligibility for Ebola vaccination, as well as “hiring more local health care staff, involving Ebola survivors and traditional health care providers in response activities, and decreasing Ebola response visibility by reducing the number of vehicles used” (Earle-Richardson et al., 2021, p. 337). These tangible, actionable changes in protocols in response to community feedback result in an Empowerment Score of 2 for Consultation.

Gillespie et al. (2016) report lessons learned from an after-action review of social mobilization activities conducted by UNICEF in Guinea, Liberia and Sierra Leone during the 2014-2016 Ebola outbreak. These activities were reported to have applied UNICEF’s Communication for Development (C4D) framework, which is described in Chapter 2 of this work. In their introduction, Gillespie et al. describe the role of social mobilization as designed to “help facilitate change at multiple levels—from leveraging support to influence and implement policies, to motivating and mobilizing civil society, to actively empowering households and communities to identify problems, propose solutions, and act upon them” (Gillespie et al., 2016, p. 628). However, the activities discussed in this article are all forms of Information Provision, and none relate to the domains of Consultation, Participation or Community Empowerment. Therefore, the article is scored at 0 for the latter three domains.

- **Information Provision:** Early in their article, the authors criticize “the predominance of top-down communication in the early stage of the response” (Gillespie et al., 2016, p. 627), and further point to the fact that “the formal response ... did not acknowledge traditional community coping strategies and influences on behavior” (Gillespie et al., 2016, p. 627). To address these early shortcomings, the authors report implementing the C4D approach, which is described in the article as “a 2-way process for sharing ideas and knowledge, including social norms, using a range of communication tools and other approaches that empower individuals and communities to change behavior and take actions to improve their lives” (Gillespie et al., 2016, p. 628). This bidirectional communication strategy results in an Empowerment Score of 2 for the language of the approach.

The activities described by the authors include “identify[ing] key influencers and channels of communication” (Gillespie et al., 2016, p. 633), “influencing key behaviors such as care seeking, infection control, and burial practices ... [and] continually adapt[ing] messages and strategies” (Gillespie et al., 2016, p. 635). However, these activities as reported were basically unidirectional and the authors report little, if any, change of message content resulting from community input. For this reason, this article receives an Empowerment Score of 1 for the actions implemented.

Hu and Qiu (2020) report on risk communication and community engagement strategies in the People’s Republic of China during the COVID-19 pandemic. “As a socialist country, China strived to establish the joint prevention and control mechanism in communities through community engagement strategies with[in] the strong national administrative system to ensure all the social approaches needed for epidemic containment” (Hu & Qiu, 2020, p. 170). No Consultation or Community Empowerment activities are described in this article, so these two domains are scored 0.

- **Information Provision:** The authors describe a “unified, authoritative, timely, and efficient information release process” (Hu & Qiu, 2020, p. 169) focused on “releasing the disease statistics and ... recommendations for disease prevention and control” (Hu & Qiu, 2020, p. 169), as well as “reducing the spread of rumors and misunderstandings that may undermine the disease prevention and control response, [and] minimiz[ing] the social disorder caused by the epidemic” (Hu & Qiu, 2020, p. 170), ultimately to “improve the compliance of the affected population with the public health emergency response” (Hu & Qiu, 2020, p. 170).

There is a bidirectional component to the information provision activities described in this report, particularly on the monitoring of rumors and misunderstandings, and “understanding the risk perception and knowledge of different groups” (Hu & Qiu, 2020, p. 170). The feedback mechanisms reported by the authors do not appear to have led to changes in the content of key messages, but rather were used to inform communicators’ efforts to counter misinformation or misunderstanding of the centrally-defined key messages. Accordingly, these efforts receive an Empowerment Score of 1.

- **Participation:** There are several participatory activities described in this report. Government leaders are exhorted to “strengthen their communication and cooperation with ... key opinion leaders in domestic and international social media platforms [who] have the advantage of high community engagement, strong community mobilization, and widespread social influence” (Hu & Qiu, 2020, p. 169). They further report that “most local community response teams included members not only from the primary healthcare facility and quarantine office but also from many mass, grass-roots, and self-governing organizations in an urban or rural community [who] are very familiar with the residents and more effective in conducting screenings of suspected cases and epidemiological investigation of community outbreak[s]” (Hu & Qiu, 2020, p. 170). As the participatory activities described are implemented according to centrally-mandated standards, they are assigned an Empowerment Score of 1.

Summary of Report Analysis

Table 1 and **Figure 4** summarize the foregoing analysis. As mentioned in Methods, some articles showed a discrepancy between the level of empowerment suggested by the article’s language, and that evident in the activities described. In these instances, a different Empowerment Score was assigned for the “Language” and the “Action” of each article. For ease of reading, both **Table 1** and **Figure 4** present a separate “Language” and “Action” column for all articles, whether there was a discrepancy or not. When there is no discrepancy, the same Empowerment Score is recorded in both the “Language” and “Action” columns.

Several observations arise from the analysis shown in **Figure 4**. First, it is notable that the majority (7/8) of these articles reported community engagement in the domain of Information Provision (as shown by

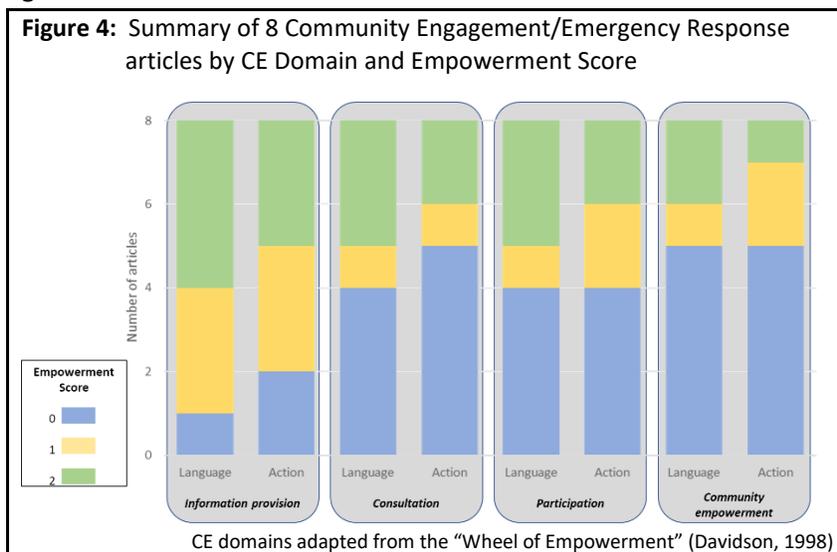
an Empowerment Score of 1 or 2, yellow or green bars), while (4/8) reported engagement in Consultation and 4/8 (though not entirely the same four) in Participation. 3/8 articles reported activities in the Community Empowerment domain. As was previously suggested, substantive changes to protocol or action (as opposed to solely messaging changes) on the part of an emergency response would result in an Empowerment Score of 2 in at least one of the three domains other than Information Provision.

Table 1: Selected Community Engagement/Emergency Response Articles by CE Domain and Empowerment Score

Article	Information provision		Consultation		Participation		Community Empowerment	
	Language	Action	Language	Action	Language	Action	Language	Action
Abara et al. (2014)	2	2	2	2	2	2	2	2
Ali et al. (2017)	0	0	0	0	2	2	1	1
Bedson et al. (2020)	2	2	2	1	2	1	2	1
Brewer et al. (2020)	1	1	1	0	0	0	0	0
de Vries et al. (2016)	1	0	0	0	0	0	0	0
Earle-Richardson et al. (2021)	2	2	2	2	0	0	0	0
Gillespie et al. (2016)	2	1	0	0	0	0	0	0
Hu and Qiu (2020)	1	1	0	0	1	1	0	0

5/8 articles described or advocated for “two-way communication” between the response and affected communities, and all but one used the terminology either of “empowerment” (6/8) or “community ownership” (6/8). However, only the Abara et al. (2014) and Earle-Richardson et al. (2021) articles reported any situation in which community feedback was provided to response leadership with the intention and effect of changing at least one non-communication behavior or intervention in the response, earning an Empowerment Score of 2 in at least one of Consultation (both Abara and Earle-Richardson), Participation (Abara), or Community Empowerment (Abara). The third article which earned a 2 in a non-Information Provision domain was Ali et al. (2017), scored at 2 because of the community authority for distribution of building materials.

The remaining 5 articles identified portray community engagement strictly in terms of unidirectional activities aimed at increasing lay knowledge, and winning the support and participation of a community to perform according to externally-determined expectations (i.e., Empowerment Scores of 0 or 1 in Consultation, Participation, and Community Empowerment.



Applying the Empowerment Score Metric to International Agency Standards Documents

Numerous international and governmental agencies respond to public health emergencies. To exhaustively document the approaches of all of them would be beyond the scope of this work. The

guidelines published by five such agencies are examined in this section, according to the Empowerment Score rubric of **Figure 3**. **Table 2** summarizes the findings of this examination; following the tabulated findings, a narrative for each agency demonstrates the rationale behind the Empowerment Scores assigned to each.

Table 2 - Summary of Empowerment Score Analysis of Various Agencies' Emergency Response Protocols					
Agency	Document(s) Reviewed <i>(listed in order of citation)</i>	Empowerment Scores			
		Information Provision	Consultation	Participation	Community Empowerment
CDC	<ul style="list-style-type: none"> Crisis and Emergency Response Communication (CERC, B. Reynolds & Seeger, 2014) CERC 2018 Update: Community Engagement (CDC, 2018a) CERC 2018 Update: Messages & Audiences (CDC, 2018b) Engaging the Community With Credibility (B. Reynolds, 2017) CASPER: Community Assessment for Public Health Emergency Response Toolkit, 3rd Edition 3.2 (Schnall et al., 2020) Framework for Implementation of COVID-19 Community Mitigation Measures for Lower-Resource Countries (CDC, 2021) 	1	0	0	0
ECDC	<ul style="list-style-type: none"> Guidance on community engagement for public health events caused by communicable disease threats in the EU/EEA (de Vries et al., 2020) Risk communication as a core public health competence in infectious disease management: Development of the ECDC training curriculum and programme (Dickmann et al., 2016) 	1	0	1	0
UNHCR	<ul style="list-style-type: none"> Accountability to affected people (AAP) (UNHCR, 2015a) Community-based protection (UNHCR, 2015b) 	2	2	1	1
UNICEF	<ul style="list-style-type: none"> Minimum quality standards and indicators in community engagement (UNICEF, 2020) 	2	2	2	2
WHO	<ul style="list-style-type: none"> Health cluster guide: a practical handbook (WHO, 2020) Ebola and Marburg virus disease epidemics: preparedness, alert, control, and evaluation (WHO, 2014) How to conduct safe and dignified burial of a patient who has died from suspected or confirmed Ebola or Marburg virus disease (WHO, 2017b) WHO community engagement framework for quality, people-centred and resilient health services (WHO, 2017a) 	1	1	0	0

As was illustrated in the previous section, it is possible that the actions of these agencies 'on the ground' in an emergency may differ from their published standards. The Empowerment Score rubric may be a useful tool for the evaluation of emergency interventions in-progress, or for after-action evaluations. If it is so utilized, the reader is reminded that evaluators should not presuppose that an Empowerment Score of 2 in any domain is necessarily the appropriate or desirable state for an emergency response. For this reason, the best use of the Empowerment Score rubric in evaluation may be to compare an agency's actions to the intended levels of empowerment put forth in that agency's own standards and guidelines, or to invite reflexive analysis of agencies' claims to empower affected communities.

Centers for Disease Control and Prevention (CDC)

The US CDC does not publish comprehensive guidelines for emergency response methodology,³⁷ however, there are a variety of documents available from CDC from which that agency's approach to community engagement can be triangulated. That those documents which do describe community engagement fall entirely under the rubric of Crisis and Emergency Response Communication (CERC, B. Reynolds & Seeger, 2014) is indicative of an Information Provision-centric focus. Although the main CERC document once mentions "empower[ing] local decision making [and] provid[ing] feedback to responders" (B. Reynolds & Seeger, 2014, p. 94), the vast bulk of its 400-plus pages are centered on a process wherein "experts ... provide information allowing individuals or an entire community to make the best possible decisions about their well-being ... inform[ing] and persuad[ing] the public in the hope that they will plan for and respond appropriately to risks and threats" (B. Reynolds & Seeger, 2014, p. 7).

It is perhaps instructive that CERC documentation refers to the community primarily as "audiences" (CDC, 2018b, p. 2) and casts community feedback in terms of "allow[ing] communicators to understand how audiences receive and interpret messages" (CDC, 2018b, p. 9). One CERC document casts a major objective of community engagement as ensuring that the public "believ[es] they have been heard" (B. Reynolds, 2017, pp. 8, 12, 13,18) in order to "preserve trust in authorities who must make final decisions" (B. Reynolds, 2017, p. 11). Where CERC guidelines do provide for community participation in finding solutions, the text actually describes a process whereby communications experts guide community members to "persuade themselves" (CDC, 2018a, p. 9) to adopt recommended actions.

Outside of the CERC framework, a recent CDC document on COVID-19 mitigation activities emphasizes "government and community responsibility to make sure people have access to information and resources required to follow recommended actions ... [and] to pass setting-specific and population-specific policies endorsing recommended actions" (CDC, 2021, "Community Mitigation" section, bulleted list).

Finally, CDC's Community Assessment for Public Health Emergency Response Toolkit (Schnall et al., 2020) provides for a quantitative, epidemiologic assessment of community needs in an emergency. This document instructs users that in order "to decrease analysis time and increase accuracy, avoid open-ended questions and request only information that will satisfy the objectives" (Schnall et al., 2020, p. 14), necessarily precluding community feedback beyond strictly predefined parameters.

Taken together, the limited options for community members to influence the content of communications, and the clear preference for centrally-driven messages, suggest that CDC's emergency response Information Provision achieves an Empowerment Score level of 1. The Empowerment Scores for Consultation and Community Empowerment are both 0, as neither is really contemplated in CDC's documents. Likewise, the only mentions of participation in these documents are in the recruiting of

³⁷ Lest this statement be misunderstood: CDC publishes a vast array of resources on emergency preparedness, including but not limited to those at <https://emergency.cdc.gov/index.asp>. Many of these involve personal or local/state readiness and the availability of material and financial support in the event of an emergency. There is not, however, a comprehensive manual of the form shown below from other agencies. The US National Incident Management System (NIMS, FEMA, 2017) provides more of this methodology, but as with the CDC documents, it focuses on command and control, resource management, and interagency relationships, not on community engagement. FEMA does promote the notion of community leadership in post-disaster recovery (FEMA, 2011, see pp. 14-16), a notion also endorsed by the US Department of Health and Human Services in long-term community development (McCloskey et al., 2011). However, no similar directive appears in documents guiding response efforts during the acute phase of an emergency.

trusted messengers to assist in Information Provision. Accordingly, the Participation domain (which focuses on participation in implementation/control activities) is scored at 0.

European Centre for Disease Prevention and Control (ECDC)

Two documents summarize ECDC's approach to community engagement in an emergency: one a comprehensive guidance document (de Vries et al., 2020), and the other a report on the development of ECDC's risk communication training curriculum (Dickmann et al., 2016). The de Vries document begins with the assertion that "Community members need their voices heard in the outbreak preparedness and response process, and want to be seen by the authorities as genuine partners" (de Vries et al., 2020, p. 4), and includes a version of the ladder of engagement attributed to McCloskey et al. (2011). The document exhorts response authorities to "be willing to allow community stakeholders to take control of some processes, and be open to input on others" (de Vries et al., 2020, p. 5).

The extent to which communities are empowered, and in what domains, is somewhat complicated by the fact that the ECDC document breaks the "preparedness cycle" (de Vries et al., 2020, p. 4) into three phases: Anticipation, Response, and Recovery. The bulk of community engagement language in the document lies in the Anticipation and Recovery phases, which roughly translate to pre-disaster preparedness in the former phase and after-action analysis and rebuilding efforts in the latter.

The ECDC document lists a number of principles as being applicable to all phases of the preparedness cycle, which are instructive. It suggests that "public health authorities can enable community members and groups to be recognised and to define themselves as partners who shape their own roles and identities in the process" (de Vries et al., 2020, p. 5), and later on the same page that public health leaders should "be willing to allow community stakeholders to take control of some processes, and be open to input on others." However, the roles which are contemplated for community members to fill are limited to "communications liaison, social media monitor ... [and] roles in peer-support structures" (de Vries et al., 2020, p. 5), all of which fall squarely in the Information Provision domain. The framing of community listening as "enabl[ing] authorities to respond to misinformation or rumours ... [and] improv[ing] community health literacy" (de Vries et al., 2020, p. 6) reinforces the centrality of Information Provision, along with the reservation of authority to official entities. The limited role of community input is reinforced in Dickman et al. (2016) who, while making a strong case for communicators taking time to understand their audience, states directly that "During an outbreak, time is short and crisis communication therefore needs to be concise and often unidirectional" (Dickmann et al., 2016, p. 3). Perhaps most tellingly, the document states that "During a public health event, however, public authorities lead activities on the contact tracing and exchange of information between concerned individuals and other relevant cross-sectorial institutions without further devolution of responsibility to community-based actors" (de Vries et al., 2020, p. 10).

The ECDC document does suggest that community actors might be included in logistics during a response (de Vries et al., 2020, p. 14), and further that volunteers might fulfill unspecified roles. For this reason, and for the limited involvement described in the previous paragraph, it is appropriate to assign to ECDC's plans an Empowerment Score of 1 to both the Information Provision and Participation domains. The Consultation and Community Empowerment domains are scored at 0. There is a possibility that, if sufficient coalition building were to happen in the 'Anticipation' phase described in these documents, it could result in higher scores for Consultation and Community Empowerment;

however, since one cannot assume that disaster response structures were ‘Anticipated’ in the area where a disaster actually strikes, this coalition may or may not be present.

The United Nations High Commissioner for Refugees (UNHCR)

UNHCR has a detailed Emergency Handbook that is published only online. Two sections in particular outline UNHCR’s approach to community engagement: “Accountability to Affected People (AAP)” (UNHCR, 2015a) and “Community-Based Protection” (UNHCR, 2015b). The reader may recognize that AAP resembles the ‘Accountability to Affected Populations’ document previously cited (IASC, 2013a), and in fact, UNHCR is a member of the IASC and explicitly cites the latter’s publications.

UNHCR summarize their approach toward community engagement thus: “UNHCR is accountable to persons of concern from the outset of an emergency until durable solutions are achieved. This requires direct and continuous work with communities of concern for the duration of their displacement, to make sure that they are able to participate meaningfully in decisions that affect them” (UNHCR, 2015a, p. 2). Elsewhere, they highlight their efforts to “harness the knowledge and resources of communities and to strengthen their capacities” (UNHCR, 2015b, p. 2), and to do so through “consultation and participation” (UNHCR, 2015b, p. 2). The UNHCR community-based participation (CBP) approach envisions community involvement in:

- “Preparing situation analyses (both the initial analysis and subsequent analyses).
- Setting priorities.
- Designing and implementing responses and interventions.
- Monitoring implementation and adjusting interventions as needed.
- Evaluating and reporting results” (UNHCR, 2015b, pp. 2–3).

It is unclear from these documents, to what extent communities might actively participate in interventions; nevertheless, UNHCR documents appear to convey a genuine commitment to ensuring community members (including those of marginalized groups within the community) are listened to and involved in the planning/priority setting process.

The UNHCR approach is not one of complete devolution of control to the community level. Their documents are unambiguous in circumscribing their interventions and assistance to the protection mandate which is UNHCR’s domain, and further that “the community may not recognize some threats that external professionals consider to be urgent” (UNHCR, 2015b, p. 3). In such a situation, “emergency responders should therefore show that they have listened and should explain the decisions they make, including why certain actions cannot be taken” (UNHCR, 2015a, p. 4).

The level of involvement UNHCR’s documents describe for Information Provision and Consultation suggest an Empowerment Score of 2 in each of these domains. The less-certain involvement in implementation suggests an Empowerment Score of 1 for Participation; likewise, the clear retention of ultimate authority for interventions, balanced by the CBP mandates for inclusion, suggest an Empowerment Score of 1 for Community Empowerment.

UNICEF

UNICEF, the United Nations agency focused on protecting the rights of children, has published a set of “Minimum Quality Standards and Indicators for Community Engagement” (UNICEF, 2020) that form the

basis for analyzing their approach. The careful reader may notice that some of the indicators listed refer to “policies and procedures” (Indicator A.1.1, UNICEF, 2020, p. 38), “mechanisms” (Indicator A.3.1, UNICEF, 2020, p. 38) or a “system” (Standard A.4.2, UNICEF, 2020, p. 38). It is possible that implementers could be satisfied to have such policies, mechanisms or systems described in plan documents while failing to implement them in practice. Despite this, the overall tenor of UNICEF’s standards voices a strong commitment to community empowerment, as the following examples show:³⁸

- Government indicator A.4.2 provides for a “two-way information and knowledge exchange system ... to communicate local strategies to officials, and to provide local communities with information, resources, etc.” (UNICEF, 2020, p. 38).
- Government indicator B.8.2 calls for “Community representatives [to be] engaged in government planning and preparation activities” (UNICEF, 2020, p. 39).
- NGO indicator A.1.6: “Community members identify the needs and priorities of various groups and sub-groups in the community” (UNICEF, 2020, p. 40), and NGO indicator B.10.4 “Community members were involved in monitoring progress towards goals” (UNICEF, 2020, p. 43).
- NGO indicator A.5.7: “Course corrections have been made when community members and leaders indicated issues with activities and strategies” (UNICEF, 2020, p. 42).

UNICEF’s guidelines, therefore, suggest an Empowerment Score of 2 for each of the four domains of Information Provision, Consultation, Participation, and Community Empowerment.

[World Health Organization \(WHO\)](#)

The sheer volume of documents available on the World Health Organization’s (WHO) website complicates the process of identifying WHO’s response standards. Four publications were selected as sufficiently recent and germane to emergency responses such as Ebola to be examined here. *Health Cluster Guide: A Practical Handbook* (WHO, 2020) is a comprehensive and recent reference manual for WHO’s overall response structure. *Ebola and Marburg virus disease epidemics: preparedness, alert, control, and evaluation* (WHO, 2014) is, as the title suggests, specifically directed towards hemorrhagic fever outbreaks of the sort encountered in the Chapter 1 case. A companion document, *How to conduct safe and dignified burial of a patient who has died from suspected or confirmed Ebola or Marburg virus disease* (WHO, 2017b) includes community-engagement concerns in the safe-burial realm. Finally, the *WHO community engagement framework for quality, people-centred and resilient health services* (WHO, 2017a), while contextualized to long-term health development rather than emergency response, contains insights into WHO’s definition of community engagement as a concept, and explicitly cites lessons learned during the West African Ebola epidemic as drivers of WHO’s current vision for community engagement.

As with UNHCR and UNICEF above, WHO is a member of the Inter-Agency Standing Committee (IASC), and grounds its community engagement imperative within the AAP framework, which it describes as “taking account of, giving account to, and being held to account by the affected population” (WHO, 2020, p. 23). Later in the same document, it is stated that a well-managed health cluster (the WHO-led health coordination unit of a complex response) will “be accountable to affected people by ensuring that women and men, girls and boys, have equal opportunity to participate throughout the programme

³⁸ Note that the UNICEF document contains distinct tables of Government and NGO indicators, each of which are quoted in the following text.

cycle, including through community feedback mechanisms that are inclusive and consultative” (WHO, 2020, p. 100). WHO’s Community Engagement Framework perhaps says it best:

“In the 21st Century, we have a large and growing body of research that recommends that we shift from ‘telling and selling’ (top down instruction and guidance) to ‘sharing and caring’ (working with members of the community, recognizing the value and power of local expertise)” (WHO, 2017a, p. 7).

WHO’s practical guidelines for Ebola and Marburg suggest more reservation of authority to the response than the preceding paragraphs might suggest. They provide for a “behavioural and social interventions subcommittee” (WHO, 2014, p. 38) whose role is to “engage in extensive dialogue and communicate the risk factors and the necessity of prevention measures” (WHO, 2014, p. 38) relevant to the outbreak. The committee is charged to conduct “active listening and dialogue with communities in the affected and surrounding areas about the behaviours that are being promoted to reduce risk and protect local communities ... including but not limited to: outreach to and education of village chiefs, use of printed support materials (posters, brochures, etc.) radio messages, and public meetings” (WHO, 2014, pp. 38–39). It is this subcommittee that is tasked to provide the larger response organization with feedback “on community concerns and potential barriers to compliance with control measures” (WHO, 2014, p. 39). In the community, the committee is to “understand the views of the population from their sociocultural perspective and respond to their needs and concerns accordingly” (WHO, 2014, p. 39) and, more broadly, to promote response-determined priorities.

WHO’s revised burial guidelines (WHO, 2017b), clearly reflect lessons learned regarding some objections to burial practice during the 2014–2016 epidemic. For example, the guidelines are explicit that burial team members should not arrive at a home already clad in PPE, but should only put it on after having negotiated face-to-face with bereaved family members (WHO, 2017b, p. 4). There are also instructions specific to accommodating Christian and Muslim funerary practices, and an exhortation to “**obtain the formal agreement of the family’s representative before proceeding**” (WHO, 2017b, p. 4, emphasis in original). The instructions further suggest ways family members might participate in certain aspects of the burial, including carrying a coffin containing the fully-encapsulated body, digging the grave, offering objects to be buried with the deceased, and witnessing all preparations that are done. However, apart from one phrase “their [i.e., family members’] needs to be locally adapted and discussed” (WHO, 2017b, p. 6) which is not further explained, nothing in the safe burial document suggests how the team is to respond if families do not give the consent mentioned above, or if the family’s ‘needs’ do not comport with the provisions of the burial standard.

The above documents suggest that WHO’s overall intent is to greatly improve (in its own judgment) its responders’ compassionate listening to community needs, to “put a human face on interventions, striking a balance between compulsory measures and understanding and compassion” (WHO, 2014, p. 41), while retaining sole authority for substantial changes to interventions/approaches. This stance is best characterized as an Empowerment Score of 1 for both Information Provision and Consultation. So little is mentioned about community participation in any of the documents examined, that the Empowerment Score for Participation is 0. Nor did this review identify any situation in which authority to implement even limited interventions would be delegated to a community, so Community Empowerment is likewise scored at 0.

Results of Delphi Survey of Ebola Response Experts

A total of 17 experts were purposively approached to participate in the Delphi panel. These were a combination of epidemiologists, anthropologists, and other individuals known by the author, or recommended by other panelists, to have had extensive experience working on, or studying the West African Ebola response, mainly in Sierra Leone. Approached experts included men and women, represented multiple agencies, and included Sierra Leonean nationals, other Africans, Europeans, and North Americans. All of the approached experts had at least a Bachelor’s-degree education, and most had either a Master’s or Doctorate degree.

Of the 17 panelists initially approached, three (18%) did not respond at all, and a fourth stated that they could not participate, leaving an initial response of 13/17 (76%). Of these 13, 11 (85%) formally consented to participate and were invited to complete the first online questionnaire. Eight individuals (62%) completed the Round 1 questionnaire, but one of these did not complete Round 2 or 3, leaving a total of seven panelists (54%) who completed all three Delphi rounds. Of those seven:

- Four were women (57%) and three were men (43%).
- Three (43%) worked under the auspices of CDC at some point during the response, two (29%) for WHO, two (29%) for non-governmental response organizations and one (14%) in academia (one individual worked in two different agencies at various times throughout the response).
- Two (29%) were Sierra Leonean nationals, one (14%) hailed from another African country, and four (57%) were from the United States.
- Three (43%) served as epidemiologists, two (29%) as anthropologists, one (14%) was a communications specialist and one (14%) a district-level response coordinator. Two (29%) served part of the epidemic in response leadership at the national level (some individuals filled multiple roles at different times).

Results from the Delphi questionnaires (all questionnaires appear in Appendix A) are reported in two sections below: first, the quantitative answers to defined questions; and second, major themes analysis of the textual data captured from panelists’ open-ended comments.

Answers to Defined, Closed-Ended Questions

Questions 1a-1d – Community Engagement Domains

The first four Delphi questions in each of Rounds 1-3 asked panelists to characterize the Ebola response efforts in Sierra Leone in each of the four Community Engagement Domains, using the Empowerment Score rubric of **Figure 3**. The Round 1 questions used the following format for each domain:

Is Information Provision necessary component of community engagement in an emergency response? <input type="checkbox"/> Yes <input type="checkbox"/> No					
If “Yes,” please rate the level of engagement for Information Provision for each line below. Your answer should reflect your observations/knowledge for whatever region or response area in which you have experience. If you feel you do not have sufficient information to answer for one period of the response, please mark “N/A” for that period and answer where you can do so.		0	1	2	N/A
<input type="checkbox"/>	This accurately describes what happened early in the response, before Dec. 31, 2014	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	This accurately describes what happened later in the response, after Jan. 1, 2015	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="checkbox"/>	Regardless of what happened in the 2014-2016 Ebola response, this would be the appropriate posture for future emergency responses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any “N/A” answers as well as any other comments you wish to offer):					

No panelist answered “No” to any of the four domains being necessary. Two panelists did not answer for the period before December 31, and stated in the comments that they did not participate in the response during that period. A third respondent took issue with the cutoff date as framed in the questions. For this reason, the early period was not included in the questions for Rounds 2 and 3. Additionally, the question about the domains being necessary, and the “N/A” option were omitted from Rounds 2 and 3.

For Questions 1a-1d, panelists were given a Reference Guide (also in Appendix A along with the Round 1 questionnaire) that contained a brief synopsis of the Empowerment Score methodology, including a copy of **Figure 3**. They were asked to refer to the Reference Guide in determining the appropriate Empowerment Score for each Community Engagement domain.

However, panelists’ comments were not always congruent with the level of empowerment suggested by their numeric Empowerment Scores. For example, in Round 1, Panelist 5 scored all four domains at 2 for the early part of the response, but then for Information Provision stated *“The lack of correct information to the community in the early stage of the outbreak cause a lot of rifts and misconception about the response team.”* Similarly, for Participation, Panelist 5 stated *“Delay[s] in involving the community to participate in the preparedness and response contributed to the high community resistance.”*

In contrast, Panelist 2 scored all four domains at 0 for the later part of the response (Panelist 2 did not provide early-response scores). Despite these scores, this panelist wrote: *“Ground-up information provision in particular was essentially non-existent in the early months of the outbreak ... [but] by the summer of 2015, there was a significantly more proactive effort to seek out dialogue through traditional chiefs and other community members as a routine component of daily response activities”* (Panelist 2). The panelist further stated that *“in Port Loko and Kambia, community feedback did actually change the response’s approach at times”* which could have merited an Empowerment Score of at least 1 if not 2.

