New communication strategies for preventing misinformation

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Contents

Section 1 -
Executive summary
pp 4-9

Section 2 -
The anatomy of misinformation in 21st century outbreak communications
pp 10-13

Section 3 -
Mapping the origins and sources of misinformation
pp 14-23

Section 4 -
Where does it all start? The “incubation process” of misinformation
pp 24-35

Section 5 -
Why so persistent? The sticky effect of misinformation and medical myths
pp 36-43

Section 6 -
The importance of preventing misinformation from transforming into common knowledge
pp 44-49

Section 7 -
The critical role of opinion leaders to control the spread of misinformation
pp 50-53

Section 8 -
Strategies for prevention and response to misinformation in the course of a major infectious disease outbreak
pp 54-67

Section 9 -
Bibliography
pp 68-71
Section 1

Executive summary

Scope
pp 6

Aims
pp 7

Methodology
pp 8

Target audience
pp 9
It is common in situations of an emergency to have messages being distorted and misinterpreted for various reasons. These include inconsistencies in the language used to communicate complex messages, the existence of information gaps, shifts in communication priorities as situational factors change according to new information made available, public perceptions based on prior experiences, and so forth. In addition, more recent advancements in the field of information-communication technologies (ICT) and the establishment of new social media as a key component in the process of risk and outbreak communication, simply adds another layer of complexity for public health authorities and officials in the communications field. This is due to specific features and functions of social media, which can create a distorted mirror effect where important information may be modified and/or misinterpreted, while misleading or erroneous information can appear to be sensible, if presented convincingly.

The present document takes a specific focus on issues related to the emergence and spread of misinformation and rumours, within the wider outbreak communications environment and across the four pandemic phases (inter-pandemic – alert – pandemic – transition), as specified by the World Health Organization (WHO). While the original intention was to develop guidelines for preventing misinformation within the boundaries of influenza pandemics, it was decided to extend the scope of this document to cover infectious diseases where both preventive (e.g. social distancing) and protective (e.g. vaccination) measures are likely to be introduced.

Methodology

The recommendations and guidance is largely based on the findings identified following a comprehensive exercise carried out in the context of the TELL ME project\(^2\), which included a broad study of population behaviour during major epidemics and pandemics (Work Package 1), and the investigation of emerging challenges and new methods for outbreak communication (Work Package 2). Furthermore, this document builds on the concepts and elements introduced in the TELL ME Framework Model for Outbreak Communication\(^3\), such as the use of a participatory approach to outbreak communications planning, the role of opinion leaders and the use of social media to reach target audiences.

Target audience

This guidance document is intended for public health officials, communicators or professionals with a role in the development and implementation of communication strategies during major infectious disease outbreaks.

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\(^1\) The TELL ME project. Accessible at [http://tellmeproject.eu/](http://tellmeproject.eu/)

\(^2\) TELL ME Deliverable D3.1 New framework model for outbreak communication. Available from [http://www.tellmeproject.eu/content/d31-new-framework-model-outbreak-communication](http://www.tellmeproject.eu/content/d31-new-framework-model-outbreak-communication)
Section 2

The anatomy of misinformation in 21st century outbreak communications

It is a widespread notion that the revolution in the information-communication technologies (ICT) field epitomised modern society. In essence, new communication technologies aspire to satisfy an innate desire for humans to know more about their immediate environment, and to overcome ignorance or stereotypical views about the world – mostly at socio-cultural or political level. Because of the advancements in ICT, national borders have been virtually removed, while new pathways have opened for cooperation on a global scale, considering the “single-click” speed by which information can travel. Most importantly, the world experienced a radical transformation in the landscape of communications, in direct consequence of information becoming more dynamic in nature and less confined to the boundaries of institutional mechanisms or structures.

Information and communication are two inseparable concepts, embedded in each other at their core. Any process that contains the element of communication implies availability and sharing of information. For instance, the World Health Organization (WHO) defines risk communication as “an interactive process of exchange of information and opinion on risk assessors, risk managers, and other interested parties”\(^4\), while crisis communication is “concerned with transferring of information to significant persons (publics) to either help avoid or prevent a crisis (or negative occurrence), recover from a crisis, and maintain or enhance reputation” (Fearn-Banks, 2007; p. 2). While communication can be defined in explicit terms as a process, the meaning of information is rather implicit. In essence, information can be described as a signal or a stimulus transmitted that could reach intended and unintended recipients. Information is a message that requires the recipient to decode based on additional contextual parameters accompanying that message.

Etymologically, the word “information” traces its roots in the Latin word forma [:form], and more specifically the verb formare, which means to give shape, to form. This would seem to apply in the context of major infectious disease outbreaks, where information transmitted by public health authorities, the media and the public can actually shape (or influence) perceptions and behavioural responses to an outbreak. In the more recent potential and actual epidemics (e.g. H7N9 influenza, MERS-CoV, Ebola Virus Disease), we have witnessed the unstoppable pace by which information can spread and the distances it can reach, especially through online media and internet-based communication channels. We have also witnessed a form of deinstitutionalisation of information in the sense that information escaped the conventional one-way route of transmission from public health authorities to the public, to become more of an instrument used in online communications for people to satisfy the need to communicate, to connect, to share information and know more about what happens in other parts of the world. Nowadays, information has become less of a commodity; belongs to no one and is in the hands of everyone.

This attempt to conceptualise information would be incomplete without considering another layer that is particularly important in the context of outbreak communication. It has to do with the general assumption that information is true, and is projected in that way during communications. But what happens in the case where a statement or message does not conform to someone’s established perception of reality? Or when information is misinterpreted and appears wrong or misleading due to some contextual factors, relevant to quality, format, amount and source of information? As much as accurate and timely information is imperative in the outbreak communication process to achieve a successful intervention, the diffusion of false and inaccurate information could have the exact opposite effect.

This document focuses on misinformation, i.e. the unintentional spread of erroneous or inaccurate information, which could have a major and direct impact on perceptions and attitudes toward public health measures related to an infectious disease outbreak, with the effect of creating delays in response, spread of damaging rumours, inadequate resource allocation, misdirected efforts, and ultimately, unnecessary loss of life. In contrast to disinformation, where there is deliberate spread of false information with the aim to serve or protect private interests by evoking certain reactions. Misinformation is more a consequence of contextual factors which prevent the information or message from arriving intact and clear to the recipient. There are multiple sources from which misinformation can be generated and spread in the event of an outbreak (for different reasons), including the mass media, internet-based communication channels, public health authorities and the scientific community, to name but a few. Despite the source, however, the outcome remains the same; the emergence of misinformation can intensify scepticism, influence the decision-making process and lead to indifference or resistance toward recommended protective measures, particularly with regards to prophylactic measures, such as social distancing and vaccination.

As an extension of the above, misinformation can have serious consequences both at individual and community level. Misconceptions about the mode of transmission of a virus have been associated with heightened emotional distress, and can lead to potential proliferation of panic for entire communities (Lau et al., 2009). This highlights the importance of public health authorities providing clear and consistent information and updates about the disease, as well as the need to continuously assess whether the messages are being received intact and understood within the community (Lau et al., 2009).

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Section 3

Mapping the origins and sources of misinformation

Public health authorities
pp 17

Mass media
pp 17

Social media and internet
pp 18

Scientific community
pp 19

Industry
pp 20

Medical myths and rumours
pp 20

Literary fictions and films
pp 21-23
In the context of major infectious disease outbreaks that receive wide news coverage and generally spur public interest, the emergence of misinformation inevitably makes its appearance from an early phase of an outbreak. The rapid sequence of events that unfold over a short period of time makes it difficult to filter the relevance, importance or quality of information that is made available from a number of different sources, whether these are official statements from public health authorities or personal accounts and reflections presented by people who are directly affected by the outbreak.

