Executive Summary Rapid Grey Literature Evidence Review to Support the Guideline on Emergency Risk Communication

Supplemental Question: What are the risk communication lessons learned from grey literature reports of recent events and emergencies with public health implications?

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Rationale and Objective

As part of its guideline review and development processes, in 2015 the World Health Organization (WHO) commissioned a rapid review of recent grey literature evidence to underpin development of the Emergency Risk Communication Guideline. This was intended to provide additional knowledge about building national-level capacity to integrate effective risk communication practices and structures into healthcare and response for public health emergencies. The principles of systematic reviewing as described by Cochrane were adapted to undertake this rapid review: The term public health emergencies included infectious disease outbreaks, natural and human-made disasters and spanned all phases of preparing for, responding to, and recovering from a public health crisis.

Twelve questions were initially elaborated and specified according to the Setting, Perspective, Phenomenon of Interest, Comparison, Evaluation (SPICE) framework. They were designed to answer "what works for whom in what contexts". This was further extrapolated in order to better understand 'what happened' or 'what was happening', positive and negative consequences, and lessons learned.

The reviews were commissioned to cover a time period from 2003 to the end of 2015. Given the fact that risk communication received a lot of attention in the wake of the Ebola, Zika and yellow fever outbreaks, it was felt that it would be beneficial to conduct an additional review of grey literature to capture these most recent developments. The supplemental question was elaborated guide this review. This question was to be answered in terms of each of the twelve original questions.

Methods

Search strategy

The search was designed to locate recent grey literature sources 'published' in 2015 and 2016. Keyword searches were conducted in online databases greylit.org, worldcat.org, opengrey.eu, evidenceaid.org and disasterlit.nlm.nih.gov. In addition, several particularly relevant websites were searched, zikacommunicationnetwork.org, Ebola Response Anthropology Platform (ebola-anthropology.net), ebolacommuniationnetwork.org. Site searches combined keyword searching and following links.

In addition to the online searching, the WHO team of experts was contacted for document suggestions. An online request for documents from partner and non-partner organizations was posted on various risk communication platforms. In addition, a number of experts submitted documents via email. Submissions were accepted through 31 December 2016. This proved to be a rich resource, returning higher numbers of documents from more credible sources than were located with other forms of searching.

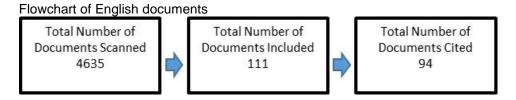
To be included, documents needed to fall within the search date limits, relate to emergency risk communication, and contribute to lessons learned and be available in full text.

Search outcomes, credibility assessment and data extraction

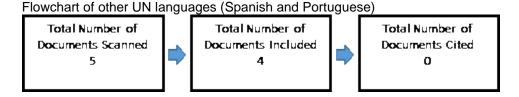
Potentially relevant documents were identified for all twelve search questions. However, this should not be construed as meaning evidence was found for all twelve questions. Although documents

discussing the topics were found, sometimes these documents did not represent lessons learned or study results.

As presented in the flowchart below, a total of 4635 English documents were scanned, of which 111 met inclusion criteria and 94 were cited in the report. Documents included in results but not cited were documents which provided background information potentially of interest to the search process, but which did not directly pertain to the search questions. Please note that the total number of documents scanned represents the total number of results returned by the various searches. Many of these overlapped, with the same document appearing in the results for multiple searches. As such, this number does not represent individual, discrete documents. Furthermore, although exact numbers of results returned were provided by most databases, EvidenceAid.org did not provide the total number of results listed, nor did other individual websites searched. In addition, although documents from the team of experts were provided in spreadsheet form from which a total number could be derived, many of the cells in this spreadsheet contained multiple documents. For these reasons, the total number of documents is an estimate.



A total of five documents in other UN languages were scanned, two in Spanish and three in Portuguese. The flowchart of other UN Languages, below, summarizes the search process for documents in other UN languages.



All documents were assess for credibility using an Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) checklist. If the document contained a qualitative study, a Critical Appraisal Skills Programme (CASP) Qualitative Study checklist was also completed. Although some cross-sectional data collection was found, no appraisal of methodological strengths and limitations was undertaken due to lack of time. No other form of study type was included in the reviewed literature

A rapid content analysis of included sources was undertaken with relevant portions either extracted verbatim or summarized and mapped against the questions. A database subset was created for each question and citations were assigned to the subset(s) for which they contained relevant information. Multiple designations per document were common. Once all documents had been sorted in this way, the database subsets were used to synthesize the results into a coherent narrative.

Findings

Potentially relevant documents were identified for all twelve search questions. However, this should not be construed as meaning evidence was found for all twelve questions. Although documents discussing the topics were found, sometimes these documents did not represent lessons learned or study results. More information about this can be found in the individual search question results presented below. Detailed summaries of the evidence, listed by question, are provided in Appendix 4.

Of the 111 documents included in this review, 16 reported the data collection and analysis of primary data such as cross sectional surveys. The other documents reported situation analyses or evaluations

drawing on analysed data from internal organisational or external published sources. The credibility of the majority of the document sources varied and findings are presented by each question. In common with grey literature reports few sources reported any methods or references to support the analysis.

Q1: How can emergency risk communication best be integrated into national leadership planning and execution for events and emergencies with public health implications?

