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Executive Summary

Following the 2009 H1N1 outbreak there was considerable disquiet amongst medical practitioners over the widespread non-compliance of immunization by the public and a tangible sense of mistrust and lack of transparency that was widely reported. It was believed that this was caused by the apparent communication gap between global and local health organizations and the public. There was a desire to identify how the general public could be better motivated to take effective preventive measures during an epidemic at a time of uncertainty, potential misinformation and even malicious information. This concern inspired the TELL ME Project.

TELL ME (**T**ransparent Communication in **E**pidemics: **L**earning **L**essons from experience, delivering effective **M**essages, providing **E**vidence) was a 36 month EU-funded collaborative project headed by a consortium of multi-disciplinary experts from prestigious institutions in eight countries. The objective of TELL ME was to identify new communication strategies for improving the effectiveness of the preventive measures undertaken during epidemics and to define and design a new framework model for outbreak communication. To achieve this TELL ME brought together an international consortium that combined public health, social sciences, behavioural sciences, political sciences, law, ethics, communication and media expertise.

The project considered the fundamental key components and issues to build appropriate outbreak communication in the context of some of the critical elements that might have negative effects on communication efficacy: human rights, stigmatization, the risk of discrimination; narratives and urban myths particularly related to the anti-vaccination movements and general mistrust**.** An important goal of the project was therefore to address the challenge of low adherence to non-pharmacological protective measures by people and the increasing refusal for vaccination among different segments of the population; a growing trend which could become a major challenge in future epidemics and pandemics.

At the heart of the TELL ME research was the development of the **Framework Model for Outbreak Communications** which embraces the opportunities presented by the expediential growth of new media and crucially places the public at the heart of the communication process underlining the importance of a continual dialogue between the Health Care Professionals, other major stakeholders and those who need protecting from the risks at each stage of an outbreak. Complimenting the Framework Model TELL ME developed a set of strategies and recommendations encapsulated in an integrated **Practical Guide for Outbreak Communication**, an **Online Course for Health Workers** and an I**nnovative Social Simulation Software Package for Decision Makers**. The latter is specifically designed to allow public health officials and agencies to plan communication policies and strategies for future infectious disease outbreaks. The practical and innovative products that emanate from the project are available on the **TELL ME website**.

The outcomes of the TELL ME project have rapidly gained traction both in the field of pandemic flu but also in wider health related emergencies such as the Ebola crisis in West Africa. Approximately 30,000 Italian Health Care Workers have already undertaken an Ebola e-learning course based on the TELL ME communication guidelines. Exploitation and dissemination of the TELL ME products continue via the TELL ME website and via associated and ongoing EU projects such as ASSET.

1 TELL ME Project Context and Objectives

TELL ME is the acronym standing for: Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. The project was a 36 month Collaborative Project characterised by its innovative, multi-national, and multi-institutional dimension. The project was brought together by the inspirational and professional management of the Centre for Science, Society and Citizenship (CSSC) in Italy. Due to unforeseen circumstances, CSSC handed over the management of the final year of the project to ZADIG in February 2014. The main objective for TELL ME was to develop evidence-based models and tools for improved risk communication during major infectious disease outbreaks, epidemics or pandemics.

After the mixed results of public health campaigns aimed at preventing the spread of influenza during the 2009 A(H1N1) pandemic (including the controversies raised by vaccination and anti-viral drug campaigns), it became apparent that there was a need to revise the current wisdom concerning human behaviour in pandemics, communication policies, and the involvement of health professionals at each stage of the process – preparation, response and recovery.

The project was co-funded by the European Commission under the Seventh Framework Programme for Research and Development. TELL ME, as an integrated research project, combined public health, social sciences, behavioural sciences, political sciences, law, ethics, communication and media expertise and civil society, in order to develop an evidence-based behavioural and communication package to respond to major epidemic outbreaks. To achieve this the project gathered a wide range of expertise from twelve institutions, including universities, national institute of health, media and communication companies, research centres, professional organizations, civil society organizations from eight countries (Belgium, France, Hungary, Israel, Italy, Latvia, United Kingdom and United States).