At the outset of an infectious disease outbreak, the state of communications is most unstable due to heightened public emotions and limited availability of scientific evidence from which to draw conclusions, which in turn gives room for the emergence of tenuous criticisms, speculations and rumours, mostly relevant to issues around vaccination. At the time when people need clear-cut information and reliable guidance to help them develop a better understanding concerning the outbreak, it is usually the exact same period where people are bombarded with information in the form of opinions expressed by a number of experts that suddenly flood the media, the breaking news with correspondents from the field and personal stories and experiences shared with a click of a button.

It should be noted that the presence and origins of misinformation extend beyond the visible boundaries where communications and exchange of information take place during the time of an outbreak. There is another – more implicit – level, where misinformation concerning infectious disease outbreaks and preventive measures trace its roots back to urban myths and misconceptions that were formed in the past, but have been established in the conscience of people as facts with the passage of time. Finally, the role of literary fiction and films on infectious disease outbreaks should be acknowledged as another source of misinformation, not only influencing behavioural responses towards the disease or suggested preventive measures, but also with regard to expectations and understanding of public health authorities’ roles and responsibilities in times of an emergency.

Based on the available scientific literature, this section identifies potential sources and origins of misinformation, specific to major infectious disease outbreaks, whose presence can lead to distortion and misapprehension of public health messages, and influence perceptions and the decision-making process for individuals, especially with regards to adherence to medical recommendations and adoption of preventive measures.

Public health authorities

It may seem like a paradox, but dissemination of misinformation can have their origins in public health authorities’ method and style of communications in the initial phases of an outbreak, when efforts are made to transmit an overall sense of reassurance and control over the situation, avoiding at the same time making any statements that could raise alarm in the general public. At other times, public health authorities keep a reserved stance in the face of uncertainties, especially with regards to the type and level of information being disclosed to the general public, either due to missing input from experts or simply in order to avoid criticisms about possible overestimation or underestimation of risk. As highlighted in the TELL ME Framework Model for Outbreak Communication, silence by public health authorities cannot be an option, since missing information and communication gaps can easily evolve into misinformation (Myers & Pineda, 2009).

Public health authorities can also become a source of misinformation due to situational factors, especially due to external pressures. This could occur when there is a need to make an official statement or to take action on the basis of risk assessments, despite unverifiable information or limited evidence, which later proves to be erroneous, consequently requiring corrective action to be taken in response.

Mass Media

Traditionally, mass media (i.e. TV, radio, newspapers and magazines) are associated with the spread of misinformation, since the need for timely news coverage inevitably produces some inaccuracies in reporting. According to Lewandowsky et al. (2012), there are several systemic reasons to explain why mass media constitute a source of misinformation. Most importantly, there is a tendency by the mass media to oversimplify or misrepresent scientific results in an effort to capture the attention of that portion of the audience with limited interest in scientific data. Additionally, in the case of TV or radio broadcasts journalists often aim to present a “balanced” story, however it is suggested that in some cases the outcome can be highly misleading due to the “asymmetric” choice of experts selected to take part in debates.

1 TELL ME Deliverable D3.1 New framework model for outbreak communication. Available from http://www.tellmeproject.eu/content/d31-new-framework-model-outbreak-communication
New communication strategies for preventing misinformation

Social media and internet

The case of the social media and internet is somewhat different to the role of mass media with regards to the spread of misinformation. Although the internet and widespread use of social media (especially Twitter) have revolutionised the availability and sharing of information at international level, at the same time the spread of misinformation has been facilitated in the absence of conventional peer review or “gate-keeping” mechanisms, such as professional editors (Lewandowsky et al., 2012). The interactive nature of social media and the fact that everyone can actively generate (and access) content through different communication channels (e.g. websites, blogs, Twitter, YouTube etc.), increase probabilities for the spread of misinformation online, due to the overflow of subjective views and interpretations of factual information presented by the authorities.

The internet can be a valuable resource for people seeking to keep up-to-date and well-informed about the course of an outbreak, however the quality of health information retrieved online is extremely variable and difficult to evaluate. It is a common practice for people to use an online search engine (e.g. Google, Yahoo etc.) to locate information and have questions answered, but these search engines are limited to identifying relevant websites whose reliability of content cannot be determined. Lewandowsky et al. (2012) note that the internet (and social media, as an extension) can be considerably misleading, and to some extent online resources progressively start to replace expert advice from official and well-established sources of information, including healthcare professionals and public health officials. Due to the fact that the internet offers a vast selection of different sources for someone to retrieve information from, and considering that people generally seek to confirm their already established opinions over an issue, it has been made much easier to find these sources, which may be untrustworthy but support existing views, a phenomenon known as selective exposure (Prior, 2003). Particular reference should be made to online videos as an effective and popular means of spreading misinformation and rumours in the event of an outbreak. It is characteristic that following the H1N1 influenza pandemic, a study revealed that almost 1 in 4 videos uploaded on YouTube during the time of the outbreak, presented viewers with misleading information (Pandey et al., 2010).

Scientific community

The scientific community can be considered as another potential source of misinformation during infectious disease outbreaks, due to the extensive use of technical language in the description of characteristics of the outbreak. In their work on misinformation about vaccines, Myers and Pineda (2012) provide a list of examples where scientific terms used by experts can be misinterpreted by the general public. An example is the use of the expression “vaccine adverse event” to describe something that has occurred temporally related to vaccine administration, which may or may not be caused by the vaccine, whereas many misconstrue that term to mean "vaccine side effect".

Additionally, the approach adopted by many academic scientists to carry out initial risk assessments and publish research findings from the early phases of an outbreak, can also lead to unintentional spread of misinformation or generate misconceptions about the seriousness of the outbreak, either due to the lack of sufficient epidemiological data to support a hypothesis or because of some intuitive judgements made by recognised experts in the field. The fact that no absolute truths exist in the field of scientific research, eventually sets the arena for different and conflicting views to be expressed by scientists, which contributes to generating more confusion and uncertainty from the perspective of the general public.

Healthcare professionals also form part of the scientific community, and traditionally have been regarded as trustworthy and reliable sources of information. However, healthcare professionals can also become another potential source of misinformation. This is particularly the case when healthcare professionals are approached by their patients and asked to provide expert advice about an issue for which they are uninformed or their information is incomplete. Another characteristic of healthcare professionals is the lack of available time to fully engage in discussion with concerned patients or parents about issues around vaccination, and any uncertainties or doubts not effectively addressed could evolve into misinformation spread among individuals.
New communication strategies for preventing misinformation

Industry

Different industrial sectors can be negatively affected by the spread of misinformation following the emergence of an infectious disease on a large scale. This includes the pharmaceutical industry, the transportation sector and tourism industry, to name a few. However, these sectors can also constitute a source of misinformation, by holding back some information or communicating messages that are misleading in order to secure their interests, which are not always in line with recommendations made by public health authorities in the event of an outbreak.