Five documents were identified as potentially relevant to this question. Of these, three were assessed as being high credibility sources and two as moderate credibility. Although identified as possibly relevant, none of these documents provided evidence regarding intervention or action outcomes, nor did they specifically address risk communication per se.

The closest a document came to listing results was the statement that countries like Uganda have demonstrated that building a public health system capable of responding to and containing an outbreak of infectious disease is possible; it requires leadership. Critical to such a system is community engagement, as well as their awareness, trust and cooperation (1). This implies risk communication.

In BBC Media Action's policy briefing, Caroline Sugg noted that despite acknowledgement of the important role it plays in health, communication too often remains an underfunded afterthought. She stated that social and behavioural change communication should be included as an integral part of health programs and that an "institutional home" should be created for health communication (2).

The United Nations General Assembly stated that International Health Regulation (IHR) compliance includes establishing preparedness and response mechanisms. Community engagement and culturally appropriate communication form an integral part of such mechanisms (3). This also implies integration or risk communication into national health plans.

Additionally, in its Ebola Response Improvement Plan, the United States Department of Health and Human services noted the importance of prioritizing risk communication. A department-wide emergency risk communication strategy was to be developed, including training staff to serve as spokespersons and planning to ensure an adequate supply of such trained personnel (4).

These findings indicate that action does not yet meet intention. Political will needs to be engaged to ensure appropriate prioritizing of risk communication as an integral part of public health.

Q2: What are the best types of mechanism(s) to establish effective, cross-jurisdictional linkages for information sharing for emergency risk communication and internal coordination?

Five documents from high credibility and four moderate credibility sources were identified as pertinent to cross-jurisdictional coordination. Of these, all but two dealt with WHO and the International Health Regulations. Since most coordination findings also pertained to interagency coordination (Question 6, below), they are not addressed here. Only items not covered in Question 6 are discussed here.

One model for improving cross-jurisdictional linkages and coordination came from the polio eradication campaign. When eradication efforts stalled, an independent monitoring board of experts drawn from around the world was established. This board used a combination of strong leadership, clear goals against which to measure progress, and frank speech about under-performing programs, as well as a program of cross-border meetings and synchronization to encourage compliance and make great strides in the eradication of this disease (5, 6).

The second example of cross-jurisdictional linkages and coordination came from WHO and the International Health Regulations (IHR), and is undergoing a significant readjustment. Prior to the West African Ebola outbreak, the question remained open as to whether WHO should be an operational agency in addition to its norm-setting and coordinating capacity (7). Post-Ebola, various

review bodies and the Member States articulated that WHO should become an operational agency, taking the lead in emergency preparedness and response. A new Health Emergencies Program was established to be the nerve centre of global emergency preparedness and response (3, 8, 9). Its implementation is still too new for evaluation. The IHR were found not to be in need of revision, but in need of implementation instead (10, 11).

Q3: How to best develop and sustain emergency risk communication staff capacity for preparedness and response?

Sources addressing capacity agreed that building capacity was needed. One document reported that national capacities to detect and respond to emergencies needed to be built, along with personnel capacity, especially in rural areas (12). Another observed that the presence or absence of a risk communication plan does not necessarily indicate capacity, nor do elements of infrastructure indicate operational capabilities (13). A third stated that health communication capacity building, especially for local health agencies and personnel, has long been neglected (2). This failure to develop local risk communication capacities has led to reliance on outside experts being brought in in times of crisis (14).

Two documents addressed this imbalance in the locus of risk communication capacity. Rather than relying on outside assistance, risk communication capacity should be based at each "geographic" level, local, national, regional and global, with clearly defined roles, responsibilities and infrastructure (13). Particular focus needs to be on developing national capacities (14).

Most documents relevant to this question focused on listing the specific capacities that need strengthening. Softer communication and interpersonal skills (15, 16), along with consensus-building (including document preparation), analysis, documentation (17), monitoring and evaluation were all considered important to build (13). Staff need to learn to recognize variables known to provoke outrage, such as perceived unfairness, moral indifference, and impacts on vulnerable populations, and treat them as central to public health objectives, rather than dismiss them (18).

Other important functions in need of capacity building included strategic communication strategies, plans and standards of practice, trust building strategies and activities, and coordination skills and capacity. Stakeholder and partner communications, community engagement, socio-political, economic and cultural analysis for risk communication, and translational communication of technical expertise into understandable, contextualized material also received mention (14).

A cadre of personnel should be trained in health crises and risk communication, and refresher training provided should be provided at least annually (19) (20). Media personnel should be trained in public crisis communication (21).

In contrast to most of the documents included for this question, one study focused on staff slated for crisis deployment. It found that sharing a basic training program and actually serving in the field together helped foster trust between emergency risk communications specialists, enabling them to engage effectively more quickly upon deployment (22). Creating and maintaining a roster of such specialists, or teams of such specialists, could also represent one way to develop and sustain staff capacity.

Greater prominence needs to be given to health communication capacity building. Benchmarks need to be agreed upon, and universities need to integrate it into their courses (2).

Thirteen documents were identified as potentially relevant to the question of developing and sustaining staff capacity in emergency risk communication. Of these, eight were from high credibility sources and five from moderate.

Q4: How to ensure sufficient and sustainable financing for emergency risk communication?