1.1 Participants

The following organisations participated in the project:

- ABSISKY FRANCE (Originally VITAMIB SAS (VITAMIB))
- BMJ PUBLISHING GROUP (BMJ) UNITED KINGDOM
- CEDARTHREE LIMITED (CEDAR3) UNITED KINGDOM
- UNIVERSITY OF SURREY (SURREY) UNITED KINGDOM
- INSTITUTO SUPERIORE DI SANITA (ISS) ITALY
- UNION EUROPEENNE DES MEDECINS OMNIPRATICIENS/MEDECINS DE FAMILLE AISBL (UEMO) BELGIUM
- LATVIJAS CILVEKTIESIBU CENTRS BIEDRIBA (LCHR) LATVIA
- VRIJE UNIVERSITEIT BRUSSEL (VUB) BELGIUM
- NATIONAL DISASTER LIFE SUPPORT FOUNDATION INC (NDLSF) UNITED STATES
- UNIVERSITY OF HAIFA (HU) ISRAEL
- ZADIG SRL (ZADIG) ITALY

NB. CENTRE FOR SCIENCE, SOCIETY AND CITISENSHIP (CSSC) ITALY handed over management of the project to ZADIG in February 2014

1.2 Objectives

The main objectives of TELL ME were to:

1. **Collect and assess evidence about population behavioral responses** to infectious disease outbreaks, and ways in which different types of communication can affect human behavior.
2. **Identify and report emerging challenges**, new methods and tactics in communication concerning infectious disease outbreaks.
3. **Develop a new framework model** for outbreak communication.
4. **Develop an online course** for primary care staff.
5. **Develop an integrated communication package** including a series of guidance documents for different actors and a practical guide for outbreakcommunication.
6. **Develop a simulation model prototype** for simulating the actions and interactions of autonomous decision-making entities in the course of an influenza epidemic.

To achieve these objectives the project was divided into the following 5 Work Packages (WP) with appropriate participant organisations having overall or supportive roles within each project.

- WP1 – Population behaviour during epidemics
- WP2 – New challenges and new methods for outbreak communication
- WP3 – Developing new communication strategies
- WP4 – Agent-based social simulation
- WP5 – Dissemination and policy dialogue

1.3 Research Questions

To focus the research and development of the new outbreak communication strategies TELL ME was tasked with answering three distinct research questions:

1. How can the general population be better motivated through public health communication to take effective preventative actions (e.g., vaccination, antiviral therapy, hygienic norms, etc.)?
2. What are the most appropriate communication methods to deal with complexity, uncertainty, ignorance, information asymmetries, overwhelming information, biased information, misinformation and malicious information?
3. What are the best communication strategies to maximise vaccine uptake, and to assist health professionals and agencies to engage with vaccine-resistant groups?

1.4 Major Issues

As the project progressed the following major issues, which are discussed in more detail later in this report, were highlighted as central to the review and the development of effective outbreak communication strategies:

1. Vaccine acceptance/refusal, resistance to vaccination
2. Narratives and urban myths on epidemics and vaccinations
3. Human rights, stigmatization and risk of discrimination
4. Behavioural response to infectious disease outbreak among the general population and target groups.

1.5 Key Subjects Addressed

Additionally as the project progressed so the focus of the project addressed the following key subjects:

1. Stakeholder mapping
2. Stakeholder communication requirements
3. Healthcare professional communication requirements
4. Strategies and interventions needed to prevent influenza transmission, with particular regard to vaccine acceptance.

In considering these different aspects, the project researched case studies and lessons learned undertaken by various countries and international organizations. The aim was to look for the most straightforward and effective ways to communicate in order to prevent misinformation and address resistance to vaccination.