Medical myths and rumours

Medical myths are characterised by their persistence to surface again and again during infectious disease outbreaks, in which case it could be argued that misinformation, partly, has its origins in those myths. On several occasions, medical myths appear in the form of personal stories and may seem to be plausible in the absence of scientific evidence or any official response to discredit certain claims. Individual misconceptions about an infectious disease or the necessity to take up preventive measures can also have their roots in urban myths that circulated at some point in the past, within the context of another infectious disease outbreak.

 literary fiction and films

According to Lewandowsky et al. (2012), works of fiction can give rise to lasting misconceptions for people, and such effects of fictional misinformation have been shown to be stable and difficult to eliminate. Particular attention is drawn to the case where literary works of fiction or films pretend to accurately portray science based on extensive research, however they fail to do so in some respect. A recent example would be the 2011 film Contagion, with inaccuracies being reported from the perspective of public health officials’ response to the outbreak, and certain procedures followed to develop a vaccine to contain the virus.8

Literary fiction and films share some characteristics with urban myths and rumours. First, they use some factual information as point of departure to construct their narrative, which makes it difficult for the reader or viewer to distinguish between valid and inaccurate information. Second, in the cases where misinformation presented as part of a story is consistent with prior erroneous beliefs over an issue that an individual may have, then misinformation would be accepted as valid information. Finally, in the event of an infectious disease outbreak, static misinformation deriving from works of fiction can resurface as misconceptions, yet appearing to the individual as actual knowledge.

Figure 1 overleaf: Possible sources and origins of misinformation in the event of an outbreak.

New communication strategies for preventing misinformation

- Public Health Authorities
- Scientific Community
- Industries
- Social Media
- Rumours
- Traditional Media
- Literature
- Fiction and Films
- Popular Myths
- Family
- Friends
Section 4

Where does it all start? The “incubation process” of misinformation

Misinformation in-between scientific uncertainties and information overload
pp 27-33

Approaches to reporting scientific uncertainties
pp 34-35
The appearance of misinformation and rumours during major infectious disease outbreaks and issues surrounding vaccination can be attributed primarily to communication aspects at the early (alert) phase of the outbreak. In particular, from the onset of an infectious disease outbreak, international public health authorities are expected to provide critical and timely information – in the form of official announcements or press releases – and carry out initial risk assessments about clinical and epidemiological data, including modes of transmission, level of severity and geographic spread of the virus. According to the World Health Organisation (WHO), announcing early constitutes a best practice in outbreak communication (WHO, 2005). However, there are two potential problems identified – and solutions offered – in the case of early announcements (WHO, 2005; p. 3):

- Rapid announcements may surprise important partners who might disagree with the initial assessment. This can be minimized by having well-established communication pathways in place among key and predictable stakeholders.
- Early announcements are often based on incomplete and sometimes erroneous information. It is critical to publicly acknowledge that early information may change as further information is developed or verified.

In the case of major infectious disease outbreaks, early announcements set the scene and trigger a process for misinformation and rumours to emerge, since conditions of urgency can seriously affect the quality and flow of information, while the release of misinformation takes the form of a snowball as more actors progressively get involved in the communication process.

Misinformation in-between scientific uncertainties and information overload

The departure point for possible emergence of misinformation and rumours are scientific uncertainties about a novel or re-emerging infectious disease. Any efforts to share uncertainties with the general public in a context where the general assumption is that public health officials should be in a position to know, can raise concerns and generate mistrust towards recommendations and specific measures taken by the authorities. Misinformation may be generated not only as a direct result of scientific uncertainties per se, but also depends on the method of communication and how these uncertainties are handled by the authorities. Thus, it is important to consider and evaluate at a secondary level the role and contribution of scientific experts in the process, who are often reluctant to share uncertainties with public health officials and decision makers who actually need this kind of knowledge. This reluctance results from a desire to avoid possible criticisms or become misinterpreted in their estimations about the outbreak. In essence, scientific uncertainties are about probabilities and risks, so it is not enough for public health authorities to simply acknowledge any uncertainties, but demonstrate control over these uncertainties and explain the way responses become tailored based on expert advice and probabilities, so that misinformation and rumours cannot be generated in this direction. In the opposite case where scientific uncertainties remain concealed for a significant period of time following the outbreak, there is a greater possibility also for conspiracy theories to emerge, which can be very difficult to discredit afterwards.

It could be argued that any uncertainties openly expressed by official sources implies a weakness of scientific evidence and the need to gather more epidemiological data or to analyse other contextual factors, before the next official statement or announcement is made. A lack of evidence can make the authorities have silent intervals and consequently create some information gaps, at which time many aspects of the outbreak remain open to interpretation, while multiple scenarios about the disease start to take shape in internet blogs, forums and social media platforms. Again, the role of the scientific experts involved in the evaluation of the outbreak is pivotal at this stage, since information gaps can be a direct product of scientific experts’ scepticism and delayed disclosure of information or uncertainties to public health officials and decision makers. These information gaps are important for groups of stakeholders that progressively become engaged in the communication process, namely representatives from the scientific community and the traditional mass media. On the one hand, people representing the scientific community may become a source of misinformation due to premature assumptions made about the outbreak, with the limited information they have on their disposal.

\(^9\) According to Lipsitch et al. (2009), there are two main sources of uncertainty that critically affect severity estimates and makes it difficult to provide an assessment with confidence. The ratio of severe cases is overestimated in the occasion where a considerable amount of mild cases is not reported or tested, as public health officials may become unable to test a large fraction of suspected cases. In contrast, severity estimates are biased downwards when there is a calculation as a function of a simple ratio of number of deaths to the number of reported cases.
On the other hand, the existence of information gaps can lead to speculation or generation of misleading information from the media, affecting public perceptions about the risk which is amplified with the systematic use of figurative speech and overstatements to capture people's attention. As suggested by TELL ME deliverable D1.2, there is an information mismatch presented at the very beginning of any type of crisis, since the information needs of different actors and organisations involved progressively in the process, exceed the information that can be made available by official organisations due to the uncertainties described earlier (see Figure 2).

The presence of scientific uncertainties and information gaps during the initial phases of an outbreak, often leads to conflicting messages mostly as a combination of different opinions and positions expressed by experts from the scientific community, and the approach made by traditional mass media with regards to the coverage of the story. It is a common practice in news reports about vaccine safety or vaccination issues in general, to host the views of scientists, healthcare professionals and self-proclaimed experts, as well as some personal stories of people. The last takes the form of an investigation based on testimonials from those who wish to share their concerns or influence the perception of others by providing subjective arguments on the risk of vaccination. On such occasions, it is not uncommon for journalists to also assume the role of an expert on scientific issues related to public health to provide a more convincing story.

Depending on the media hype created over an infectious disease outbreak, the probabilities for emergence and widespread dissemination of misinformation increases when individuals make the passage to active information-seeking behaviour, with the utilisation of internet-based communication channels as primary sources of information. The online environment hosts an infinite number of resources, positions, opinions and perspectives, of varying degrees of accuracy and credibility. Combined with media reports and comments on the public health authorities' response and official announcements on the outbreak, individuals eventually become subject to information overload which creates a serious risk for misinformation since there is insufficient time to assess the validity, accuracy and usefulness of each piece of information posted online. Information overload can generate confusion, but most importantly repeated and unfulfilled scares can lead to indifference, apathy and mental exhaustion (Strother, Ulijn & Fazal, 2012), in which case messages and communications about personal protective measures and vaccination become particularly difficult to reach individuals at the time of the actual crisis.

Figure 3 overleaf: Critical aspects for the emergence of misinformation and eventual side-effects.