Similar to the previous literature review conducted for the question of sustainable financing for emergency risk communication (23), this quick review of grey literature found very little relevant material. Of included sources, 26 mentioned financing or funding in some way, 12 of which had high credibility sources and 14 moderate. Several of these discussed health funding in general or for specific programs, without mentioning risk communication funding (3, 7, 10, 24-31). Others mentioned specific amounts allocated for risk communication activities, but these were one-off grants, and therefore not sustainable funding sources (32-38).

Although of those discussing risk communication funding, several called for increased funding from national governments and donors, or expressed need of it (2, 3, 39), real action in terms of supplying such funds, except as if in afterthought, appeared scarce (2).

Several sources referenced WHO's new Health Emergency Programme. While true that the Programme's mandate and budget include risk communication, this still does not answer the question of sustainable risk communication funding, as the Programme itself needs sustainable funding (1). Furthermore, funding public health systems, emergency or otherwise, remains a responsibility primarily of domestic budgets (1). Several mechanisms for sustainable funding were suggested, such as a combination of varying levels of domestic funding coupled with funding from other sources for LMIC, but no information about the effectiveness of such mechanisms was provided (1).

One source mentioned user fees, taxes and donor support as possible ways of funding health care, noting that user fees are the least equitable of these mechanisms as they punish the poor (26). Another suggested that funding previously earmarked for polio now be used for social mobilization for general health education (6). A third report noted that Congress did not approve additional funding for Zika prevention, so the CDC has taken money previously marked for local health department preparedness and reassigned it to the national Zika campaign (40). Rather than being an example of sustainable funding, this seems a case of robbing one part of a programme to pay another.

One thing several reports seemed to agree on: A number of reports mentioned that lack of funding hampered initial risk communication efforts at the beginning of the West African Ebola outbreak (36, 41-43).

Q5: What are the best and most generalizable emergency risk communication activities that build trust in health authorities as a source of health protection information among affected communities and other stakeholders?

One of the most important steps toward building trust is community engagement, the grey literature was nearly unanimous about this. Community engagement builds trust, and greater trust fosters community engagement. Because of this overlap, much of what pertains to trust-building is covered in Question 9. Rather than duplicate this, examination of lessons learned here will be limited to those which were listed nearly exclusively in relation to trust-building.

The populations of all three countries most strongly hit by the Ebola outbreak, Guinea, Liberia and Sierra Leone, displayed strong mistrust of government and outsiders. Their political realities played crucial roles in this situation(7): All three recently experienced devastating civil wars. All three had ethnic diversity, with tensions between ruling parties and those groups not in power. Other factors contributing to mistrust included the legacy of colonialism, attempts to "modernize" that involved efforts to eliminate traditional religion, lack of local representation in government, and the necessity of frequently having to bribe authorities just to get through daily life. This lack of trust gave rise to vicious rumours (government plots to market human organs or eliminate minority populations) and hampered response efforts in general (42-45).

Initial messages warning people not to eat bush meat further increased mistrust, as local populations recognized that this did not explain Ebola transmission (45-47). Political pressure undermined transparency and trust, as did measures of force, such as placing over a million people under quarantine, or state-enforced cremation (13, 43, 48).

Although written about communications experts trained for deployment by WHO to emergency situations (Emergency Communications Networks or ECN), Bastide's study shed light on why certain types of interventions build trust. One thing these networks succeeded at is spreading trust. Bastide noted that this trust comes from shared experience. People have trained together or have already worked together, so they share common experiences, which builds bonds and generates complicity trust. Sharing a base of technical skills, norms and values fosters recognition trust. The study further noted that complicity trust is deeper and stronger than recognition trust, because it is emotional and involves intimate experience of those trusted (22).

As mentioned above, community engagement and building trust work together. The single greatest factor in successful community engagement was maximum local involvement (see the discussion of Question 9, below). Local populations come with ready-made complicity and recognition trust. They share both experiences and a common set of life skills, norms and values. However, as one report noted, not all locals have equal trust-building effect. Some leaders were not trusted, and some people did not trust those being paid to do Ebola work (49). Use of volunteers helped address this latter issue.

Trust in health systems is based not only on objective measures of these systems (the number of facilities or quality of service delivered), but also on people's perceptions of these systems. If people think a system is unlikely to help them, they will not use it. Once again engaging people is the solution, for example, by involving people in service delivery meetings (15, 50).

Healthcare workers treating people disrespectfully erodes trust. Staff needed training/development of softer communication and interpersonal skills to help build trust (15, 50, 51). One report also noted that providing mental health services to healthcare workers helped relieve their stress and enabled them to interact better with members of the public, thereby also helping to build trust (51).

Timing also plays a role in trust building. Communication needs to acknowledge a crisis immediately and be open about uncertainties (13).

Of the 17 documents referenced in this section of the report, 11 were from high and six from moderately credible sources.

Q6: What are the best ways to ensure coordination of risk communication activities between responding agencies across organizations and levels of response?

The grey literature covered in this quick review offered little information about best ways to ensure coordination of risk communication activities. A total of 33 documents were identified as potentially relevant to this question, 18 from sources of moderate credibility and 15 of high. Most sources did not focus on risk communication coordination specifically, addressing general collaboration and coordination instead. Many documents provided details of collaborative or coordinating activities or bodies, but no details about their effectiveness. In addition, Quite a number of documents focused on the role of WHO and the establishment of its Health Emergencies Programme.