1.6 Outcomes

TELL ME has developed a new participative model for risk communication, which provides a framework to assist public health authorities secure optimal preparedness for infectious disease threats by increasing the resilience of all communities during epidemics and pandemics.

The new framework indicates how information becomes modified as it passes between the actors: not only with some facts being distorted, but also with emphases changing, priorities shifting as the context changes. Through consideration of the framework model and what it implies for these effects, guidelines for decision-makers were constructed to help them create messages that will have the desired impact in different contexts.

The TELL ME communication strategies and products together will do much to inform and prepare those responsible for responding to the threat and actual outbreak of flu pandemics. The strategies embrace the following tangible and intangible attributes:

- Effective communications
- Promotion of transparency, honesty and trust
- Engagement with the public through dialogue with health care professionals and other stakeholders
- Avert public panic through knowledge and regular informed communication
- Monitor public messages to ensure consistency and appropriateness

- Acknowledgement of uncertainty
- Messages for target populations

2 Key Scientific and Technical Findings of Deliverables

2.1 Work Package 1 – Population Behaviour During Epidemics Overview

The main tasks of work package one was to collect and assess evidence about components and issues related to outbreak communication. Within this context, several aspects were researched in relation to behaviour adopted both by the general population and specific target groups during outbreaks of infectious disease. Furthermore, the effects of communication on human behaviour in such circumstances were studied.

Work package 1 comprised six reports (deliverables) which have been carried out by WP1 Partners, each of them having been assigned a single task.

2.1.1 Population Behaviour During Epidemics

TELL ME considered a range of demographic, ethnic cultural and social factors in relation to associated protective behaviours. These included; age, gender, ethnicity, educational level and other socio-economic factors such as unemployment. In order to classify the perception of susceptibility, psychological factors associated with carrying out the protective behaviours were also considered such as; worry about developing the disease and chance of disease.

Our findings indicated that older people are generally more willing to be vaccinated and to put into practice protective measures. It was also highlighted that audience segmentation for communication messages that consider demographic, ethnic, cultural and social differences may allow for more effective and targeted communication to promote influenza vaccination and recommended behaviours. Intervention studies and communication strategies therefore should focus on particular demographic groups, and on raising levels of pandemic disease-perceived threat and individual/community belief and confidence in the effectiveness of protective measures. In addition, public health officials should take into account differences in population subgroups as they develop communication strategies in order to avoid or to exacerbate inequalities.

Public health messages are often subject to widely different interpretation according to the individual perception of the risk, trust in the government or in the ability to understand and interpret data and information. This interpretation is especially evident in the context of uncertainty.

Demographic differences in opinions about recommended behaviour, influenza vaccine and disease suggest that improving communication strategies within these groups may improve vaccination coverage and the implementation of protective behaviours.

Different studies have shown that one of the most trusted sources are the general practitioners and family pediatricians (Schwarzinger et al 2010; Seale et al 2010; Maurer et al 2010; Ferrante et al 2011; Jehn et al 2011; Walter et al 2012). This confirms that involving family doctors in the communication strategies is important for designing effective communication. Trust in institutions and clarity and transparency in the communication itself are important factors for the adoption of protective behaviours and vaccination compliance. Messages about risk should not be alarmist and should be combined with advice about how to manage the risk effectively (Witte et al 2000).

2.1.2 Components of Outbreak Communication

In the context of an outbreak situation, the success of Crisis Communications is to some extent determined by the success of prior Risk Communication. All the following factors play their part:

- **Source:** The source of information in a crisis can affect the way in which communications are interpreted, perceived and accepted. Different individuals will respond differently to different media. The Health Communicator's strategy will benefit from using all the communication channels and medium available in order to meet the varying needs of the public.
- **Type:** Type, tone and terminology used for communication should be appropriate to the understanding and knowledge of the audience. Empathy and understanding are important. Messages must be consistent and core messages repeated often.
- **Media:** Social media is increasingly prominent and a powerful means of leveraging large sections of the public. This together with telephone hotlines have proved effective.
- **Timing:** Early detection and decision-making are crucial in managing outbreak situations.
- **Trust Building and Public Acceptance:** Trust is one of the most significant factors related to successful communications and will affect people's judgments and subsequent acceptance of recommended measures.
- **Current Pandemic Plans:** Crisis Communication plans should be prepared as early as possible and then staff trained and exercised in their use. Plans should embrace new technology, in particular social media and allow a two-way flow of information between officials and the public.
- **Stakeholders:** Plans need to be made from the perspective of those they target and be sensitive to the needs and challenges of the audience. Misconceptions and unrealistic assumptions are barriers to a successful implementation of strategies, which need also to consider the life circumstances and communication needs that influence decision making and behaviour (Vaughan and Tinker, 2009). Stakeholders need also to be represented during the planning process (WHO, 2010).
- **Coordination and Leadership:** A major outbreak situation requires significant and prolonged central government coordination. Beyond this, it also requires multi-sectoral and international coordination (Hine, 2010). Strong leadership is required not only during a pandemic response, but also during the pandemic planning stage. Multi-sectoral engagement and co-ordination are also required (WHO, 2010) with international planning and interoperability between countries and regions to achieve consistency and coordination.

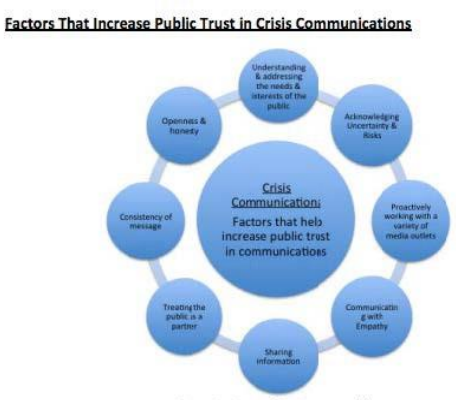


Figure 2 – Factors that increase public trust

Figure 3 – Factors that decrease public trust

2.1.3 Segmentation and Communication Needs of Target Groups

Compliance with influenza vaccination is highly variable, both between target groups, within the target groups and between countries. Communication strategies to improve compliance should take into account these wide variations. It is likely that different strategies will be needed for different target groups and sub-populations in different countries and tailored strategies for such factors as geographical location and socio-demographic variables.

The evidence for the efficacy of non-pharmacological interventions to prevent influenza is very limited.

A Need for Further Research: The TELL ME Findings highlight the need for further research in a number of important areas for example including; more coordinated, focused trials to assess the efficacy of hand washing and mask use; more standard studies to assess the compliance with different non-pharmacological interventions; studies about different subpopulations; media campaigns in different countries based on the components of social segmentation and support. There have also hardly been any formative research studies into communication strategies that accompanied and built social marketing campaigns to promote the issue of vaccines against seasonal and epidemic flu. We found that with regards to the various media channels available for communication, as a rule the most studied communication medium is the “mass media,” mainly through the television and press. However, mass media is not all about television. It has been learned that computerized messages and voice and text messages, sent directly to mobile phones, can help increase influenza vaccination (Krishna, et al..2002; Stockwell, Kharanda, Martinez, Lara, et al., 2012; Stockwell, Kharbanda, Martinez, Vargas, et al., 2012). The literature examines who creates the messages, how they are being created, what their effects are, but not how people are using the information with which they are presented (Duffy & Thorson, 2009; Gesser-Edelsburg, Forthcoming; .C.Glik, 2007). Also, there are no studies about the involvement of journalists themselves in the process, nor their responses and thoughts about their role in pandemic and seasonal vaccine coverage (Garrett, 2001; D.C. Glik, 2007; May, 2005).