More information is presented in TELL ME Deliverable D1.5 Narratives and urban myths. Available from http://www.tellmeproject.eu/content/d15-report-narratives-and-urban-myths

Information overload has been described by E. Rogers (2003) as “the state of an individual or a system in which excessive communication inputs cannot be processed and utilised, leading to breakdowns”(pp. 368-369).
In the era of new digital media and advanced information-communication technologies, people have developed a need for immediate answers to any issue of interest or concern, as part of the “technological promise” to have information available whenever, wherever and however one desires. What constitutes to be informed or to be kept informed during the course of an infectious disease outbreak varies with the actual information needs and communication requirements of each person. In addition, public health authorities’ interpretation of what the perceived information needs are or what the general public should know about in different phases of an outbreak, given that priorities and information needs change as the pandemic unfolds, is a contributing factor.

As a general rule, it should be the needs and concerns of the general public that drives the process and shapes the content of communications. For instance, the audience may desire simple instructions or they may be looking for a range of information on which to make independent decisions, and instead may be the recipients of sophisticated epidemiological information about disease patterns or assessments on the quality of public health response and accountability issues. Obviously, any kind of information has its own value, but it requires evaluation for its relevance in different phases of an outbreak.

The TELL ME Framework Model for Outbreak Communication suggests that during the early phases of an outbreak, communication gaps and silence from the part of official organisations and public health authorities can set the stage for misinformation and rumours to emerge. Indeed, as cited by WHO (2005) in their outbreak communication guidelines, keeping an outbreak hidden from the public is almost impossible and it is therefore recommended that early reporting by health authorities will help to prevent rumour and misinformation (WHO, 2005a). However, as has been highlighted in previous sections, special attention should be given to the fact that misinformation can also occur as a result of the information overload when different actors start to become involved in the communication process. To this end, internet-based communication channels and mass media not only contribute to the information overload, but also provide the arena where conflicting – and often distorted – information is presented.
As has been highlighted by TELL ME deliverable D1.4\(^1\), although two-way communication is listed as a strength of social media, this can also be used negatively to further perpetuate misinformation. It is relatively easy for messages to get distorted or to be used out of context. For example, in popular social media platforms such as Twitter or Facebook, with each “retweet” or “share” the original message can potentially be modified or added to according to the user. While the initial source of information will remain the same, the commentary/interpretation on such initial source of information can be altered drastically. From the side of public health authorities, it is crucial that any information presented in relation to an outbreak is clear and precise in content, without leaving any gaps or room for interpretation since it is common practice for people to infuse personal traits and beliefs in the dissemination of information or messages.

While population demographic characteristics (e.g. education, religion, language etc.) and cultural factors can influence the interpretation of information and messages that circulate in the event of an infectious disease outbreak, it is important to delineate at this point the different type of information provided by public health authorities at early phases of the outbreak, which can possibly trigger the spread of misinformation and rumours, in the presence of communication gaps and inconsistencies or in the absence of key information which correspond to the actual communication needs of the general public (see Table 1).

Figure 1 overleaf: List of possible information gaps and uncertainties that can generate misinformation and rumours.

<table>
<thead>
<tr>
<th>Key information</th>
<th>Critical aspects that may contribute to the diffusion of myths and misinformation</th>
</tr>
</thead>
</table>
| Signs and Symptoms | • No information on how to detect early signs of the disease  
• No information about the incubation period  
• Lack of evidence about actual symptoms  
• Misidentification of symptoms  
• Reported symptoms are non-specific  
• Reported symptoms are similar to other infectious diseases |
| Transmission | • Uncertainty about the origin of the virus  
• Uncertainty about the mode of transmission, e.g animal-to-human, human-to-human  
• Uncertainty about how the virus spreads  
• Misapprehension/Confusion over some terms, e.g. “bodily fluids, direct contact” |
| Risk of exposure | • Limited availability of epidemiological information on disease attributes, e.g. infectivity, virulence  
• Limited availability of information about environmental determinants of disease  
• Uncertainty about which population segments are more susceptible to the disease |
| Prevention (Non-pharmacological measures) | • Lack of evidence on the effectiveness of recommended measures  
• Information overload regarding recommended measures for prevention  
• Cultural factors that influence compliance with recommended measures or interpretation of messages  
• Excessive use of authoritarian language in the communication of messages |
| Prevention (Vaccination) | • Uncertainty about vaccine efficacy  
• Uncertainty about vaccine safety  
• No information about possible vaccine side-effects  
• No information about vaccine ingredients  
• No information about testing methods used  
• No information about how to find out more about the vaccine |
| Geographic spread | • No information about the spatial distribution of the disease  
• Inconsistencies in reporting of new cases elsewhere in the world (false alarm) |

\(^1\) TELL ME Deliverable D1.4 Vaccine acceptance and refusal to vaccination. Available from http://www.tellmeproject.eu/content/d14-report-vaccine-acceptance-refusal-vaccination
Approaches to reporting scientific uncertainties

The early phase of a major infectious disease outbreak is perhaps the most delicate to handle from a communications’ perspective, since misinformation and rumours can become generated in the absence of available scientific information and spread fast via different communication channels such as mass media and social media. Therefore, it is paramount that any uncertainties in relation to an outbreak are put in the proper dimension and context, in order to establish a relationship of trust with the general public and successfully implement a communication strategy.

Public health officials with a decision-making capacity need to convincingly demonstrate the rationale and legitimacy of decisions taken for the reduction of threat posed by an outbreak. To achieve this, a key part in the process of communications and development of messages for the general public is the transfer of knowledge and views expressed by public health experts who operate both at national and local level. According to Fischhoff (2012), “scientists are often hesitant to share their uncertainty with decision makers who need to know it”. The following recommendations highlight a few points of consideration for public health officials and communicators to ensure that uncertainties can be reported in official statements without the fear of generating speculation and misconceptions from the side of the general public when communications take place.

#1: Organise regular meetings with representatives from the scientific community and public health experts to delineate qualitative characteristics of existing uncertainties and deepen discussions around issues where opposing views are expressed.

#2: Explain the importance of disclosure of uncertainties to the general public as part of an effective communication strategy, and specify how these uncertainties are to be presented in the process of developing messages for different sub-populations and at-risk groups.

#3: Obtain a clear view on probabilistic parameters presented for the transmission of the virus and make independent evaluations on scientific grounds about which information would be crucial to release at which phase in support of a public health message to promote a protective action.

#4: Take note of semantic aspects in the development of messages as similar expressions or words (e.g. “we can estimate...”, “we can predict...”, “we suppose...”) to convey uncertainty may evoke different reactions or perceptions in respect to the value of the message.

#5: Determine what other contextual factors need also to accompany the message such as the reasons why and under what circumstances these uncertainties occur.

#6: Once a message has been produced that contains an element of uncertainty, have it evaluated by a group of public health experts to understand whether the message creates any possibility to be misinterpreted or be misleading.
Why so persistent? The sticky effect of misinformation and medical myths

Characteristics and continued influence of misinformation over time
pp 38-42

Recommendations for the retraction of misinformation in outbreaks
pp 43
Characteristics and continued influence of misinformation over time

This analysis of misinformation related to infectious disease outbreaks continues with a common observation which concerns the remarkable persistence of misinformation and medical myths over time, despite the overwhelming evidence presented by the scientific community and efforts made to correct these misconceptions as they often make their (re)appearance at periods of considerable uncertainty, suspicion or concern about an outbreak that receives global attention. In the first instance, this persistence on reappearance of medical myths can be attributed to stereotypical views and established misconceptions among the general public about the mode of transfer of a virus or the effectiveness of pharmacological and non-pharmacological interventions.

TELL ME deliverable D1.5 provides a list of misinformation and myths that circulated at the time of the more recent influenza pandemic, retrieved by various sources and divided into sub-categories according to their content (see Box 1 overleaf).