Of the 33 documents identified, all but four grew directly out of either the Ebola or Zika responses, and even one of these touched on the Ebola outbreak, although it was not the main focus. One paper reported a disconnect between risk assessors and risk communicators, seeming as if they spoke different languages. Simulation exercises and training of risk communications personnel on the principles of risk assessment were recommended as possible solutions to this challenge (13). Two documents presented the importance of coordinating with the press, before and during an

incident, meeting their needs and remaining available to them. This type of coordination was found especially important as many people depend on the media for their health information (18, 52).

The overwhelming majority of sources for this question, 28 documents, dealt with the Ebola outbreak. Three highlighted local collaboration efforts. In Montserrado County, Liberia, OFDA funded the International Rescue Committee (IRC) to lead a consortium of four other non-governmental organizations (NGOs). This proved to be more effective than their efforts working separately, as it allowed organizations to focus and capitalize on their areas of strength. It also allowed them to advocate more effectively with the government. Sharing information between consortium members was vital to effective work and helped build trust, as did getting technical input from WHO (53). Another report also found that a consortium improved coordination. This consortium, the Social Mobilisation Action Consortium (SMAC), worked through local religious and community leaders, social mobilizers and local radio, ensuring coordination not only of interventions, but also of messages (36). Y Care also found that the National Ebola Taskforce and the Pull Slum Pan Pipal Consortium helped improve coordination (41).

Another report focused on the specific nature of needed coordination, noting that, "More attention needs to be paid to the connections, feedback loops and relationships between different individuals and different organisations across the local, district and national levels. Priorities for attention include: data reporting and management; sustained supportive supervision of health workers; integration of grievance mechanisms and other social accountability tools into public services; and coordination methods that actually facilitate coordination rather than just information sharing" (50).

Where coordination efforts should be based also received attention, as did the importance of clearly defined roles and responsibilities. One report recommended that well-organized coordination systems be based at the district level (54). Another noted the importance of clearly defined roles for all those implicated in a response effort (52).

Fifteen documents focused on WHO and its role in the Ebola response. In this response, WHO served as technical lead, providing training, monitoring and evaluation, as well as leading the overall health response (27). This response was perceived as too slow and inadequate, overly political and not independent. Member States felt that in order to fulfil its mandate, WHO must improve its performance and change these perceptions (9).

Member States expect WHO to play a primary role in responding to outbreaks or other health emergencies, providing leadership, expertise, support, backstopping and coordination (9). A potential tension was identified between the expectation for WHO to lead coordination efforts and the necessity of tailoring risk communication for local populations and circumstances. Primary responsibility for response must rest with national governments, and WHO's role will need to flex, sometimes leading, sometimes "getting out of the way". Focus should be on building local capacity (55). For both WHO and other organizations, leading and coordinating crises was seen as the biggest skills gap (56). A number of recommendations addressed filling this gap.

As global health cluster lead, WHO has been tasked with coordinating partners and their activities before, during and after health emergencies. This includes developing mechanisms for local, as well as global coordination and articulating common risk communication goals, building strong relationships with partners and clarifying roles and responsibilities (14). These coordination efforts should be led through meetings and teleconferences, and establishment of Emergency Response Centres (11). These centres should include risk communications expertise (57). Response capacity needs to be based at the district level, and WHO should to continue to lead district-level coordination, ensuring that each district has a tailored and flexible plan (58).

In addition to these measures, WHO established a standing advisory committee to review its risk assessment and risk communication. It also created an intermediate level of alert via a new category of risk that requires specific follow-up, called an International Public Health Alert (IPHA), and developed an updated communication strategy (10).

These reforms have begun to be implemented (31, 37) and the initial Zika response looks promising (12, 16), but it is still too early to determine the effectiveness of these reforms (59).

Q7: What are the elements and steps of effective, strategic communication planning?

According to the grey literature, effective, strategic communication planning begins long before a crisis and involves a number of steps. A number of documents found that groundwork needs to be laid before an emergency. This includes creating a strategy and framework for communicating with all stakeholders, developing and vetting basic messages for issues likely to arise during a crisis, training communications personnel, and developing a system for rapid message review and approval (4, 14, 18, 19, 52). Roles and responsibilities should be outlined and clearly defined (14, 52), and a network of communication partnerships should be created and maintained. A plan for working with the media should be developed (14, 18, 21, 52), as should a media toolkit (52). Adequate and timely funding should be secured (2).

A second finding was that the communication process needs to start early (42). An essential beginning step of communication planning is to discuss the situation with community leaders and members and to conduct an initial assessment. This helps identify the best communication channels to use and any barriers or potential problems, as well as potential solutions (24, 60).

One study noted that medical anthropological assessment should be used at the beginning of a response, so that messages and responses can be shaped accordingly (61). This assessment should include listening to complaints and taking into account the customs and cultures of all involved groups (18, 44). Top-down communication should be avoided, as this can exclude and alienate people (62). Instead, messages should be tailored to their target groups (52).

An example of these steps was provided by the Community Led Ebola Management and Eradication (CLEME) approach. CLEME started with an assessment of the situation, community mapping, collecting information about caring for the sick and the dead and a walk-through of the community. As a community, interventions were decided upon, tailored for specific groups and implemented. Contextual analysis, follow-up visits and feedback shaped intervention adjustments on an on-going basis. Ebola and other health education was then to be integrated into all community programs to prevent future outbreaks (63).