It was hypothesized that these panelists, and perhaps others, may have misunderstood the Empowerment Score criteria, or perhaps had difficulty linking the Reference Guide rubric to their answers. In an attempt to address this concern, Questions 1a-1d were changed for Round 3 to incorporate the Empowerment Score rubric directly into the question format (see Appendix A for full questionnaires). Panelists were also directed to focus on application of the four domains to the concept of Safe and Dignified Burial. The resulting Round 3 question format was as follows:

Please choose the statement below that best characterizes the level of engagement around Information Provision for Safe and Dignified Burial, first in the Ebola Response column, and again what you believe should be the case for Future Responses in the second column		Ebola Response	Future Responses
0	Information comes from above. Disease control efforts and messages are developed by response leadership or international agencies. The only changes that may be made involve language translation or modified wording.	○	○
1	Messages and how they are communicated are tailored to the local situation by communications experts and/or anthropologists, but the underlying content (“key messages”) is predetermined by response authorities or international documents.	○	○
2	The content of messages is developed in two-way conversation with the community. Messages are refined, or even replaced, based on community feedback.	○	○

Individual panelists’ responses to Questions 1a-1d are shown in **Table 3**.

Table 3: Individual Panelists' Responses to Question 1a-1d by Community Empowerment Domain

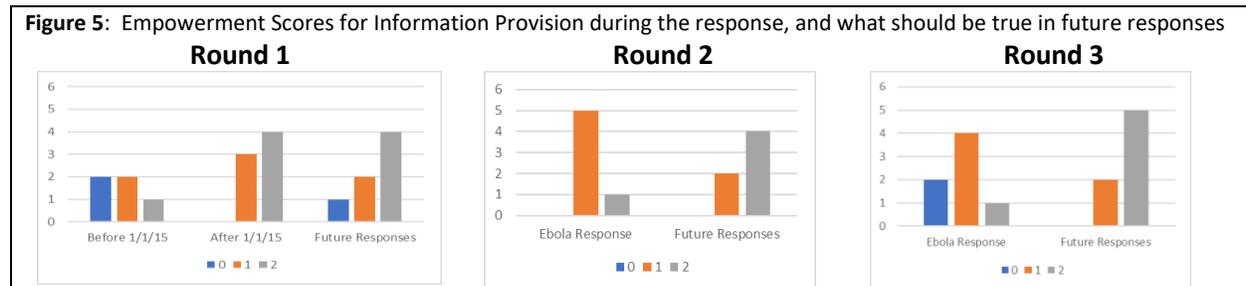
	1a - Information Provision			1b - Consultation			1c - Participation			1d - Community Empowerment		
	Early	Late	Future	Early	Late	Future	Early	Late	Future	Early	Late	Future
Panelist 1	1	1	1	1	1	1	1	0	2	0	1	2
Panelist 2		0	1		0	2		0	1		0	1
Panelist 4	0	1	2	0	0	2	0	1	2	0	0	1
Panelist 5	2	2	2	2	2	2	2	2	2	2	2	2
Panelist 6	0	0	2	0	1	2	0	1	2	0	1	2
Panelist 7	1	1	2	1	1	2	1	1	2	0	1	2
Panelist 8		1	2		2	2		1	2		1	2

Because the Delphi methodology allows panelists to revise their answers on the basis of previous round results, only the panelists' last answers for each time period are included in **Table 3** – this means that answers for the “Early” (i.e., before 12/31/2014) columns are taken from Round 1, and the “Late” (after 1/1/2015) and “Future” columns are taken from Round 3. Note that, although the “Early” responses are reported for completeness, they should be interpreted with caution given the blank responses from some panelists and the issue other panelists took with the time division, as mentioned above.

It is notable that the aggregated Empowerment Scores analyzed in the following paragraphs mask important inter-panelist disagreements, as Panelist 2 scored all four domains at 0 for the Ebola response, while Panelist 5 scored them all at 2. These disagreements should be borne in mind as scores and trends are discussed below.

1a - Information Provision

Panelists were asked to assign an Empowerment Score for Information Provision during the early response, the late response, and as they would consider appropriate to future responses. Their answers are shown in **Figure 5**.



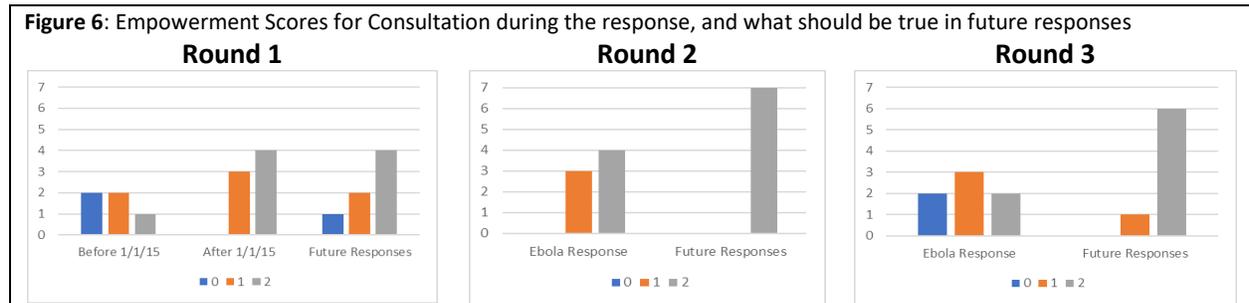
It is evident from **Figure 5** that the panel did not have a complete consensus regarding the appropriate Empowerment Scores for Information Provision. The apparent trend in Round 1 that empowerment increased from early in the Ebola response to later is likely confounded by the fact that two panelists did not answer for the first period, and a third disputed the timeline for improvement (this was true for all four domains). However, there was a consensus that, whatever level of empowerment was true for the Ebola response, future responses should empower communities more, not less.

Panelists' responses for Rounds 2 and 3 in **Figure 5** suggest a decrease in their assessed Empowerment Scores from Round 2 to Round 3. This may be due to the clearer delineation of the Empowerment Score rubric in Round 3. Additionally, the phrasing of the question in Rounds 1 and 2 may have been understood by panelists to refer to the overall Information Provision efforts in the response, while in

Round 3 the panelists were asked to focus specifically on Information Provision related to Safe and Dignified Burial (SDB).

1b - Consultation

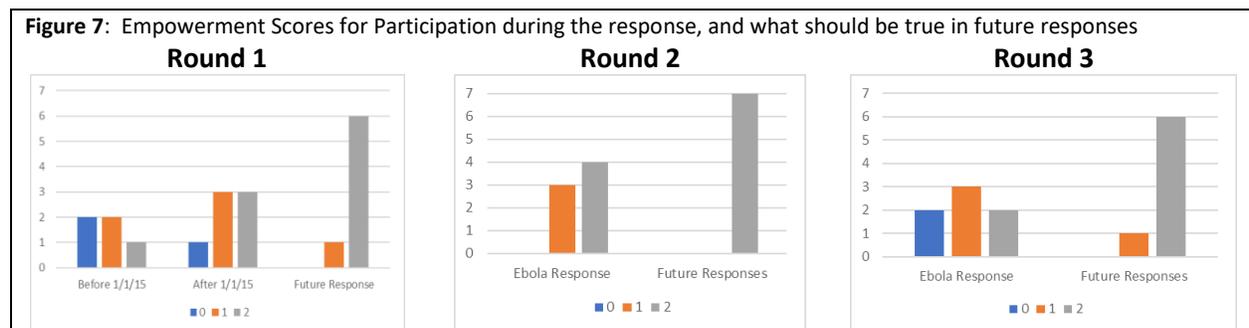
Panelists were asked to assign an Empowerment Score for Consultation during the early response, the late response, and as they would consider appropriate to future responses. Their answers are shown in Figure 6.



Comparing the Ebola Response answers for Round 2 and Round 3, panelists rated a lower Empowerment Score for Consultation regarding SDB than they did for the response more broadly, although once again, this may be confounded by the inclusion of the full Empowerment Score rubric in the format of the question for Round 3. There was a near-unanimous consensus among panelists that the level of empowerment in Consultation for future responses should be higher than occurred during this Ebola response. By the conclusion of Round 3, there was no consensus among the panelists regarding the level of empowerment regarding SDB that existed during the response, but near-unanimous consensus as to the level of empowerment appropriate in future emergency responses.

1c - Participation

Panelists were asked to assign an Empowerment Score for Participation during the early response, the late response, and as they would consider appropriate to future responses. Their answers are shown in Figure 7.

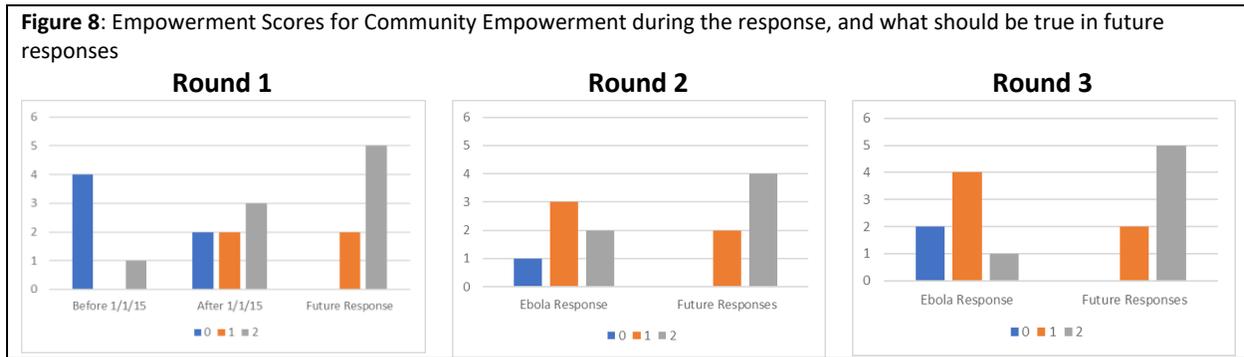


The change in Empowerment Scores for Participation between Rounds 2 and 3 may represent a lower level of empowerment regarding Participation in SDB than in other elements of the response, although once again, the incorporation of the Empowerment Score rubric in the questions may also have influenced this change. Ultimately, there was no Round 3 consensus among panelists regarding an accurate Empowerment Score for Participation in the context of SDB during the response, but near-

unanimous agreement that future responses should empower communities at a higher level than occurred in the response.

1d - Community Empowerment

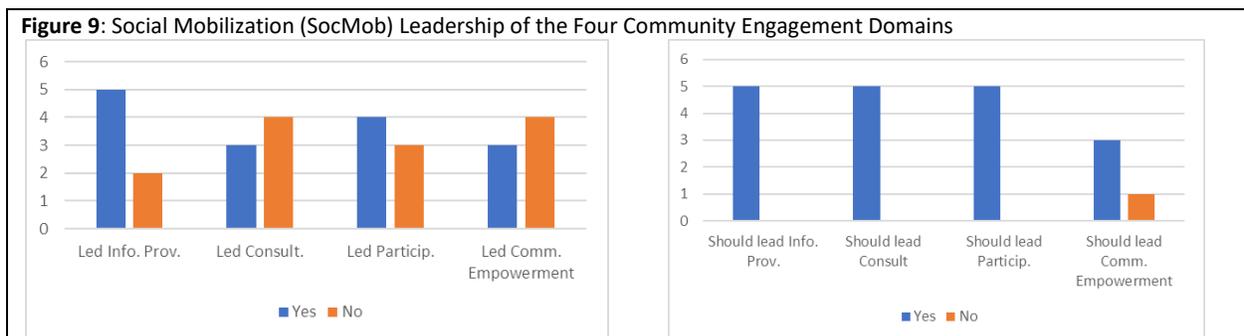
Panelists were asked to assign an Empowerment Score for Community Empowerment during the early response, the late response, and as they would consider appropriate to future responses. Their answers are shown in **Figure 8**.



As Round 1 in **Figure 8** shows, more panelists rated Community Empowerment at zero during the early phase of the response, than for any of the other three domains. By Round 3, there was no consensus among panelists around the level of empowerment that occurred in the Community Engagement domain. Once again, the majority of panelists felt that future responses should reflect an Empowerment Score of 2 for Community Empowerment, substantially higher than the scores they assigned to the Ebola response.

2 – Social Mobilization (SocMob)

As previously described, community engagement activities in the Ebola response were largely tasked to an organizational unit within the response called the Social Mobilization Pillar (referred to colloquially as SocMob). In Round 1, panelists were asked whether the response SocMob pillar led activities related to each of the four Community Engagement domains and whether the equivalent SocMob structure should lead those domains in future responses. The panelists’ answers are shown in **Figure 9**.



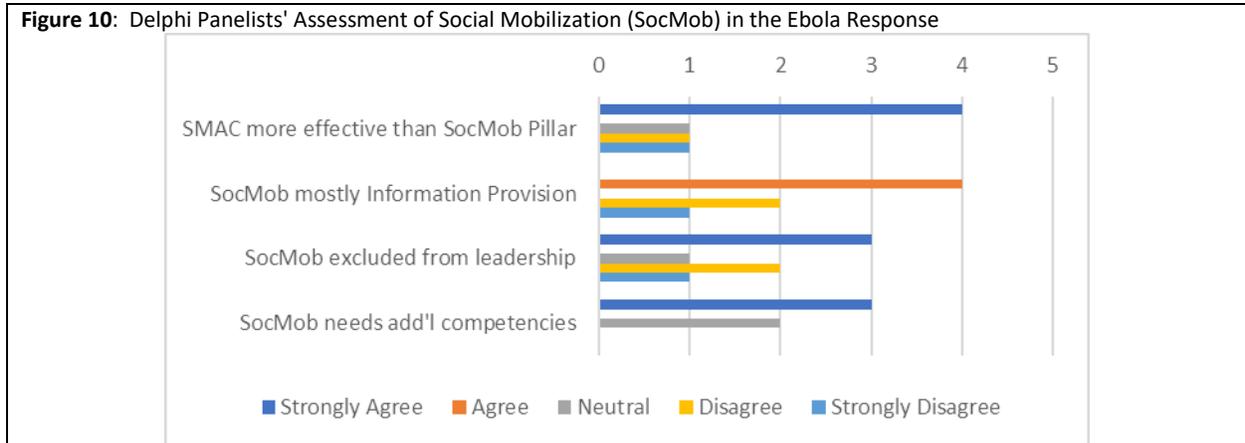
Panelists were divided on the extent to which SocMob led community engagement efforts. Although the left-hand chart in **Figure 9** suggests that panelists were split on the extent of SocMob’s leadership, all 5 of the 7 panelists who included comments suggested that the SocMob pillar led these efforts ineffectively, if at all (this is discussed further in the qualitative analysis in the next section). Although it

appears that there was near-unanimous consensus around the idea that a SocMob-like pillar should lead such efforts in future responses, two panelists did not answer this question. One of the panelists who did not answer commented “I’m not even convinced that the ‘social mobilization pillar’ should exist, in an ideal world” (Panelist 2). The other stated “I am not sure of the current leadership of the social mobilization pillar” (Panelist 5).

Based upon panelists’ comments in Round 1, several clarifying questions were asked in Round 2. First, several panelists in Round 1 had mentioned the Social Mobilization Action Consortium (SMAC), a collaborative effort of multiple agencies led by a Sierra Leonean nongovernmental organization which led some, but not all, SocMob activities in the response. For Round 2, panelists were asked to rate their agreement or disagreement with a Round 1 statement: “SMAC was the primary, and perhaps only entity, that was doing on-the-ground work on consultation, participation, and community empowerment going beyond information provision” (Panelist 7). In further questions, panelists were asked their agreement/disagreement with these statements summarized from other Round 1 comments:

- SocMob primarily engaged the community in the Information Provision domain and not in the other three domains;
- SocMob personnel were excluded from key leadership roles in the response; and
- SocMob personnel lacked important competencies necessary for effective community engagement.

Panelists’ answers to these four Round 2 questions are presented in **Figure 10**.



There was no pattern among panelists who selected “Strongly Agree” or “Agree” among the four questions, versus those who were neutral or disagreed. Different panelists took the positive or negative position on each question.

3 – Community Engagement

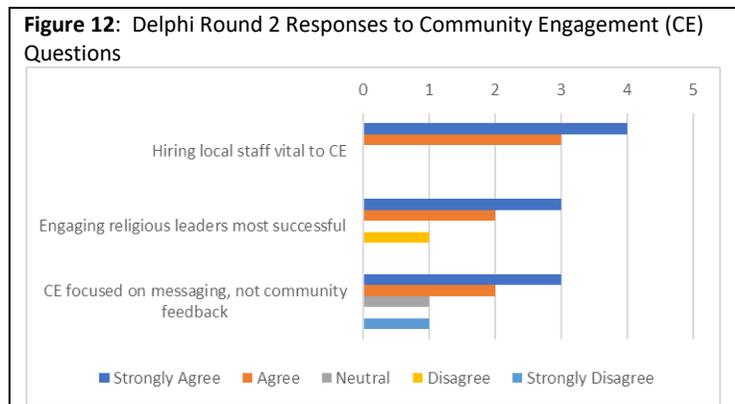
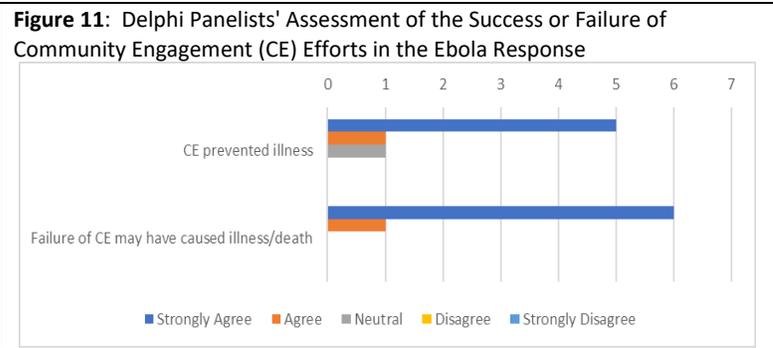
As with Social Mobilization, sufficient agreement on Community Engagement (CE) was achieved in two rounds, such that no further questions were asked in Round 3. Round 1 asked two level-setting questions concerning community engagement by the Ebola response. The first asked the panelists whether they believed successful CE efforts prevented Ebolavirus disease in Sierra Leone; the second,

whether they believed that failure to engage the community properly may have contributed to excess Ebola illness or death. Panelists' answers are presented in **Figure 11**.

As **Figure 11** shows, panelists largely agreed with both statements. From the comments offered on this question, three more questions

were asked in Round 2: first, whether the hiring of local staff to work in the response was vital to CE efforts; second, whether the engagement of religious leaders represented the most successful CE strategy; and third, whether CE efforts focused inappropriately on messaging to the exclusion of obtaining feedback from the community. Panelists' responses to these questions appear in **Figure 12**.

As **Figure 12** shows, there was near-unanimous agreement ('Strongly agree' or 'Agree') on all three questions. The dissenter on the second question commented that the engagement of religious leaders was highly successful but not the 'most' successful; the dissenter on the third question stated that they felt other commenters had over-generalized on a topic in which that panelist had the opposite experience.

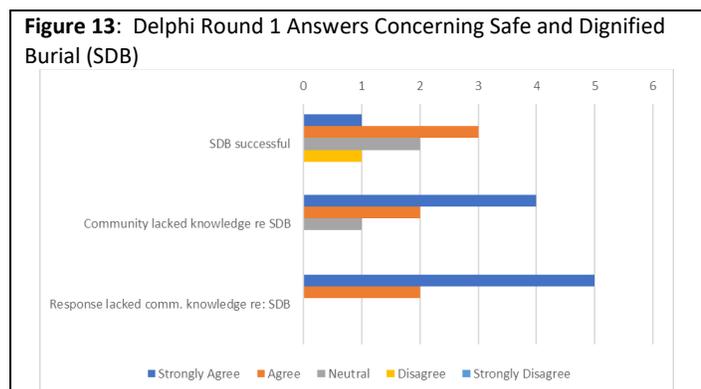


4 – Safe and Dignified Burial (SDB)

Questions on Safe and Dignified Burial (SDB) were asked in all three rounds of the Delphi study. In Round 1, three questions were asked: first, whether the panelists believed that SDB protocol was successful overall at reducing the spread of Ebolavirus Disease in Sierra Leone; second, whether community members lacked important knowledge regarding SDB; and third, whether response leadership and implementers lacked important community knowledge in the context of SDB. Panelists' answers to these questions in Round 1 are displayed in **Figure 13**.

As the data in **Figure 13** show, panelists were divided over the overall success of SDB protocols, with 4 who 'strongly agreed' or 'agreed' that it was successful, two neutral and one who 'disagreed.' The two who were 'neutral' elaborated in their comments (the one who 'disagreed' did not):

- *"I believe the impact was bidirectional. On the one hand, it*

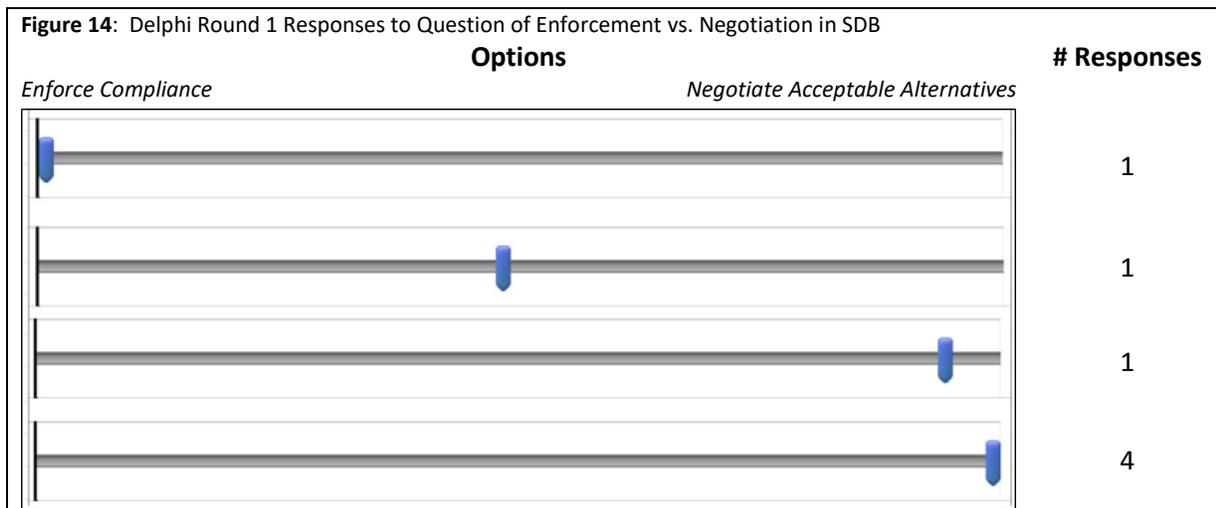


escalated the profile of burials, and knowledge about infection associated with burials and death. On the other, I believe that it contributed, inequitably, to hiding, concealment, and secret movements of persons who were ill” (Panelist 4).

- *“Of course, corpses of Ebola positive individuals are highly infectious, and burials represented superspreader events. The need to safely bury individuals was unambiguous. I also know that a significant number of people refused to report burials because the SDB system usually meant they could not participate in the burial of their loved ones, and so instead, they hid the death from the Ebola response and buried them unsafely themselves. Therefore, I recognise the need for managed burials, but also know full well that it distanced many communities from robustly reporting deaths when they occurred” (Panelist 2).*

There was consensus among the panelists, however, that both communities and response personnel lacked key knowledge that could have better informed SDB.

A final Round 1 question on SDB invited respondents to choose a point on a sliding scale representing the extent to which they believed the Ebola response should have met resistance to SDB with enforcement vs. negotiation of alternatives. The range of panelists’ responses is shown in **Figure 14**.



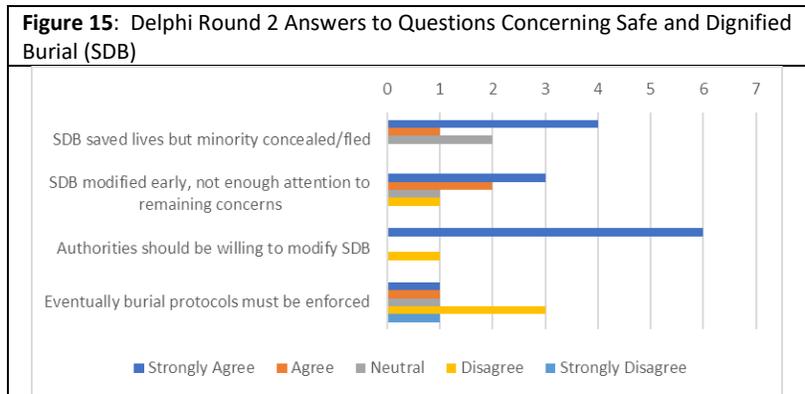
The commentary that panelists added to their answers in **Figure 13** and **Figure 14** showed a diversity of opinion that required further clarification (this commentary is analyzed in greater detail in the following Qualitative Analysis section). For Round 2, panelists were asked to rate their agreement/disagreement with four summary statements (these are not direct quotes from any one panelist):

- While SDB very likely saved lives, a substantial minority concealed illness and even fled authorities due to the conflict between their cultural/religious standards and SDB requirements.
- Although Sierra Leone’s SDB protocol revised in late 2014 attempted to address some community concerns, SDB as implemented did not pay sufficient attention to the objections which remained.

- The burial of a loved one is such a culturally and spiritually significant practice, that even in the case of a disease such as Ebola, authorities and responders should be willing substantially to modify their protocols in dialogue with communities.
- Regardless of any negotiation which may or may not take place as described in 5a above, there comes a point at which the burial protocol must be enforced, by law or coercion if necessary.

Panelists' answers to these four questions are presented in **Figure 15**. Consensus was strong, but not universal, on the first three questions. On the first question, only one of the 'neutral' panelists

commented, saying *"Problems with SDB [sic] because community members adhered strongly to their traditional-cultural beliefs. They found SDB traumatic, alien and in most cases an abomination-taboo. This is a very complex phenomenon and needs in-depth engagement with reasons why members were against response team"* (Panelist 8).



On the second question, the person who disagreed did not comment, nor did one of those who were 'neutral.' The other 'neutral' (Panelist 8) referenced their comment that is quoted in the previous paragraph.

The fourth question on enforcement showed no consensus at all, although a slight majority (4/7) 'Disagreed' or 'Strongly disagreed' with the concept of enforcement in the closed-ended question. Comments, however, showed considerable reservation among two of the three who did not choose a 'disagree' or 'strongly disagree' option. The panelist who 'Strongly agreed' (Panelist 1) and the one who 'Strongly disagreed' (Panelist 8) offered no commentary, but the panelist who 'agreed' stated that *"enforcement should only happen after failed negotiation, and consideration should be given to the extent to which a) enforcing through threat of force might further increase the number of secret burials, but also b) that by not enforcing, others may feel empowered to disengage from proper protocols"* (Panelist 2). The 'neutral' panelist stated that *"affirming the ultimate need for enforcement in part assumes that the enforcers are capable and present. That was definitely NOT the case in Sierra Leone at many times and in many places"* (Panelist 4). Those who 'Disagreed' (Panelists 5-7) all insisted that negotiation had to supersede coercion, with two of them (6 and 7) stating that realities of community members resisting or fleeing precluded ever giving up on negotiation.

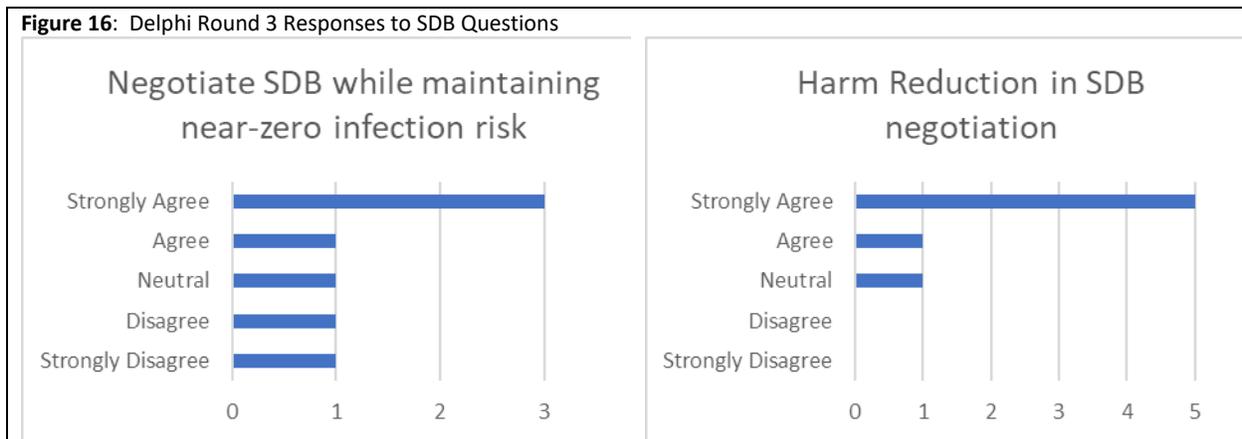
The two panelists who most strongly supported the enforcement of SDB expressed concerns about the risk of unsafe burial in both Round 1 and Round 2. The strongest supporter of enforcement pointed out in Round 1 that SDB was *"so important to slowing transmission"* (Panelist 1) and the second supporter had previously stated in Round 1 (in which they left the enforce/negotiate slider in the center position) the caveat that *"there is an extent to which burials must be safe, which will require some adaptation of typical practices"* (Panelist 2). Even among those who 'disagreed' in Round 2, one stated in Round 1 that

“SDB is critical” (Panelist 5) and a second that “one always has to balance the needs of the few against the well being [sic] of the entire community” (Panelist 6).

Given the reservations expressed in Round 2, two Round 3 questions attempted further to clarify panelists’ positions by asking their agreement/disagreement with the following statements:

- Responders should be willing to negotiate and implement modified rituals or observances related to burial, but only to the extent that zero or near-zero increase in the risk of infection is acceptable.
- A harm-reduction perspective³⁹ considers reduced – not eliminated – biomedical risk if the reduction increases compliance and reduces overall risk to the aggregate population. Responders should be willing to apply Harm Reduction principles to negotiate and implement modified funeral practices (for example, providing PPE and chlorine to people who wash a body) that might decrease community rejection in a situation such as the Ebola epidemic.

Panelists’ responses to these two questions are presented in **Figure 16**.



As the data in **Figure 16** show, panelists largely agreed with the application of Harm Reduction to SDB. On the other hand, there was incomplete consensus on the near-zero-risk standard for SDB negotiation, although 4/7 panelists ‘agreed’ or ‘strongly agreed’ with that statement. Only the person who ‘strongly disagreed’ commented on this point, and said in part that “*there has to be an acceptable level of risk given cultural sensitivity, revered traditional practices especially as it pertains to the dead*” (Panelist 8).

³⁹ The principle of Harm Reduction and its possible application to the Ebola response is discussed in Chapter 5.