Box 1 overleaf: Misinformation and myths that appeared during the 2009 influenza A(H1N1) pandemic.

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Misinformation and myths in relation to the influenza virus

PERSONAL CONCERN

- The swine flu is just a bad cold / The swine flu is annoying but harmless / The symptoms are like the seasonal flu.
- This is a mild flu, death rates are lower than seasonal flu.
- It is unlikely for healthy adults and young people to get the swine flu.
- The swine flu can prove to be dangerous only for the elderly / pregnant women.
- The swine flu does not pose a major threat for children over 5 years old.
- The swine flu is transmitted by pork products / Someone could catch the swine flu by simply being around pigs.
- By shaking hands with people, one could spread/get the swine flu.
- Only those who live in cold weather regions can get the swine flu.
- Immunity is conferred by contracting the swine flu.
- A person cannot get the flu twice during the same season.
- It is better to get the swine flu at early stages while the symptoms are mild, than risk catching it later or getting vaccinated.

GENERAL CONCERN

- The swine flu is man-made.
- The swine flu was intended as a weapon of mass destruction.
- The swine flu is an excuse for mass vaccination.
- Governments wanted to create a global crisis.
- Governments wanted to use the H1N1 strain as beta test / a biological warfare agent.
- Once this pandemic is over, the humanity is safe for another few decades.
- The H1N1 outbreak is declared a pandemic, therefore millions will die.
- Outbreaks like the swine flu pandemic are inevitable and cannot be prevented.

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(TELL ME Deliverable D1.5 Narratives and urban myths. Available from http://www.tellmeproject.eu/content/D15-report-narratives-and-urban-myths)
Misinformation and myths in relation to vaccines and other preventive measures

**VACCINE-RELATED**

- The flu can be transmitted from the vaccine.
- The flu vaccines are dangerous / more dangerous than the H1N1 virus.
- Squalene, ingredient of the flu vaccine used as a booster, caused the Gulf War Syndrome.
- Thimerosal, ingredient of the flu vaccine used as a preservative, contains mercury, a poisonous substance responsible for autism and other developmental disorders.
- Flu vaccines cause the Guillain-Barré Syndrome.
- Flu vaccines actually weaken the immune system weaker, making people less able to withstand viruses on their own, same as the antibiotics leading to the creation of more resistant viruses.
- Governments plan to make mandatory vaccinations for people against the H1N1 virus.
- If someone gets vaccinated against regular flu each year, there is no need then to get vaccinated for the swine flu.
- The flu vaccine needs to be administered before November (or December), in order for it to be effective.

**NON-VACCINE RELATED**

- It is enough that someone just eats organic food, takes vitamins, wears a mask, washes hands and drinks plenty of liquids.
- Face masks alone can protect someone from the swine flu.
- Bringing a child to a ‘swine flu party’ is the better option for building a natural immunity to the virus.
- There is no treatment for the flu.
- Antibiotics can effectively fight the flu.
- Resting is the best treatment for the flu.

It is noteworthy to mention that most of these medical myths presented during the most recent influenza pandemic in 2009 were not created and emerged ex nihilo. Instead, these medical myths and misinformation trace their roots back to other major infectious disease outbreaks and pandemics of the past. In an effort to explain what causes this phenomenon of persistence of medical myths in sizeable segments of the population and the reason behind difficulties in correcting widespread belief in misinformation, the study by Lewandowsky et al. (2012) concludes that this can be attributed in principle to cognitive variables that rest within each person as well as the ability to reach the target audience. This study suggests that at first level individuals thoughtfully evaluate the “truth value” of information and make their judgements on the basis of the following factors:

- Personal experience (i.e. information is compatible to personal beliefs)
- Internal coherence (i.e. information does not create contradictions with existing knowledge)
- Source credibility (i.e. information is presented by a trusted source)
- Perceived social consensus (i.e. information is widely accepted as truthful by others)

It is understood that misinformation can easily be adopted as factual information on the basis of the abovementioned factors, and once accepted as factual information then become highly resistant to change. This leads to another critical part in the process that explains the persistent effect of misinformation, or the continued influence effect as described by Johnson and Seifert (1994), in which it is suggested that misinformation can be particularly difficult to correct and can have lasting effects even after this has been discredited. One reason for this persistence concerns the way in which people make causal inferences based on available information about a given outcome. As a result, erroneous information may continue to have a lasting influence on beliefs and attitudes, even after this information has been corrected, if not replaced by an alternate causal explanation (Johnson and Seifert, 1994).

Besides the problem of continued influence effect for misinformation, also characteristic in the process at cognitive level is the backfire effect, which is a term used to denote any attempt of debunking a myth with the undesired outcome of fortifying this myth in people’s mind. In their work, Lewandowsky et al. (2012) collected and summarised the different manifestations of the “backfire effect” as described in the literature, offering also solutions of practical value that could be used for the retraction of misinformation (see Table 2).

**Table 2 overleaf:** Strategies to avoid backfire effects in the effort to retract misinformation.
New communication strategies for preventing misinformation

<table>
<thead>
<tr>
<th>Problem</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Familiarity backfire effect</strong></td>
<td>Repeating the myth increases familiarity which reinforces the myth (Skurnik, et al., 2005)</td>
</tr>
<tr>
<td><strong>Emphasis on facts</strong></td>
<td>Avoid repetition of the myth; focus on facts that need to be communicated</td>
</tr>
<tr>
<td><strong>Overkill backfire effect</strong></td>
<td>Simple myths are more cognitively attractive than trying to process scientific information instead (Schwarz, et al., 2007)</td>
</tr>
<tr>
<td><strong>Simple, brief rebuttal</strong></td>
<td>Keep content easy to process and make use of visual cues (i.e. infographics) to communicate messages and reduce misconceptions</td>
</tr>
<tr>
<td><strong>Worldview backfire effect</strong></td>
<td>Evidence that threatens worldview can strengthen initially held beliefs (Nyhan and Reifler, 2010)</td>
</tr>
<tr>
<td><strong>Affirm worldview</strong></td>
<td>Frame evidence in worldview-affirming manner by endorsing values of the audience</td>
</tr>
</tbody>
</table>

(Source: “Misinformation and correction: Continued influence and successful debiasing” by Lewandowsky et al., 2012, Psychological Science in the Public Interest, 13(3), p. 122)

Recommendations for the retraction of misinformation in outbreaks

On the basis of principles presented in the work of Lewandowsky et al. (2012) on the persistent effect of misinformation, a sequence of steps is suggested for the construction of a replacement narrative for an effective retraction of misinformation.

1. Find a trustworthy, recognisable and respected source to communicate the message.
2. Put emphasis and map out the core facts you wish to be communicated.
3. Avoid making reference to the myth from the beginning of the narrative.
4. Reinforce core facts by enriching the narrative with additional details and scientific evidence.
5. Present core facts in a simple, straightforward worldview-affirming manner.
6. Make use of visual cues (i.e. infographics) to present core facts, when possible.
7. Warn explicitly before the “false information” is about to appear in the narrative.
8. Ensure the replacement narrative leaves no gaps to be filled with new myths.
9. Evaluate content as per the potential to threaten the worldview and values of the audience.