Once initial messages were disseminated, it was important to monitor their effectiveness and adjust them as necessary. One option for this was to use barrier analysis, comparing those who had adopted behaviour changes with those who had not, to help elucidate barriers to change, uncover perceived positive and negative consequences of behaviour changes, and fine tune messages accordingly (49). Social mobilizers could be used in this process. They could listen for misinformation and rumours, which could then be addressed swiftly (14, 21, 24). Two documents noted that the process of listening to the community, taking their concerns seriously and adapting messages accordingly should continue throughout the emergency (18, 21).

Additional elements of good communications planning were found to include distinguishing evidence-based messages from uncertain ones (36), ensuring that lessons learned are captured and applied (2, 21), and building local communication capacities (14, 36).

For this question, 16 potentially relevant documents were identified, 11 from sources of high credibility and five from moderate.

Q8: What are the best ways and most appropriate tools for gathering, analyzing, and interpreting emergency risk communication data and feedback and integrating results into emergency risk communication planning, strategy development, execution and evaluation?

Only three documents with potential relevance to this question were identified, two of high and one of moderate credibility. This low number of results seems appropriate, as two of the three sources concurred in expressing a paucity of evidence in this area.

Participants in one study expressed a lack of evidence about the effectiveness of different types of risk communication, as well as a lack of methodological frameworks and tools to evaluate risk communication. They further stated that having each country at a different level made comparative analysis difficult (13). Another report echoed these sentiments, noting that gaps and misalignments existed in the evidence, along with disagreement about what types of studies were acceptable. Even when studies were performed, the tendency was to focus on numbers of people reached, rather than on whether behaviour actually changed. Finally, funding for risk communication evaluation has diminished: apparently little demand for rigorous research exists (2).

Still, one document noted several aspects of risk communication that lend themselves to measurement: the time between threat perception and message release, the time between message release and public uptake, and the level of coordination with stakeholders and across units. Data could also be collected about how the message was delivered, received and acted on. Efficiency could be measured in terms of time saved, political pressure reduced and minimized media incidents. Effectiveness could be measured with KAP studies. These types of measurements should be taken before, during and after emergencies, to establish a baseline and to determine if messages need to be adjusted, as well as to evaluate overall performance (13).

Several study methods were presented as possibilities for evaluating risk communication programmes. According to one study, quasi-experimental research designs, interrupted time series analysis and studies that use statistical controls like propensity score matching to reduce the potential bias of confounding variables are being used more frequently, along with qualitative research. These represent best health communication evaluation (2). Other methods for evaluation include focus groups, interviews, KAP and other population surveys, opinion surveys and media/social media monitoring (13). With the Community Led Ebola Management and Eradication programme, revisits to communities were used to monitor, evaluate and adjust programs (63).

Q9: What are the best ways to engage communities in emergency risk communication activities to respond to events/contexts?

Overwhelmingly the grey literature found that engaging communities should play a central role in emergency responses. Not only is community engagement key to building trust, but as one report noted, local efforts also played the most important role in turning the Ebola tide, because the turning point was reached before the full-blown response was operational (53). It is fitting, then, that more documents were found relating to this question than to any other.

Sixty-eight documents were identified as contributing to this question, thirty from high credibility sources, 36 from moderate and 2 from low. The two low credibility sources were retained, as they represented opinions of those working on the frontlines of the Ebola outbreak, and as such were considered worth noting, even if they were not well documented. Lessons gleaned from these materials fell into two categories: Things which improve community engagement, and barriers to community engagement. Each are addressed below.

Things which improve community engagement

The grey literature examined in this quick review found a number of methods which improve community engagement, thirteen of the most common of which are listed in Table 6.1 Community Engagement Methods, below. In the table, each engagement method is followed by the number of documents which mentioned this method as improving engagement success. Essentially, these lessons learned could be summarized in two words: Go local. The literature found that communities responded best when as much as possible was done locally – involving local people, respecting local

culture, language and circumstances, and listening to local concerns and opinions; all this on an ongoing basis.

Table 6.1 Community Engagement Methods (by number of documents*)

Engagement Method	Total Documents
Engage local leadership and key people	31
Tailor interventions for population, gender, circumstances, language	26
Use locals as mobilisers	16
Community creates own interventions	15
Engage local groups	15
Listening & 2-way communication	15
Use local media	12
On-going monitoring & evaluation (feedback)	11
Use anthropological assessments	10
Start communication early	8
Use visual aids, role plays & story telling	6
Community conducts own outbreak analysis	3
Decisions made at local level	3

^{*}Sources provided in Appendix 5.

Involving local leadership was listed by 31 documents as an important step toward community engagement. Using local people as mobilisers and engaging local groups were also seen as important, with 16 and 15 documents respectively mentioning this as helping gain access to communities and to successful uptake of behaviour changes. Further detail about who these people and groups are is provided in Table 6.2 People and Groups to Engage, below.

Table 6.2 People and Groups to Engage*

Table 0.2 T copie and Groups to Engage	1
People to Involve	Total Documents
Religious leaders	18
Traditional leaders, chiefs, elders	16
Other local authorities or leaders	11
Women & Women's groups	11
Health Workers	10
Youth groups	9
Traditional healers	7
Others (hunters, taxis, market groups,	
hospitality industry)	5
Survivors	4

^{*}Sources provided in Appendix 6.