Qualitative Analysis of Free-Text Answers

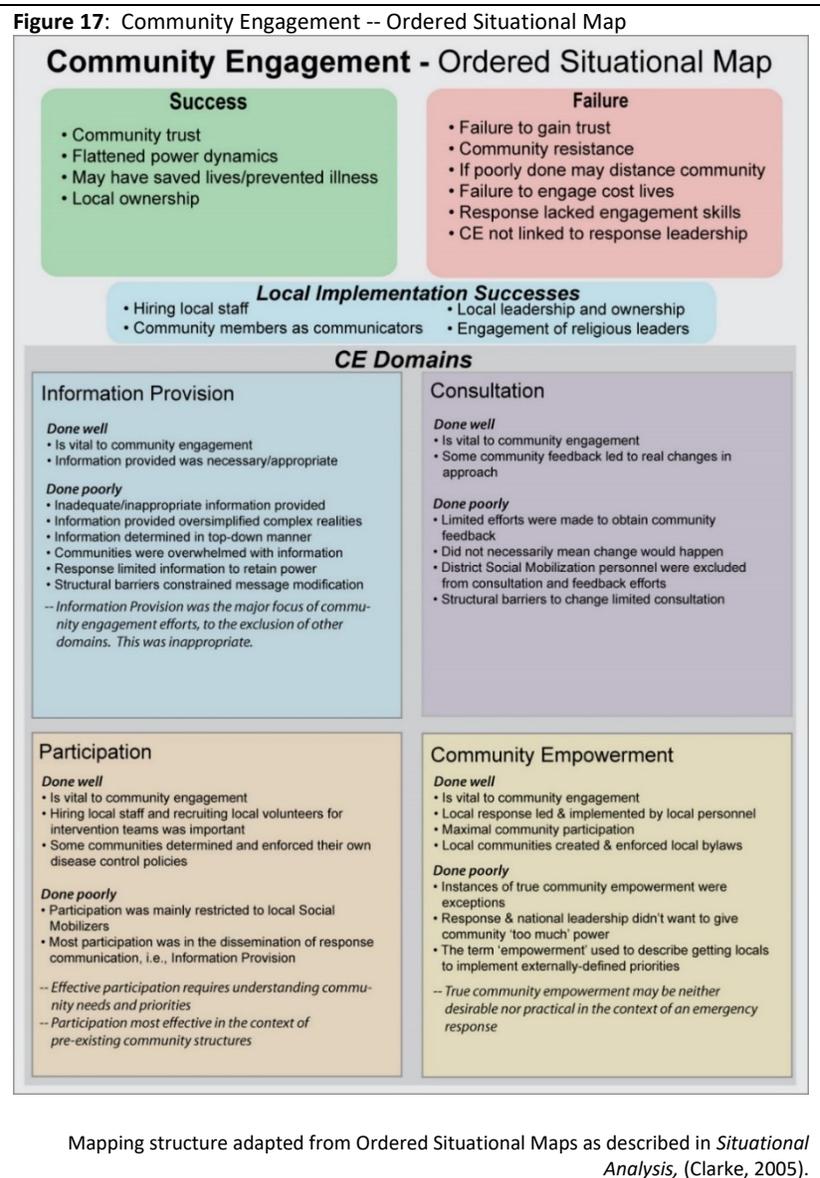
Of the seven panelists who completed all 3 rounds of the Delphi survey, six provided at least one free-text comment with their answers in Round 1, all seven provided comments in Round 2, and two commented briefly in Round 3. Because the concepts voiced in each round were broadly similar, the text from all three rounds was coded in a single codebook. As described in Chapter 3 ‘Methods,’ coding began deductively using the broad, high-level themes of Community Engagement with the four domains of Information Provision, Consultation, Participation, and Community Empowerment as second-level nodes. The Community Engagement theme is presented in **Figure 17**. The theme of Safe & Dignified Burial (SDB) was also created as a deductive, high-level node and is presented in **Figure 18**. One theme entitled “Structural Issues” comes partly from the deductively-coded topic of Social Mobilization, and partly from an inductively-coded topic of the utilization (or not) of local capacity. This Structural theme is presented in **Figure 19**. There were three additional themes that emerged inductively from the qualitative data, but which were not part of the initial code list: “Power,” “Fear,” and “Cultural Sensitivity.” These three themes are presented in **Figure 20**.

A complete list of qualitative codes organized by theme can be found in Appendix B.

Community Engagement

As shown in the previous quantitative analysis, Delphi panelists were divided regarding the success or failure of community engagement efforts during the Ebola response. Themes describing this success or failure are listed in the top portion of **Figure 17**, and are color-coded in green (positive) or red (negative) to reflect the value-judgment tone of the language used by the panelists themselves.

Some panelists felt that efforts led to an increase of community trust, engendered a sense of local ownership, flattened power dynamics, and contributed to preventing Ebola disease and saving lives. Sample quotes from panelists:



“I would say empowering the community to be fully involved at each stage of the response helped me to gain the trust of the community” (Panelist 5).⁴⁰

“[When] sufficient FUNDING became available for community engagement response activities, [it] fundamentally flattened out response power dynamics and nationalized and localized response activities” (Panelist 4, emphasis in original).

“While it is difficult to tease out which aspects of community engagement were most useful, collectively, I strongly believe that community engagement efforts were the driven [sic] force in preventing new Ebola cases and bringing the Ebola outbreak to an end” (Panelist 7).

Other panelists criticized community engagement efforts quite harshly. They stated that authorities failed to gain the community's trust, and further that some poorly-executed efforts may have distanced communities from the Ebola response, leading to substantial resistance in some communities. Panelists further suggested that those in the response who were tasked with community engagement failed to do it well in part because they lacked the requisite skills, and that where elements of the response structure did engage the community, those elements were unable to influence response leadership. Ultimately, these panelists believed that failure to effectively engage communities added to disease transmission and likely cost lives. Here are sample quotes from these issues:

“Rather than the intended effect of getting people to take [Ebola] seriously and follow self protective measures, the messaging terrified people, and many people simply fled the public health system” (Panelist 6).

*“Ebola response leaders lacked the knowledge (and perhaps most importantly, they lacked the *skills*) on how to engage communities to build trust and confidence in Ebola burials” (Panelist 7, asterisks in original).*

“Delayed [sic] in involving the community to participate in the preparedness and response contributed to the high community resistance” (Panelist 5).

“... when families ‘resist’ it tells you that they don’t believe what you’re doing is best for their loved ones” (Panelist 7).

“I really really [sic] believe that poor social mobilisation and community engagement practices contributed to excess illness and death” (Panelist 2).

On the concept of community engagement failure costing lives, one panelist pointed out that in their zeal to deal with the Ebola crisis, response actors and Ebola Treatment Units (ETUs) overlooked the harm caused by the epidemic’s impact on the broader health systems, as much non-Ebola care was suspended during the epidemic. While this panelist did not blame the response for the closure of care

⁴⁰ In this and following sections, when panelists are quoted, they are identified by numbers 1-8. This is because the identifiers were assigned during the first round in which 8 responded, even though Panelist 3 failed to complete later rounds and was therefore excluded from analysis.

facilities, they did suggest that appropriate community engagement would have recognized the issue and identified ways to mitigate the harm:

“... women who were going into labor and did not have access to hospital or ETU care had no informational or referral recourse, and were left to fend for themselves in the hands of village midwives who would not abandon them. Many bled to death” (Panelist 4).

Panelists pointed to several aspects in which the involvement of local personnel was a successful element of community engagement (this is also addressed below in the “Participation” domain). Panelists highlighted hiring local staff, recruiting community members as communicators and social mobilizers, and engaging of religious leaders (nearly 6,000 Islamic and Christian leaders, according to Panelist 7) to promote Ebola prevention messages as points of success. However, these successes were qualified by Panelist 2, who described the “co-option” of local Paramount Chiefs to lead local task forces. Several panelists pointed to instances in which local personnel did lead response efforts, for example:

“By the end, the majority of personnel controlling the Magazine Wharf Cluster, the last community cluster of Ebola in Sierra Leone, were local personnel organized from community groups” (Panelist 1).

“Another example would be the co-option (or at least encouragement) of involving Paramount Chiefs in the response, not only for consultation, but as shepherds of 'task forces' that could implement local level interventions” (Panelist 2).

“[When] sufficient FUNDING became available for community engagement response activities, [this] fundamentally flattened out response power dynamics and nationalized and localized response activities” (Panelist 4, caps in original).

“Engaged community groups were now taking proactive steps to organize themselves without external entities needing to facilitate. This was a sign of the local ownership that had begun to take place” (Panelist 7).

The Four Community Engagement Domains

Panelists identified instances in which all four domains of community engagement were done well and provided value to the response. However, they also offered pointed criticism of the manner by which each domain was manifested in community engagement activities.

In **Information Provision**, one panelist felt that people ultimately got at least some of the information they needed:

*“the sheer scale of information provision meant people could not *not* be aware [sic; i.e., could not be unaware; emphasis in original] of prevention techniques and advice” (Panelist 2).*

However, multiple panelists felt that the information that was disseminated was inadequate or inappropriate, oversimplified the realities of the outbreak, and was of such volume as to be overwhelming:

“I believe that information provision is extremely important to an overall community engagement effort (though is far from the be all end all, as it was in Sierra Leone), in the West Africa case, it was overwhelming, poorly designed, and poorly implemented. Communities were barraged with ‘social

mobilisation' messages from myriad poorly trained individuals with little knowledge or capability" (Panelist 2).

"At a certain point (November 2014) in the response, people were still being asked 'if they had ever heard of Ebola' when they were seeking information about how to protect themselves from intra-HH transmission" (Panelist 4 ... note 'HH transmission' means 'household transmission').

"The lack of correct information to the community in the early stage of the outbreak cause a lot of rifts and misconception about the response team" (Panelist 5).

"In the beginning, there were a lot of mistakes made when health communicators focused on convincing people that EVD was deadly and not treatable. Rather than the intended effect of getting people to take it seriously and follow self protective measures, the messaging terrified people, and many people simply fled the public health system" (Panelist 6).

Panelists also criticized the manner in which Information Provision was managed or implemented. Panelist 4 suggested that *"response leadership didn't want people to empower themselves to take on aspects of the response that they considered 'technical' like healthcare, supportive care, and burial."* This panelist, who had previously highlighted the difficulty people had accessing regular medical care during the response, further stated:

"But informational sharing about how people should deal with the consequences of the international response's rules and decisions was very low. It was almost like the international response did not want informational accountability for its decisions, and providing such information would be an admission of the limitations of their decisions. That was the wrong posture to take" (Panelist 4).

Several panelists agreed that information was provided in a top-down manner; i.e., the information and messages were developed centrally and not in dialogue with the community:

"Ground-up information provision in particular was essentially non-existent in the early months of the outbreak" (Panelist 2).

"The anthropologists and message crafting was [sic] a positive, but there was no sense that the public/community had anything really to offer in crafting communications" (Panelist 6).

"Although Ebola in West Africa taught us some very important lessons about the importance of having two-way conversation and dialogue with communities during health emergencies, whenever there has been a new health emergency the initial approach has often been to resort to one-way information dissemination" (Panelist 7).

However, one panelist disagreed and felt that the balance of community input and central guidance was appropriate:

"... underlying content was developed by response authorities with extensive community consultation, which I thought was the correct approach" (Panelist 1).

Four of the seven panelists made comments about their judgment that community engagement efforts were too focused on information provision to the exclusion of the other engagement domains:

“This isn't because I think information provision isn't essential - I very much do. But, I think that it cannot and should not be privileged above other forms of community engagement (i.e., consultation, participation, and community empowerment). Unfortunately, because information provision is easy and cheap to scale, it can and usually does become an overwhelming component of community engagement” (Panelist 2).

“I believe that consultation, participation, and community empowerment were regarded as handmaidens to the ‘real function’ of information provision for the purpose of behavior change” (Panelist 4).

“I didn't hear nearly as much about religious leader involvement in local level interventions. It was much more focused on having them [the religious leaders] say the right thing to get people to follow the prevention steps that the response had prescribed” (Panelist 6).

“In social mobilization, the focus is on the end-goal and doing whatever it takes to get it achieved in the shortest period of time (with or without consultation, participation, and empowerment)” (Panelist 7).

In **Consultation**, Panelist 2 listed two instances in which responders accepted community feedback and materially changed their behavior on the response, including limiting the number of vehicles going to a village at any one time,⁴¹ and improving the supplies offered to quarantined families.

There was a range of panelist assessments about how willing response authorities were to accept and act upon community feedback. Two participants judged these efforts positively:

“I would say responders were serious about listening to communities, but would not have changed their policies 100% of the time based on community feedback” (Panelist 1).

“Consultation happened at a level 2 because responders (especially through SMAC) actively sought feedback from communities on what is working and what is not working” (Panelist 7).

Three other panelists related a far more pessimistic assessment of Consultation efforts:

“By and large, there was no robust or systematised mechanism for (or effort to) really focus on hearing and addressing community objections or concerns” (Panelist 2).

“I don't think that the response ever truly realised a consultative approach to community engagement (meaning that information received from the community was used to actually inform/guide/change the response itself)” (Panelist 2).

“Community consultation occurred according to pre-determined priorities. When communities implemented responses that were dissonant with the overall priorities of the response, often “consultation” meant turning a blind eye, rather than acknowledging that local responses were yielding epidemiological results” (Panelist 4).

“There seemed to be a mentality that community input was only feasible and useful from a standpoint of how to get the community to do the predetermined thing we want them to do” (Panelist 6).

⁴¹ This author personally recalls the complaint from a villager of “too many white people in too many white cars” coming to their village, and from another of feeling “like fish in a bowl” due to the constant flow of officials, epidemiologists, and others.

“... the notion that procedures could be changed, particularly at the request of the public was not seriously entertained in my experience” (Panelist 6).

Two panelists opined that the Social Mobilization personnel who would have been most likely to receive feedback from people in the affected communities were not enabled or empowered to implement a consultative approach to disease management:

“... social mobilization leads at the district level were excluded from key areas of consultation, and from having inputs into the information provision that was being required by the other pillars” (Panelist 4).

“The consultations with the communities were not done robustly. The social mobilization pillar at the national level focuses more on the end goal than on coordinating with the district social mobilization pillar” (Panelist 5).

Panelists were again divided as to how well **Participation** functioned in the response. Panelists 1, 7, and 8 gave largely positive assessments, pointing to local staffing and activities and community-directed local interventions:

“Participation by community members was massive - community members were generally the majority of teams that went into communities” (Panelist 1).

“In the period after January 2015, we saw that the engaged community groups were now taking proactive steps to organize themselves without external entities needing to facilitate. This was a sign of the local ownership that had begun to take place” (Panelist 7).

“In the Western areas and Port Loko there was a ... process where the community members were the key actors and in most cases led the community engagement process to great success” (Panelist 8).

On the other hand, panelists 4, 5, and 6 were largely negative in their views:

“In epidemic response, maximal participation is required of the entire population for control measures, but minimal investigation goes into understanding the practical/tactical needs and priorities of the participants” (Panelist 4).

“Delayed [sic] in involving the community to participate in the preparedness and response contributed to the high community resistance” (Panelist 5).

“While there were isolated examples of true community participation, I did not get the impression that this was widespread” (Panelist 6).

Two panelists (numbers 2 and 7) referred, as already described, to the hiring of staff and recruitment of other volunteers from local community members as a vital element of gaining community participation. However, Panelist 2 pointed out that the vast majority of such staff were restricted to the role of Social Mobilizer and Panelist 7’s positive description of participatory work was almost entirely in communications (i.e., the Information Provision domain). Panelist 2 also wrestled with the question of whether an outside observer would consider the staffing of the official response – even by local citizens – as an appropriate indicator of community participation:

“But is this community engagement with a participation focus? It depends who you ask. I would say that it is, and in this sense, that it could have been done a lot worse in Sierra Leone. Indeed, I’m quite proud

reflecting back on how much of the Port Loko and Kambia responses were being operated by Sierra Leoneans from the respective districts. Others, though, have argued that participation is only genuine if it includes the ‘most local’ people. What exactly this means is unclear to me, but I suppose it must mean people at the most local and rural levels, such as those actually in quarantine. In this sense, I think the response did not do this very robustly – however ... I’m also not really convinced that this is what the ‘most local’ people want” (Panelist 2).

Two panelists highlighted key preconditions that enable or impede community participation. Panelist 2 noted that community members need to be informed as to *what* to do in various circumstances before they can effectively participate, and Panelist 6 stated that the most effective participation “*requires a highly organized and functional community health system, and it has to be in place before the health emergency.*”

Panelists’ answers regarding questions of **Community Empowerment** overlapped significantly with statements already quoted in the “Consultation” and “Participation” sections above. Echoing these quotes, panelists 1 and 7 spoke of the extent to which community members were performing actual field response duties, guiding and enforcing local practice during the latter stages of the epidemic. As previously quoted, Panelist 4 referred to the fact that once the response provided funding to support community activities, those communities were more empowered to take action, “flattening” the power differential between community actors and national response authorities. Panelist 4 heavily qualified their statement in this regard, however:

“In reality, power comes from capacity, and a great deal of capacity can be purchased with money, political power, and political support. So the decentralization of power happened when money became decentralized ... but were communities allowed to be the author of decisions about how those funds were expended? Not really - that role still largely belonged to district health decision makers and coordination teams” (Panelist 4).

Other positive descriptions of Community Empowerment included:

“I would say empowering the community to be fully involved at each stage of the response helped me to gain the trust of the community” (Panelist 5).

“[Although] it took much longer to move toward true empowerment where community voices had a substantial decision-making power in the response ... it is remarkable that it actually reached that level toward the middle of 2015” (Panelist 7).

In contrast, Panelist 2 stated that only limited empowerment ever happened in the response, and Panelist 4 held that the limited devolution of power was quite deliberate:

“I think that, essentially, [Community Empowerment] occurred in only the most limited ways in Sierra Leone. There was a huge amount of local capacity that was not considered, empowered, or utilised in Sierra Leone” (Panelist 2).

“... the response leadership didn't want people to empower themselves to take on aspects of the response that they considered ‘technical’ like healthcare, supportive care, and burial” (Panelist 4).

Two panelists raised the issue that real Community Empowerment may be neither possible nor desirable in an outbreak setting. Panelist 6 pointed out that the pragmatic “*realities of emergency response make*

[Community Empowerment] very challenging” and further observed that “I have a hard time imagining either [named responding agency] or an MOH [ministry of health] ever letting a community decide what DISEASE CONTROL measures are going to be undertaken” [caps in original]. Panelist 2 agreed: “I can’t foresee the response to a life-threatening epidemic ever being fully handed over to community members to operate without some exogenous intervention in support (including in an oversight and accountability role).”

Panelist 2 took the question a step further, asking whether communities necessarily always want as much power as advocates demand on their behalf:

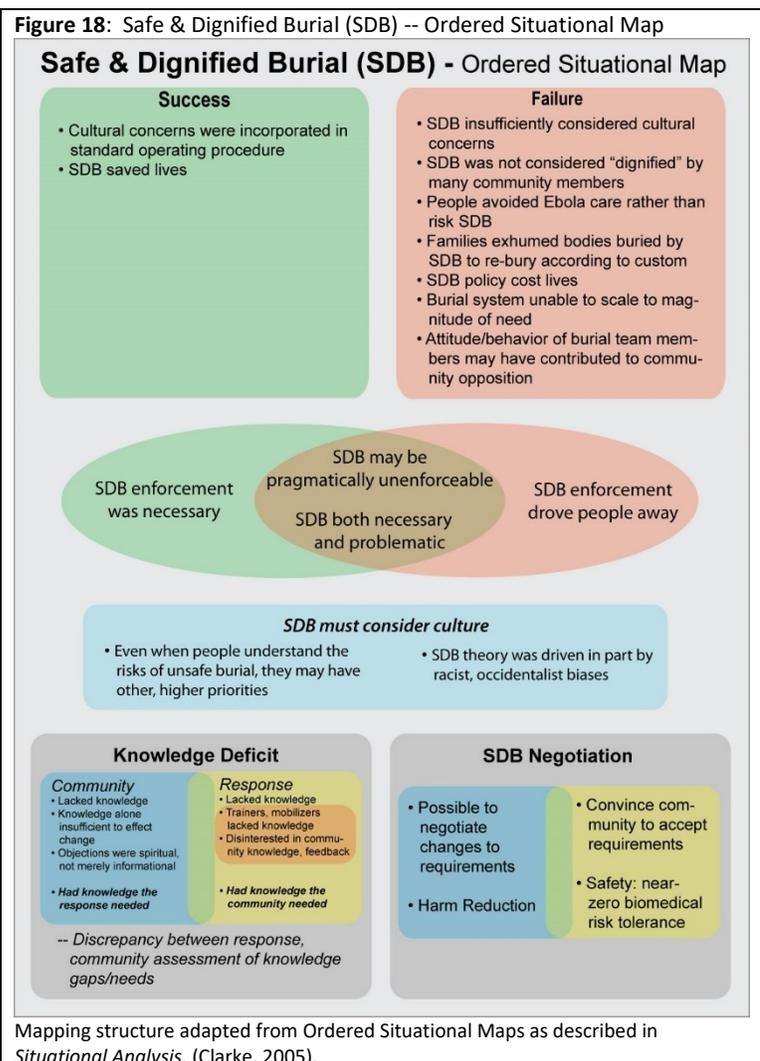
“... while participation is also crucial, it's fair to say that a lot of people aren't interested in participating even if they care about the mission at hand ... I fundamentally believe in the value of technical expertise and input. On that basis, I've never been truly convinced by the ‘it's not effective community engagement unless the community are operating the response themselves’ approach. In the Global North, we wouldn't want to fight our own fires, or arrest our own criminals, or pave our own roads. We want people to help take care of these things for us, understanding that they support us, and are better at it than we are - if for no other reason that we're busy doing other things” (Panelist 2).

Safe and Dignified Burial (SDB)

As with community engagement, there was a diversity of opinion among panelists on the success or failure of the Safe and Dignified Burial (SDB) policy imposed by national and response authorities in Sierra Leone during the Ebola epidemic. The themes that emerged in consideration of SDB are illustrated in **Figure 18**. As above, the themes in the top two sections in which panelists conveyed a value judgment about their assessments, are color-coded in green for positive assessments and red for negative ones.

Six of the seven panelists commented that they believed the SDB protocol was at least partially necessary due to the infection risk posed by the body of a person who had died of Ebola:

“... the epidemic spiralled out of control very quickly, and dead bodies represented an extreme risk” (Panelist 2).



“I thought that safe and dignified burial was so important to slowing transmission that I thought it should be performed by government enforcement if necessary” (Panelist 1).

“[SDB] escalated the profile of burials, and knowledge about infection associated with burials and death” (Panelist 4).

“The protocol helped at the later stage, especially when the cultural and religious beliefs of the community were incorporated” (Panelist 5).

“Yes I think it was ultimately successful. Early on there were several super-spreader events at funerals and I expect there would have been many more without SDB” (Panelist 6).

“Once the safe burial protocol incorporated feedback from community engagement that made the process more respectful, then yes I'd agree” (Panelist 7).

Three panelists qualified their positive assessment of SDB with statements about the protocol having taken cultural concerns into account in the later stages of the epidemic. In addition to the comments by Panelists 5 and 7 above:

“While one always has to balance the needs of the few against the well being [sic] of the entire community, in this case, there were solutions that could work, (later efforts to improve SDB proved that)” (Panelist 6).

That said, six of the seven panelists also stated that SDB protocol and practice did not sufficiently consider cultural concerns and that community members did not consider the SDB process to be ‘dignified.’

“... better understanding and consideration of community needs related to SDB - essentially, more compassion for it as something that some may understandably elevate [sic] above containment of the Ebola outbreak - would have been extremely valuable” (Panelist 2).

“[Part of] the failing of the SDB guidance and implementation was ... its failure to develop protocols that were aligned with local values from the beginning” (Panelist 4).

“The none [sic] involvement of the communities in performing their religious and cultural right [sic., perhaps ‘rites’] before the burial was a significant factor in the secret burials, the washing of the corpse before informing the responders etc.” (Panelist 5).

“People were also being asked to change practices that were important to them based on theories of Western medicine and infection that weren't part of their daily lives” (Panelist 6).

“... in the early part of the response (up until around November 2014), the burial process lacked respect as per cultural norms and likely contributed to people not wanting to report Ebola deaths and instead secretly buried loved ones to avoid medical burial teams” (Panelist 7).

“The dead may be buried according to ebola safe and dignified protocols but community members in most cases, did not deem the burial practices dignified- practices were seen as an abomination, an anathema and culturally unacceptable and inappropriate” (Panelist 8).

As the quotes from Panelists 5, 7, and 8 above demonstrate, the panel also acknowledged that in at least some instances, the unacceptability of SDB to bereaved family members directly influenced

decisions to conceal disease or death, or even to exhume bodies that had been buried as occurred in the case described in Chapter 1. Additional statements from the panelists further reinforce this connection:

"I also know that a significant number of people refused to report burials because the SDB system usually meant they could not participate in the burial of their loved ones, and so instead, they hid the death from the Ebola response and buried them unsafely themselves" (Panelist 2).

"I believe that [SDB] contributed, inequitably, to hiding, concealment, and secret movements of persons who were ill" (Panelist 4).

"... trying to force people to comply would result in people evading authorities and spreading disease" (Panelist 6).

"If the dead are not buried according to traditional norms and customs, community members have been known to exhume diseased bodies" (Panelist 8).

Panelists 2 and 4 both stated that, at least in some cases, communities were disillusioned regarding SDB by the fact that the response system was stretched too thin to accommodate all burial requests promptly, and panelists 6 and 7 reported that actual or rumored disrespectful conduct by burial teams further hampered acceptance of SDB.

Panelists were asked directly about whether, in the end, safe burial should be enforced despite objections. As **Figure 15** and **Figure 16** in the quantitative analysis show, only a minority held that eventually, enforcement is appropriate:

"Of course, corpses of Ebola positive individuals are highly infectious, and burials represented superspreader events. The need to safely bury individuals was unambiguous" (Panelist 2).

Even so, panelists acknowledged that such enforcement is not without problems; that *"the impact was bidirectional"* (Panelist 4). Panelist 2 elaborated: *"... I recognise the need for managed burials, but also know full well that it distanced many communities from robustly reporting deaths when they occurred."* Two panelists questioned whether, regardless of intent, SDB really can be universally enforced:

"I don't really agree with the premise that the authorities can enforce or coerce a burial. As we have seen, plenty of families are able to flee or to bury the person before the authorities get to them. So public health officials need to acknowledge that they really don't have a choice, they have to keep trying to negotiate" (Panelist 6).

"I'm a firm believe that punitive actions and coercion to adhere to practices during health emergencies are almost always doomed to fail, especially in this context of Ebola. Going after the small minority who may fail to 'comply' with the SDB or any other protocol/policy for that matter, is only going to alienate those who were already willing to adhere" (Panelist 7).

Panelists stressed that interventions such as burial policy must consider cultural distinctiveness. One panelist suggested that there were *"... mechanisms that could permit a greater degree of consideration for community needs (including limited roles in helping perform burials, as requested or desired on a case-by-case basis) that were not meaningfully considered"* (Panelist 2). Another stated *"There has to be an acceptable level of risk given cultural sensitivity, revered traditional practices especially as it pertains to the dead; psycho-social and economic importance of burying the dead 'properly'"* (Panelist 8).

Others pointed out that even when fully informed about the risks of funeral practices, people may have other priorities that supersede the avoidance of biomedical risk:

“People will go to extraordinary measures to manage the ends-of-lives of the people they love, even - and perhaps especially - during epidemics” (Panelist 4).

“... better understanding and consideration of community needs related to SDB - essentially, more compassion for it as something that some may understandably elevate above containment of the Ebola outbreak - would have been extremely valuable” (Panelist 2).

Finally, one panelist suggested that the failure of SDB guidelines was due in part to the fact that they were developed in the context of a *“pejorative and racist representation of local populations as bound by tradition and unwilling to take steps to promote the health of their communities” (Panelist 4).*

Two further sub-themes regarding SDB are shown at the bottom of **Figure 18**, “Knowledge Deficit” and “SDB Negotiation.”

Knowledge Deficit

The first sub-theme is linked to the two knowledge deficit questions whose quantitative answers are shown in **Figure 13**. As the data in **Figure 13** show, all seven panelists agreed that the response lacked knowledge that could be obtained from communities regarding SDB, and six out of seven agreed that the community lacked knowledge the response could impart. The main themes of panelists’ comments regarding this topic are coded in yellow and blue at the bottom of **Figure 18**, to demonstrate contrasting opinions expressed by the panelists, but which were expressed without language suggesting a positive or negative value judgment on the part of the panelists. The red rectangle in the “Knowledge Deficit” section represents a subset of panelists’ critiques that did convey a negative value judgment.

On the one hand, panelists stated that the community indeed needed more or better information regarding the need and rationale for SDB:

The “lack of correct information to the community in the early stage of the outbreak cause a lot of rifts and misconception about the response team” (Panelist 5).

“This form of burial was totally new to Sierra Leoneans. It went against everything they had been told about how to perform a burial for a loved one. Therefore, community members needed to understand why safe burials were important to prevent Ebola deaths” (Panelist 7).

However, a few panelists were careful to qualify their answers in this regard. Panelist 7 observed that *“knowledge alone wasn’t sufficient to bring about change”* and that spiritual concerns within the community had to be addressed by those religious and traditional leaders who were authorities in the realm of spiritual belief. Other comments reinforced this:

“[People had] problems with SDB because community members adhered strongly to their traditional-cultural beliefs. They found SDB traumatic, alien and in most cases an abomination-taboo” (Panelist 8).

“Their spiritual understanding of death and burial in the time of Ebola needed to change. People needed to hear from their religious and spiritual leaders that it was permissible for burial customs to be modified (i.e. not washing and having any contact with the corpse). So summary, knowledge was important, but wasn’t sufficient. A change in mindset/beliefs was required and that was the hard part” (Panelist 7).

On the other hand, panelists were unequivocal that the response lacked information that needed to be gained from the community:

“... through all phases of the response, Ebola response leadership and implementers lacked important knowledge that needed to be gained from the community” (Panelist 1).

“There were clear gaps in understanding [within the response] about the scale and complexity of the SDB problem” (Panelist 2).

“As with any community intervention that affects a critically important family and community function, the response really needed to better understand how it would impact people” (Panelist 6).

*“Ebola response leaders lacked the knowledge (and perhaps most importantly, they lacked the *skills*) on how to engage communities to build trust and confidence in Ebola burials” (Panelist 7).*

One panelist elaborated that the Social Mobilizers tasked with educating the community were themselves *“poorly trained individuals with little knowledge or capability” (Panelist 2)*. In contrast, two panelists suggested that elements of the response leadership were not all that interested in learning from the community and showed *“selective blindness [in] listening to what communities were saying during community engagement” (Panelist 4)*, believing that *“it's the community that needs to change, not us” (Panelist 6)*.

One panelist stated that when the response sought to provide information to communities, there was a discrepancy between the information provided and what communities felt they needed:

“At a certain point (November 2014) in the response, people were still being asked ‘if they had ever heard of Ebola’ when they were seeking information about how to protect themselves from intra-HH [i.e., intra-household] transmission. Throughout the response, the informational needs exceeded the response's willingness to provide such information ... there was a structural information gap between medical leaders and people responsible for other people at the community level” (Panelist 4).