Except the cognitive part associated with the persistence of misinformation, there is also the pragmatic context to consider, such as the frequency of exposure or repetition of misinformation, which is known to lead to the acceptance of presented statements as truthful (Begg, Anas and Farinacci, 1992). For some infectious diseases the systematic recurrence of misinformation can be attributed to the cyclical nature of media reporting, such as the case of seasonal flu and associated protective measures. Moreover, the media are characterised by the tendency to publish stories with a potential to stir up some debate, such as the case of MMR vaccination, which continues to appear as a controversial issue despite the fact that no legitimate link has been found between childhood vaccinations and autism (Gerber and Offit, 2009).
Section 6

The importance of preventing misinformation from transforming into common knowledge

In the introductory part of this document, it was highlighted that the more recent advancements in the field of information-communication technologies have instigated a more dynamic and total diffusion of information from multiple sources. It has also been noted that the speed by which information can travel, the continuous information overflow and individuals’ habit to “consume” easy-to-digest information, constitute factors that foster the emergence and spread of misinformation in situations where levels of uncertainty and fear are high, such as the case of infectious disease outbreaks.

Prior to the 21st century revolution in information-communication technologies, misinformation and rumours had a considerably long distance to cover from emergence to wide diffusion and possibly acceptance as “common knowledge” in the absence of alternative narratives. Nowadays, considering that misinformation and rumours become diffused in an uncontrollable pace via online resources and the social media, the focus moves to the mechanisms involved for the adoption of misinformation as factual information and eventually become common knowledge for the wider population.

At the level of outbreak communications, the adoption of misinformation and rumours as factual information can be explained under the lens of a theory suggested by Everett Rogers in the 1960s, known as the diffusion of innovations theory. According to Rogers (1995), “diffusion is a process by which an innovation is communicated through certain channels over time among the members of a social system”. According to the authors of the TELL ME Framework Model for Outbreak Communication, in the context of outbreak communications, misinformation and rumours can indeed be considered as a particular type of innovation. As suggested by the abovementioned theory, the communication channel constitutes a key element and is defined as “the means by which messages get from one individual to another and information is transmitted to or within the social system.”.

The communication channels used for the diffusion of an innovation are: a) interpersonal channels (one-to-one), b) mass media channels (one-to-many), and c) internet-based communication channels (many-to-many).

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15 From the Wikipedia is indicated that the assertion of something being “common knowledge” is sometimes associated with the fallacy argumentum ad populum (i.e. the assumption that just because everyone believes something to be true, then it must be true), which is of particular relevance to the persistent effect of misinformation.
Internet-based communication channels (e.g. social media, blogs, forums etc.) constitute one of the key elements in the TELL ME Framework Model for Outbreak Communication\(^{16}\) considering that online social networks are fully incorporated into – and on some occasions even govern – daily life activities for an ever-expanding number of users around the world. Social media has dramatically influenced the way information and ideas become shared in real time. From the wide range of social media that exist nowadays, Twitter and Facebook are considered to be the prime communication channels used by individuals to share information and diffuse their opinions and perceptions over different issues. The unique qualities and characteristics of social media urged governments to utilize these communication platforms as integral part of preparedness and response plans regarding communications during emergencies\(^{17}\).

Despite the benefits and positive impact of social media in situations of emergency, there are two main problems associated with this type of communication platform; namely, the possibility for information overload and the ease with which misinformation and rumours can spread. It is characteristic that during the 2009 influenza A(H1N1) pandemic, journalists described Twitter as “a hotbed of unnecessary hype and misinformation about the outbreak”\(^{18}\). According to the TELL ME Framework Model for Outbreak Communication, public health authorities and organisations still remain sceptical about how social media, such as Twitter and Facebook, could be better utilised in response to an outbreak, and present factual information amid a sea of speculative statements made by online users.

Another internet-based communication channel that merits attention is the YouTube channel, with unique features and the potential to widely influence public perceptions, especially when projected videos/interviews/messages are associated with a campaign led by certain individuals or groups. Of particular interest is that a significant number of videos available from the YouTube channel have been identified as deceptive or scientifically inaccurate with regards to infectious disease outbreaks and vaccination. Indicatively, Kata (2012) performed an analysis of YouTube immunization videos and found that 32% of these videos opposed vaccination, with higher ratings and more views than pro-vaccine videos, while 45% of negative videos conveyed information contradicting reference standards.

Coming back to the application of the diffusion of innovations theory in outbreak communications, and considering the qualities and characteristics of internet-based communication channels regarding the spread of misinformation and rumours, it is also important to carefully consider the element of time in the effort to explain how misinformation can be adopted as factual information and eventually be transformed into common knowledge. When an emergency occurs, such as a major infectious disease outbreak, individuals instinctively start seeking for information that will help them alleviate their uncertainty. They want to acquire information that will help them process their situation and respond effectively to the risk it presents (Ulmer, Sellnow & Seeger, 2007). This means that from an early phase of an outbreak there are a lot of people who adopt an information seeking behaviour through utilisation of internet-based communication channels, which automatically makes these people susceptible to misinformation generated and spread by anyone whose views and beliefs find a “corner” to be presented.

The adoption curve by Rogers (1995) presents clearly the process followed for the adoption of an innovation/misinformation or rumour, which could apply in a major infectious disease outbreak (Figure 4). Although individual users who generate and spread misinformation online may be a small minority (innovators), the content of misinformation can quickly reach a significant part of the community/connected users (early adopters). The crucial point is the moment when misinformation reaches the critical mass, i.e. the passage from early adopters to the early majority. Since this segment represents about 1/3 of the community, further adoption can become self-sustaining and misinformation then enters into common knowledge.

Figure 4 overleaf: The adoption curve and the transformation of misinformation into common knowledge.

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\(^{16}\) TELL ME Deliverable D3.1 New framework model for outbreak communication. Available from http://www.tellmeproject.eu/content/d31-new-framework-model-outbreak-communication

\(^{17}\) TELL ME Deliverable D2.5 New social media. Available from http://www.tellmeproject.eu/content/d25-new-socialmedia

Figure 4: The adoption curve and the transformation of misinformation into common knowledge.

Source: Everett Rogers, Diffusion of Innovations
The critical role of opinion leaders to control the spread of misinformation

To include another variable in the diffusion of innovations theory, the critical role of opinion leaders should not be overlooked in the spread of misinformation. Opinion leader is understood as any individual with a capacity to influence other individuals’ attitudes or behaviours with some relative frequency. Similar to social media, opinion leaders comprise another key element of the TELL ME Framework Model for Outbreak Communication, and the combination of the two can determine to a large extent the degree of success or failure of a communication strategy or campaign. Individuals who are positioned at the centre of a virtual community of people can accelerate the process by which misinformation and rumours become adopted, and enter the realm of common knowledge, as presented above.

It has been suggested by Nisbet and Kotcher (2009) that opinion leaders’ views, behaviours and actions can have even a greater influence than the mass media with regard to shaping public perceptions and attitudes toward an issue. According to the authors of the TELL ME Framework Model for Outbreak Communication, this could be attributed to the fact that opinion leaders are seen as trustworthy members within a community, and any positions expressed are not interpreted with suspicion that serve some underlying interests. This suggests that misinformation and rumours are more likely to be rapidly adopted by a significant number of people (early adopters) as soon as released via use of internet-based communication channels.