The group of people listed most as important to involve were religious leaders (18 documents), followed by traditional leaders, other local authorities or leaders, and women or women's groups. Targeting women particularly, not only for epidemic response efforts, but for health improvement in general, has proven very effective (64, 65). One report stated that engaging women is critical to changing behaviour. It likened Ebola to a fire and women to water, noting that water puts out the fire (66). Health workers, youth groups, traditional healers and other groups, such as hunters, taxi drivers, market groups and those involved with hospitality businesses (restaurants, bars, hotels) were also found to be important inroads into communities. Using locals as mobilizers also proved affective,

although Quinn emphasized that locals should be selected based on their understanding of local culture and for being trusted by the local community (12).

Tailoring interventions for gender, language, local cultural nuances and circumstances has also proven effective, ideally with communities assessing the situation themselves and crafting their own messages, with regular monitoring and feedback to allow for further adjustments.

This makes sense, because as a general rule, most people prefer to have a choice in what they do. Since communities are conglomerates of people, not surprisingly this holds true for them too. A number of sources noted that response efforts were most effective when they were owned and driven by local communities and local leadership (3, 28, 35, 54, 67, 68). Another report also emphasized this, along with the importance of participatory decision making and focusing on the strengths of local populations (53). Communities need to be allowed to differ from each other (28) and compassion should be communicated. People's fears and concerns need to be acknowledged, and a sense of self-efficacy conveyed (3, 18, 21, 36, 56).

Community engagement in emergency risk communication should start long before an emergency occurs. Connection with community entities should be established and relationships of trust developed before a crisis, so that these networks of Ailles may be activated should an emergency occur (18, 21, 55). The importance of building on these existing relationships was noted in several documents (20, 55, 69). Two others expanded this to include recognizing and building on local organization (60, 70). The public should also be considered an ally to partner with (18, 21).

As far as specific forms of engagement were concerned, radio was identified as a particularly effective means of accessing communities (42) (20, 41, 43, 71), although De Roeck notes that if specific, limited groups are the target audience, broadcast media may not be the best choice for communication (24). House-to-house visits (35, 41, 43, 69, 72-74) and religious gatherings (43) were also found to be effective. Some reports found that door-to-door visits worked best, followed by the use of drama and dance (73, 74).

Another form of community engagement that has proven effective, especially in value-laden situations of an educational nature and where guidelines are being provided, is public deliberation. This involves recruiting an inclusive selection of community representatives, presenting the expert evidence and guidelines to them, then facilitating discussion and making decisions in a participatory manner (75).

How safety measures are implemented also effects their uptake. Richards noted that rural communities regret these measures (curtailing traditional handshaking and burial rituals), but they understood and were willing to comply, although they would prefer to be trained to do safe burials themselves (76), or at least have their traditions respected as much as safety protocols would permit (46).

Miller noted that attention must be paid to political realities, both historic and current (7). Political realities shape the landscape of relations between power structures and communities, including issues of mistrust. Community engagement efforts must bear this in mind or engagement efforts will be frustrated. Involvement of trusted local leaders is imperative (7, 36). Transparency is also important (77).

One report also listed school-based programs as an effective engagement strategy (78).

Barriers to community engagement

The grey literature identified several barriers to community engagement. DuBois noted that top-down communication, stereotyping and paternalism broke down trust, created fear and alienated communities whose support was critical to a successful response (62). Use of force or trying to force change was also counter-productive (48, 69, 73, 74).

Another barrier to successful community engagement and uptake of prevention messages was the failure to distinguish evidence-based messages (avoid contact with bodily fluids of infected and dead) from uncertain messages (eating bush meat). This was compounded by the apparent unwillingness of those issuing health messages to admit and explain their errors. Richards cited the initial ban on bush meat consumption to illustrate this, noting that the later change of this message was not explained, nor error admitted (46). Lack of message coordination further confused the issue (36).

It may also be possible that not all community engagement efforts are equally engaging or community led. Gautier noted that despite engagement with local leaders, shaking hands and respecting safe burial practices remained a challenge (73, 74). One could question whether this was due to the intervention still being top-down in that training was provided to community health workers and local leaders, rather than allowing the community to conduct its own assessment and devise their own solutions and protection measures. One report noted that the age (young) of the sensitizers may have negatively impacted the uptake of messages (74). It is unclear whether initial training was provided to both community health workers and local leaders together, or if training was provided primarily to (young) community health workers (CHWs), and only through them to community leaders. If the latter, this could have represented a continued failure to acknowledge, respect and work with local leadership.

Barriers to successful engagement and uptake of prevention measures may find their root in a quite different source. Both Gautier reports noted that lack of resources (gloves, boots, financing) hindered implementation of safe burial practices. Both state that more focus should have been placed on the practicalities of implementation (73, 74). Oxfam also noted the need for sanitation supplies, such as bleach, gloves, and boots (79), and Y Care noted that lack of funding impeded early response (41). These reports highlight that the success of behaviour change communication can be confounded by lack of resources. This does not necessarily mean the communication has been ineffective.