New media technologies, which enable the policy makers and the Government to communicate seasonal and pandemic vaccines more dialogically – in a two-way conversation are also increasingly important. They make it possible to address subpopulations with persona, or personal-group tailored messages. However, the literature on this topic reveals that it has been little studied. It seems that a lot of thinking and consideration should be invested in investigating and planning in the new media sphere.

2.1.4 Vaccine Acceptance/Refusal to Vaccination

Today, antiviral drugs are available and can be effective to a limited degree. However, the only preventative measure proven to be effective for controlling a viral epidemic is vaccination.

A critical consideration, when we look at the course of the novel H1N1 pandemic of 2009-2010, is that there was a 6 month time gap between the initial cases in March 2009 and limited vaccine availability in early October. More general vaccine availability, at least in the US, took another month or two. A secondary problem with delayed vaccine availability in the 2009 pandemic was that maximum anxiety level, when public acceptance of a vaccine is greatest, peaked well before the vaccine was generally available (Gidengil, Parker, & Zikmund-Fisher; 2012).

Poor vaccine uptake of influenza vaccine among the general population and healthcare workers in the E.U. and US is concerning, as is the documented poor uptake of pandemic H1N1 vaccine during the 2009 influenza pandemic.

Two highly effective strategies apply to each of the vaccination efforts include;

- Targeted messaging and interventions are highly effective for the key strategic groups most likely to affect overall vaccination success.
- Improved health care provider support and participation. It is strongly recommended that health care professionals' knowledge of vaccines be improved, and that measures be taken to improve support of vaccine efforts by all healthcare settings, as currently modeled within pediatrics.

Preparedness for a novel epidemic or pandemic event *(*for which a vaccine is not available and must be developed): Messaging must not only address vaccine uptake strategies, but also strategies to help ensure that population behaviours are positively influenced to optimize the balance of adopting protective efforts and minimizing those that enhance transmissions and/or exposure prior to the availability of an effective vaccine.

Effective messaging and exerting a positive influence on protective population behaviours depend on an aggressive, global epidemiological surveillance system with public health assessment and communication capabilities. The governments of all nations, through the World Health Organization, must be continuously encouraged to support in spirit and deed the global efforts needed to isolate, identify and fully characterize, both genetically and epidemiologically, an infectious agent in as short a time as possible. Public health messaging will not only be critical, it will have to change and adapt as the outbreak and our understanding of its epidemiological characteristics expand. Finally, the criticality of appropriate, internationally consistent messaging will become more urgent and thus more difficult with agents of increased virulence and/or lethality.

Historically, most pandemic threats stem from highly communicable and rapidly reproducing pathogens. Such a pathogen would require achieving herd immunity to effectively minimize morbidity and mortality, thus necessitating mass vaccination programs rather than risk group targeted initiatives. It makes sense, therefore, to have a plan in place that would facilitate mass vaccination in the event of a new pandemic or epidemic event. Tentative plans to target risk groups would be more difficult to have in place, as the risk groups for a new pathogen are unknown.

Vaccination uptake is greatest when vaccine availability coincides with high levels of public anxiety and awareness. This suggests that clear, consistent, synchronized media communications must accurately inform the public of ongoing disease threat as vaccine is made available and throughout the vaccination effort, until desired goals are reached. This will be easier to facilitate in nations with nationalized broadcasting; it will likely require greater advanced planning in nations with privatized media control. In

addition to synchronized communication, capitalizing on public anxiety and maximizing vaccination benefits require rapid synthesis and distribution of effective vaccine.

A Collaborative Approach: The complexities involved in vaccination strategies, policies and resistance are well characterized by the "wicked problem" concept described in a treatise by Horst Rittel and Melvin M. Webber. Rittel and Webber discuss three available strategies for coping with wicked problems - authoritative, competitive and collaborative. In open societies, confronting contentious issues with an authoritarian approach is ineffective and often offensive; and for any endeavor requiring the cooperation, knowledge and abilities of multiple adverse entities, a competitive approach would almost certainly lead to suboptimal results. Collaboration, on the other hand, provides an opportunity to find the overall best solution for all stakeholders. According to Rittel, the collaborative approach is "to make those people who are affected into participants of the planning process. They are not merely asked but actively involved in the planning process" (Wikipedia, 2012).