It could be argued that there are two critical phases concerning the release of misinformation by opinion leaders (see Figure 5). In the first phase (pre-release), an individual is the recipient of information which is made available by a specific source (or sources). This information becomes distorted or misinterpreted for a number of reasons, with most common the complexity of the message, information gaps and scientific uncertainties. It is crucial that in the wider context of preparedness for an emergency, public health authorities and other government actors to establish some type of connection with identified opinion leaders in order to provide resources, raise awareness and instil a sense of responsibility regarding their role in the outbreak communication process. The aim of this approach would be to encourage individuals to critically evaluate and responsibly share any information in the event of an infectious disease outbreak, to prevent possible misinformation from reaching a wider audience.
At the second phase (post-release), where misinformation or rumours are released via an internet-based communication channel, it calls for an immediate and effective intervention by public health authorities to prevent misinformation entering the realm of common knowledge, when it would be considerably more difficult to contradict an established worldview over an issue. So, which is the approach to be adopted by the authorities for an effective and rapid intervention to the spread of misinformation and rumours?

This can be achieved by systematic monitoring of the web and by performing a real-time analysis of possible misinformation, rumours and myths that circulate and spread from the onset of a major infectious disease outbreak. According to Savoia et al. (2013), “a real-time analysis of the information environment is valuable in knowing what is being communicated to the public and could be used for course correction of public health messages during a crisis”. Also, provided that systematic monitoring of the web in case of an outbreak is governed by rules of transparency and respect for privacy and data protection, this could be a useful tool in the hands of officials to better understand what are the main sources of concern, doubts, fear or anxiety, and opinion leaders’ presence can contribute in the direction of eliciting these sentiments and proceed to more precise interventions to counter misinformation and rumours.

Figure 5: The influence of opinion leaders in the diffusion of misinformation and response measures.
Section 8

Strategies for prevention and response to misinformation in the course of a major infectious disease outbreak

Preliminary context
pp 56-57

Good practices for preventing the emergence of misinformation and rumours
pp 58-59

Strategies to control misinformation in different phases of an outbreak
pp 60-67
New communication strategies for preventing misinformation

Preliminary context

In 2013, the World Health Organisation (WHO, 2013) published interim guidance on pandemic influenza risk management which defines four global phases with reference to the spread and impact of a potential new influenza subtype (see Box 2). Notably, in the context of risk and outbreak communications, and especially in relation to the emergence and spread of misinformation and rumours during major infectious disease outbreaks (epidemics or pandemics), it could be suggested that this categorisation between the four phases can find application also to other communicable infectious diseases, apart from the influenza subtypes.

Box 2: The four phases of influenza pandemic according to the WHO.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpandemic phase</td>
<td>A period between influenza pandemics.</td>
</tr>
<tr>
<td>Alert phase</td>
<td>The phase when influenza caused by a new subtype has been identified in humans. Increased vigilance and careful risk assessment, at local, national and global levels, are characteristic of this phase. If the risk assessments indicate that the new virus is not developing into a pandemic strain, a de-escalation of activities towards those in the inter-pandemic phase may occur.</td>
</tr>
<tr>
<td>Pandemic phase</td>
<td>This is the period of global spread of human influenza caused by a new subtype. Movement between the inter-pandemic alert and pandemic phases may occur quickly or gradually as indicated by the global risk assessment, principally based on virological, epidemiological and clinical data.</td>
</tr>
<tr>
<td>Transition phase</td>
<td>As the assessed global risk reduces, de-escalation of global actions may occur, and reduction in response activities or movement towards recovery actions by countries may be appropriate, according to their own risk assessments.</td>
</tr>
</tbody>
</table>

(Source: “Misinformation and correction: Continued influence and successful debiasing” by Lewandowsky et al., 2012, Psychological Science in the Public Interest, 13(3), p. 122)
Good practices for preventing the emergence of misinformation and rumours

<table>
<thead>
<tr>
<th>Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Be sincere</td>
</tr>
<tr>
<td>Admit to present mistakes, acknowledge errors made in the past and demonstrate how lessons have been learned.</td>
</tr>
<tr>
<td>2 Be transparent</td>
</tr>
<tr>
<td>Open disclosure of information on risk assessments and scientific uncertainties to allow people make informed decisions on the basis of available data.</td>
</tr>
<tr>
<td>3 Be clear</td>
</tr>
<tr>
<td>Adapt the content of statements and/or messages in a language that is clear and comprehensible by different population sub-groups or at-risk groups.</td>
</tr>
<tr>
<td>4 Be specific</td>
</tr>
<tr>
<td>Present evidence-based messages and give precise instructions as to what, when and how people should act upon this information.</td>
</tr>
<tr>
<td>5 Be consistent</td>
</tr>
<tr>
<td>Decide on and adhere to a specific communication strategy as regards the style of communications and methods used to disseminate messages to the public.</td>
</tr>
<tr>
<td>6 Be cooperative</td>
</tr>
<tr>
<td>Establish two-way and open communication channels with different stakeholder groups from both the public and private sector, in order to understand the communication requirements for each group and tailor messages according to the varied information needs.</td>
</tr>
<tr>
<td>7 Be confident</td>
</tr>
<tr>
<td>Provide reassurance about the level of preparedness and acknowledge possible weaknesses of the response mechanism, accompanied with a plan of action to mitigate risks.</td>
</tr>
<tr>
<td>8 Be perceptive</td>
</tr>
<tr>
<td>Accept cultural truths as important as health truths and consider the effect and influence of socio-cultural and religious factors in the interpretation of messages.</td>
</tr>
<tr>
<td>9 Be respectful</td>
</tr>
<tr>
<td>Acknowledge there are other perspectives and make efforts to approach people with opposing views and engage into constructive dialogue to understand where the opposition stems from.</td>
</tr>
<tr>
<td>10 Be proactive</td>
</tr>
<tr>
<td>Anticipate the increase in demand for more information from the side of the general public, and focus on presenting educational messages that increase awareness, promoting actions “to prevent” rather than “to control”.</td>
</tr>
<tr>
<td>11 Be creative</td>
</tr>
<tr>
<td>Introduce metaphors and other forms of figurative language to communicate complex information to the general public.</td>
</tr>
<tr>
<td>12 Be quick</td>
</tr>
<tr>
<td>Establish online mechanisms for timely dissemination of trustworthy information and early detection of misinformation and rumours that spread via internet-based communication channels.</td>
</tr>
<tr>
<td>13 Be methodical</td>
</tr>
<tr>
<td>Consider the factor of health literacy for different population sub-groups and introduce increasingly more complex messages as people learn over time, so that information can find target, and not evoke fear or feelings of uncertainty instead.</td>
</tr>
<tr>
<td>14 Be present</td>
</tr>
<tr>
<td>Reach out and actively seek for feedback from people on their experiences, concerns, fears, anxieties and doubts in the course of an outbreak. Provide up-to-date information on the status of the outbreak, signs and symptoms, transmission and protective measures.</td>
</tr>
</tbody>
</table>
New communication strategies for preventing misinformation

This section offers recommendations and a sequence of suggested actions to be taken by public health authorities across the different phases of a major infectious disease outbreak (epidemic or pandemic), for preventing the emergence and spread of misinformation. For each phase, distinct recommendations are offered for different components presented in TELL ME framework model, and form part of the public sphere. These components are: a) social media, b) mass media, c) opinion leaders, and d) the general public (public segmentation).

The interpandemic phase

The interpandemic phase is the best time to develop and enhance emergency risk capacities. With regard to the model, it is the time for ethnographical research that is aimed at constructing profiles of diverse risk groups, emphasizing their beliefs, their community leaders and ideologies. In a sense, when the level of perceived risk is low there is little chance to educate the public or involve other stakeholders in the pandemic plan hence we do not see real movement on the model.