SDB Negotiation

The final sub-theme in SDB was the question of what people meant when discussing negotiating strategies related to SDB. Comments fell into two opposing camps. In the first instance, panelists looked at negotiation in the context of responders being willing to consider altered requirements for burial, utilizing harm-reduction strategies and taking into account local concerns:

“I do believe more emphasis could have been placed on safe methods of compromise (this might sound crazy, but for example, I seem to remember later in the outbreak that community members felt better if they were able to wash the body using a sponge attached to a long pole, rather than not wash the body at all. It's hard to imagine how this represents a significant risk, when weighed against its importance to family members)” (Panelist 2).

“People will go to extraordinary measures to manage the ends-of-lives of the people they love, even - and perhaps especially - during epidemics. Public health needs to start thinking about the lives of those who die as lives that must be honored in sickness, healing, and death, and pivot towards public health as an affirmation of human dignity” (Panelist 4).

“I have seen this done more or less successfully in Congo in 2019-2020. The strategy was to locally adapt the practices, through trial and error, until families were satisfied. We were able to detect a reduction of angry community feedback as a result of this work. It all comes down to a mindset that there is not one single protocol, but rather local staff need to have the authority to make revisions” (Panelist 6).

*“If response authorities want to succeed, the burden should then be on them to try to *understand* how the burial process could be modified so that families can see it as acceptable even if it is not what they would have otherwise preferred as being the best” (Panelist 7, asterisks in original).*

Even in the context of such negotiation, several panelists cautioned that there is a level of biological safety that must be maintained. They therefore framed negotiation in part as convincing the community of what had to be done to maintain acceptable (near-zero) risk:

“Agree [with a negotiated strategy], with the caveat that protocols must in fact be safe” (Panelist 1).

“... ‘substantial’ modification - in my use here, to mean modifications that meaningfully introduce elements of heightened risk of further transmission - should not be negotiable” (Panelist 2).

“Negotiation helps the community to understand the reason why SDB is critical and use real scenarios for better understanding” (Panelist 5).

“... one always has to balance the needs of the few against the well being [sic] of the entire community” (Panelist 6).

“To stop Ebola spread and eliminate the risk of new clusters, burial practices needed to change at a nationwide scale. This only could have been done with the blessing and active promotion of safe burials by religious leaders” (Panelist 7).

One panelist summarized a balance between these divergent strategies:

“The harm reduction principle should reduce rejection by the community of alien burial practices, whether negotiated or not. There has to be an acceptable level of risk given cultural sensitivity, revered traditional practices especially as it pertains to the dead; psycho-social and economic importance of burying the dead ‘properly’” (Panelist 8).

Structural Issues

Panelists offered a number of comments related to structural issues in the Ebola response, particularly on the topics of Social Mobilization and the utilization of local capacity for response activities. These topics are presented in **Figure 19**.

Broadly speaking, one panelist noted that a “challenge” to effective community engagement during the response was that “Ebola was such a huge crisis that response structures were set up outside the general public health system” (Panelist 6).

Social Mobilization

Several questions were asked in Rounds 1 and 2 of the Delphi survey, about the Social Mobilization activities and structures in the response (see **Figure 9** and **Figure 10**). As with previous diagrams, in **Figure 19**, panelists’ assessment of what was done well or poorly with regard to Social Mobilization are color coded green and red, respectively.

In the category of Social Mobilization activities done well, four panelists stated in their comments that Social Mobilization entities or personnel were included in the governance of response activities (note that in the fixed-answer question shown in **Figure 10**, panelists were evenly divided on this question, with three Strongly agreeing that SocMob⁴² was excluded, one neutral, and three Disagreeing or Strongly disagreeing). Panelist 1 simply stated “that was not my experience” in their Round 2 response to another panelist’s Round 1 claim that SocMob had been *excluded*. Other panelists commented:

“I think SocMob personnel were very much included in the decision making process - namely, participation on a daily basis in DERC activities and decision making processes” (Panelist 2).

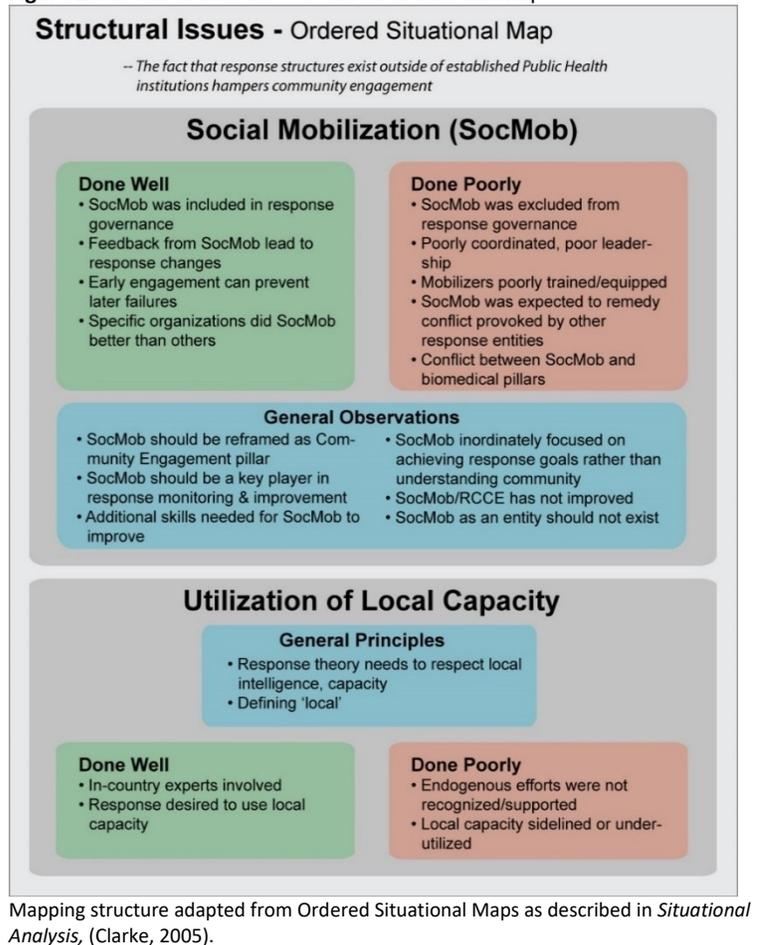
“In the districts, I worked, this [exclusion of SocMob] was not the case. The Social Mobilization pillar was actively involved in community-engagement activities” (Panelist 5).

“While it was formally part of the Government of Sierra Leone, the Consortium [Social Mobilization Action Consortium or SMAC] was established with a clear goal of directly supporting the Health Promotion Division in the Ministry of Health and SMAC was a key member of the Social Mobilization Pillar co-chaired by the MOH and UNICEF” (Panelist 7).

Panelist 7 also nuanced their comments about SocMob involvement in governance in a later comment:

“I am not sure if this statement can be entirely true or false -- the truth is somewhere in the middle. It was definitely an uphill battle for representatives from the Social Mobilization Pillar to have meaningful influence on decision-making and many times there was push-back from the more biomedical and operations pillars to move fast while SM pillar was advocating for engagement that requires time investments” (Panelist 7).

Figure 19: Structural Issues -- Ordered Situational Map



⁴² The term “SocMob” was a shorthand used almost universally among response personnel during the time this author was present in Sierra Leone. It is used here because it was also used in the comments by some Delphi panelists.

One panelist went into specific detail: *"In Port Loko and Kambia, community feedback did actually change the response's approach at times"* (Panelist 2). The panelist went on to detail improvements in quarantine supplies, limiting the number of vehicles visiting quarantined compounds, and even military personnel assisting quarantined families by helping to tend their fields while working members were in isolation.

Another panelist advocated for early investment in Social Mobilization activities to prevent bigger problems later:

"... time investments made very early on in engaging communities will reduce the time required to engage communities later in the emergency when the situation has worsened" (Panelist 7).

Two panelists, while criticizing failures of Social Mobilization efforts writ large, pointed specifically to the Social Mobilization Action Committee (SMAC) and one of its constituent organizations, Restless Development, as exceptions that modeled positive engagement:

"As a side point, the much more targeted social mobilisation organisations - e.g., Restless Development, who had a handful of properly trained people per district - felt to be a much, much more effective and safe approach" (Panelist 2).

"... responders (especially through SMAC) actively sought feedback from communities on what is working and what is not working" (Panelist 7).

One panelist disagreed with these Round 1 statements, however, responding directly to a Round 2 question referencing SMAC:

"Totally false; my experience of SMAC [was of] minimal intervention that had no lasting positive outcome. They were ineffective and had no impact in my opinion. This is what I observed on the ground" (Panelist 8).

In contrast to the above (and as also shown in **Figure 10**), other panelists felt Social Mobilization activities had been done poorly, and pointed to their contention that personnel had been excluded from response governance:

"... let's be honest with ourselves, none of us knew who these social mobilisers were, there was no real sense of accountability" (Panelist 2).

"The Social Mobilization Pillar was decisively walled off from core coordination capabilities and ascribed the role of information dissemination" (Panelist 4).

[SocMob leadership] "ended up spending a hell of a lot of time fighting for control over who should say what when, rather than supporting communities and listening" (Panelist 4).

"Qualitative research found that social mobilization leads at the district level were excluded from key areas of consultation, and from having inputs into the information provision that was being required by the other pillars" (Panelist 4).

"The role of the social mobilization pillar was underrated by the district coordinators, not knowing that this was the backbone of the response" (Panelist 5).

Moreover, as quoted on the previous page, Panelist 7 described the two-sided reality that at times SocMob was at the table with response leadership, while at other times it was *“an uphill battle for representatives from the Social Mobilization Pillar to have meaningful influence on decision-making.”*

Among panelists who felt Social Mobilization activities were poorly done, two pointed to the pillar being poorly led: *“weak leadership for the social mobilization pillar from the side of the MOH”* and *“a lack of coordination”* (Panelist 5) with *“no real sense of accountability”* (Panelist 2). Panelist 2 further stated that Social Mobilizers *“mostly just served to distribute flyers and chat amongst themselves.”*

Additionally, Panelist 2 felt that SocMob activities were conducted by *“myriad poorly trained individuals with little knowledge or capability”* and further criticized *“mass one-off one-or-two-day trainings of hundreds of people”* conducted by a large international agency.

Two panelists pointed to forces external to the Social Mobilization pillar, which complicated the pillar’s work:

“SocMob was accountable within the response for mitigating conflict, and for responding and alleviating conflict provoked by non-SocMob pillar actions and decisions” (Panelist 4).

“... many times there was push-back from the more biomedical and operations pillars to move fast while SM pillar was advocating for engagement that requires time investments” (Panelist 7).

Beyond praising or criticizing the activities of the Social Mobilization pillar during the 2014-2016 Ebola response, multiple panelists offered thoughts about the potential role and structure of Social Mobilization in future responses. Panelists 2, 4, 5, and 7 all spoke of the need for Social Mobilization to be more fully integrated into response leadership structures, and in so doing, to reframe it more broadly as Community Engagement rather than strictly Social Mobilization. Several spoke of competencies such as a Community Engagement focus would require, that might not have been entirely in evidence during the Ebola response:

“The more that I think about it, the more that I think the whole [Social Mobilization] ‘pillar’ should be done away with, and instead, a focal point for community consideration be integrated into every other pillar of the response. And, perhaps in its place, a social science pillar - for the robust collection of community information and data, operated by professional social scientists” (Panelist 2).

“Social Mobilization pillars need to be more empowered in the response in order to have meaningful influence on the conduct of the response overall. It needs to be fully integrated into all other aspects of response activities in order to highlight critical response gaps, and both lead and support on steps to fill those gaps” (Panelist 4).

“A social mobilization/community engagement role requires analytical capacities that connect its leadership to the core response infrastructure, in an integrated analytics capacity” (Panelist 4).

“... there is a need to add risk communication as this will help them get the correct information when engaging the community” (Panelist 5).

“What was then considered [the] social mobilization pillar would need a new name because social mobilization is quite different [from] community engagement (although the two may have some similar strategies) ... Therefore, future responses should consider changing the name from social mobilization

pillar to community engagement pillar. But this should not just be a name change on paper. The pillar's understanding of community engagement would also need to align with these four components of information provision, consultation, participation, and community empowerment. Clear metrics for assessing progress on each of the four components should be defined upfront by the pillar and must be aligned and integrated with the other aspects of the response structure.” (Panelist 7).

Two panelists criticized Social Mobilization efforts as being inordinately focused on top-down behavior change to the detriment of more collaborative community engagement imperatives:

“The term ‘social mobilization’ really means getting the community do what you want them to do, rather than bringing information and strategies, and letting the community lead the decision-making. However, during outbreaks, there are a lot of people in leadership positions who strongly believe that the best thing to do is come into a community with a set protocol and to stick with that protocol, no matter what” (Panelist 6).

“In social mobilization, the focus is on the end-goal and doing whatever it takes to get it achieved in the shortest period of time (with or without consultation, participation, and empowerment)” (Panelist 7).

To these assessments, another panelist offered two further critiques of Social Mobilization as it is presently implemented in emergency responses beyond the 2014-2016 Ebola crisis:

“I’m not even convinced that the ‘social mobilization pillar’ should exist, in an ideal world. Ideally, the principles of social mobilisation should be built into a response itself - effective hierarchy and coordination should permit the decentralisation of response activities, which implicitly requires information provision, consultation, participation, and community engagement” (Panelist 2).

“In later responses that I’ve worked in, ‘social mobilisation’ has been replaced by ‘risk communication and community engagement’ or RCCE - but, even in its most enlightened form, I have still never seen it do much beyond information provision” (Panelist 2).

Utilization of Local Capacity

Although fewer panelists commented on the use of local capacity in the Ebola response, those who did so provided several insights. Two panelists stressed the need for responders to respect community members’ autonomy and intelligence in approaching those communities with interventions:

“Current RCCE theory postulates that the best health messaging is the simplest, the most specific, and the least complex. Negotiating acceptable alternatives requires a totally different framework that understands that most people can hold more than one fact in their minds at one time” (Panelist 4).

[The effectiveness of community-initiated interventions such as movement restriction] “was never explicitly recognized or acknowledged as a part of the entirety of the response, even though community engagement actors, and all other actors, were working with full knowledge and experience of these measures” (Panelist 4).

“In my experience, it is sometimes difficult to convince public health officials that they are accountable to every member of the public, even the poor and uneducated, and they need to listen to their perspectives” (Panelist 6).

Finally, the question of defining a ‘local’ ‘community’ was raised by one panelist:

“I suppose in this instance my main thought would have to circle back to the ambiguity around what we mean by ‘community’ ... I think it really depends on where you define ‘local.’ Is ‘local’ household level? Village? District? National?” (Panelist 2).

The panelist elaborated by posing the question mentioned previously as to whether professional members of the Ebola surveillance team, hired by the response from among existing District health personnel, constituted true local participation. While this panelist felt that indeed such hires were a good and valid form of community involvement,

“Others, though, have argued that participation is only genuine if it includes the ‘most local’ people. What exactly this means is unclear to me, but I suppose it must mean people at the most local and rural levels, such as those actually in quarantine. In this sense, I think the response did not do this very robustly - however, as in my prior answer, I’m also not really convinced that this is what the ‘most local’ people want” (Panelist 2).

One other panelist offered a related nuance:

“One thing that is not super-clear to me in this framework is whether when you say, ‘local leaders,’ you mean local government officials, or you mean community groups and non-governmental entities. In some contexts, there can be a big difference. Some local leaders can also be very top down” (Panelist 6).

As with previous topics, panelists offered several instances of the utilization of local capacity, done well or poorly; and as in previous graphics, these instances are placed in color-coded boxes in **Figure 19**, with green for instances in which the comments conveyed a positive value judgment, and red for negative judgments.

On the positive side, panelists spoke both of the active desire on the part of the authorities to capitalize on local capacity, and on specific instances where this was done. These instances have already been quoted in the paragraphs above, so here the reader is reminded that Panelist 1 spoke of the vast extent of community leadership in controlling the last urban cluster in Sierra Leone in an area called Magazine Wharf. Panelist 2 spoke approvingly of the hiring by the response of District health office personnel to serve as surveillance officers in the response, and Panelist 7 spoke of the engagement of Christian and Islamic leaders to weave health-promotion messages, grounded in their respective scriptures, into their religious teaching. One panelist offered an additional explanation:

“... the DERs [District Ebola Response Centres] actually endeavoured quite hard to rely on local staff, if for no other reason because they had to - there weren't enough international staff to perform these functions even if people thought it would be better that way. I was very proud of the amount of local staff we were able to train up and support” (Panelist 2).

Contrasting with these positive stories were two comments that critical capacity was sidelined or underutilized:

“There was a huge amount of local capacity that was not considered, empowered, or utilised in Sierra Leone” (Panelist 2).

“When communities implemented responses that were dissonant with the overall priorities of the response, often ‘consultation’ meant turning a blind eye, rather than acknowledging that local responses were yielding epidemiological results. A good example of this was the blind eye shown to the nearly

universal adoption of community restrictions on movement across Sierra Leone, which has been shown to have had a major preventive impact and was a structuring mechanism for grassroots surveillance and response” (Panelist 4).

Emergent Key Themes

Three additional themes emerged from the inductive coding of the Delphi text data: Power, Fear, and Cultural Sensitivity. These three themes are presented in **Figure 20**.

Power

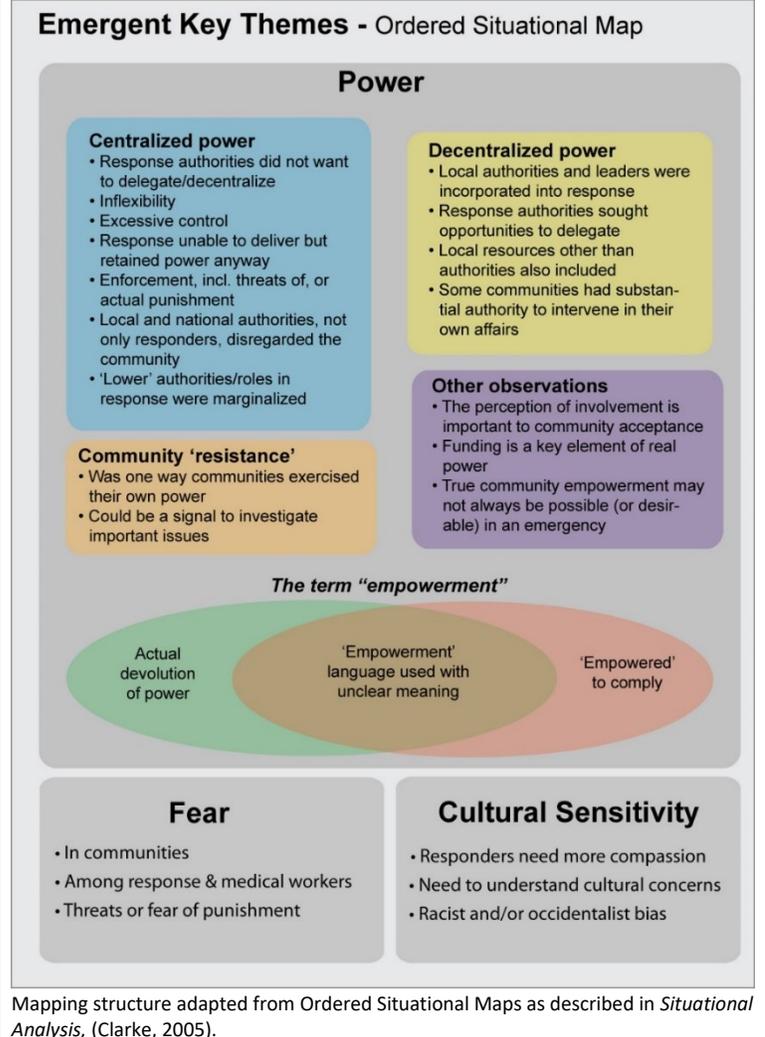
By far the most significant theme to emerge from the Delphi data was that of Power, and how varying types and loci of power manifested themselves in the actions of formal authorities at multiple levels and in the actions of members of Ebola-affected communities. Panelists spoke of power both as it was centralized in the response system or national authorities, and as it was decentralized and delegated to local authorities, informal leaders, and others in various communities. As is evident in the top two blocks of **Figure 20**, diverse panelists expressed opposing views on this theme.

Two panelists repeatedly spoke of ways in which response authorities “didn't want people to empower themselves to take on aspects of the response that they considered ‘technical’ like healthcare, supportive care, and burial” (Panelist 4); this same panelist also stated that consultation by the response was

“strictly limited to pre-determined standards and mandates, regardless of the local measures that communities wanted to take or felt was necessary” (Panelist 4). Another panelist, as previously quoted, observed that “Local public health professionals may have felt that their professional status would be undermined by the notion that ‘community members are experts about their own lives’” (Panelist 6).

Linking their experience to another, more-recent Ebola outbreak in the Democratic Republic of the Congo, this same panelist reported that “We actually had a [international agency] representative tell us that to revise an already ‘validated’ material based on community feedback would have been seen as suggesting that the original material was ‘wrong’ and would have had serious ramifications” (Panelist 6).

Figure 20: Emergent Key Themes -- Ordered Situational Map



Panelists 2 and 6 both used the term “inflexible” or “not flexible” in describing the Response position toward SDB, and Panelist 6 stated that “... during outbreaks, there are a lot of people in leadership positions who strongly believe that the best thing to do is come into a community with a set protocol and to stick with that protocol, no matter what.” Panelist 4 elaborated that authorities remained unwilling to delegate “despite the fact that the response was never able to provide technical services at scale.”

Three panelists criticized the coercive nature of response interventions, with Panelist 5 referring to “the use of force,” and Panelist 7 to “punitive actions and coercions” and to “persecuting” those who did not comply. Panelist 2 represented such coercion as at least partially ineffectual, mentioning “rituals which people will follow through with even at risk of punishment.” By contrast, Panelist 1 held that the risk of Ebola transmission through unsafe burials was sufficient that SDB “it should be performed by government enforcement if necessary.”

One panelist observed that it was not merely international responders, but also local and national staff, who maintained a centralized grip on power in the response:

“One of my very clear memories from that time is realizing that it wasn't so much [named response agency] staff that were disregarding the ability of communities to contribute so much as it was some of the local staff. That was a really memorable lesson. I had to look at power dynamics in a whole new way. We, as privileged outsiders, could afford to think of members of the public as knowledgeable and important contributors without feeling any sense of threat to our professional status. Local public health professionals may have felt that their professional status would be undermined by the notion that ‘community members are experts about their own lives’” (Panelist 6).

One panelist also stated that “social mobilization leads at the district level were excluded from key areas of consultation, and from having inputs into the information provision that was being required by the other pillars” (Panelist 4); the ‘other pillars’ this panelist mentioned referred to the structures that managed the national response.

In contrast to the foregoing, panelists also described clear efforts to decentralize power and involve local authorities in the management of intervention efforts:

“The local political system in Sierra Leone was extremely important to engage, particularly in more rural parts of the country” (Panelist 1).

“... there were also proactive efforts to get Paramount Chiefs involved in the response, and to use their ‘chiefdom task forces’ to get local people on board” (Panelist 2).

“The use of paramount chiefs was very effective in the response. I used them as community entry points, and I was able to get the cooperation of the communities” (Panelist 5).

“... paramount chiefs were indeed ‘shepherds’ and instrumental in local interventions. This was my experience especially in port Loko” (Panelist 8).

As quotes from Round 1 were shared in the questionnaire for Round 2, one panelist directly contradicted the claim by another panelist that authorities did not want to share authority:

“It is false to state leadership did not want community ownership or leadership- this was a complex process and [the] response team was trying to find an equilibrium and to understand this aspect of response” (Panelist 8).

“... response teams were desperate to involve community members, to collaborate and to achieve a more inclusive process. Although there were false starts, the end product was a collaborative process where community members were key actors” (Panelist 8).

Not only were authorities such as chiefs included in response efforts; Panelist 1 stated that in the latter stages of the response *“community members were generally the majority of teams that went into communities,”* and Panelist 2 added that as more people were brought into response roles, *“there wasn't necessarily a clear line between communities and those that comprised the response.”*

Three panelists described situations where at least some communities had substantial agency in determining their own affairs:

“By the end, the majority of personnel controlling the Magazine Wharf Cluster, the last community cluster of Ebola in Sierra Leone, were local personnel organized from community groups” (Panelist 1).

“I think there are exceptions to the rule here, where communities did have a degree of control over what was done in their community to control the epidemic. Examples include local bylaws, the use of chieftdom task forces, more holistic quarantine support, and so on and so forth” (Panelist 2).

“... communities were listened to and supported to develop their own community bye-laws to govern local protective measures. So doing saw emergence of local innovations that were tailored to the local context” (Panelist 7).

Four panelists described ways in which communities exercised their own power by resisting interventions related to SDB:

“... a significant number of people refused to report burials because the SDB system usually meant they could not participate in the burial of their loved ones, and so instead, they hid the death from the Ebola response and buried them unsafely themselves” (Panelist 2).

“[Responders should] recognize community participation for what it is - a vote in favor, a vote against, or a vote with their feet” (Panelist 4).

[A responder related that] “he could well understand people's resistance to safe burials because some of the workers were so afraid that they were simply dumping the bodies” (Panelist 6).

“... when families “resist” it tells you that they don't believe what you're doing is best for their loved ones” (Panelist 7).

Two panelists stated that community ‘resistance’ should be taken as an impetus to investigate potential issues:

“Every person who bypasses the SDB protocol is an opportunity for the response to learn something new for next time. Therefore, finding ways to identify these individuals without making them fearful of consequences of their actions will be important. We have a choice to either persecute/punish or identify/understand the ‘objectors’” (Panelist 7).

[Resistance to SDB] “is a very complex phenomenon and needs in-depth engagement with reasons why members were against response team” (Panelist 8).

A few other observations regarding power do not fit neatly into any of the above categories, but deserve mention. Two respondents highlighted the importance of a community perceiving that they are involved in order to gain buy-in for intervention activities:

“Ultimately, community engagement and participation in epidemics amounts to the politics of making the public health happen. The more people who ‘cast a vote’ for public health, the more successful the public health intervention is going to be. The politics of public health in non-authoritarian contexts requires a hell of a lot of persuasion, wheedling, begging, exchange, and any other measures possible, including peer pressure” (Panelist 4).

“Consultation with the community makes them feel part of the response” (Panelist 5).

Three panelists mentioned the link between funding and power:⁴³

“I think that the uncritical push to ‘empower communities’ is therefore quite neoliberal in its approach - it is about placing responsibility at the level of the crisis-affected individual, rather than robustly funding and supporting (public) health systems to ensure appropriate care is provided” (Panelist 2).

“In reality, power comes from capacity, and a great deal of capacity can be purchased with money, political power, and political support. So the decentralization of power happened when money became decentralized... but were communities allowed to be the author of decisions about how those funds were expended? Not really - that role still largely belonged to district health decision makers and coordination teams” (Panelist 4).

[By mid-2015] “community engagement was evidently backed up strongly with financial support, including the work done by the religious and traditional leaders, where they themselves were leading their interventions and receiving funding to be part of the response” (Panelist 7).

Although the topic was already addressed in the “Community Empowerment” discussion earlier in this chapter, it bears repeating that several panelists suggested that community empowerment in the sense of a genuine devolution of power is not always possible or even desirable in an emergency context.

Finally, the ways in which panelists used (and public health personnel more generally use) the term ‘empowerment’ is diverse enough to merit examination. However, the sense of the term is not always clear in context. At opposite ends of the spectrum, some uses of the term by panelists suggest an actual devolution of power to affected communities:

“... the majority of personnel controlling ... the last community cluster of Ebola in Sierra Leone, were local personnel organized from community groups” (Panelist 1).

“Where ‘community engagement’ meant training and empowering locals to perform response functions themselves, this, I would argue, was hugely useful, and in limited circumstances did occur” (Panelist 2).

⁴³ This author is reminded of the ‘other golden rule’ ... ‘Whoever has the gold makes the rules.’ Attributed to *Wizard of Id* cartoonist Johnny Hart: <https://economicsociology.org/2015/08/28/remember-the-golden-rule-whoever-has-the-gold-makes-the-rules/>

“... engaged community groups were now taking proactive steps to organize themselves without external entities needing to facilitate. This was a sign of the local ownership that had begun to take place” (Panelist 7).

On the other hand, at least one use of the term ‘empowerment’ (wittingly or not) seems to be applied to a situation where specific community members were persuaded or coerced to comply with the expectations of response authorities:

“A hallmark of this empowerment is the example of how traditional leaders were empowered to engage with their members to halt all traditional healing activities to reduce risk of transmission and to encourage their patients to seek care from health facilities” (Panelist 7).

Fear

Only a few texts mentioned the concept of ‘fear,’ but they represented three distinct ideas : fear of disease among communities, fear of disease among burial team members, and fear of punishment in communities.

One panelist noted fear within affected communities, leading to some public health messages backfiring: *“Rather than the intended effect of getting people to take it seriously and follow self protective measures, the messaging terrified people, and many people simply fled the public health system” (Panelist 6).* This same panelist noted that *“some of the change in behavior was due to people seeing people dying around them.”*

The same panelist also noted, in the context of burial teams, that *“there was an extreme degree of fear among the response workers as well,”* and further that *“some of the [burial] workers were so afraid that they were simply dumping the bodies” (Panelist 6).*

Finally, as noted in the “Power” section above, Panelists 2 and 7 alluded to the fear of punishment among affected persons, though the context of those statements was that fear is insufficient to change behavior effectively.

Cultural Sensitivity

Three briefly-mentioned themes emerged under Cultural Sensitivity: compassion, cultural understanding, and racism/occidentalism. Two panelists called on response authorities to show more compassion in emergency interventions:

“However, better understanding and consideration of community needs related to SDB - essentially, more compassion for it as something that some may understandably elevate above containment of the Ebola outbreak - would have been extremely valuable” (Panelist 2).

“Public health needs to start thinking about the lives of those who die as lives that must be honored in sickness, healing, and death, and pivot towards public health as an affirmation of human dignity” (Panelist 4).

Five panelists spoke of the need for responders to understand cultural concerns in the implementation of SDB:

“It's clear that burials and funerary practices more generally are inescapably part of people's rituals - rituals which people will follow through with even at risk of punishment” (Panelist 2).

“The failing of the SDB guidance and implementation was [in part] its failure to develop protocols that were aligned with local values from the beginning” (Panelist 4).

[SDB achieved success] “when the cultural and religious beliefs of the community were incorporated” (Panelist 5).

“People were also being asked to change practices that were important to them based on theories of Western medicine and infection that weren't part of their daily lives” (Panelist 6).

“... in the early part of the response (up until around November 2014), the burial process lacked respect as per cultural norms and likely contributed to people not wanting to report Ebola deaths and instead secretly buried loved ones to avoid medical burial teams” (Panelist 7).

Finally, two panelists referred to response approaches being at least in part rooted in Occidentalist or racist biases:

“... donor- and institutionally-driven theories about Community Engagement substantially shaped community engagement practice” (Panelist 4).

“... the pejorative and racist representation of local populations as bound by tradition and unwilling to take steps to promote the health of their communities” (Panelist 4).

