

FP7 – TELL ME: Note on the Ebola Epidemic in West Africa The Contribution of the TELL ME Project for Risk Communication in Europe. 7th November, 2014

1. Introduction

The current Ebola epidemic in West Africa is the largest ever documented. New cases are occurring at an increasing rate and control measures have had limited effects. Due to the mobility of the populations, infected people have already arrived in European countries and the USA. While the disease does not spread like respiratory droplet-borne diseases, infection can result from minimal contact with body fluids from infected cases. The high case-fatality rate makes it a greatly feared disease. Effective risk communication is essential in the control of the epidemic and to minimise the harmful effects of misinformation. In this regard, tailored communication strategies are required for informing the public and other major stakeholders on the risks of contracting Ebola and the preventive measures to be adopted.

While the WHO, the USA CDC, the ECDC and other international health organisations produce high quality materials to inform the public and the healthcare workers, it is not clear to what extent this information actually reaches the general public and other stakeholders and to what extent the information is understood. The EU funded TELL ME project is directed at elaborating and highlighting the advantages of effective risk communication in order to enhance the control of infectious disease epidemics and pandemics and minimize the risks of “adverse effects” during the outbreaks. One of the main questions posed in the project is phrased as follows: “What are the most appropriate communication methods to deal with complexity, uncertainty, ignorance, information asymmetries, overwhelming information, biased information, misinformation and malicious information?” This question is very relevant for the Ebola epidemic.

2. What is the TELL ME Project?

Since communication during infectious disease epidemics is of major importance in influencing behavior and reducing the spread of disease, public health communication should be directed towards influencing beliefs and standards rather than just providing information. In recent years the emphasis has moved from "one to many" type of communication to "many to many" communication. As a result, new communication strategies must be developed to mitigate the impact of major epidemics, taking into account globalization and utilizing new information technologies.

The TELL ME project was designed to answer three research questions:

1. How can the general population be persuaded through public health communication to take effective preventive actions during infectious disease outbreaks?
2. What are the most appropriate communication methods to deal with the complexity, uncertainty, misinformation and malicious information?
3. What are the best communication strategies to maximize compliance with vaccination, and to assist health professionals and agencies to cope with vaccine-resistant groups?

TELL ME relies on a combination of primary and secondary research, interviews and questionnaires with stakeholders, workshops, expert meetings, textual analysis, simulation software, scenario building and focus groups. The TELL ME project comprises five work packages (WPs). WP1 focused on collecting and assessing evidence about population behavioral response to infectious disease outbreaks, and about how communication may change behavior. WP2 identified new challenges and new methods, mapping relevant stakeholders and exploring the information needs for different groups. New social media and digital resources for disease detection and the global health security regime were evaluated. WP3 focused on developing a set of communication strategies to support health professionals, agencies, institutional actors and decision makers in communications with patients, vaccine-resistant groups and various populations. The main outcome of WP3 was an integrated, evidence-based communication package which includes major project outputs such as a new framework model for outbreak communication, a series of guidance documents for risk and crisis communications, an e-learning course for primary healthcare workers and a new health threat index. WP4 deals with the design, construction and testing a prototype of a computational method for simulating the actions and interactions of autonomous decision-making entities within a virtual environment during an epidemic outbreak. Results of each WP have been summarized in reports which integrate the results of each task within the WP. Results of the entire TELL ME project will be summarized in a final report which integrates the results of each WP.

3. The Ebola epidemic and risk communication

Michele Bellone (ZADIG) has published an article¹ on how TELL ME can contribute to the risk communication needs for the current W. African Ebola epidemic. The following are some abstracts from the article:

"Any infectious disease can become much more dangerous when supported by wrong or missing information. On the one hand, misinformation can spread far and fast, especially online, often crossing geographic borders before local organisations have ramped up their response to an outbreak. On the other hand, the lack of proper

¹ Michele Bellone- What Ebola taught us about risk communication-
<http://www.tellmeproject.eu/content/what-ebola-taught-us-about-risk-communication>

information about, for instance, how people get infected, may slow down efforts to contain the diffusion of the disease. The Ebola outbreak that is currently raging in West Africa has highlighted these issues."

In the article, the fear factor is described as having a number of components:

1. Fear of being quarantined, which could drive infected people away from the surveillance system or push them to hide their sick relatives
2. Fear of becoming infected by their own patients, which led healthcare professionals to refuse to go to work, thus depleting the already scarce health resources available
3. Fear of not being able to provide for food, due to the block and the strict controls across the borders
4. Fear of having been cursed, as, in some areas, Ebola is thought to be a product of witchcraft

Michele Bellone states that *"Fear is nurtured by both misinformation and lack of information. This is the very reason why an effective risk communication may help to save lives."*

The TELL ME consortium comprises experts in various aspects of risk communication and come from eight countries. They have collected and studied the existing evidence about risk and crisis communication during epidemics and pandemics². Their research suggests that risk communication requires a multi-layered approach that takes into consideration technological, cultural and social developments. They developed a Framework Model aimed at different sectors³, which translates concepts and theories into a practical approach that can be adapted to specific risk situations and serve as the foundation for a communication guide.