The less-settled ways of urban areas can make community engagement more difficult than in rural communities. One report noted that the absence of traditional community structures and organizations in urban areas made the work there more challenging (53). Richards fine-tuned this observation, noting that in rural communities, villagers had "face-to-face social knowledge" of Ebola – they could name everyone who has died or survived and trace the pattern. This and villagers "mutual accountability" helped them understand the necessity of safe practices in regard to the sick and dead. This knowledge and accountability are absent in urban areas where all are "strangers" (76).

Finally, the tone of communication with communities also mattered. When health workers "talked down" to community members, community members did not wish to interact with them and therefore avoided them and the health care facilities. Use of respectful speech by health workers and providing tours of health care facilities helped reduce fear and enabled improved engagement with communities (51). Other reports also emphasized the importance of treating people respectfully (55, 58, 68). This respect should include respect for their opinions (2).

Q10: What are the best social media channels and practices to promote health protection measures and dispel rumours and misinformation during events and emergencies with public health implications?

The grey literature covered in this rapid review offered little information about the best social media channels and practices for risk communication. Of the 20 documents included as potentially relevant, only two (2, 80) provided numbers, and even these numbers did not really indicate effectiveness. Other documents described uses of social media, but judging their effectiveness was difficult (81), as they took place in the context of a number of other simultaneous interventions. What these documents can do, is point the direction, showing what these new media forms may be able to do. Of the documents reviewed, two were from low credibility sources, eight from moderate and 10 from high.

That social media is being used is an accepted reality. During the Ebola outbreak, MSF's online and social media saw an upswing of use, as did their blogs and Facebook pages (17). WhatsApp showed use around Freetown in Sierra Leone (82). In New York City, social media was used to counter rumours when Dr. Craig Spencer tested positive for Ebola (83), and one study found that 87% of doctors in Brazil 87% use WhatsApp to communicate with patients, one of the highest rates of such use in the world (80). In West Africa, chat apps, especially WhatsApp, were considered better than SMS because they were cheaper. WhatsApp also proved useful in tracking rumours(36). Other new useful media tools included RapidPro and SMS systems (65). It was also found that social media is being used increasingly to monitor what the public is saying about public health issues (13).

SMS or text messaging was used successfully to track and combat rumours and to communicate with quarantined areas during the Ebola outbreak (21, 42, 43). In addition, a collaborative effort between BBC and WhatsApp enabled messages from WHO, UNICEF and the CDC to be channelled directly to 20 thousand subscribers, most of whom were in West Africa. The Sierra Leonean version of this channel had 15 thousand subscribers by the end of the outbreak (2). SMS was also used for real-time monitoring (84). Nigeria used mobile phones to disseminate Ebola messages (26), and the government of Sierra Leone chose WhatsApp as one of its official response channels (81).

One innovative feature of social media use during the West African Ebola outbreak was the way it enabled the Sierra Leonean diaspora to play a role in in-country social mobilization. Sierra Leoneans living abroad used Skype, Facebook and WhatsApp plus their in-country connections' smart-phone-enabled Internet access to share information about the outbreak. Facebook discussion groups were also created and used. Although at least initially, some members of the diaspora circulated rumours over social media, some also did their best to communicate accurate messages. Later on, members of the diaspora who were in health professions used social media to mobilize their in-country family, professional, business and political connections (81).

The communication potential of social media was perhaps best illustrated by Brazil, where phone use has overtaken television as the main form of media consumption. For good or ill, traditional media and social media are now equal partners in Brazil's media world (80).

But the news about social media was not all positive. One report listed social media as a source of Zika-related rumours, as well as a place for ministries of health and other public health bodies to post messages (16). This was also true for Ebola (81). And social media's apparent success in urban Sierra Leone should be balanced against the observation that most mobile phone use was concentrated in larger urban areas. Rural areas remained relatively isolated from social media's effects (81).

In addition, documents found that social media suffers from a credibility issue. Although in the United States, most people received Zika information via TV, radio, social media and blogs, the CDC and family doctors were considered the most credible sources (29).

Another challenge posed by social media was the difficulty in controlling messages. Once on the loose in cyberspace, video clips or other messages took on cyclical lives of their own, peaking, dying down, then resurfacing. This held true for rumours as well as official messages (80).

Nor did social media necessarily represent the best solution. One study found that people who used conventional media or government sources for their health information were more likely to be knowledgeable about Zika than were those who relied on friends, family or social media for health information (85). Another stated that despite the current trend of wanting technology to provide nearly magical solutions to problems, Ebola was a problem that was solved by "brute force", meaning the physical labour of sanitation work and the human contact of social mobilization. It found that, "No form of engagement was more effective than face-to-face discussion, and there are no technological short-cuts for safe burial and body management. This was not a crisis solved by new technologies and innovations, but by an enormous amount of human and other resources" (69).

These detractors, rather than showing that social media should not be pursued, serve instead as a reminder that conventional media still plays a dominant role in most health communication situations. One report expressed this well, advising that the concept of media be expanded to include social media (18). When it comes to getting messages out, both conventional and social media should be used, rather than just one or the other.

Q11: What are the best ways to communicate uncertainties to public audiences, at-risk communities, and stakeholders?

When discussing communication about uncertainties, the grey literature contends that how one communicates a message is nearly equally important as the message content itself.