“Community empowerment comes from a long history of community self-help initiatives, which emerged from a long narrative about dependency theory, which itself was fundamentally racist” (Panelist 4).

“People were also being asked to change practices that were important to them based on theories of Western medicine and infection that weren't part of their daily lives” (Panelist 6).

Chapter 5 – Discussion

Discussion of Delphi Data

Community Engagement

The Delphi survey revealed a genuine disagreement between the panelists as to the quality and success of community engagement efforts during the Sierra Leone Ebola response. In all four domains of community engagement, some panelists scored the efforts of the response at each of the three Empowerment Score levels 0, 1 and 2. While these data must be interpreted with caution due to the possible confusion regarding the meaning of the Empowerment Scores, they are nevertheless consistent with the literature reviewed in Chapter 2 and the analysis of emergency response articles in Chapter 4, which also included some authors reporting positively on their community engagement activities while others decried failures of engagement. In fact, if the discordance between the language and action of community engagement described in the Chapter 4 (**Figure 4** and **Table 1**) was replicated in some Delphi panelists' assessments, this could also contribute to the diversity of Empowerment Scores as various panelists perceived the empowerment of communities in a different light.

In addition, as the qualitative analysis revealed, panelists perceived some community engagement activities as successful and others as failures. This reality is particularly evident in **Figure 11**, in which panelists agreed on the one hand that community engagement efforts prevented disease, but on the other that community engagement failures may have caused additional illness and death. Individual panelists' opinions were not consistently positive or negative; in fact, the three panelists who wrote the most commentary (Panelists 2, 4, and 7) provided detailed assessments of both successes and failures at different points in the Delphi survey. Panelist 7 tended to assess community engagement efforts more positively (though by no means exclusively so) than either Panelist 2 or 4, and Panelist 7's numeric scores also tended to be higher than those of Panelists 2 and 4 (**Table 3**). Nevertheless, the commentary by panelists critiquing shortcomings in all four community engagement domains far outweighed positive assessments both in terms of the volume of comments and the pointed language used.

Notwithstanding the panelists' disagreement as to how well community engagement was done in Sierra Leone, at least five panelists maintained that future responses should reflect an Empowerment Score of 2 in all four domains, with six out of the seven desiring an Empowerment Score of 2 for Consultation and Participation. Taken together with their written critiques, it is reasonable to conclude that every panelist except for Panelist 5 (who rated all response engagement at 2) believed that efforts in Sierra Leone left substantial room for improvement.

Panelists universally agreed that the hiring of staff from local communities to work in the response, and the engagement of religious leaders were important contributors to the successes that were achieved (**Figure 12**, see also lower half of **Figure 19**). However, consistent with the information-centric focus noted in the first two sections of Chapter 4, a majority (5/7) of panelists also agreed that community engagement efforts were disproportionately focused on Information Provision to the exclusion of the Consultation, Participation, and Community Empowerment domains that would better have provided community feedback to the response.

Safe & Dignified Burial (SDB)

The Delphi panelists' responses to questions on SDB in the context of Ebola were complex and nuanced (**Figure 15**). Six out of seven panelists acknowledged the biomedical risk of handling the bodies of those

who died from Ebola, and the consequent need for burial protocols to address this risk (Panelist 8 did not comment). A different six out of seven (Panelist 1 in dissent) held that SDB as implemented in Sierra Leone paid insufficient attention to the collision between biomedical requirements of SDB and the cultural objections of community members, and four directly cited community resistance to safe burials as a result of this collision.

Consistent with the review of Community Engagement literature in Chapter 2, the Delphi panelists supported the idea that a knowledge deficit existed among response leadership, regarding drivers of community behavior in relation to funerals and burials. Coupled with the imbalance between Information Provision and the other three domains as noted above, this deficit may have been perpetuated by the lack of effective community feedback mechanisms.

Six of the seven panelists answered in Round 2 that authorities should be willing to negotiate modified burial protocols if necessary to address community concerns. The dissenting panelist (Panelist 1) agreed in their comments that negotiation would be appropriate as long as the protocols remained 'safe.' The idea that they reserved some sense of keeping the protocols biomedically safe was reflected in the comments of the rest of the panelists as well; only Panelist 4 expressed no such reservation. These reservations were further nuanced in Round 3 (**Figure 16**), in which four panelists 'Strongly agreed' or 'Agreed' that negotiations of SDB protocols should maintain a 'zero or near-zero increase in the risk of infection.' At the same time, all but one panelist 'Strongly agreed' or 'Agreed' that responders should apply Harm Reduction principles in the negotiation of burial protocols (Panelist 2 was 'Neutral').

On the other hand, panelists in Round 2 were unexpectedly divided about the idea that eventually a safe burial protocol, however negotiated, must be enforced (fourth question in **Figure 15**). Once again, however, panelists' comments to this question and elsewhere in the three surveys made clear that those who supported enforcement did so in the context that negotiation should precede enforcement; and several who opposed enforcement still spoke of educating communities as to the necessity of SDB, and of balancing the needs of the broader committee against the opposition of the few. It is therefore reasonable to infer a greater consensus than implied by panelists' answers to the closed-ended questions, that while burial/funeral protocols should be far more negotiable than they were during the 2014-2016 Ebola outbreak, there ultimately remained a need for some form of enforceable (and enforced) burial standard.

Power and 'Empowerment'

Perhaps the most profound observations Delphi panelists shared in their comments relate to the exercise and perception of power among the various actors – both responders and recipients of response activities – in the Ebola crisis (**Figure 20**). Panelists discussed specific ways that power in the response remained centralized with international or national-level actors, and other ways in which power was delegated or devolved to local leaders, be they district-level health authorities, or formal and informal community leaders. Some panelists criticized the unwillingness of central authorities to let go of power, and pointed to Western prejudice (in international responders) and a desire not to acknowledge error (in both responders and local authorities) as drivers of this grip on power. Multiple panelists criticized the coercive enforcement of various Ebola protocols, particularly for quarantine and SDB.

On the other hand, panelists described an overt desire on the part of response authorities to decentralize power – not only to gain buy-in from local leaders and communities, but to encourage them to play an active part in disease control in their communities. Panelists related multiple accounts of community leaders or community-based groups actively assisting in message dissemination and disease control activities, as well as situations where key district-level response staff were recruited and hired from the communities in which they worked.⁴⁴

An important, if less-obvious, observation was that when communities ‘resisted’ the demands of disease control authorities, they were in fact exercising their own power over a situation in which they felt otherwise powerless. The concealment of Ebola disease or death, far from being grounded in ignorance as the Knowledge Deficit Model (see Chapter 2) might have suggested, was in many cases community members’ way of asserting their own risk calculus in place of that presupposed by the response community – of “*vot[ing] with their feet*” (Panelist 4) for practices that comported with their own worldviews rather than meekly submitting to the demands of outsiders. As another panelist observed:

“Families want what they believe is the ‘best’ for their loved ones. This belief is amplified when they feel responsible for honoring the wishes of a family member who can [no] longer have a say for how they should be buried. Therefore when families ‘resist’ it tells you that they don’t believe what you’re doing is best for their loved ones” (Panelist 7).

Related to this last point is the contrast, also highlighted in **Figure 20**, between the different ways the term and concept of ‘empowerment’ were used by the panelists. In several instances, panelists described genuine devolution of power to communities to conduct key disease-control interventions. However, similar to the issues noted in the first two sections of Chapter 4, at least one panelist described ‘empowering’ traditional healers to stop performing healing activities, apparently missing the irony that being forced to abandon one’s livelihood is hardly ‘empowering.’

Limitations

This Delphi study is subject to at least two limitations. All seven Delphi panelists readily adopted the four-domain model for examining community engagement activities, and engaged the model to examine their observations of the Ebola response. However, the use of the Empowerment Scores appeared to present more challenges, as evidenced by the discrepancies between panelists’ narrative answers and their Empowerment Scores described in the previous chapter. Although Round 3 involved a questionnaire redesign to foreground the definition of the Empowerment Scores in each domain, the continued apparent discord between numeric scores and panelists’ written assessment of response actions may suggest that at least some panelists may have used the numeric 0-2 scale as a metric of the overall quality of response activities rather than applying the criteria listed on their Reference Guide and presented in **Figure 3**. Future application of the Empowerment Score methodology, therefore, may require better training of raters in the principles underlying the Empowerment Scores, to ensure that ratings accurately characterize the probability of community feedback effecting change in interventions and messages.

⁴⁴ This author personally witnessed just such local leadership near the end of the Ebola response when, in Kambia District, the response lead and key epidemiologists were Sierra Leonean nationals who resided in that district. One evening in January, 2016, these local staff demonstrated admirable command of a highly-risky Ebola exposure situation and mobilized the necessary control resources with efficiency and professionalism that more than matched any efforts international experts could have offered (Martin, 2018, timestamp 67:00).

Furthermore, the limited sample size and the purposively-selected panelists mean that the data presented above cannot be considered representative. These traits are innate to the Delphi methodology which, as previously described, is designed to elicit expert opinion, not to represent a population.

Reflections on Power

The recognition of power differentials and the various applications or assertions of power within the outbreak context should lead responders to examine the manner in which we inhabit our positions of power and privilege. As was shown in Chapter 1, an emergency response of the magnitude of that for the 2014-2016 Ebola outbreak necessarily involves people from different cultures and worldviews. The insights of the Delphi panelists, as well as the analysis of response literature, demonstrate the reality that international responders, national and indigenous authority structures, and lay villagers occupied wildly divergent levels of power and privilege. The coercive enforcement by Sierra Leonean authorities of burial protocols described in Chapter 1 – and the sometimes-passive, sometimes violent resistance by rural citizens – spoke to a disparity in power between those mandating, and those acquiescing to or resisting what was mandated. Acknowledging our privilege, we have an obligation to “turn the lens back on the ... enterprise that legitimizes the power structure and perpetrates inequalities of health” (Dutta, 2010, p. 534). By maintaining a posture of ‘reflexivity’ (Wallerstein et al., 2019) with regard to our own actions, we can “disrupt the universalist assumptions of altruism” (Dutta, 2010, p. 534) that might otherwise lead us to ignore the power dynamics of our actions. Simply, as we consider our actions, it helps first to examine our motives and presuppositions.

In this vein, it must be acknowledged that efforts such as the international Ebola response are never purely altruistic. Responders – this author very much included – acted with a genuine desire to stop death and misery on the local level. However, the response was also about a larger, global public good of keeping a terrifying disease from spreading to the rest of the world. The dual paradigms of Global Health Security and humanitarian biomedicine (Lakoff, 2010) – the former focused worldwide and the latter on individual human suffering – are grounded in different (sometimes competing) ethical frameworks, with the humanitarian impulse grounded more in individual human rights, and the health security impulse in utilitarianism.

International responders certainly operated under a desire to protect their own nations – and themselves while in the theater of operations – from the spread of Ebola. This ‘protection’ impulse (Dunn, 1984), captured so succinctly in Simon Rushton’s impudent question “Global Health Security: Security for Whom? Security from What?” (Rushton, 2011, title), deserves a closer examination than it has received (see also Epelboin et al., 2007, p. 26).

Indeed, the bald truth is that for a rural community in a low-income country, the crisis that brings Westerners to their door may well not be a priority issue compared to their own lived experience of need (Caremél et al., 2017; Feierman et al., 2010; UNHCR, 2015b). It is undeniable that part of what drove the response was the perspective that “the [Ebola] virus represents a threat to Western populations. It could travel from *there* and infect us *here*” (Jones, 2011, p. 1, emphasis in original).⁴⁵ As

⁴⁵ For an interesting analysis of epidemics in popular American culture and myth, see *Social Responses to Epidemics Depicted by Cinema* (Han & Curtis, 2020).

then-CDC director Tom Frieden repeatedly pointed out, part of the imperative for global health security is the truth that “... an outbreak anywhere can be a risk everywhere” (Frieden et al., 2014, p. 1179).

The international health intervention regime has been suggested more than once to be rooted in – or at least descended from – Western colonialism (Adams, 2010; Dunn, 1984). It would, however, be facile to dismiss the protection impulse as wholly inappropriate; in point of fact it has been and remains a common reality in societies throughout history (Dunn, 1984). Nor is self-protection necessarily harmful to others: for example, it was “the principal motive force” (Dunn, 1984, p. 1092) behind the successful global effort to eradicate smallpox.⁴⁶ It is not this author’s intention to assail the protection motive, but rather to ensure that the full spectrum of motivations, from ulterior to altruistic, is acknowledged.

All of this being said, the ethics of controlling a disease such as Ebola do not fit neatly into a dichotomous power dynamic of wealthy-vs-poor, Global North-vs-Global South. Poor people in Sierra Leone, Guinea and Liberia really were dying – nearly 12,000 of them by epidemic’s end – and it wasn’t only wealthy foreigners who wanted the misery ended. In fact, the hard on-the-ground work of disease control was performed far more by citizens of the three affected countries than by outside responders. The herculean (and successful) efforts of the Nigerian Ministry of Health and partners to head off the spread of Ebola to Lagos (Frieden & Damon, 2015) was about preventing a potentially-devastating expansion of the outbreak in Africa, not in the West.

Nor were coercive interventions strictly the imposition of outsiders. At least some local communities in Sierra Leone instigated their own control measures quite apart from any external pressures: measures which, although developed in community dialogue, carried stiff penalties for dissenters (Goguen & Bolten, 2017; Parker et al., 2019). This author personally witnessed numerous instances where local Sierra Leonean officials intervened with a heavy hand, including the military-police shutdown of Bamoi Luma, a regional market, in an attempt to compel a community to reveal the whereabouts of a popular leader who had hidden from Ebola investigators (Le Marcis et al., 2019; Martin, 2018, timestamp 42:00). That such local exercise of coercive power may in part be rooted in colonial and post-colonial power structures (Fairhead, 2014; Goguen & Bolten, 2017; Wilkinson & Fairhead, 2017) does not obviate the fact that coercion took endogenous as well as exogenous forms.

Ultimately, reflexivity in the context of the Ebola response must hold the twin impulses of altruism and self-preservation in tension. The Ebola outbreak really *was* killing poor and marginalized people, and it really *was* a threat to the outside world. Stopping it was legitimate for both reasons, and more than a few interventions reasonably supported both objectives.⁴⁷ It is this author’s belief that neither perspective can, nor should, be eliminated from the mix; rather, that we should remain conscious of both as we examine what was done well or poorly.

One final note on reflexivity: much of this document is focused on the collision of cultural beliefs within the response. It is easy for Westerners to think that the only cultural beliefs that need examination are those of the communities into which they have parachuted – falling into the trap of assuming that

⁴⁶ This author acknowledges that, although global eradication of smallpox was and remains a great public good for billions, it is also true that some individuals and communities were coerced and possibly harmed in the eradication effort.

⁴⁷ As Leach (2008) observed, “At one level, minimising suffering from haemorrhagic fevers is a broad, shared goal within all narratives [local vs. global]. Yet there are differences in the relative priority given to global vs. local populations, and to narrowly-defined qualities focused on mortality vs. other qualities such as community solidarity and maintaining valued lifestyles” (Leach, 2008, p. 3).

traditional practices are “backward or barbaric” (Mokuwa & Richards, 2020, p. 6), and styling themselves as ‘experts’ over against the ‘laity’ they are trying to serve (Bolten & Shepler, 2017). Quite to the contrary, the biomedical community has its own cultural beliefs (Hewlett & Amola, 2003) that undoubtedly colored the response, not least the presumption that eliminating infection risk was the paramount concern of body management, and that physical death was the greatest fear to be avoided.

This primacy of preventing death likely has many roots, but one which merits particular reflexive attention is the extent to which Western medicalization⁴⁸ of death (Conrad, 2007; Illich, 1974; Zola, 1972) has framed the natural process of dying as something to be fought at all costs by the biomedical system, resulting in “medical teams emphasiz[ing] biosafety to the neglect of families’ spiritual and social obligations” (Wilkinson et al., 2017, p. 2). This framing comes in part from the “expropriation of death” (Illich, 1974, p. 920) by the biomedical establishment itself, and the fact that “one of our most deeply held shared belief systems, and our legal systems all say that medicine is there to fight death” (Rothman, 2021, p. 86). As a result, death in the West has become largely an in-hospital event rather than at home surrounded by family and friends, and the “social and cultural setting of death, essential for providing meaning, connection, and lifelong support for those grieving, risks disappearing” (Sallnow et al., 2022, p. 845). In contrast to the sterile distance from death that frequently supervenes in the West, for much of the rest of the world (indeed, for an increasing proportion of Westerners as well),

“... death is principally a relational and spiritual process rather than simply a physiological event. As a result, the balance of care changes. Relationships are prioritised and made central to care and support when dying or grieving, across all settings from care homes and hospitals to people’s homes” (Sallnow et al., 2022, p. 870).

The divergence between responders’ emphasis on death as a physiological event to be managed and prevented, and community members emphasis on relationships and spirituality in the context of death may have contributed to responders’ inability to comprehend community resistance to medical burial as described in Chapters 1 and 2.⁴⁹

⁴⁸ Although many authors have written on medicalization, one of the clearest definitions comes from Wendy Simonds: “the dynamic set of processes by which medical authorities, institutions, and ideologies come to (re)organize, (re)define and (re)structure our everyday experiences, culture, and social life” (Simonds, 2017, p. 11).

⁴⁹ The pitfalls of overmedicalization in the response context were not limited to the issue of safe burial. In fact, a great deal could likely be gleaned by applying the medicalization lens to the entire process of contact tracing, quarantine, isolation, and treatment for Ebola; however, exploration of these topics is beyond the scope of this work.

Harm Reduction

Why Harm Reduction?

As has been discussed in previous chapters, it is probable during an emergency response that in at least some circumstances a collision between cultural mores and response requirements will occur.

Regardless of whether the collision is discovered at the assessment phase, by active community feedback, or through analysis of an instance of community resistance, the next question to be asked is the same: What should be done about it?

As has been shown in the literature reviews in Chapter 2 and the qualitative data in Chapter 4, the answer to this question during the Ebola outbreak in Sierra Leone tended to be either to increase attempts at community education and messaging, or to increase enforcement pressure to bring about compliance. This work proposes a third way, grounded in part in Core Humanitarian Standard #3: “Communities and people affected by crisis are not negatively affected and are more prepared, resilient and less at-risk as a result of humanitarian action” (CHS Alliance, 2014). Recognizing that the phrase “not negatively affected” must necessarily include ‘negatively’ as defined by community mores and customs, this third way would require engaging with appropriate community representatives in an attempt to design or refine interventions that meet both disease-control and cultural needs.

When efforts were made to consider culturally-acceptable modifications to interventions, the approach of responders in Sierra Leone was to “identify aspects of the VHF/IPC⁵⁰ protocol that might then be adjusted to improve cultural congruence, *without any risks to individual resident/health care worker or community safety*” (Marais et al., 2016, p. 444, emphasis added). A similar risk-averse qualification to negotiating burial standards is in evidence in the Delphi results presented in Chapter 4. As illustrated in Chapter 1, a substantial problem with this ‘no-risk’ standard was the divergent risk calculus between responders and community members.

The purpose of this section is to examine the “Harm Reduction” (HR) philosophy for its potential to mediate between opposing risk paradigms. After reviewing the historical and ethical grounds of HR, the second half of this section considers ways that HR might have been applied in the context of the Ebola case report in Chapter 1.

Principles of Harm Reduction

The definition of the term ‘Harm Reduction’ is not necessarily intuitive. At first blush, all of public health – and many civil systems outside the health domain – aim to reduce some kind of harm. As used in public health literature, however, HR has a narrower focus that:

- Pragmatically acknowledges that complete elimination of a problematic behavior may not be possible in the real world, despite scientific, legal, societal, or moral pressure;⁵¹ and therefore

⁵⁰ VHF refers to “Viral Hemorrhagic Fever,” an umbrella term that describes Ebolavirus disease and other diseases with similar profiles; IPC refers to “Infection Prevention and Control,” the term for the processes implemented to monitor and prevent the spread of any infectious disease from one individual to another, especially in medical care settings.

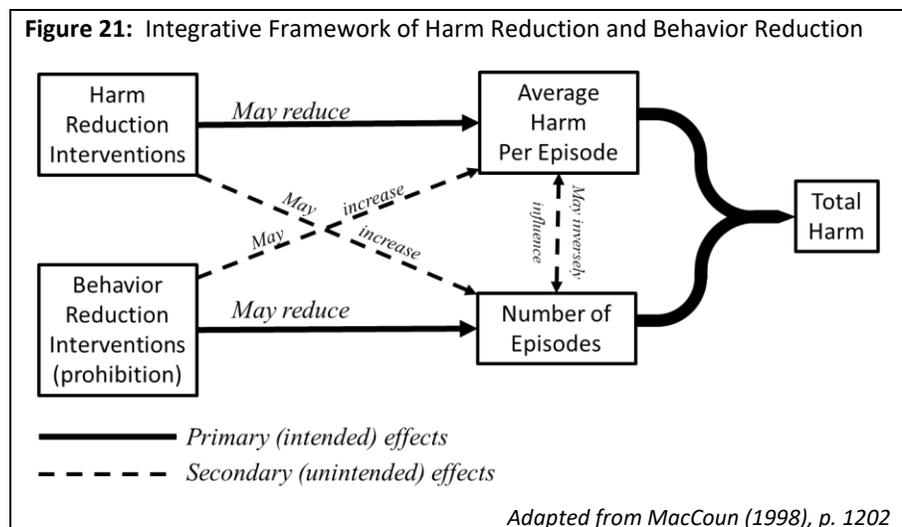
⁵¹ As MacCoun (1998) illustrates: “Although it is true that abstinence from drugs (or teenage sex, or drinking among alcoholics) is ‘100% effective’ at reducing harm, the key policy question is whether we are 100% effective at convincing people to *become* abstinent” (MacCoun, 1998, p. 1200, emphasis in original).

- Seeks to mitigate harms both to the individual and to society, that might otherwise result from the continued practice of the subject behavior (Marlatt, 1996; Reuter & Caulkins, 1995; Riley et al., 1999; Single, 1995).
- Ideally, includes the affected population in defining harm as they experience it, and involves them in negotiating acceptable solutions (Marlatt, 1998; Woods, 1998; Wotton, 2007).
- Additionally, some – though by no means all – proponents of harm reduction actively seek to reduce social and moral stigma surrounding the activity in focus. Destigmatization can take the form of “promoting more accepting attitudes” (Clements et al., 1991, p. 37) toward those who engage in that activity; others explicitly advocate for decriminalization of such activities where illegal (Bowen, 2012; Nadelmann, 1989; Woods, 1998; Wotton, 2007). This approach will be discussed further in “Ethics of HR” below.

HR attempts to view problems and potential solutions as a continuum of risk rather than a binary (Marlatt, 1998), and “encourage[s] any movement toward decreased harm as steps in the right direction” (Marlatt, 1996, p. 786). HR “eschews the false dichotomy between legalization and prohibition” (Erickson, 1995, p. 284) and “seeks to adopt practical rather than idealized goals” (Single, 1995, p. 288). Therefore, HR may seek modifications to behaviors seen as problematic, in such a manner that even without eliminating the behavior altogether, dangerous effects to the individual or others may be reduced or mitigated.

HR is grounded in “‘rational decision-making’ and ‘reasoned action’ theories ... wherein rational behaviour is viewed as synonymous with risk avoidance” (Rhodes, 2002, p. 86). As shown in Chapter 1, however, one must approach the definition of ‘risk’ with caution. Risk can better be understood by considering the notion of ‘total harm’ which is characterized as the product of average harm per use⁵² times total use (MacCoun, 1998, p. 1202; Marlatt, 1996, p. 779; Reuter & Caulkins, 1995, p. 1059). Harm per use is defined as a combination of harm to the individual user plus harm to others resulting from the use episode – for example, domestic abuse or violent crime related to the use and distribution of illicit drugs (Hilton, 2001; Reuter & Caulkins, 1995).

Total harm can be complicated by the fact that interventions can have unintended harmful effects that run counter to the intended benefit (Figure 21). On one hand, making an activity safer may lead to more-frequent instances of the activity (MacCoun, 1998). On the other hand, attempts to



⁵² The term ‘use’ occurs in the context of literature studying illicit drug use. For broader application, substituting the term ‘episode’ allows the generalization of HR theory to other domains.

prevent behavior through criminal/legal sanctions may increase harm both to individuals and society through violent or criminal actions that people take to evade sanction (Nadelmann, 1989). For this reason, it is necessary to recognize harm as defined by the community, as well as by any given individual, understanding that “a culture of self-survival can serve to blur the social and environmental bases of risk as well as opportunities for community, environmental and structural change” (Rhodes, 2002, p. 87).

History of HR in Public Health

Harm Reduction for users of illicit drugs was first formally discussed in early 90s, both in the United States (Denis-Lalonde et al., 2019; Marlatt, 1996; O’Connor & Saunders, 1992) and the United Kingdom (Clements et al., 1991), although needle exchanges were introduced in Amsterdam as early as 1984 in an attempt to address the high incidence of Hepatitis B among injecting-drug users (Buning, 1991, p. 1304). HR gained additional attention and, in some quarters, support, in the context of the HIV/AIDS crisis (Buning, 1991; Riley et al., 1999).

Although ‘Harm Reduction’ first appeared as a term of art in the public health lexicon around 1990 (Denis-Lalonde et al., 2019), the concept was not at all new. As far back as the early 20th century, a committee convened by the British Ministry of Health concluded that it was not always medically possible to cure opiate addiction, and held that in such cases prescribing morphine or heroin to people dependent upon opiates was considered medically advisable, and could permit them to function successfully in society (Rolleston et al., 1926). This approach informed methadone-maintenance programs that have been operated in the United States and around the world for decades (Buning, 1991; Marlatt, 1996; Nadelmann, 1989).

Much more recently, this author recalls his field training in syphilis-control strategies in 1989, in which promotion of ‘safe sex’ (or, at least, *safer sex*) methods had been the stock in trade for at least twenty or thirty years, though absent the HR terminology. References to HR in sexuality, sex work, and sexually transmitted infections appear in the literature of the mid 90s (MacCoun, 1998; Marlatt, 1996), although not to the extent they occur in discussions on safer drug use. A vital perspective on HR among sex workers came in a keynote address to the 18th International Harm Reduction Conference in Poland, by Rachel Wotton, spokesperson for The Scarlet Alliance – The Australian Sex Workers’ Association (Wotton, 2007), who highlighted the centrality of genuine community engagement in determining HR strategy:

“This is no place for token gestures. It is about providing real opportunities for sex workers to participate in and drive the process, whether it be project development, needs assessment, focus testing, legal reform or the implementation and analysis of research. This process must be respectful and inclusive of the incredible diversity of sex workers and the different communities with which we identify” (Wotton, 2007, p. 4).

Wotton’s observation reinforces Marlatt (1998), who stated that “unlike many traditional interventions, harm reductionists do not apply externally developed techniques without collaboration and negotiation with the people who are the recipients of these services” (Marlatt, 1998, p. 62). In a specific cultural context, Woods (1998) states that “without a working knowledge of African American culture, respect for the black agenda, and appreciation of the complexities involved, any harm reduction endeavor targeting the black community will fail” (Woods, 1998, p. 322).

HR principles are, of course, not exclusively applied to the domains of drug use and sexual health:

“There are many other examples of harm reduction strategies that have been implemented successfully. These include condom machines in high schools, seat belt legislation and programs promoting safe participation in sports (eg, wearing bike helmets, life vests for boating and hockey visors). The basic premise of harm reduction holds for all of these programs (ie, there are inherent risks involved with any behaviour, and there are interventions that, when followed, reduce these risks for those who choose to engage in the behaviours)” (Canadian Paediatric Society, 2008, p. 55).

Ethical Opposition to HR

For as long as there have been Harm Reduction interventions, there have been opponents to HR efforts, based as they are upon a “pragmatism [which] may offend politicians, program providers, prevention funders, and even some users” (O’Connor & Saunders, 1992, p. 178). Opposition has often centered around the perception that, in essence, HR condones and may even promote harmful activities, the ultimate result of which may be even more use and harm (Vearrier, 2019). Some such opposition is grounded in the behavioral theory of “risk homeostasis” (Wilde, 1998), which suggests that people may actually increase risky behaviors to the extent their perception of the risk quantum per unit of behavior decreases (leading to the secondary effects described in **Figure 21**).⁵³ A 1988 New York City needle-exchange program received accusations of “genocidal” (Marriott, 1988) intent against people of color who, it was alleged, would be at greater risk for HIV/AIDS if the program continued.

For others, the objection to HR is moral. “The harm reduction philosophy itself is intrinsically unacceptable to those who oppose drug use on moral grounds” (Reuter & Caulkins, 1995, p. 1060). Similarly, HR in sex education has been opposed in concept and practice by mandates to teach abstinence-only sexual health (Arsneault, 2001).

It is undeniable that some proponents of HR oppose moral or legal strictures in their fields. One prolific researcher described HR as “a public health alternative to the moral/criminal and disease models of drug use and addiction” (Marlatt, 1996, p. 785). A 1991 HR training manual stated in its introduction that young people “should be given as much information and develop as many skills as possible, with the minimum pollution by others’ morality” (Clements et al., 1991, p. 4). Another derided US drug policy as “largely driven by values and morals, instead of logic, economics, or principles of public health” (Bowen, 2012, p. 122). Some key HR experts are quite direct in their advocacy for legalization or decriminalization of drug use (Nadelmann, 1989; Woods, 1998) or sex work (Wotton, 2007).

A great number of HR researchers, however, take what they characterize as a “value-neutral” stance (Denis-Lalonde et al., 2019; Erickson, 1995; Fry et al., 2005; Klein, 2015). Such a stance attempts to evaluate HR interventions “primarily in terms of whether they are harmful or helpful to the drug user and to the larger society, and not on the basis of whether the behavior itself is considered morally right or wrong” (Marlatt, 1996, p. 785). This “commitment to non-judgmentalism and to value neutrality vis-

⁵³ Current literature suggests that such ‘risk compensation’ does not, in fact, occur to any significant extent in drug use or sexual behavior (Blumenthal & Haubrich, 2014).

à-vis drug use itself” (Klein, 2015, p. 451) is of course, still problematic to those who consider drug-using behavior to be intrinsically immoral.⁵⁴

Other HR researchers emphasize that while one may disagree with an individual’s choices with regard to drug use or sexual behavior, the fact remains that individuals do choose these behaviors despite laws and moral strictures against them. As O’Connor and Saunders (1992) explain, “there is little value in perpetuating a perspective that emphasizes *don’t* but persuades few not to, while simultaneously ignoring those that do” (O’Connor & Saunders, 1992, p. 178, emphasis in original). Accordingly, HR “involves a *prioritization* of goals, in which immediate and realizable goals take priority when dealing with users who cannot be realistically expected to cease their drug use in the near future, but it does not conflict with an *eventual* goal of abstention” (Single, 1995, p. 289, emphasis in original).