The model identified seven main components of risk communication and the inter-relationships between the public sphere, mass media, social media, opinion leaders and stakeholders. They have proposed that effective outbreak communication should be a dialogue between all these elements, with the public sphere at the centre. Acknowledging people's concerns is thus crucial in order to establish a link between them and the institutions, a link that may become a channel to be used to fight both misinformation and the lack of proper information. TELL ME experts highlighted the importance of "listening to the public", in order to acknowledge that public fears should not be disregarded as irrational. On the contrary, they should be taken into account when planning an outbreak communication strategy, in order to build trust with the authorities and avoid the generation of misinformation from the onset of the outbreak.

Members of the TELL ME consortium have stressed that trust in the authorities can be strengthened by establishing a presence on the media, especially on the social media. This creates a sense of community and encourages interactive communication, based on the exchange of information and opinions between individuals, groups and institutions. "Listening to the public" requires a combination of both "top-down" and "bottom-up" strategies. This is essential, since risk perception affects the risk analysis.

² <http://www.tellmeproject.eu/content/d17-population-behaviour-epidemics-summary-report>

³ <http://www.tellmeproject.eu/node/314>

4. Questions

Currently, we have identified a number of questions related the risk communication during the current Ebola epidemic:

1. What are the existing gaps in information about the Ebola virus?
2. What are the most common misconceptions and misinformation widely spread around Ebola in Europe?
3. How can we reduce stigmatization of "foreigners" particularly from Africa?
4. How do we inform the public on the issue of healthcare workers returning and the possible need for quarantine?
5. How do we communicate issues related to the ethics of trials of the treatments and vaccines?
6. How do we explain the ethical aspects of setting up special treatment centers with improved care for healthcare volunteers in affected areas?
7. How do we explain the efficacy (or lack thereof) of screening travelers from affected countries at points of entry into other countries?
8. How do we deal with demands for excluding from schools pupils who originate from affect areas?
9. How do we communicate the low risks of being infected by healthcare workers returning to work after returning from infected areas?
10. How do we communicate to the public the level of preparedness of healthcare centers for admitting and safely caring for Ebola patients?
11. How do we communicate to the public the ways in which Ebola spreads?
12. How do we use communication to increase the public trust in the authorities managing the Ebola epidemic?
13. How do we increase transparency between the authorities and the public?
14. How do we use communication to increase trust in the pharmaceutical companies?
15. How do we reach the general public to correct popular misconceptions about the Ebola virus?
16. What methods do we use to counter misinformation spread online about Ebola?

5. The contribution of the TELL ME project to the current Ebola epidemic

5.1 The overall aims are:

1. To minimise the impact of the Ebola epidemic on Europe
2. To keep the public well-informed about the epidemic and its associated risks
3. To enhance the alertness for possible imported cases, avoiding at the same time "artificial" fear and panic
4. To reduce the possibility of stigmatisation and discrimination of immigrants/refugees/tourists in general and from areas affected by Ebola in particular

The TELL ME consortium has produced several products resulting from intensive discussions between experts in various aspects of risk communication for infectious disease crises:

1. Literature reviews, commentaries, description of a theoretical model and a compilation of communication guidelines for professionals in the field of public health^{4,5,6}
2. An online course for medical practitioners⁷
3. Surveys to assess the public's understanding of the disease and its spread
4. Development of a group of experts who can assess the different communication strategies
5. An agent-based simulation program.⁸

5.2 How can this be applied to the Ebola epidemic?

1. Supply the extensive documentation from the project to relevant risk communication groups
2. Adapt selected documents to be relevant for the Ebola epidemic
3. Carry out desk-based research, online surveys and focus groups to identify gaps and misinformation
4. Act as an advisory group to departments responsible for risk and crisis communication, we have developed a strong group on different aspects of communication during infectious disease crises and we could provide considerable expertise as consultants.
5. Assess communication strategies being used in Europe to inform different target groups on the Ebola epidemic and what is expected from the public. Identify gaps in communication

6. Stakeholders for the Ebola epidemic

The relevant European stakeholders in the Ebola epidemic are:

1. The general public
2. Transport authorities
3. Border control authorities
4. Healthcare authorities and institutions
5. Media/Journalists
6. NGOs
7. Community leaders

⁴ <http://www.tellmeproject.eu/content/d17-population-behaviour-epidemics-summary-report>

⁵ <http://www.tellmeproject.eu/content/d31-new-framework-model-outbreak-communication>

⁶ <http://www.tellmeproject.eu>

⁷ <http://www.tellmeproject.eu/node/300>

⁸ <http://www.tellmeproject.eu/content/d42-software-design>

7. Methods

1. Identify the communication needs of the public and the various stakeholders in Europe
2. Provide the TELL ME framework model for developing improved risk communication
3. Provide online technologies
4. Provide guideline documents
5. Provide guidelines for the use of the social media
6. Provide guidelines for reducing stigmatisation
7. Identify the different media suitable for transmitting messages
8. Monitor the social media for content on the Ebola epidemic to assess the public's communication needs

8. Responsibilities

1. Partners in the TELL ME consortium (give specific names and tasks)
2. WHO, ECDC, CDC (what do we need from them?)
3. Stakeholder - defining their needs (how do we obtain this?)

9. Monitoring of the impact of the communication strategies

1. Monitor the impact of the communication strategies (surveys, focus groups)
2. Supply the methodology and carry out surveys

10. Resources

The TELL ME consortium does not have specific resources for carrying out the different tasks mentioned above. We can act as advisory group for others, or if additional resources were to be provided, we can possibly carry out the tasks.