When Nina Pham contracted Ebola after caring for Thomas Eric Duncan, a wave of fear swept the United States. Had communications been handled better, more in line with the best practices of risk communication, most of this fear could have been avoided. Two risk communication errors were made. First was the failure to communicate openly: no mention was made of the fact that Personal Protective Equipment (PPE) protocol had been breached. Second, scientists failed to communicate clearly about true risk levels facing average Americans at that point in time. Rather than clearly enunciating that no single case of Ebola had been transmitted by asymptomatic infected persons or by aerosol transmission, answers to such questions hedged on the one hand (asymptomatic cases) and speculated on the other (aerosol transmission). A frank answer that chances of such kinds of transmission were as near zero as is possible to get would have been better (86). Sources concurred that if uncertainties exist, they need to be admitted openly (13, 18, 21).

Conversely, the CDC's first communications expressed great confidence that there was no risk of American health workers contracting the disease. This over-confidence gave the impression of more certainty about Ebola than actually existed. It also ignored or silenced other, more cautious voices in the medical community, pretending to a consensus that did not exist (83). This violated one of the cardinal rules of communicating uncertainty: Admit it (18, 21, 83).

Another lesson about communicating uncertainty came from the messages concerning Ebola and the consumption of bush meat. Initially messages warning against touching dead bodies or body fluids and against eating bush meat were presented as equally important. Later the bush meat messages were discontinued, yet no explanation of this change was made (46, 47). This was counter to another principle of risk communication: If something uncertain has been communicated as certainty and then discovered to be incorrect, acknowledge and clarify the error.

In summary, when uncertainties exist, they need to be admitted openly and frankly.

A total of eight documents were identified as relevant to communicating uncertainties, one source was of low credibility, three of moderate, and four of high.

Q12: What elements and timing of messages are best at influencing public/community levels of concern to motivate relevant actions to protect health?

Twenty-one documents contained evidence pertinent to the question of message elements and timing that are best at motivating behaviour change, 12 from moderately and nine from highly credible sources. Of these, seven were Knowledge, Attitude, Practice (KAP) studies. Although their findings are relevant to their particular outbreak in their particular location, they are not necessarily generalizable. As such they are not discussed here.

The grey literature found that uptake of protective health messages was impacted by a number of different factors. One was where the messages were placed. It is critically important to know where people get their health information (85). Without this, even the best-crafted message may be wasted

by placing it where it will not be noticed. This should be assessed by target group, as media consumption varies greatly. Nor was the message medium the only concern.

Sources' credibility and trustworthiness also impacted the adoption of behaviour changes. Several documents found that invoking credible sources (18, 21, 87), or the opinions of trusted community leaders, family members or friends could influence behaviour changes (49). Use of survivor numbers and stories also encouraged behaviour uptake (20). One report noted that if experts were used, reference must also be made to their trustworthiness (21).

One document stated that information about risks needs to be communicated promptly so that people have time to make informed choices. It also should take place while debate is on-going. If one waits until a situation calms down, public attention will wander elsewhere. It also found that repeating messages frequently facilitates uptake (18).

Communities were more likely to accept and act on messages when the messages were practical (42) and tailored to their culture and circumstances (18, 20, 42, 43, 63), and when they had participated in the messages' development (42, 63). The uptake effect was amplified still more when the community assessed the outbreak themselves (43). A two-way process of communication and feedback increased messages' effectiveness, as did responding to people's fears (18, 21, 36, 42). One report emphasized that special focus should be directed to minority populations (18).

Two studies found that inconsistencies breed mistrust. If messages change over time, the reasons for the changes must be explained and puzzling elements clarified (18, 46). Communications need to be candid, open and honest and uncertainties need to be acknowledged (18, 21). Clear distinction should be made between messages that are evidence based, and those that are less certain (36). Messages should be coordinated (36) and communicate confidence while allowing for improved knowledge and changing circumstances (18, 21). Their effectiveness should be continually monitored so they may be improved and adapted as needed (66).

Capturing the imagination with story-telling and drama was also found to improve message uptake and implementation (36, 42).

The tone of messages was also found to be important. Messages needed to convey compassion, concern, empathy (18, 21), and self-efficacy (18, 21, 36, 49). They needed to be phrased in clear, non-technical language, preferably the local language. They should clearly state who should do what, where, when, how and why (18). Messages need to be framed in terms of the values of those who oppose the desired behaviour change. Opposition strong points should be worked into messages, along with appreciation of different points of view (18).

Finally, it was found that messages need to clearly state what the difference is between the crisis situation and a normal one (52). They also need to address perceived norms and positive and negative consequences (49).

Conclusion

Although yielding only sparse results in terms of studies and hard data, this rapid review of grey literature provided a wealth of contextualizing information, particularly in relation to community engagement, trust-building and message content. It also contributed background to interagency coordination, staff capacity and communicating uncertainties. The lack of results found for some questions, such as the integration of risk communication into national health plans, and sources of sustainable financing for risk communication, indicate a need for further implementation and documentation to feed back into the research process. At least in regards to sustainable funding for risk communication, progress appears to have been made: Several documents indicated that risk communication is now being allocated dedicated funding by some programmes. Although this does not represent sustainable funding yet, it still is a step in the right direction. The same holds true for

community engagement and other aspects of risk communication. The literature indicates movement toward greater recognition of this vitally important element of public health.

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