Interestingly, in recent years the moral objections of some conservatives appear to have given way to a more pragmatic approach, as evidenced by then-governor Mike Pence’ instigation of a needle-exchange program to deal with an HIV outbreak in Indiana (Rich & Adashi, 2015; Weinmeyer, 2016). Nevertheless, as will be discussed below, HR efforts may still need to engage with emotional, if not always moral, objections from those who take a purist approach to risk elimination.

Applying Harm Reduction to the Ebola Context

As mentioned above, applying HR to any specific intervention must involve dialog with the affected communities and/or individuals in the time and place of that intervention. Written international protocols already prescribe negotiation with family; in fact, a WHO/Red Cross/Red Crescent manual on managing the dead following a disaster explicitly states that “no burial process should take place until agreement is obtained” (Cordner et al., 2016, p. 56) from family and community members. Likewise, as observed in Chapter 2, another WHO document speaks of communities being involved in “shaping the intervention” (WHO, 2010, p. 6), and still another, that “ways of humanizing the ceremonies but still making them safe should be negotiated with family members, religious leaders and community members” (WHO, 2012, p. 36).

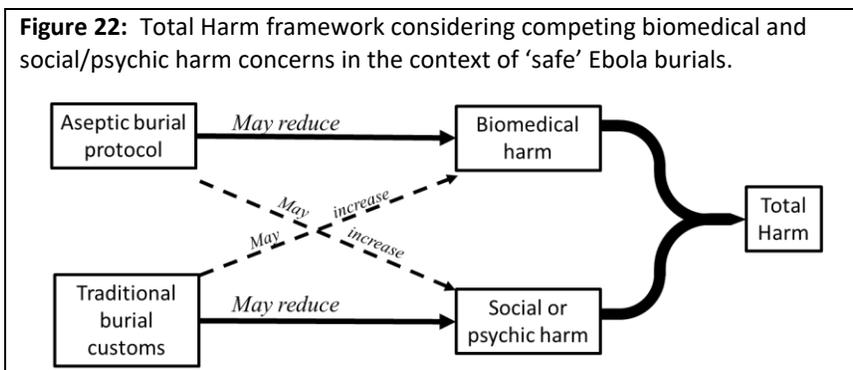
It is, of course, over seven years since the incident described in Chapter 1, and the time for negotiation with the affected families is long past. Accordingly, any retrospective examination of possible HR strategies in the West African Ebola epidemic is necessarily hypothetical. Nevertheless, based upon what is known of community objections to burial protocols, it is possible to imagine how HR might have been realized in this setting.

As described in Chapter 2 and in the Delphi data of Chapter 4, the burial protocols implemented in Sierra Leone and in other Ebola outbreaks presumed that eliminating (as opposed to mitigating) the danger of virus transmission during funerary practices was the one absolute non-negotiable. Accordingly, the approach of the response was to reject anything that might compromise “safety” defined strictly as infection control (Marais et al., 2016; Mokuwa & Richards, 2020). Entirely unasked was Manguvo & Mafuvadze’s question “should we completely abandon cultural burial practices and enforce scientifically prescribed methods that presumably reduce the spread of the disease (Manguvo & Mafuvadze, 2015)?”

⁵⁴ By contrast, Vearrier (2019) asserts that HR is not value-neutral, but rather “value-rich and based upon the moral values of mutual respect, compassion, and equality” (Vearrier, 2019, p. 122).

The answer to Manguvo and Mafuvadze’s (2015) question starts with recognition that, just as MacCoun (1998) observed regarding abstinence from drug use or sex, the fact that established burial protocols are likely the safest option from a biomedical perspective does not necessarily make them acceptable to the affected population. If people refuse to accept those protocols, the result is likely to be an increase in the harm (in this case, more Ebola infections and deaths) the protocols were meant to prevent. An HR approach requires that estimates of total harm take into account, not merely the biomedical harm that Western responders are trying to prevent, but also the countervailing social or psychic harm which a community may perceive to result from an intervention such as burial by unacceptable means (**Figure 22**). In such context,

negotiation with the family or community will seek to balance mitigation of biomedical and psychosocial harms – that is, reducing the harms which are of greatest concern to each party: both the response structure and the affected community.



If, in fact, such a negotiated strategy leads to greater community acceptance, it could result in a net reduction of biomedical harm, because fewer evasion incidents may take place.⁵⁵

Specific to the Ebola response in Port Loko, Sierra Leone, WHO medical anthropologist Lily Owusu-Darkwa (2015) reported local objections to the ‘Safe and Dignified Burial’ protocol (Government of Sierra Leone, 2015) to include at least the following factors:⁵⁶

- The appearance of burial team members in “space-like suits” (Owusu-Darkwa, 2015d, para. 5), a reference to the PPE worn by burial teams;
- The encapsulation of the body in a body bag (Owusu-Darkwa, 2015d, 2015b);
- The prohibition of the traditional washing of the body (Owusu-Darkwa, 2015c, 2015d); and
- The spraying of the body, body bag, households and household effects with chlorine, which was seen by the families as poisoning the living and disrespectful of the dead (Owusu-Darkwa, 2015d).

Since each of these factors flows from the risk of infection incumbent in the handling of the body of an Ebola-infected decedent (Brainard et al., 2016; Curran et al., 2016), it is appropriate to begin by considering the mechanism of that risk.

Even in the context of treating living patients, the potential for aerosol transmission of Ebola is controversial. Laboratory studies demonstrate that such transmission is physically possible, but these studies have used mechanically-aerosolized virus droplets (Johnson et al., 1995; Zumbrun et al., 2012) or

⁵⁵ The possibility of such negotiation has also been suggested by the American Anthropology Association (2014, p. 10).

⁵⁶ The fact that these reports exist, and yet that no meaningful changes in practice resulted from them, may be indicative of the disconnect between soliciting anthropological insight and implementing it.

intentional inoculation of the upper respiratory tract (Nfon et al., 2013). Epidemiologic evidence of aerosol transmission in humans is limited at best (Baron et al., 1983; Dowell et al., 1999; Heymann et al., 1980; Khan et al., 1999; Mekibib & Ariën, 2016), although it has been documented as a probable transmission route in nonhuman primates (Jaax et al., 1995; Rollin et al., 1999). Given the evidence, it is plausible to consider (and therefore, protect against) aerosols in the treatment environment; however, a dead body neither coughs nor vomits, and funerals are unlikely to produce aerosolization (Khan et al., 1999). “Direct contact due to burial rituals, which included washing and touching the cadaver” (Khan et al., 1999) has been repeatedly implicated in infection (Brainard et al., 2016; Curran et al., 2016).

Considering these realities of transmission, one might reasonably ask whether head-to-toe personal protective equipment (PPE) – the “space-like suits” referenced above – is actually necessary for those burying the body of an Ebola patient. Allowing burial teams to appear less “alien” (Owusu-Darkwa, 2015d, para. 5) might mitigate the impersonality communities expressed regarding burial teams. Indisputably, gloves (perhaps arm-length gloves) and gowns or aprons would likely remain necessary to prevent contact-mediated infection, but careful training and/or supervision of those handling the body may minimize the improbable production of droplets or aerosols.⁵⁷ While it is reasonable that official burial team members might desire to maximize their own protection, it is conceivable that family or community members with a vested interest in the psychosocial health of their community might gladly accept these less-extreme protective measures – even at a moderate increase of biomedical risk – if they permitted the family, rather than outside strangers, to care for the body of a loved one. A similar adaptation has previously been proposed by medical anthropologists working in Congo: “traditional burial ceremonies at home should be permitted with protective gear” (Hewlett et al., 2005, p. 236); several of the modifications suggested in this section also echo recommendations made by Epelboin et al. (2007, pp. 33–34).

This same rationale extends to the washing of the body. As already noted, Port Loko communities objected strenuously to the spraying of chlorine upon the bodies of their dead. However, in the very same report, Owusu-Darkwa (2015c) noted that the traditional *janaba* washing of the body is done by a person wearing “long white gloves” (Owusu-Darkwa, 2015c, para. 9). Perhaps if waterproof aprons and arm-length white medical gloves were provided to family members, and burial teams merely supervised rather than conducting the preparation and burial of the body, the risk of infection could have been greatly reduced while still permitting the family to practice valued ceremonies.⁵⁸

Similarly, while a watertight body bag is a reasonable – even necessary – precaution if the body is to be transported, especially by vehicle, it would be fair to question whether the body must be interred in the bag at all. Ebolavirus is considered to survive poorly in the environment outside the host (CDC, 2019b; WHO, 2021), and there is no evidence of Ebolavirus transmission through groundwater (WHO, 2021); therefore, it is unlikely that an interred body, even unencapsulated, presents any meaningful infectious risk as long as not disinterred. Especially if the family are permitted to bury their deceased loved one

⁵⁷ One should not automatically assume, however, that even gloves would be universally accepted; although in some cultures they are perceived to symbolize professionalism or modern care, in other cultural settings the use of gloves has been reported to introduce an unacceptable impersonality into close-family situations (Brown & Kelly, 2014, p. 291).

⁵⁸ Some of these concepts have been proposed in the context of an Ebola outbreak in Uganda: “We know that the disease kills. I think they should also distribute the items which they tell people to buy like gloves, gumboots and soap. With those items people can take care of their relatives who develop the symptoms and even visit them at the Ebola clinic (de Vries et al., 2016, p. 9).” A related strategy that was accepted in one location in Congo was the introduction of chlorinated water in hand-washing ceremonies at a traditional burial (Hewlett et al., 2005).

close to the home (this author has seen graves just behind, or within less than a hundred meters, of a rural home in Port Loko), dispensing with the body bag entirely may not lead to a meaningful increase in biomedical risk, while substantially reducing the psychic risk described above. Alternatively, the use of transparent, rather than opaque body bags has been suggested (Moran, 2017), and in fact this change was welcomed in another Ebola outbreak in the Democratic Republic of the Congo (Earle-Richardson et al., 2020, 2021).

Finally, the issue of chlorine disinfectant could be addressed in several ways. One possibility would be to explore different disinfectants that might have a less noxious odor in the minds of community members. While sodium hypochlorite (bleach) is both ubiquitous and inexpensive, the provision of a more tolerable disinfectant (perhaps simply soap) would be a trivial cost in view of the magnitude of expenditures incident to an international response. It would also be appropriate to explore whether washing, rather than spraying of surfaces/items to be disinfected would be more acceptable to communities.

Biomedical experts may well find fault with a number of the modifications suggested in this section. Undoubtedly each change would be at least somewhat riskier to affected families – from a strictly biomedical perspective – than would stringently following existing protocols. The reader is reminded that at least some families were *not* following those protocols, perhaps due to the psychosocial or spiritual risks previously discussed. A spirit of reflexivity suggests that biomedical objections may be grounded in part, if not exactly in religious/moral objection, at least in an emotional commitment to biomedical purity that could in some ways mirror conservative objections to HR in the drug use and sexual domains as described in the “Ethics of HR” section above. Only in mutually-respectful discussion between responders and communities, can the appropriate risk balance be struck.

Integrating Anthropology into Emergency Response Assessment and Monitoring

In Chapter 2, literature showed that the discipline of anthropology can (and did) provide insights into the work of public health and emergency response that could complement and strengthen certain interventions, and critique others. Nevertheless, bringing anthropologists to the table has not often been a priority. As Leach (2008) observed in earlier Ebola efforts, “the incorporation of anthropologists in response teams appears as a ‘blip’ in the institutional business-as-usual of dominance by epidemiologists and medical scientists ... rather than a frontrunner in a broader process of institutionalised interdisciplinarity in epidemic framing and response.” (Leach, 2008, p. 15). Or, as a former anthropologist and epidemiologist at the US CDC lamented recently:

“A few months into an outbreak, the CDC will typically say: ‘Why are people continuing to do these things that are spreading the disease? Maybe we could use some anthropologists.’ They use them, but it is always late in the game. It’s never a routine part of planning a response to public health problems” (Hahn, 2020, para. 5).

At least some public health professionals and institutions have recognized the need to incorporate anthropology into their work, though sometimes only after the fact. An interim assessment of the Ebola response by a team from WHO found that “the difficulty of effectively engaging communities was a problem that could have been foreseen had a social and political analysis been conducted to complement the epidemiological assessments” (WHO, 2015, p. 20). This critique is somewhat ironic given that WHO’s own documents recommended that an anthropologist be included as a member of any initial epidemiologic assessment team (WHO, 2014, p. 26), and that previous WHO standards had mandated a “situational market analysis” (WHO, 2012, pp. 28–30).⁵⁹ The IASC mandate to integrate Accountability to Affected Populations (AAP) principles into needs assessment (IASC, 2013a, 2017) also suggests that anthropologic/ethnographic expertise should be front-loaded on a response, and the WHO interim assessment previously referenced concluded that social/anthropologic assessment to “inform those who are at the front line ... must become part of standing protocols and standards for health emergencies” (WHO, 2015, p. 20).

Despite more than a decade of guidance such as that just described, epidemic preparedness and response agencies still lack key expertise in cultural and community assessment: “The core competencies needed to generate robust insights from time-pressured studies that accept uncertainty and ... generate rapid analysis and insights, have not been sufficiently developed” (Bardosh et al., 2020, p. 10). Such social science integration as has been done remains disproportionately concentrated in the realms of health communication and health promotion, and rarely informs epidemiologic efforts (Abramowitz et al., 2018; Bardosh et al., 2019). Addressing this shortfall, Bardosh et al. write, will require bringing social scientists into the structure of emergency preparedness and response, and leveraging their perspective to expand the focus of emergency response beyond “an exclusively biomedical gaze” (Bardosh et al., 2020, p. 3) to instead recognize the “complex, sociopolitical” (Bardosh et al., 2020, p. 3) nature of these emergencies. This section explores some possibilities for how anthropologic methods and expertise might fit into a response structure, no longer “siloes within the

⁵⁹ Once again, the fact that this ‘situational market analysis’ is recommended in the context of Communication for “Behavioural Impact (COMBI)” (WHO, 2012) may explain why non-communication-focused response elements failed to capitalize on social science skills and insights.

risk communication, health promotion and community engagement fields” (Bardosh et al., 2019, p. 16), but fully integrated into response strategy and implementation.

Rapid Assessment

A rapid initial assessment of the situation is integral to any emergency response. Current WHO guidance provides for several levels of assessment to take place over the course of an emergency response (Table 4). If not in the ‘Initial’ phase of the WHO paradigm, at least in the ‘Rapid’ phase, integrating an anthropologic component in the assessment could be vital to, among other outcomes, effectively “establish key priorities with affected populations” (WHO, 2020, p. 322).

Table 4: Types of Needs Assessment as defined by the WHO				
CRITERIA	INITIAL	RAPID	IN-DEPTH	MONITORING
Time frame	24–72 hours	3–14 days	2 weeks +	Ongoing
Assessment duration	3 to 5 days	1 to 4 weeks	1 to 6 months	Varies, but should be relatively swift if conducted regularly
Description	<p>Define scale and severity of the health crisis</p> <p>Identify and locate affected areas</p> <p>Establish key immediate priorities</p> <p>Define access constraints</p>	<p>Define impact of crisis</p> <p>Estimate populations in need</p> <p>Assess severity of needs of affected groups and areas</p> <p>Establish key priorities with affected populations</p> <p>Identify information gaps</p>	<p>Define and quantify needs, including more in-depth sectoral information</p> <p>Provide detailed and statistically representative data</p> <p>Capture representative views of affected populations through joint consultation</p> <p>Establish baseline for needs and response monitoring</p>	<p>Track potential risks and hazards</p> <p>Track existing capacities and resources</p>
Type of decisions to inform	<p>Initial response decisions</p> <p>Rapid assessment design</p> <p>Emergency funding appeals</p>	<p>Initial planning of humanitarian response</p> <p>Define focus for subsequent in-depth assessments</p> <p>Provide recommendations for strategic planning</p>	<p>Inform detailed planning</p> <p>Adjust ongoing response</p> <p>Provide recommendations for programme and operational planning</p>	<p>Identify when a situation becomes concerning or when significant changes are occurring</p> <p>Trigger an assessment (initial/ rapid)</p>
Design	<p>Secondary data analysis</p> <p>Small number of field visits, if feasible</p>	<p>Secondary and primary data analysis</p> <p>Primary data are gathered primarily at community level</p> <p>Qualitative research methods</p>	<p>Secondary and primary data analysis</p> <p>Primary data are gathered at community, institution, household or individual level</p> <p>Quantitative and qualitative research methods</p>	<p>Primary data continually reported</p>

Excerpt from Table 10.2 of WHO (2020, p. 322)

Properly engaging anthropologic insight in rapid assessment would not be without challenges. As the timeline in **Table 4** suggests, at least preliminary information about community concerns must be available to respond within the first two weeks – ideally the first week. While the necessity of such a compressed timeline is obvious to workers in biomedical and emergency response spheres, it may clash with the deliberative decision process intrinsic to many communities (Alexander et al., 2015), as well as with established methodologies in ethnography, which can involve developing relationships and observing behavior over years (Beebe, 2014; Bernard, 2018).

There is, however, historical support for rapid acquisition of limited data about culture in contexts where the need for actionable information precludes deeper, more time-intensive investigation. In 1979, a pair of symposia at the University of Sussex, Institute for Development Studies advanced the concept of Rapid Rural Appraisal (RRA) in response to the problem that, in rural development, “a great deal of the information that is generated is, in various combinations, irrelevant, late, wrong and/or unusable” (Chambers, 1981, p. 95). Contemporary with Chambers, Hildebrand (1981) described the ‘Sondeo’ method by which a team of agronomists and social scientists conducted a rapid assessment of agricultural interventions in Guatemala. Early pioneers of rapid anthropologic assessment, Scrimshaw & Hurtado (1984, 1987), developed field guides for rapid assessment in the realm of community nutrition and primary health care that remain touchstones in the discipline. Manderson & Aaby (1992) brought rapid assessment procedures to bear in the field of epidemic response, although Carruthers and Chambers (1981, see p. 409) had previously mentioned the possible use of RRA in the emergency context. More recently, Beebe (2014) prepared an entire handbook to guide both lay and academic practice of ‘Rapid Qualitative Assessment.’

Opinions vary on the timeframe in which actionable data can be collected; different authors have suggested timelines of as little as three or four days (Manderson & Aaby, 1992), 4 or 5 days to six weeks (Beebe, 2014, p. 3), 6-10 days (Hildebrand, 1981), 10 days (Allen & Lacson, 2015),⁶⁰ “a few days to a few months” (McNall & Foster-Fishman, 2007, p. 158), 3 weeks (Stimson et al., 1998), 4-8 weeks (S. Scrimshaw & Hurtado, 1987), 8 weeks (Pellecchia et al., 2015), 1-2 months (Mital et al., 2016), and 12-16 weeks (Boyce et al., 2004). Even for non-emergency applied research, it is possible to conduct culturally-focused needs assessment in only a few weeks (Bernard, 2018, p. 280). Of these sources, only Manderson & Aaby, Allen & Lacson, and Pellecchia et al. were speaking in the context of an emergency response.

Necessarily, a rapid assessment process cannot capture a complete, in-depth picture of a culture and/or community. To this end, “rapid ethnographic procedures ... isolate specific behavioural and/or cultural variables of relevance” (Manderson & Aaby, 1992, p. 843) and focus on those. What Chambers (1981) observed in rural development is doubly true in emergency response, that information which is not collected quickly may no longer be actionable when it is finally received and consequently “decisions are preempted by the passage of time” (Chambers, 1981, p. 96). Here, the concept of “optimal ignorance” (Ilchman, 1972, p. 221), which Chambers summarized as “the importance of knowing what it is not worth knowing” (Chambers, 1981, p. 99) may serve as a guiding principle to focus information-gathering efforts on select, actionable topics (see also Carruthers & Chambers, 1981, p. 411). In the public health emergency context, the rapid assessment is focused on “gathering information about health-related

⁶⁰ Allen & Lacson report 10 days for the data gathering phase; the two of them spent 3 weeks prior doing “formative work” (Allen & Lacson, 2015, p. 1).

problems and their prevention” (Harris et al., 1997, p. 377). Rapid ethnographic procedures are designed to “isolate specific behavioural and/or cultural variables of relevance” (Manderson & Aaby, 1992, p. 843) to the transmission of disease or the control measures proposed or implemented by the response (Sams et al., 2017).

The ‘optimal ignorance’ suggested by Ilchman (1972) and Chambers (1981) invites the concern that rapidly gathered data may be insufficiently rigorous to be of value – at worst, lending “a false or spurious air of efficiency or precision” (Carruthers & Chambers, 1981, p. 409) to the results. It is undeniable that the very rapidity of rapid assessment limits the extent to which observations can be considered representative (in fact, they are not).⁶¹ The time constraints of an emergency may lead to “opportunistic” (Manderson & Aaby, 1992, p. 846) sampling which may bias the resultant information. A variety of precautions can improve the validity of rapid-assessment data, including ensuring that at least some assessment personnel have prior familiarity with an area or culture, and ideally involving “local insiders as team members” (Beebe, 2014, p. 124). Enhancing diversity of multimembered teams and triangulation of results from multiple methods of inquiry (Allen & Lacson, 2015; Dupont et al., 2015; Harris et al., 1997; Manderson & Aaby, 1992; McNall & Foster-Fishman, 2007) also improve the likelihood of valid results.⁶²

It may be appropriate for community leaders and other key informants (see next section) who provide information to the rapid assessment, to form a community advisory board or committee (Abara et al., 2014; Boyce et al., 2004; Chambers et al., 2016; Corbin et al., 2021; Schoch-Spana et al., 2007; Stimson et al., 1998), to formalize the feedback loop described in the previous paragraph. Such a board’s impact may be even more important in recovery efforts beyond the end of the emergency (Abara et al., 2014; Corbin et al., 2021; Svendsen et al., 2010), but it also can provide a focal structure to enable both input from a community and the conveyance of decisions or recommendations back to the community (Stimson et al., 1998, see pp. 39-41).

Particularly in the context of engaging communities to provide ongoing feedback, assessment teams “must be careful not to make unrealistic promises to the community about the purposes or results of the [assessment]” (S. Scrimshaw & Hurtado, 1987, p. 3, see also p. 12). Failure to set realistic expectations can lead to a sense of “bogus empowerment” (Beebe, 2014, pp. 170–172; Ciulla, 2014) within the community, which in turn could compromise the entire engagement effort and turn what began as an attempt to gain trust into a principal cause of community mistrust and suspicion.

Choosing the Right Team and the Right Sources

As suggested above, the process of conducting a valid and actionable rapid assessment must start with the right team. Ideally, such a team should be led by a senior anthropologist (S. Scrimshaw, 2018; S. Scrimshaw & Hurtado, 1984), but others trained in qualitative data collection methods may also be effective (S. Scrimshaw & Hurtado, 1987). An early proponent of rapid assessment in the agricultural domain, Hildebrand (1981) proposed a multidisciplinary team (in his case, social scientists and

⁶¹ The US Centers for Disease Control & Prevention (CDC) toolkit “Community Assessment for Public Health Emergency Response (CASPER)” (Schnall et al., 2020) provides a method for representative assessment of community needs in an emergency, but it explicitly discourages open-ended questions of the sort that would be necessary to elicit community concerns as discussed in this work, and opts instead for closed-ended questionnaires that are amenable to rapid analysis and statistical validity.

⁶² “Paradoxically, short-cut procedures are more and not less demanding of expertise, and optimal ignorance can only be achieved if investigators are both well informed and sensitive to what they may not know” (Carruthers & Chambers, 1981, p. 411).

agronomists) in which members “must be willing to consider a wide range of variables and constraints and ... be capable and willing” (Hildebrand, 1981, p. 424) to engage in a cross-discipline critique of findings that improves the final product. In their Rapid Assessment Procedure (RAP) manual, Manderson & Aaby (1992) argued that having people already well-versed in local culture and in the situation being assessed could be more important than having degreed professionals; consequently their guidelines “do not presume professional skill” (Manderson & Aaby, 1992, p. 843) and are designed to be “used either by a social scientist without disease specific or public health background, or by a biomedical researcher lacking social science experience” (Manderson & Aaby, 1992, p. 845). At the very least, “every [rapid assessment] team [should] have at least one member with expertise in the assumptions and techniques of qualitative research” (Beebe, 2014, p. 2).⁶³

Following Hildebrand’s (1981) methodology, it could be useful to structure the assessment teams such that fieldwork is conducted by multiple pairs of an epidemiologist and an anthropologist or other social scientist. The pairs would rotate such that over the course of several days, each epidemiologist would work with each anthropologist in turn in order “to maximise interdisciplinary interaction and minimise interviewer bias” (Hildebrand, 1981, p. 427).

The assessment team(s) should seek out a variety of key informants⁶⁴ to provide insight into community concerns. Due both to time constraints and a desire to capture appropriately-diverse insights, purposive selection of informants is not only appropriate but likely necessary (Bernard, 2018; Manderson & Aaby, 1992; S. Scrimshaw & Hurtado, 1984). As potential informants (or team members/leaders), anthropologists already in the field may be highly useful (Chambers, 1981), not only for their knowledge, but for the fact that they may understand the culture and beliefs of expatriate responders as well as those of the local population. Likewise, if there are any active CBPR activities in the region, advisory boards that already work with these activities could be a valuable resource (Wallerstein & Duran, 2006). Additional informants might include schoolteachers and local officials (Chambers, 1981), persons employed locally by the response or health system (Allen & Lacson, 2015; Pellecchia et al., 2015), traditional (i.e., non-Western) health practitioners (Anoko, 2014a), religious or spiritual leaders (Jalloh, Bunnell, et al., 2017; Pellecchia et al., 2015; Stimson et al., 1998), market sellers (Pellecchia et al., 2015), and others who may uniquely represent a local constituency.

The selection of informants should not presume that people in positions of leadership are necessarily the best or only sources. In some situations there are “bridging individuals” (Valente, 2012, p. 50) who may be more effective as influencers than those with nominal authority. One anthropological intervention in Guinea considered “... traditional practitioners, heads of the sacred forests, religious leaders (Christians and Muslims), circumcisers, village birth attendants, hunters, youth in general through the consultative Framework youth nationals [sic], returned migrants from the city or in other countries, and the elders” (Anoko, 2014a, p. 7) as groups that required engagement. As Anoko further

⁶³ With appropriate planning, a corps of response-ready anthropologists could be deployable on short notice. A recent publication proposed that international response agencies “better define core competencies and if possible institutionalize a field training program (such as the WHO-led SocialNet initiative, and based on existing field epidemiology training programs, FETPs) including certification, simulation exercises, field learning, and training on basics of outbreak response” (Bardosh et al., 2020, p. 10). Existing efforts such as the Social Science in Humanitarian Action platform (SSHAP, n.d.) and prior ones like the Ebola Response Anthropology Platform (Bolten & Shepler, 2017) may provide additional paradigms for involving anthropologic expertise.

⁶⁴ The concept of key informants, and specifically ‘key informant interviews,’ is ubiquitous in anthropology and rapid assessment literature (e.g., Bernard, 2018; Chambers, 1981; Manderson & Aaby, 1992; S. Scrimshaw & Hurtado, 1987, and many others). The term is uncited in these works, and this author has been unable to identify a source for its origin.

observed, “those who are often ignored hold key information for understanding the context and find[ing] solutions to critical problems” (Anoko, 2014a, p. 8).

Of course, conducting even cursory interviews with every type of individual mentioned in the previous two paragraphs would inevitably remove the ‘rapid’ from rapid assessment. The assessment team will need to make cost-benefit decisions as to which informants can be engaged immediately, and which may be sought out during later iterations. Anoko (2014a) demonstrated that even seasoned anthropologists can be surprised by who turns out to have import insights and influence within a community; as previously described in Chapter 2, a list of informants recognized over time may bear little to no resemblance to that initially compiled (Wilkinson et al., 2017). Opponents of the response intervention (Anoko, 2014a), or simply people who are known/believed within a community to be contrarian (Honadle, 1982, p. 643) may turn out in the long run to be vital sources for understanding and addressing community concerns.

Finally, the assessment team should seek information, not only from its own interactions with key informants, but also from sources already extant. These could include existing ethnographies or other formal or informal documents created by social scientists who have previously conducted research in the relevant region(s), such as the Fairhead (2014) document repeatedly cited in this work. Additional important sources of information may include government or academic archives and records, and relevant reports or academic literature (Chambers, 1981). Information from these sources should be triangulated (Jick, 1979) with that gathered *di novo* to maximize confidence in the validity of conclusions drawn (Allen & Lacson, 2015; Dupont et al., 2015; Manderson & Aaby, 1992; McNall & Foster-Fishman, 2007; S. Scrimshaw & Hurtado, 1987).

Asking the Right Questions

Several authors have suggested key categories of information that are necessary in the early stages of a rapid health assessment. In child mortality surveillance, Blevins et al. (2019) sought information on influential individuals or groups in a community, community attitudes and activities around maternal or child disease or death, and the extent to which intervention activities “align with or stand in tension with the community’s own priorities, norms, and perceptions” (Blevins, O’Mara Sage, et al., 2019, p. S282). The World Health Organization’s Ebola and Marburg preparedness handbook (WHO, 2014, see Annex 12, pp. 76-77), and Scrimshaw and Hurtado’s rapid assessment procedure guide (S. Scrimshaw & Hurtado, 1987, Appendix 1, pp. 35-65) provide a variety of detailed questions and, in the case of Scrimshaw and Hurtado, data collection guides, which can help the assessment team flesh out its own data collection strategy.

Scrimshaw and Hurtado also offer important cautionary notes: first, that any list of questions must be seen as a menu from which to select only that which matters in a given context; and second, that all questions must be adapted to the local situation and populace rather than simply used as printed in their (or this) document (see S. Scrimshaw & Hurtado, 1987, p. 3).

In the context of an epidemic response, it is proposed that a rapid anthropologic assessment address three major topics (Table 5): key informants/influencers, health authorities/health-seeking behaviors,

and cultural practices or norms that may impact the response.⁶⁵ Each will be addressed in the following paragraphs.

Table 5 - Rapid Anthropologic Assessment Topics for the Emergency Response Context	
Key informants/Influencers	
<ul style="list-style-type: none"> • What communities/groups exist? What groups of people are either likely to see themselves as a unit, or in competition with other groups? (see Wilkinson et al., 2017 for important nuance regarding “communities”) • Who are the formal authorities that influence behaviors related to the emergency or its mitigation? <ul style="list-style-type: none"> ○ Government ○ Religious ○ Other secular ○ Other traditional • Who are the important influencers who may impact emergency-related behavior without formal authority as above? <ul style="list-style-type: none"> ○ Familial ○ Elders, leaders of cultural subgroups ○ Celebrities • Who of the above leaders are perceived to be in concord or conflict? • Who (groups, individuals) in the community may not be either an authority or an influencer, but can accurately interpret the community or culture? • What is the political reality of outside groups engaging or appearing to ally with one or more of the above? Might perceived alliance with one lead to animosity from others? • Who of the above, with whom the response <i>may</i> engage (i.e. politically tenable), is willing to <i>be</i> engaged? 	
Health authorities & health-seeking behavior	
<ul style="list-style-type: none"> • To whom do people turn for information (authority) about existence or cause of disease? • How do people frame/understand the experience of this disease? • From whom, and on what conditions, do people seek care for various disease states? 	
Cultural practices/norms that may impact emergency	
<ul style="list-style-type: none"> • Social, cultural and/or religious practice (acts or abstentions, collective or individual) <ul style="list-style-type: none"> ○ Regular practice (e.g. religious service, secular assembly, etc.) ○ Episodic (e.g. holidays, festivals, whether religious or secular) • How might the normal conduct of this practice exacerbate or mitigate aspects of the emergency? (don’t assume all cultural practices are barriers/negative) • What is the cultural (social, emotional, spiritual) meaning of the practice, and meaning (consequences?) of failing to perform it? • Who are influencers that lead, guide, or regulate this practice? 	