(TELL ME Deliverable D3.1, p. 14-15)

<table>
<thead>
<tr>
<th>Component</th>
<th>Suggested actions</th>
</tr>
</thead>
</table>
| Social media / Online resources | • Identify which type of social networks and internet-based communication channels are mostly used or preferred by different audiences.  
• Identify bloggers and online writers who are seen as a reliable source of information from the community.  
• Establish and maintain presence on social media platforms and seek to provide incentives for people to keep visiting the official website and portals.  
• Build a network of organisations and develop partnerships to channel public health messages and communications through the various webbased platforms used.  
• Explore in advance the potential that each social media platform can offer and standardise the type and style of communication depending the media platform used. |
| Mass media | • Invite journalists and media representatives as legitimate stakeholders to contribute in the development of future pandemic preparedness and response plans.  
• Establish an 24/7 “enquiry point” for journalists to verify information or rumours that circulate online.  
• Organise joint workshops for journalists and health professionals with a focus on communication aspects and the impact of misinformation during infectious disease outbreaks. |
### Component Suggested actions

**Opinion leaders**
- Identify individuals who are seen as trustworthy members within a community and have the capacity to influence behaviour of others.
- Identify opinion leaders with active presence in social media and definite views on public health issues.
- Establish relationships with public figures that have a large public following in social media with the aim to recruit as “ambassadors” in future public health campaigns.

**General public**
- Promote initiatives to further improve health literacy skills and knowledge.
- Consider how cultural diversity within the population can influence reaction and response to a disease or death.

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**The alert phase**

The alert phase is characterized by the identification of a novel influenza subtype in humans. This is the time for careful risk assessment on all levels. Using open channels with Member States, activating networks of information and think tanks to conduct global risk assessment under the revised IHR (2005). In terms of the different components of the model, the mass media, the social media, the opinion leaders and the research becomes crucial. With reference to social media, people actively seek information to allay their concerns and reduce uncertainty. At this stage, both the social media and the mass media serve their integrative function, making people feel as if they are part of a larger community. The opinion leaders’ function becomes more pronounced because they serve as an alternative source of information (other than the media) and as a source of interpretation for people seeking clarification. Formative research already conducted will have gathered information on different segments of the public. It now needs to focus on relevant risk groups and on online discourse as important indicators of public risk perceptions. The transnational, European, national and local stakeholders become much more active and involved in the public sphere.

(TELL ME Deliverable D3.1, p. 15)

**Component Suggested actions**

**Social media / Online resources**
- Monitor in a systematic way social media, the web and other online platforms to detect misinformation or rumours that spread.
- Seek to identify the source or the origins of misinformation and proceed to correct immediately.
- Take note of any conspiracy or anti-vaccine websites that appear on the first pages of an online search engine, following insertion of popular keywords in relation to the outbreak.
- Perform real-time analysis of posts and user comments in social media platforms to identify public concerns, fears and popular misconceptions in relation to the outbreak.
### The pandemic phase

The pandemic phase is the most severe risk assessment concerning the global potential spread of the subtype virus. The fact that a pandemic was officially declared calls for support and response on all levels. It is the time when different level stakeholders are fully engaged in the effort to mitigate the spread and educate the public. It is the full participation of transnational European, national and local stakeholders in the public sphere. They receive input from research and mould it into specific communication strategies designed to communicate with the public. This is the stage where there is a need to emphasize self-efficacy, uncertainty and transparency as an integral part of communication with the public.

(TELL ME Deliverable D3.1, p. 16)

<table>
<thead>
<tr>
<th>Component</th>
<th>Suggested actions</th>
</tr>
</thead>
</table>
| Mass media                    | • Send press releases to news outlets at regular and fixed intervals, determined from a balance between information demand and actual availability of information.  
• Use press conferences to explain the circumstances under which any uncertainties occur and define the concept of risk in the context of the outbreak  
• Schedule meetings with editors-in-chief and other media representatives to develop a common understanding around what messages are vital to transmit to the public.  
• Promote fact-checking as a standard practice for reporting during an outbreak.  |
| Opinion leaders               | • Search and evaluate initial views expressed by already identified opinion leaders in relation to the outbreak.  
• Monitor for criticisms and negative views expressed by opinion leaders toward public health authorities’ response.                                                                                       |
| General public                | • Put emphasis on key prophylactic measures which are easy to process and implement on daily activities.  
• Develop messages that are “intrusive” or do not come into direct conflict with cultural perspectives or religious practices. Seek for a balance.  
• Provide instructions for evaluation criteria to assess the reliability of information retrieved from websites or other news sources.  
• Indicate to people where they could find reliable health information online.  
• Provide updates about existing uncertainties and differences in opinions expressed by public health experts.                                                                                       |

### Social media / Online resources

In addition to the “alert” phase:

- Use various social media and online platforms to communicate consistently key messages to the public in direct response to concerns and fears widely expressed via social media platforms.
- Keep record of which type of information or communication has been successful, by monitoring the number of people who clicked on provided links or re-tweeted specific messages.

### Mass media

In addition to the “alert” phase:

- Monitor whether there are inconsistencies in the terminologies used to describe key information in relation the outbreak. Proceed to correct.
- Monitor whether official statements are distorted by news reports or presented without an appropriate context.
### The transition phase

The transition phase signifies the return to routine. While from an epidemiological point of view this is the time to minimize response, on the level of outbreak communication it is a crucial time for recovery on all levels. All components should be thinking about lessons learned from the last pandemic and preparing themselves for a possible scenario of a future outbreak. From the point of view of ethics, it is the time to assess, through research, to what extent the experience of the pandemic had stigmatized different subpopulations and what type of public campaign can improve their image.

(TELL ME Deliverable D3.1, p. 17)

<table>
<thead>
<tr>
<th>Component</th>
<th>Suggested actions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opinion leaders</strong></td>
<td>In addition to the “alert” phase:</td>
</tr>
<tr>
<td></td>
<td>• Request from opinion leaders to actively support and take part in public health campaigns and communications to contain the spread of the outbreak.</td>
</tr>
<tr>
<td></td>
<td>• Show tolerance to criticisms and offer explanations to counter scientifically unsupported advice.</td>
</tr>
<tr>
<td><strong>General public</strong></td>
<td>In addition to the “alert” phase:</td>
</tr>
<tr>
<td></td>
<td>• Focus on communications that motivate people toward a positive behavioural change (i.e. adherence) and try not to enforce decisions (i.e. compliance).</td>
</tr>
<tr>
<td><strong>Social media / Online resources</strong></td>
<td>• Evaluation of misinformation detected in the course of the outbreak with reference to qualitative characteristics that determined the level of diffusion.</td>
</tr>
<tr>
<td></td>
<td>• Evaluation of the social media platforms used and type of inconsistencies detected between messages as a result of the distinct features of each platform.</td>
</tr>
<tr>
<td><strong>Mass media</strong></td>
<td>• Evaluation of points of criticism toward public health authorities concerning communication gaps and information mismatch in the course of the outbreak.</td>
</tr>
<tr>
<td></td>
<td>• Identify any patterns in the re-appearance of misinformation and medical myths as part of a general discourse around the risk associated with the outbreak.</td>
</tr>
<tr>
<td><strong>Opinion leaders</strong></td>
<td>• Keep connected and provide feedback on the positive contributions made to control the outbreak.</td>
</tr>
<tr>
<td><strong>General public</strong></td>
<td>• Make available a post-pandemic evaluation report to summarise what worked well in terms of communications and what could have been done better.</td>
</tr>
</tbody>
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Section 9

Bibliography

Bibliography
pp 70-71
Bibliography


For more information on the TELL ME project or to access the guidance documents and tools, please go to www.tellmeproject.eu

Alternatively, you can contact us on the details below.

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