Key informants/Influencers: As discussed in the previous section, an assessment is only as good as its information sources. Care should be taken to ensure that not only formal, but also informal authorities or influencers are considered, as the latter can at times wield more actual influence in a community than those with nominal authority. If properly approached and engaged, individuals identified may become important messengers back to the community as well as being sources of information to the response.

⁶⁵ Each of these topics would be an appropriate subject for years of ethnography. No rapid assessment, however competent, can possibly do them justice. Nevertheless, even limited data can provide crucial insights for emergency management. To the extent intelligence can be gleaned from existing or prior ethnographic projects in the subject area, so much the better.

The first issue is identifying what community or communities exist in the target area. The guidance from Wilkinson et al. (2017), previously cited in Chapter 2, should be considered in this context, recognizing that there may be functional communities that are not defined by geography; and conversely, that not all geographically adjacent individuals necessarily form a functional community.

As communities or groups are identified, the next issue is to determine who exercises influence over them. This may include national, regional or local governments, traditional extragovernmental leadership structures (i.e., ethnic groups, village elders), and other religious or secular leaders. As important as formal leadership, however, may be the identification of people who lack nominal authority but still wield significant influence, including patriarchs/matriarchs or popular celebrities. In Sierra Leone, for example, the leaders of 'secret' traditional societies (Anoko, 2014a; Jambai & MacCormack, 1996; Margai, 1948) are key influencers of practices related to health. Market and transport vendors, among others, were also found to be important influencers despite lacking any formal power (Anoko, 2014a; Pellicchia et al., 2015).

Perhaps as important as identifying influencers and information sources, can be attempting to understand the political dynamics of outsiders associating with one or another individual or group. Obviously some of this information may only emerge over time, but the team must be cognizant of not appearing to create alliances, the existence of which can result in exclusion of (or by) other important groups (Goguen & Bolten, 2017). Likewise, to the extent possible, the team (and indeed the entire response) must exercise caution that its activities not be adversely associated with governmental, military (Abramowitz et al., 2017; Goguen & Bolten, 2017; Laverack & Manoncourt, 2016), or external authorities resented by the community (Owusu-Darkwa, 2015e, para. 11).

Among the menu of possible informants, to some extent selection will be driven at least in part by their willingness to engage in dialogue. Thus, particularly for the early rapid-assessment phase, it is perhaps inevitable that information sources will represent somewhat of a convenience sample, though ideally in the longer term this potential bias can be addressed through in-depth investigation into whom community members actually trust (Anoko, 2014a).

Health authorities & health-seeking behavior: Although there may be overlap with those identified in the previous section, people may turn to distinct influencers or authorities for guidance related to health and health care (Anoko, 2014a; Jalloh, Bunnell, et al., 2017; S. Scrimshaw & Hurtado, 1984). Examples of this sort of authorities may include traditional healers, midwives/birth attendants, elders (especially elder women), and religious authorities (both indigenous and global faiths), as well as professionals working in local health facilities.

In addition to identifying these health influencers, the assessment should inquire into how people frame the concepts of health and illness, including "the moral experience of illness, disease and medical practice in places that have little power to make their knowledge heard in decision-making centres" (Feierman et al., 2010, p. 122). Understanding what constitutes 'illness' in a community may shed important light on how an outbreak disease is understood. Although a comprehensive understanding of this topic would obviously require long-term ethnography, even a limited overview may contribute important insights, especially given that traditional views can sometimes include concepts favorable to outbreak control (e.g., Hewlett & Amola, 2003, pp. 1243–1245).

Finally, the assessment should attempt to understand health-seeking behaviors: that is, “what people do in order to maintain health and/or return to health, ranging from individual behaviour to collective behaviour” (S. Scrimshaw & Hurtado, 1984, p. 2). As people often seek care for different disease states from diverse sources, a vital part of this inquiry is understanding the “hierarchy of resort” (S. Scrimshaw & Hurtado, 1984, p. 2) by which people decide from whom, and under what circumstances, to seek either advice or care. Particularly in this latter category, constructing a rudimentary health-care decision tree (Bernard, 2018, ch. 17; Gladwin, 1989) may help to understand where disease-control interventions may fit in (or clash with) the local context.

Cultural practices/norms that may impact the emergency: Absent prior cultural knowledge, it is impossible to know what cultural norms or practices may affect the emergency itself, or the implementation of mitigation activities. Importantly, such norms or practices are not necessarily obstacles; they may also “favour implementation of risk reduction practices” (WHO, 2014, p. 77). The previously-described Ugandan Acholi concept of ‘*gemo*’ and its implications for quarantine and limited personal contact (Hewlett & Amola, 2003) is a good illustration of a cultural perspective that supports epidemic control. On the other hand, traditions that involve laying hands on the ill or dying may be hazardous in the context of a disease spread by touch (Epelboin et al., 2014; Manguvo & Mafuvadze, 2015).

As customs, norms, or beliefs are identified that may complicate or impede disease control and emergency response, the assessment team should seek to establish dialogue with those who can interpret what sorts of consequences come with violation of the norm, and/or what modifications to the norm are culturally permissible. As Anoko (2014b) documented in Guinea, there may be acceptable ceremonies or alternate practices, either to conduct in lieu of high-risk traditions, or to effect ‘reparations’ for failure to follow the normal practice. Identifying and implementing these alternatives requires a spirit of openness and respect, and response teams should maintain a harm reduction posture in considering such modifications.

Rapid Assessment Methods

The specific methods used for assessment will necessarily vary with the situation, and with the experience and competencies of the assessment team. However, there is a fair amount of consensus among anthropologists who wrote about rapid assessment in one-week or shorter timelines, that structured or semi-structured interviews and direct observation (which may include participant informants) are the most practical (see for example: N. Scrimshaw & Gleason, 1992; S. Scrimshaw & Hurtado, 1987; Stimson et al., 1998). Interviews and observations should be constructed to maximize information related to the questions posed in the previous section (**Table 5**).

One author also mentions participatory mapping (Bernard, 2018) and others add focus groups (Bernard, 2018; Manderson & Aaby, 1992; McNall & Foster-Fishman, 2007). However, having observed and participated in several focus groups, this author suspects that the process of training or recruiting facilitators, recruiting participants, conducting and analyzing such groups would likely take longer than initial time constraints permit. These latter methods are therefore probably better reserved for subsequent engagement in the ‘In-Depth’ and ‘Monitoring’ phases (**Table 4**).

Iterative Monitoring

A rapid initial assessment is exactly that – initial. Part of the path to validity is ensuring that the first assessment is not the only assessment done. Responders must be careful not to fall into the trap of a “static view of local social contexts ... rather than recognizing that knowledge of rapidly changing social practices requires continual re-engagement” (Martineau et al., 2017, p. 485). An iterative approach (Beebe, 2014) to understanding community needs and concerns suggests the need for a “measurement loop ... to assess whether the health interventions undertaken are actually successful in achieving their goal – reduction of the burden of illness or unmet health needs” (Tugwell et al., 1984, p. 1097). Tugwell et al. further noted that integral to such iterative measurement would be an assessment of the ratio of benefits to harms resulting from intervention.^{66,67} During these later iterations, the methodologies of social listening (Sommariva et al., 2021) and rumor surveillance (Islam et al., 2021; Tibbels et al., 2021) may contribute helpful insights, particularly in detecting harms as perceived by community members.

The principle that first data are incomplete data and must be supplemented by ongoing monitoring was poignantly expressed by Julienne Anoko early in the Ebola epidemic, when she observed that her findings from a community in Guinea “would be ephemeral if it is not constantly renewed alongside the spread of the virus in each new village, family, community concerned” (Anoko, 2014a, p. 18). As previously noted, anthropologists writing about the 2014-2016 Ebola response explicitly warned against assuming that the work they published was conclusive and cautioned that further attention must be paid to cultural developments as they occur (Anoko, 2014a; Richards et al., 2015).

This author has previously written on the concept of ‘continuous feedback’ in the context of developing public health reporting software (Martin et al., 2020). Borrowed from the software industry, the principle of continuous feedback is also recognized in emergency preparedness (e.g., Turoff et al., 2004; UNICEF, 2020), among other fields, which in turn were derived in part from the broader business concept of Continuous Quality Improvement, credited largely to Walter A. Shewart in the early 20th century and Edward W. Deming in the 1950s (Saier, 2017).

The notion of ongoing feedback is recognized in WHO’s needs assessment methodology (WHO, 2020), which breaks needs assessment into the four stages of Initial, Rapid, In-Depth, and Monitoring (see **Table 4**). Implementation might take the form of a broader “outbreak analytics” (Polonsky et al., 2019, p. 2) structure, which would meld the real-time analysis of disease burden with analysis of the burden of interventions.

It is this author’s hope that bringing anthropologists and social scientists into partnership with emergency responders may lead to the sort of iterative feedback that can detect and respond to community concerns before they become crises.

⁶⁶ Note once again the discussion of Total Harm in the previous “Harm Reduction” section.

⁶⁷ Early anthropologic assessments of the Ebola situation in Sierra Leone specifically warned that there remained outstanding community concerns regarding burial (Nielsen et al., 2015) and that success in one location “would be ephemeral if it is not constantly renewed alongside the spread of the virus in each new village” (Anoko, 2014a, p. 18). The literature does not suggest that the advice to iterate was followed to any material degree in the 2014-2016 epidemic. By contrast, the rapid-feedback system reported by Earle-Richardson et al. (2021) for the 2018-20 DRC Ebola outbreak demonstrated tangible benefits.

Chapter 6 – Conclusions and Recommendations

In Chapter 1, a case history from the Sierra Leone Ebola epidemic of 2014-2016 presented an example of real-world, possibly fatal consequences of failing to recognize and address a collision between biomedical disease-control efforts and the lived realities of a culture who was experiencing that epidemic. Both emergency responders and a bereaved community lamented that the other would not listen to their concerns, revealing a gulf of misunderstanding as to what each considered to be unacceptable risk.

It has been shown, first from the literature, then in emergency response reports and agency guidelines, and finally through a Delphi survey of individuals associated with the Ebola response, that emergency responders are at least conceptually committed to the idea of community engagement in a crisis such as a major epidemic. However, just what is meant by ‘engaging’ a community is not universally understood. As extant literature lacked a methodology, first to define community engagement, and then to quantify its implementation, a four-domain Community Engagement Taxonomy with a three-level Empowerment Score metric was developed and its application demonstrated in a retrospective assessment of response interventions. It is proposed that this taxonomy and scoring methodology may be a useful tool for planning and evaluating other community engagement efforts in the future.

One important innovation of the Community Engagement Taxonomy and Empowerment Score methodology is that it compels a candid examination of claims of ‘empowerment’ by program and government officials. It is this author’s contention that the word ‘empowerment’ ought not to be used unless those who are putatively empowered, actually can affect the standards and conduct of interventions conducted in their communities. By this standard, very little of the community engagement done in the Ebola response legitimately empowered individuals or communities in the control of the epidemic.

The majority of Delphi panelists in this study settled on an Empowerment Score of 2 for each of the domains of Information Provision, Consultation, Participation, and Community Empowerment in the context of responses to future epidemics such as Ebola. However, as previously observed, the aggregated responses may mask important nuances revealed by individual panelists’ answers (**Table 3**). Panelists 2 and 4 expressed the most reservation in their comments about the practicality or desirability of full Community Empowerment, and they proposed future response efforts for this domain at level 1. However, Panelists 1 and 6 (who each proposed a score of 2 for Community Empowerment in future responses) also described situations where they believed power should be reserved to response authorities. Discerning whether these discrepancies between qualitative and quantitative answers are indicative of ambivalence on the part of the panelists, or to inter-panelist disagreement on the Empowerment Scores’ meaning, was beyond the scope of this study. Future inquiries or strategies that use the Empowerment Score methodology may better be able to clarify such discrepancies.

It bears repeating, as several panelists suggested, that level 2 empowerment of a community may be impossible in the context of an outbreak of international concern such as Ebola. If a community were able to contain an outbreak themselves, it would not spill out to neighboring regions or nations and would not become an international concern requiring intensive response. As Alain Epelboin et al. (2007) observed, “response to Ebola and Marburg VHF epidemics must involve coercion. It must be based on the application of coercive hygiene measures designed to break the chains of transmission” (Epelboin et

al., 2007, p. 29).⁶⁸ To the extent that such coercion does exist, regardless of whether or not it is justifiable or desirable, the appropriately-descriptive Empowerment Score would be 0 or 1.

It is in Consultation where the community engagement failings highlighted in this work may most effectively be addressed. Consultation necessarily requires early assessment and ongoing dialogue with communities, not only about the biomedical realities that have brought a response to bear, but also about the cultural, psychosocial, and spiritual realities that drive community behavior. Had legitimate consultation with communities been integral to the 2014-2016 Ebola response, it is possible that community members might not have had to resort to covert ‘resistance’ to express the unacceptability of the mandated biomedical burial protocol. At the very least, if responders had been prepared to recognize ‘resistance’ as a signal to be investigated rather than a behavior to be corrected or even suppressed, a process of consultation might have been initiated and alternatives negotiated.

Such negotiation – and indeed, public health interventions more universally – must be grounded in the philosophy of Harm Reduction. It is this philosophy that could enable the biomedical responder to assess Total Harm as it is seen by those whose harm they hope to mitigate. We in public health must come to realize that Total Harm, even if defined in strictly biomedical terms such as cases or deaths, is affected by human behavior. That human behavior is driven by far more than ‘scientific’ constructions of reality should be obvious, but it is often forgotten or dismissed by those of us who style ourselves as strictly ‘following the science.’ If an individual’s or a community’s beliefs, perceptions, or fears drive their behavior in a manner that affects health, these are for that reason alone factors with which the responsible scientist must engage. People die in epidemics; more ought not to die because of our scientific myopia and hubris.

Effectively engaging communities in true Consultation will require epidemiologists and disaster responders to partner with social scientists who can supplement biological and statistical data with qualitative data on community beliefs, practices, and perceptions. During and since the West African Ebola epidemic, anthropologists and other social scientists have demonstrated not only their ability to analyze our work and critique important shortcomings, but also to join us in seeking ways to overcome those shortcomings. The discipline of emergency response must recognize that welcoming social science fully to our teams will strengthen our own insights into the emergence and spread of epidemic diseases.

And perhaps most obviously, effectively engaging communities can only happen if community members are invited to the table as respected authorities on their own lives, and truly empowered to participate in defining those activities implemented to save their lives.⁶⁹

Recommendations

Community engagement of the sort advocated in this work can likely only be achieved by decoupling the concept of engagement from its present subordination to the disciplines of health communication and Social Mobilization. Not, it must be said, because communication and mobilization are not a part of the

⁶⁸ Epelboin added to the end of this sentence, “but only after a multi-disciplinary critical analysis of the proposed measures” (Epelboin et al., 2007, p. 29). The author submits that this ‘multi-disciplinary critical analysis’ must involve consultation with affected communities, not merely many kinds of experts.

⁶⁹ N.B., the phrase is “to participate in defining,” not “to define.” While the community has an inarguable stake in the outcome of interventions, it is not the only stake, nor the necessarily-superordinate one. Stopping an epidemic of international concern inevitably requires the balancing of priorities that legitimately may be in conflict. Empowerment need not – and likely cannot – be absolute.

community engagement process – they most emphatically are. Rather, as much of the literature in Chapter 2 revealed, the linking of community engagement with communications, including the current ‘Risk Communication and Community Engagement (RCCE) framework, tends to result in privileging Information Provision over the indispensable domains of Consultation, Participation, and Community Empowerment.

In its place, a response pillar is proposed that encompasses Assessment, Monitoring, and Community Engagement (AMCE). Such a structure would ideally have social scientists and epidemiologists working in tandem, in order to simultaneously interrogate both the epidemiologic and social/behavioral/cultural drivers of disease transmission and control. Not only among field teams, but also in leadership, the AMCE pillar of a response would need to incorporate at least one senior-level anthropologist and at least one senior epidemiologist in order to ensure that both fields of expertise drive actions and policy. The health communications and social mobilization activities that currently fall under an RCCE pillar would be incorporated into a Community Engagement subdivision of the new AMCE pillar, and would be an integral part, not merely of communicating health information, but of gathering qualitative data on the successes and failures of responders and response activities. Integral to the AMCE function must be the presumption that ‘resistance’ will be met with investigation and negotiation before (and ideally, instead of) coercion. Even education in response to resistance must be preceded by the educators learning from the community they hope to educate or persuade.

Leadership of the AMCE pillar – both the social and epidemiologic expert leaders – would then become key members of the senior command staff of the response. These leaders would not merely be tasked with communicating information and winning the hearts and minds of local communities; they would be key – ideally, along with a Community Advisory Board – to translating community objections or resistance back to the strategic planning and operations of the response. Most importantly, AMCE would be a fundamental, indispensable driver of modification and adaptation of response efforts and mandates to the local context.

For an AMCE structure to function effectively, the incorporation of social science expertise must become part of the planning and preparedness efforts that precede any response. This means, in part, developing a cadre of social science experts among response teams. At least one way to accomplish this may be to institutionalize “social science capacities ... in existing epidemiology networks, notably TEPHINET and other key national Field Epidemiology Training Programs (FETPs)” (Bardosh et al., 2020, p. 14). Importantly, hand in hand with the development of this capacity would be the incorporation of social science disciplines and Harm Reduction philosophy as integral elements of response doctrine.

Beyond all the structures and standards, however, it is this author’s intent to call on the emergency response community, of which he is a committed member, to a level of humility that we have rarely exhibited on the world stage. Our biomedical-materialist understanding of epidemics and other disasters is not wrong or false, but it is incomplete. Human existence in all of its messy complexity is more than our reductionist data, and human behavior is driven by so much more than the objective, scientific knowledge we hold so dear. The Total Harm model of safe burial described in **Figure 22** is really a tiny window into the reality that the total human consists of all of the physical, social, cultural, and spiritual realities that each human embraces. When our praxis finally engages with that total human, individually and in community, we may be surprised (though we shouldn’t be) to discover that we save more lives, even as defined in the biomedical sense.

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Appendix A – Delphi Survey Questionnaires

Round 1 Questionnaire

In the following questions, you will be asked to think back to your experiences and observations during the 2014-2016 Ebola epidemic in Sierra Leone, specifically around how communities were, or were not, engaged by response and health authorities. There is no right or wrong answer to any of the following questions; please answer each question based on your own opinions and memories of the epidemic and the response effort. In the comments that follow each response, please elaborate on your thoughts with as much detail as you deem appropriate.

Please read [this guide](#) (*text follows this questionnaire*) before you answer questions 1a-1d, and refer the table on Page 2 of the guide for explanations of the zero-to-two scoring of each question. You may wish to print the guide for easy reference.

1a - Information Provision

Is Information Provision necessary component of community engagement in an emergency response? <input type="checkbox"/> Yes <input type="checkbox"/> No					
If “Yes,” please rate the level of engagement for Information Provision for each line below. Your answer should reflect your observations/knowledge for whatever region or response area in which you have experience. If you feel you do not have sufficient information to answer for one period of the response, please mark “N/A” for that period and answer where you can do so.		0	1	2	N/A
	This accurately describes what happened early in the response, before Dec. 31, 2014	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	This accurately describes what happened later in the response, after Jan. 1, 2015	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Regardless of what happened in the 2014-2016 Ebola response, this would be the appropriate posture for future emergency responses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any “N/A” answers as well as any other comments you wish to offer):					

1b - Consultation

Is Consultation necessary component of community engagement in an emergency response? <input type="checkbox"/> Yes <input type="checkbox"/> No					
If “Yes,” please rate the level of engagement for Consultation for each line below. Your answer should reflect your observations/knowledge for whatever region or response area in which you have experience. If you feel you do not have sufficient information to answer for one period of the response, please mark “N/A” for that period and answer where you can do so.		0	1	2	N/A
	This accurately describes what happened early in the response, before Dec. 31, 2014	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	This accurately describes what happened later in the response, after Jan. 1, 2015	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Regardless of what happened in the 2014-2016 Ebola response, this would be the appropriate posture for future emergency responses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any “N/A” answers as well as any other comments you wish to offer):					

1c - Participation

Is Participation a necessary component of community engagement in an emergency response? <input type="checkbox"/> Yes <input type="checkbox"/> No				
If "Yes," please rate the level of engagement for Participation for each line below. Your answer should reflect your observations/knowledge for whatever region or response area in which you have experience. If you feel you do not have sufficient information to answer for one period of the response, please mark "N/A" for that period and answer where you can do so.				
	0	1	2	N/A
This accurately describes what happened early in the response, before Dec. 31, 2014	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This accurately describes what happened later in the response, after Jan. 1, 2015	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regardless of what happened in the 2014-2016 Ebola response, this would be the appropriate posture for future emergency responses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any "N/A" answers as well as any other comments you wish to offer):				

1d – Community Empowerment

Is Community Empowerment a necessary component of community engagement in an emergency response? <input type="checkbox"/> Yes <input type="checkbox"/> No				
If "Yes," please rate the level of engagement for Community Empowerment for each line below. Your answer should reflect your observations/knowledge for whatever region or response area in which you have experience. If you feel you do not have sufficient information to answer for one period of the response, please mark "N/A" for that period and answer where you can do so.				
	0	1	2	N/A
This accurately describes what happened early in the response, before Dec. 31, 2014	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This accurately describes what happened later in the response, after Jan. 1, 2015	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regardless of what happened in the 2014-2016 Ebola response, this would be the appropriate posture for future emergency responses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any "N/A" answers as well as any other comments you wish to offer):				

2a. Please think about the authority and action of the Social Mobilization Pillar within the Ebola response in Sierra Leone. Would you say that the Social Mobilization Pillar:

	Yes	No	N/A
Led Information Provision efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Led Consultation efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Led Participation efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Led Community Empowerment efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any "N/A" answers as well as any other comments you wish to offer):			

2b. Please think about potential future epidemic or pandemic responses. Would you say that the Social Mobilization Pillar (or equivalent response structure):

	Yes	No	N/A
Should be the lead for Information Provision efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Should be the lead for Consultation efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Should be the lead for Participation efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Led Community Empowerment efforts in the response?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments (please explain any "N/A" answers as well as any other comments you wish to offer):			

For questions 3-7, please mark the extent to which you agree with each statement. Feel free to elaborate with any relevant information or opinion in the comments to each question.

1. I believe community engagement efforts by the response prevented Ebola illness.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

2. I believe failure to successfully engage communities may have contributed to excess Ebola illness or death.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

3. I believe the protocol for Safe & Dignified Burial was successful overall at reducing the spread of Ebolavirus Disease in Sierra Leone.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

4. In the context of Safe & Dignified Burial, community members lacked important knowledge that needed to be imparted by the Ebola response.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

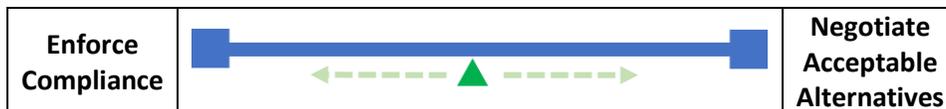
5. In the context of Safe & Dignified Burial, Ebola response leadership and implementers lacked important knowledge that needed to be gained from the community.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

Question 8 shows a sliding scale. Please use your mouse to position the slider in a manner that represents your opinion of the best balance between the two alternatives. Note this question is asking your opinion of how the response ought to have acted, which may or may not be the same as your observation of how it actually happened.

6. When families resisted Safe & Dignified Burial, I believe Response authorities needed to (sliding scale):



Please describe your recommendations or observations on enforcement or alternatives. Please also briefly explain your rationale for the position you chose on the above scale:

Round 1, Question 1 Reference Guide

The concept of ‘community engagement’ means different things to different people. Expanding upon the example set by Barker et al. (2020), this questionnaire will attempt to clarify community engagement activities during the 2014-2016 Ebola response in Sierra Leone. Two previous approaches have been combined to create the rubric used in this questionnaire:

The first approach, following Davidson (1988), breaks community engagement efforts into four separate categories of activities:⁷⁰

- **Information Provision** – Any activity designed to communicate information about the epidemic or control efforts. This communication may take the form of information moving from responders to the community, from the community back to responders, or in both directions.
- **Consultation** – Any effort made by responders to invite community feedback on the response. The difference between Information Provision and Consultation is the extent to which feedback is used to change actual activities or requirements that the response may expect of community members.
- **Participation** – The extent to which community members play an active part in the interventions in their community – that is, they actually *do something* as opposed to simply receiving what is done by the response.
- **Community Empowerment** – The extent to which community members control what is done in their community to control the epidemic.

The second approach attempts to quantify the extent to which input from a community can actually change the activities implemented by a response. Borrowing concepts from Wilcox (1994) and Popay (2010), this study uses an ‘empowerment score’ from zero to two, based on the following broad definitions:

- 0** – Input from community is unlikely to result in meaningful changes to the intervention, message, or strategy;
- 1** – Input from community may result in changes to how an intervention is framed or communicated, or in minor changes to methods, but does not change the basic activities that are implemented;
- 2** – Input from community results in real changes to activities or approach.

Combining these two approaches, Questions 1a through 1d will ask you to score the community engagement efforts of the Ebola Response in each of the four categories, as illustrated on page 2.

⁷⁰ Note that, although all four categories describe aspects of community engagement, not all necessarily apply in every context. To take the most obvious example, the response to an epidemic which presents a global threat almost certainly will take some power away from a local community – if the community were able to control it on their own, it would not have become a global threat.

Please refer to the specific descriptions for the 0-2 scores in each category when assigning your scores for these questions.

Information Provision

- 0 – Information comes from above. Disease control efforts and messages are developed by response leadership or international agencies. The only changes that may be made involve language translation or modified wording.
- 1 – Messages and how they are communicated are tailored to the local situation by communications experts and/or anthropologists, but the underlying content (“key messages”) is predetermined by response authorities or international documents.
- 2 – The content of messages is developed in two-way conversation with the community. Messages are refined, or even replaced, based on community feedback.

Consultation

- 0 – Limited consultation occurs. Occasional community meetings may take place, but they do not result in changes to disease control activities.
- 1 – Responders solicit community input to design or tailor local disease control efforts within strict limits defined by response leadership. Overall approach is not open to change: for example, quarantine must be implemented, but the community determines who enforces it.
- 2 – Responders actively seek feedback on what does & doesn’t work. Responders are serious about changing what they do based upon community feedback, concerns, and objections. For example, if quarantine is unacceptable, the community and responders together come up with another way to prevent those who are infected from exposing those who are not.

Participation

- 0 – Community members are passive recipients of epidemic control activities. Their cooperation is expected or even mandated, but they have little or no part in intervention activities. They may, for example, be required to call a certain number to report a case or death in their own families, but they do not participate in community surveillance or disease control efforts.
- 1 – Community members are mobilized to play an active part in specific, preapproved activities such as community surveillance/reporting. Operating standards remain exclusively under the control of the response.
- 2 – Community and external implementers together decide on disease control activities, which are put into action by community members with technical or financial support from the response.

Community Empowerment

- 0 – Intervention documents and leaders may (or may not) speak of community trust, empowerment and local ownership, but actual authority remains strictly with the national or international responders and/or government.
- 1 – Limited decision-making power is delegated to local leaders/community in specific areas (such as how to implement quarantine), but they have no voice in significant changes to response activities.
- 2 – Substantial decision-making authority is devolved to local communities, and backed up with financial and political support from the national response and/or government.

Round 2 Questionnaire

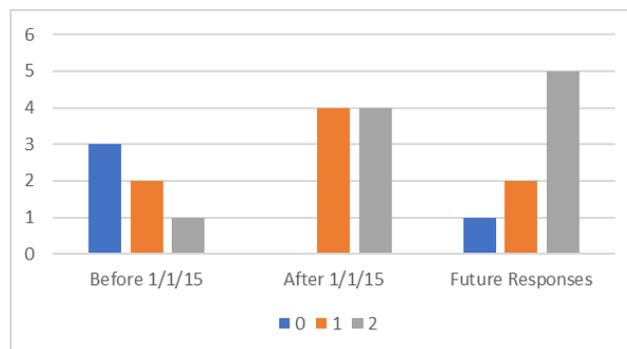
Thank you for your participation in the Delphi Round 1 questionnaire for the study “Community Engagement Around Safe Burial During the 2014-2016 Ebola Response in Sierra Leone.” This Round 2 questionnaire will seek to clarify your assessment of various elements of community engagement in the 2014-2016 Ebola response. As is standard for the Delphi methodology, the questions in this round will ask you to consider each topic in the light of your, and your fellow panelists’, responses in Round 1. A total of 8 individuals responded, representing a diverse combination of professions, nationalities, and areas of responsibility.

For each question, please feel free either to revise or hold fast to your prior opinion ... as in Round 1, there are no “right” or “wrong” answers, we are seeking your candid opinions. Also as in Round 1, your identity remains confidential and your interaction with other panelists’ responses will be strictly anonymous. I would be grateful for any free-text answers you might put in the comment block for each question, to explain or nuance your position. Please be as detailed or as concise as you deem appropriate.

For questions 1a-1d, please refer once again to the [Reference Guide](#) you used in Round 1 (a link will once again be provided). Please note, as described in the [Reference Guide](#), that the scores of 0 to 2 do not represent **how well** the activity was performed, but rather **the extent to which community input or feedback could have, or did, lead to changes** in response priorities or actions. Accordingly, please use the [Reference Guide](#) description for the scoring of each category to guide your numeric-score answers.

1a – Information Provision

In Round 1, you were asked to rate the level of engagement in **Information Provision** for two time periods of the Ebola response, as well as your assessment of the appropriate level of engagement for future emergency responses, using the rubric provided in your [Reference Guide](#). Here’s how the panel’s responses were distributed (note that not all 8 responded in the ‘before’ category):



Here are two panelist quotes that illustrate the range of opinion regarding **Information Provision**:

“I believe that information provision is extremely important to an overall community engagement effort (though is far from the be all end all, as it was in Sierra Leone), in the West Africa case, it was overwhelming, poorly designed, and poorly implemented.”

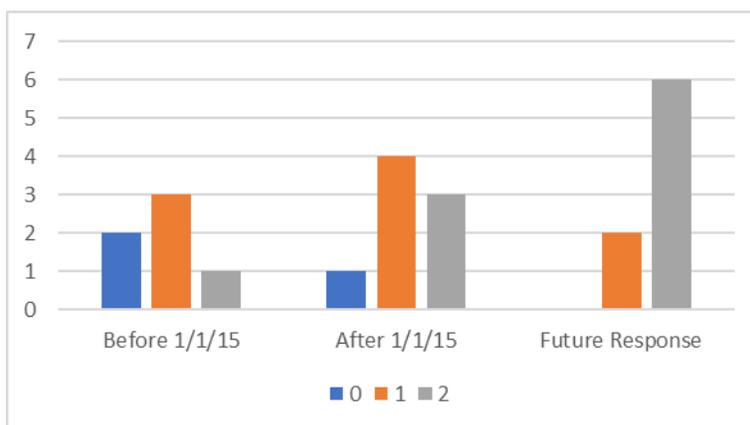
“...starting in October through December 2014, community engagement[in information provision] was strongly scaled up to the point that I may have rated December 2014 with a score of 2. My main point is that the months between October and December 2014, from my observations, was a major turning point in the information provision and consultation aspects of community engagement.”

In consideration of the above information, please state your current assessment (revised or not) of the level of community engagement (as defined in the *Reference Guide*) for **Information Provision** that was true during the latter part of the response, and that should be true in future responses. Please elaborate on your assessment in the comments block which follows.

Please rate the level of engagement for Information Provision for each line below.		0	1	2
	Please choose the number corresponding to the statement in the Reference Guide which accurately describes what happened during the latter part of the response, after January 2015.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Regardless of what happened in the 2014-2016 Ebola response, please choose the number corresponding to the statement in the Reference Guide which would be the appropriate posture for future emergency responses.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments				

1b – Consultation

In Round 1, you were asked to rate the level of engagement in **Consultation** for two time periods of the Ebola response, as well as your assessment of the appropriate level of engagement for future emergency responses, using the rubric provided in your *Reference Guide*. Here’s how the panel’s responses were distributed (note that not all 8 responded in the ‘before’ category):



Here are two panelist quotes that illustrate the range of opinion regarding **Consultation**:

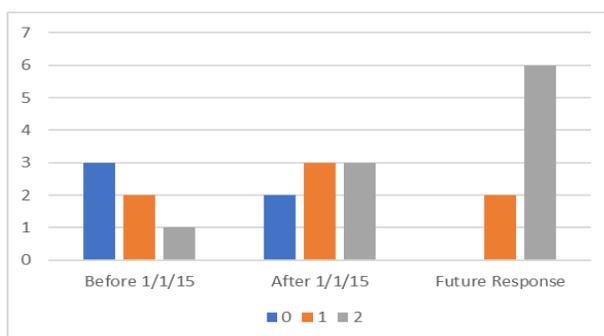
<p><i>“Throughout the response, community consultation was strictly limited to pre-determined standards and mandates, regardless of the local measures that communities wanted to take or felt was necessary.”</i></p>	<p><i>“In 2015, however, I’d say that’s when participation started to move from a score of 1 to a score of 2, because communities were brought in more strongly as part of the decision-making both at the local and national levels.”</i></p> <p>(Note: although the respondent used the word “participation” in this sentence, communities being ‘brought in’ to decision-making is deemed a consultative role according to the <i>Reference Guide</i> rubric)</p>
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In consideration of the above information, please state your current assessment (revised or not) of the level of community engagement (as defined in the *Reference Guide*) for **Consultation** that was true during the latter part of the response, and that should be true in future responses. Please elaborate on your assessment in the comments block which follows.

Please rate the level of engagement for Consultation for each line below.		0	1	2
	Please choose the number corresponding to the statement in the Reference Guide which accurately describes what happened during the latter part of the response, after January 2015.	○	○	○
	Regardless of what happened in the 2014-2016 Ebola response, please choose the number corresponding to the statement in the Reference Guide which would be the appropriate posture for future emergency responses.	○	○	○
Comments				

1c – Participation

In Round 1, you were asked to rate the level of engagement in **Participation** for two time periods of the Ebola response, as well as your assessment of the appropriate level of engagement for future emergency responses, using the rubric provided in your *Reference Guide*. Here’s how the panel’s responses were distributed (note that not all 8 responded in the ‘before’ category):



Here are two panelist quotes that illustrate the range of opinion regarding **Participation**:

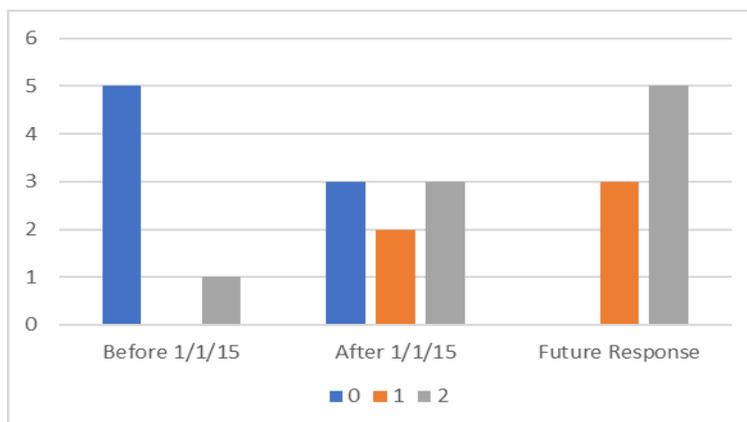
<i>“While there were isolated examples of true community participation, I did not get the impression that this was widespread.”</i>	<i>“Examples of these include the SMAC work where communities were listened to and supported to develop their own community bye-laws to govern local protective measures. So doing saw emergence of local innovations that were tailored to the local context.”</i>
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In consideration of the above information, please state your current assessment (revised or not) of the level of community engagement (as defined in the *Reference Guide*) for **Participation** that was true during the latter part of the response, and that should be true in future responses. Please elaborate on your assessment in the comments block which follows.

Please rate the level of engagement for Participation for each line below.		0	1	2
	Please choose the number corresponding to the statement in the Reference Guide which accurately describes what happened during the latter part of the response, after January 2015.	○	○	○
	Regardless of what happened in the 2014-2016 Ebola response, please choose the number corresponding to the statement in the Reference Guide which would be the appropriate posture for future emergency responses.	○	○	○
Comments				

1d – Community Empowerment

In Round 1, you were asked to rate the level of engagement in **Community Empowerment** for two time periods of the Ebola response, as well as your assessment of the appropriate level of engagement for future emergency responses, using the rubric provided in your *Reference Guide*. Here’s how the panel’s responses were distributed (note that not all 8 responded in the ‘before’ category):



Here are two panelist quotes that illustrate the range of opinion regarding **Community Empowerment**:

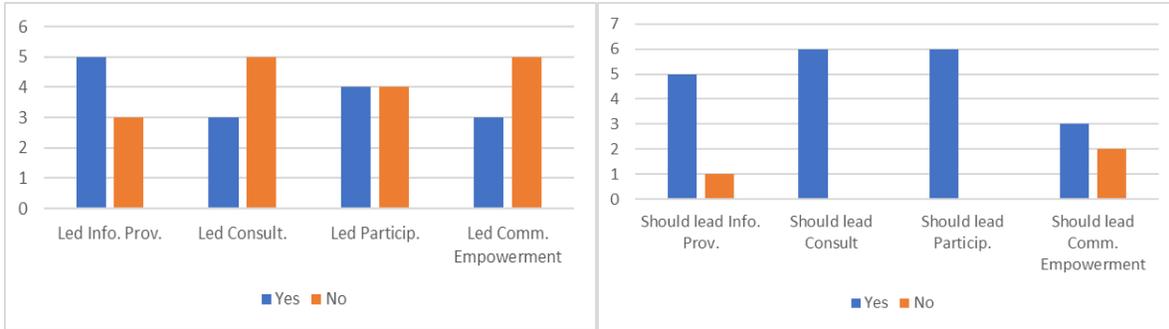
<p><i>“...the response leadership didn't want people to empower themselves to take on aspects of the response that they considered "technical" like healthcare, supportive care, and burial.”</i></p>	<p><i>“[When] sufficient FUNDING became available for community engagement response activities, [it] fundamentally flattened out response power dynamics and nationalized and localized response activities.”</i></p>
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In consideration of the above information, please state your current assessment (revised or not) of the level of community engagement (as defined in the *Reference Guide*) for **Community Empowerment** that was true during the latter part of the response, and that should be true in future responses. Please elaborate on your assessment in the comments block which follows.

Please rate the level of engagement for Community Empowerment for each line below.		0	1	2
	Please choose the number corresponding to the statement in the Reference Guide which accurately describes what happened during the latter part of the response, after January 2015.	○	○	○
	Regardless of what happened in the 2014-2016 Ebola response, please choose the number corresponding to the statement in the Reference Guide which would be the appropriate posture for future emergency responses.	○	○	○
Comments				

2 – Social Mobilization

In Round 1, Questions 2a-b asked you about the role of the Social Mobilization Pillar in the Ebola response, and its appropriate role in future responses. Here is the distribution of the panel’s responses:



Panelists’ comments revealed nuances not captured in the Round 1 questions. Please consider the following statements, rate your agreement or disagreement with each, and explain as appropriate in the comments:

2a – The Social Mobilization Action Council (SMAC), a Sierra Leonean consortium that was not part of the formal Ebola response structure, was more effective at community-engagement than the response Social Mobilization Pillar.

Sample panelist quote:

“SMAC was the primary, and perhaps only entity, that was doing on-the-ground work on consultation, participation, and community empowerment going beyond information provision.”

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

2b – Most community engagement activities during the Ebola response, whether conducted by the Social Mobilization Pillar or by SMAC (see 2a above), relied largely on Information Provision to the virtual exclusion of the other three categories of Consultation, Participation, or Community Empowerment (see *Reference Guide* for definitions).

Sample panelist quotes:

<i>“I don’t think that consultation (or participation, or community empowerment) occurred robustly or very meaningfully in the Ebola response, very much to its detriment.”</i>	<i>“In social mobilization, the focus is on the end-goal and doing whatever it takes to get it achieved in the shortest period of time (with or without consultation, participation, and empowerment).”</i>
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Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

2c – Social Mobilization personnel were excluded from having a meaningful influence (i.e., feedback or decision-making) on response activities outside of information provision.

Sample panelist quote:

“Qualitative research found that social mobilization leads at the district level were excluded from key areas of consultation, and from having inputs into the information provision that was being required by the other pillars.”

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

2d – To effectively lead future emergency responses in Consultation, Participation, and Community Empowerment, a Social Mobilization/Community Engagement response component would require competencies that were not evident in the Sierra Leone response.

Sample panelist quote:

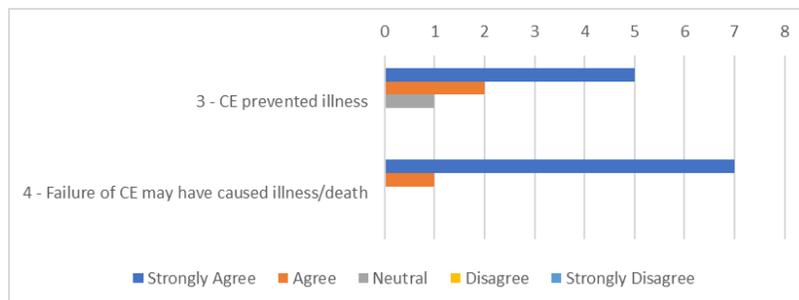
“... future responses should consider changing the name from social mobilization pillar to community engagement pillar. But this should not just be a name change on paper. The pillar’s understanding of community engagement would also need to align with these four components of information provision, consultation, participation, and community empowerment.”

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments, including any changes or enhancements to the Social Mobilization/Community Engagement structure or approach that you would suggest:

3 – Community Engagement (CE)

In questions 3 and 4, you were asked about both the success and failure of community engagement (CE) efforts in Sierra Leone, in preventing and/or causing illness and death. Here are the results from those two questions:



Once again, panelists’ comments suggested several nuances that merit closer examination. Please consider the following statements and rate your agreement with each. Please provide perspective in the comments following each statement.

3a – The hiring of local response staff (e.g. surveillance officers, contact tracers, social mobilizers) was vital to community engagement as it put a local face on response activities.

Sample panelist quote: *“Where ‘community engagement’ meant training and empowering locals to perform response functions themselves, this, I would argue, was hugely useful, and in limited circumstances did occur.”*

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

3b – Engaging religious and/or local political leaders was the most successful aspect of CE efforts in the Ebola response.

Sample panelist quotes: *“... nearly 6000 [religions leaders] had been mobilized and had become active participants through ISLAG and CHRISTAG in engaging other religious leaders and promoting Ebola protective messages to their congregations.”*

“Another example would be the co-option (or at least encouragement) of involving Paramount Chiefs in the response, not only for consultation, but as shepherds of ‘task forces’ that could implement local level interventions.”

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

3c –CE efforts were inappropriately focused on messaging and implementing of predetermined priorities. Only rarely, and in limited situations, did CE provide a conduit to convey community objections or concerns to response authorities.

Sample panelist quotes: *“... the selective blindness of response actors to listening to what communities were saying during community engagement contributed directly to Ebola illness and death.”*

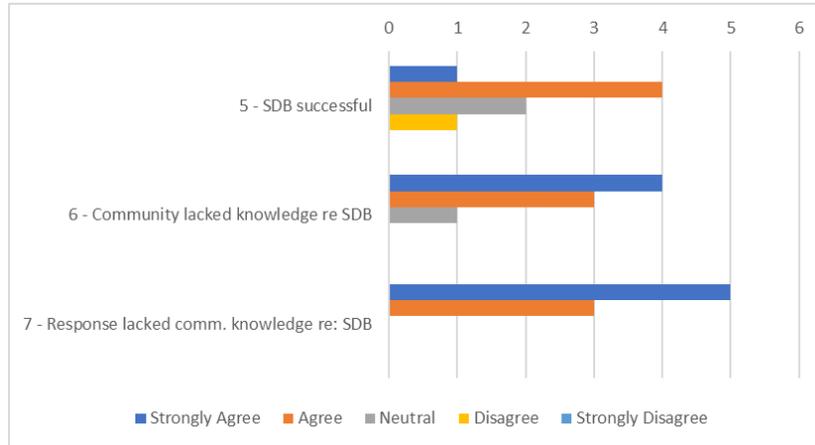
“... the notion that procedures could be changed, particularly at the request of the public was not seriously entertained in my experience.”

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

4 – Safe and Dignified Burial

In questions 5-7 of the Round 1 survey, you were asked about the success of Sierra Leone’s Safe and Dignified Burial (SDB) policy, and about the knowledge or lack thereof regarding SDB among community members and Ebola responders. Here are the results from those questions:



The following statements are summarized from panelist comments and represent areas where opinion diverged (note: there was sufficient consensus on questions 6 and 7 that no further questions are instructive). Please rate your agreement with each and provide comments:

4a – While SDB very likely saved lives, a substantial minority concealed illness and even fled authorities due to the conflict between their cultural/religious standards and SDB requirements.

Sample panelist quotes:

<i>“On the one hand, [SDB] escalated the profile of burials, and knowledge about infection associated with burials and death. On the other, I believe that it contributed, inequitably, to hiding, concealment, and secret movements of persons who were ill.”</i>	<i>“The need to safely bury individuals was unambiguous. I also know that a significant number of people refused to report burials because the SDB system usually meant they could not participate in the burial of their loved ones, and so instead, they hid the death from the Ebola response and buried them unsafely themselves.”</i>
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Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
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Comments:

4b – Although Sierra Leone’s SDB protocol revised in late 2014 attempted to address some community concerns, in practice SDB did not pay sufficient attention to the objections which remained.

Sample panelist quotes:

<i>“... better understanding and consideration of community needs related to SDB - essentially, more compassion for it as</i>	<i>“While one always has to balance the needs of the few against the well being of the entire community, in this case,</i>
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<i>something that some may understandably elevate above containment of the Ebola outbreak - would have been extremely valuable."</i>	<i>there were solutions that could work, (later efforts to improve SDB proved that)."</i>
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Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

5 – SDB Negotiation vs. Enforcement

Question 8 of Round 1 asked you to balance enforcement of SDB vs. negotiation of alternatives on a sliding scale. The distribution of panelist responses is shown below:

Enforce	Negotiate	# Responses
		1
		1
		1
		1
		3

Three panelists' comments illustrate the range of thought expressed in the graphic above:

<i>"I thought that safe and dignified burial was so important to slowing transmission that I thought it should be performed by government enforcement if necessary."</i>
<i>"I am purposefully leaving the slider right in the middle - this is a fine balance, and highly contextually dependent. There is an extent to which burials must be safe, which will require some adaptation of typical practices. Meanwhile, though, there is an extent to which traditional practices can be accommodated in a safe manner too. Where this slider falls should be the result of context-dependent robust community engagement - meaning not only information provision, but also consultation, participation, and community empowerment as well."</i>
<i>"Families want what they believe is the "best" for their loved ones. This belief is amplified when they feel responsible for honoring the wishes of a family member who can longer have a say for how they should be buried. Therefore when families "resist" it tells you that they don't believe what you're doing is best for their loved ones. If response authorities want to succeed, the burden should then be on them to try to *understand* how the burial process could be modified so that families can see it as acceptable even if it is not what they would have otherwise preferred as being the best."</i>

The following two statements break apart the original Question 8 in order to permit the panel to consider the questions of negotiation and enforcement separately. As before, please rate your agreement with each statement and then elaborate as appropriate in the comments.

5a – The burial of a loved one is such a culturally and spiritually significant practice, that even in the case of a disease such as Ebola, authorities and responders should be willing to substantially modify their protocols in dialogue with communities.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

5b – Regardless of any negotiation which may or may not take place as described in 5a above, there comes a point at which the burial protocol must be enforced, by law or coercion if necessary.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Comments:

6 – Identifying information. In order to link with your prior answers, please enter your name:

Please check all Sierra Leone districts in which you worked during the 2014-2016 Ebola response:

- | | | |
|-----------------------------------|------------------------------------|--|
| <input type="checkbox"/> Bo | <input type="checkbox"/> Kenema | <input type="checkbox"/> Pujehun |
| <input type="checkbox"/> Bombali | <input type="checkbox"/> Koinadugu | <input type="checkbox"/> Tonkolili |
| <input type="checkbox"/> Bonthe | <input type="checkbox"/> Kono | <input type="checkbox"/> Western Rural |
| <input type="checkbox"/> Kailahun | <input type="checkbox"/> Moyamba | <input type="checkbox"/> Western Urban |
| <input type="checkbox"/> Kambia | <input type="checkbox"/> Port Loko | |

Round 3 Questionnaire

Thank you for your participation in the Delphi Rounds 1 & 2 for the study “Community Engagement Around Safe Burial During the 2014-2016 Ebola Response in Sierra Leone.” There was a great deal of consensus around most of the questions asked, and the written comments you provided have offered a wealth of information.

This Round 3 questionnaire seeks to clarify only a few more points. Unlike the first two, it will be a short questionnaire with only six questions.

For the four Part 1 questions below, please consider your observations of the SDB context in Sierra Leone. In situations where you believe the Empowerment level fluctuated throughout the response, please concentrate on the time period of June-August, 2015 to characterize your answers.

In the following four questions, please choose the option that you feel best represents the response efforts in each of the four domains of Information Provision, Consultation, Participation, and Community Empowerment around Safe & Dignified Burial during the West Africa Ebola response, and the appropriate posture for future, similar responses where dead body management may be an important public health intervention.

Please remember that a score of 2 is not necessarily “better” than a score of 1 or 0. This study does not presuppose that maximal (or minimal) empowerment in all domains is either desirable or practical in an emergency response. *You may deem some of the examples provided below to be unacceptable.* The important thing is to characterize the approach as you saw it, and for future responses, to characterize the level that you feel would be appropriate in a life-threatening epidemic context.

1a – Information Provision

Please choose the statement below that best characterizes the level of engagement around Information Provision for Safe and Dignified Burial, first in the Ebola Response column, and again what you believe should be the case for Future Responses in the second column		Ebola Response	Future Responses
0	Information comes from above. Disease control efforts and messages are developed by response leadership or international agencies. The only changes that may be made involve language translation or modified wording.	<input type="radio"/>	<input type="radio"/>
1	Messages and how they are communicated are tailored to the local situation by communications experts and/or anthropologists, but the underlying content (“key messages”) is predetermined by response authorities or international documents.	<input type="radio"/>	<input type="radio"/>
2	The content of messages is developed in two-way conversation with the community. Messages are refined, or even replaced, based on community feedback.	<input type="radio"/>	<input type="radio"/>

1b – Consultation

Please choose the statement below that best characterizes the level of engagement around Consultation for Safe and Dignified Burial, first in the Ebola Response column, and again what you believe should be the case for Future Responses in the second column		Ebola Response	Future Responses
0	Limited consultation occurs. Occasional community meetings may take place, but they do not result in changes to disease control activities.	<input type="radio"/>	<input type="radio"/>
1	Responders solicit community input to design or tailor local disease control efforts within strict limits defined by response leadership. Overall approach is not open to change: for example, burial must be performed by response teams according to prescribed protocols, but family members permitted to observe and pray with a preferred spiritual leader, or to provide token items to be buried with the body.	<input type="radio"/>	<input type="radio"/>

2	Responders actively seek feedback on what does & doesn't work. Responders are serious about changing what they do based upon community feedback, concerns, and objections. For example, if community objections to burial standards persist, social mobilizers, anthropologists and epidemiologists meet with community leaders to understand and negotiate what practice changes would be acceptable to all parties. Response leaders are committed to implementing negotiated changes.	<input type="radio"/>	<input type="radio"/>
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1c – Participation

Please choose the statement below that best characterizes the level of engagement around Participation for Safe and Dignified Burial, first in the Ebola Response column, and again what you believe should be the case for Future Responses in the second column		Ebola Response	Future Responses
0	Community members are passive recipients of epidemic control activities. Their cooperation is expected or even mandated, but they have little or no part in intervention activities. They may, for example, be required to call a certain number to report a case or death in their own families, but no community members may participate in the burial process.	<input type="radio"/>	<input type="radio"/>
1	Community members are mobilized to play an active part in specific, preapproved activities such as death surveillance/reporting; select members may be trained to be a local safe burial team. Burial protocols remain exclusively under the control of the response.	<input type="radio"/>	<input type="radio"/>
2	Community and external implementers together decide on burial standards/practices, which are put into action by community members with technical support or oversight from the response.	<input type="radio"/>	<input type="radio"/>

1d – Community Empowerment

Please choose the statement below that best characterizes the level of engagement around Participation for Safe and Dignified Burial, first in the Ebola Response column, and again what you believe should be the case for Future Responses in the second column		Ebola Response	Future Responses
0	Intervention documents and leaders may (or may not) speak of community trust, empowerment and local ownership, but actual authority remains strictly with the national or international responders and/or government.	<input type="radio"/>	<input type="radio"/>
1	Limited decision-making power is delegated to local leaders/community in specific areas, such as who may observe a burial, or who may be trained to serve on a burial team. The community has no voice in significant changes to burial protocols.	<input type="radio"/>	<input type="radio"/>
2	Substantial decision-making authority regarding the handling of the dead is devolved to local communities, and backed up with financial and political support from the national response and/or government.	<input type="radio"/>	<input type="radio"/>

2 – Safe & Dignified Burial

Six out of seven respondents “Strongly” agreed with the Round 2 statement: “The burial of a loved one is such a culturally and spiritually significant practice, that even in the case of a disease such as Ebola, authorities and responders should be willing to substantially modify their protocols in dialogue with communities.” One respondent chose “Disagree” on this question, and stated:

Authorities and responders should be willing to modify their protocols in dialogue with communities, but "substantial" modification - in my use here, to mean modifications that meaningfully introduce elements of heightened risk of further transmission - should not be negotiable.

Elsewhere in their comments, various respondents suggested that burial protocols might be modifiable, but with reservations regarding maintaining the biological safety of the burial. To clarify this issue, please rate your agreement or disagreement with the following two statements:

2a

Responders should be willing to negotiate and implement modified rituals or observances related to burial, but only to the extent that zero or near-zero increase in the risk of infection is acceptable.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

2b

A harm-reduction perspective considers reduced – not eliminated – biomedical risk if the reduction increases compliance and reduces overall risk to the aggregate population. Responders should be willing to apply harm-reduction principles to negotiate and implement modified funeral practices (for example, providing PPE and chlorine to people who wash a body) that might decrease community rejection in a situation such as the Ebola epidemic.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Although final-round Delphi surveys do not usually include further comments, I would be remiss in entirely denying you the opportunity for any final thoughts. Please feel free to add comments on any topic in all 3 rounds, that you wish:

Appendix B – Qualitative Analysis Code Tree from Delphi Data

Name
Comm. Engagement
CE Domains
Community Empowerment
Community Empowerment done poorly
Empowerment term used to describe local implementation of externally-demanded
Leadership didn't want to give community too much power
True community empowerment instances were exceptions
Community Empowerment done well
Local communities created and enforced local 'bye-laws'
Local response led by local personnel
Maximal community participation
Community Empowerment important to response
Community Empowerment improved over time
Real empowerment may not be practical in an emergency response
Who led or implemented Community Empowerment
External SMAC led Comm Empowerment
Other response entities implemented Community Empowerment
SocMob implemented Community Empowerment
Consultation
Consultation done poorly
Consultation didn't necessarily mean change would happen
District SocMob excluded from consultation, feedback
Limited effort to obtain community feedback
Structural barriers to change limit consultation
Consultation done well
Community feedback did lead to changes
Consultation important to response
Consultation improved over time
Who led or implemented Consultation
External SMAC led consultation
Other response entities implemented Consultation
SocMob implemented Consultation
Information Provision
Information provision done poorly
Communities overwhelmed with information
Information provided inadequate or inappropriate
Information provision oversimplified complex realities
Response limited information to retain power
Structural barriers to change limit modifying information
Top-down IP
Information Provision done well
Information provided was beneficial
Information Provision important to response
IP engagement improved over time
IP should be driven by community information needs
Primacy of Information Provision inappropriate or inadequate
Who led or implemented Information Provision

Name
Other response entities implemented Information Provision
SocMob implemented Information Provision
Participation
Effective participation depends on pre-existing community structures
Participation done poorly
Participation mainly local social mobilizers
Participation was in community recruited to information provision
Participation done well
Participation important to response
Participation included hired or volunteer members of intervention teams
Participation included local communities determining and enforcing policy
Participation improved over time
Participation requires understanding community needs, priorities
Who led or implemented Participation
External SMAC led Participation
Other response entities implemented Participation
SocMob implemented Participation
CE may be abdication of central responsibility
Comm. Eng. Failure
Community resistance
Community trust-failure
Inappropriate CE efforts actually distanced community
Poor engagement may have caused illness or death
RCCE inadequately linked to response leadership - poor feedback
Response lacked skill to successfully engage communities
Comm. Eng. Success
Community trust-success
Good CE flattened out power dynamics, empowered locals
Good engagement may have saved lives or prevented disease
SMAC improved engagement, ownership
Early engagement can prevent later failures
Implementation by locals
Community members as communicators
Engagement of religious leaders important
Hiring local staff is legitimate community engagement
Local leadership and ownership
Political context
Alienation of community from gov't exacerbated or complicated engagement
CE limited by donor, institutional priorities and theories
Community empowerment contingent on social or political environment
Some successful behavior change happened for social reasons unrelated to response CE
Cultural sensitivity
Need more compassion
Need to understand cultural concerns
Racist and-or occidentalist bias
Fear
Fear among response workers
Fear in communities
Threat or fear of punishment

Name
Insufficient research into CE failure
Power
Centralized
Authorities did not want to delegate or decentralize
Control was excessive
Enforcement
Threat or fear of punishment
Failure to include local capacity
Inflexibility
Local-national authorities, not just responders, disregarded community
Marginalization of 'lower' authorities or roles within response
Response unable to deliver but retained power anyway
Community 'resistance' as an exercise of their own power
Community 'resistance' as signal to investigate issues
Decentralized
Direct opposition to claim of authorities not wanting community power
Incorporation of local authorities or leaders
Incorporation of local resources other than authorities
Some communities had significant intervention authority
'Empowerment'
Actual empowerment
Empowerment language, uncertain meaning
'Empowerment' to do what we wanted
Funding a key element of power
True community empowerment may not be possible in an emergency
Funding an important element of power
Perception of involvement important to community
Weak leadership
Regular medical care failed during epidemic
Response overall effective
SDB
Knowledge Deficit - SDB
Community
Community knowledge increased over time
Community lacked knowledge
Community was source of knowledge
Knowledge alone insufficient to bring change
Objections were spiritual, not merely informational
Discrepancy between response, community assessment of knowledge needs
Response
Response disinterest in community knowledge, feedback
Response gained knowledge over time
Response lacked knowledge
Response was source of knowledge
Trainers lacked knowledge
Policy
SDB both necessary and problematic
SDB enforcement may not be practicable
SDB policy (and enforcement) necessary

Name
SDB policy should consider cultural concerns
Even if people understand risk of unsafe burial, they may have higher priorities
SDB partly driven by racist and anti-tradition biases
SDB Failure
Burial teams attitude or practice may have hampered SDB implementation
Part of failure was inability to scale to magnitude of need
People avoided the system because of SDB
People exhumed bodies to bury according to custom
SDB insufficiently considered community concerns
SDB not dignified
SDB policy cost lives
SDB Negotiation
Harm Reduction
Negotiation - possibility of change
Negotiation - seen as convincing community
Safety caveats or limitations
SDB Success
SDB incorporated cultural concerns
SDB policy saved lives
Structural Issues
Response structures being external to existing PH hampers community engagement
Social Mobilization 'SocMob'
Done Poorly
Conflict between SocMob and Biomedical
Mobilizers poorly trained, equipped
Poorly coordinated, poor leadership
SocMob was excluded from response governance
SocMob was expected to remedy conflict provoked by other parts of response
Done Well
Early engagement can prevent later failures
Feedback from SocMob did lead to response changes
SocMob was included in response governance
Specific organizations did SocMob well
Direct opposite - SMAC of minimal impact
General Observations
Additional skills needed by SocMob or CE
RCCE or SocMob has not improved
SocMob as an entity shouldn't exist
SocMob inordinantly focused on achieving response goals rather than understanding
SocMob should be key player in response monitoring and improvement
SocMob should be reframed as Comm. Engagement.
Utilization of local capacity
Done poorly
Endogenous efforts WERE NOT recognized and supported
Local capacity sidelined or underutilized
Done well
In-country experts involved
Response desired to use local capacity
General principles

Name
Defining 'local'
Response theory needs to respect local capacity, intelligence
Survey Methodology Comments
Conflating all districts problematic
Endorsement of CE scoring methodology
Timeframe break meaningful due to changes in funding for activities
Timeframe in survey doesn't correspond to times of actual changes
Value Descriptors
Counterproductive
Excess structuration of CE
Incidental
Inflexibility
Lip service
Loved
Overwhelming
Pathetic
Pejorative
Poorly designed
Poorly implemented
poorly trained
Privilege
Proud
Racist
Selective blindness
Top-down
Weak leadership