2.1.5 Reports on Narratives and Urban Myths

At their core, myths are stories, as such, they are transformed in such a way that they can perfectly adapt to and effectively match the cultural framework of the societies in which they circulate. This process of transformation is crucial in order that any story may acquire some meaning, which in turn allows people to identify themselves with certain elements of the story.

All in all, myths are defined by one basic principle – they give meaning to otherwise incomprehensible phenomena that go beyond human experience, aiming to provide answers to the most complex questions around human existence.

It is evident that myths and cultures have always been interconnected (cultures forming the myth or myths forming the cultures?), and this relationship is rooted deeply in humans. And so is their need for telling or listening to stories.

"It is commonly acknowledged that an urban legend, an urban myth, a rumor can have a great impact on economic, social, and cultural level for the society. Most frequently, an urban legend is regarded as merely an amusing tale, with no real impact for society. However, there are examples of rumors or urban legends spreading to such an extent, only to be established as the absolute truth in people's consciousness, with serious repercussions for the community.

Rumor and contemporary legends abound every facet of the 2009 (H1N1) pandemic, from the cause of the illness itself, to claims about the validity or dangers of the various cures and preventative measures.

Myths are vehicles for communication of knowledge from one generation to the next, helping to preserve collective memory and establish socio-cultural constraints in the realm of the social unconscious. In addition, we have seen that myths have also been a medium of reassurance for communities in times of major epidemics, when scientific explanations of phenomena had been overly complex for people. In such cases, myths provided sanctuary for people, where they could find reason and tame their anxieties and fears, while the narrative form has been the key to let inside.

The use of online communication tools has completely changed how people access medical and health information. The globalization era, which is mostly characterized by the revolution in the field of Information and Communication Technologies (ICT), prompted significant changes in the traditional sense of forming collectives and communities for people. This means that perceptions of individuals about an infectious disease are not limited within a cultural or societal framework only, but extend to online

communities, placed under a common ideological framework. Moreover, the more recent developments in ICT – especially the emergence of social media – have opened the Pandora's box for everyone, to find in containment an infinitive amount of personal stories, accounts, tales, opinions and views about infectious diseases and the effectiveness of vaccines. As a result, different types of dynamics have been formed for people in terms of communicating and receiving information, as in essence every person could take the role of a storyteller, influencing other people's decision as a function of the persuasion modes and rhetorical tropes employed each time.

The internet and social media networks then, have proven to be a two-edged sword in medicine as they have the power both to adequately inform and deceive or confuse online users."

2.1.6 Human Rights, Stigmatisation and Risk of Discrimination

Stigmatisation is an ancient concept, one that humans as a species may have evolved as a social behaviour under certain circumstances. It is a complex phenomenon that can have negative affects for both the individuals involved and society in general.

In the contexts of epidemics, stigmatisation often involves individuals who are perceived, for one reason or another, to be at greater risk in terms of infection. Such perceptions can be founded on erroneous information. Groups that are prone to stigmatisation include those groups that have a perceived connection with the geographic origin of the outbreak in question, members of the medical profession, those who are part of pre-stigmatized groups, those who have connections to perceived animal origins of an outbreak and those individuals who actually become infected themselves. Past experience, especially the recent outbreaks of SARS, H5N1 and H1N1 have shown these groups to be vulnerable to problems associated with stigmatisation.

Those vested with responsibility for planning public health responses to epidemic situations should take into account the existence of such individuals and their susceptibility to stigmatisation when planning their actions. Such activities include the provision of public health information, testing facilities, treatment and even vaccination.

Stigmatisation should be avoided not only because of the moral issues that may be involved, but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. These include the possibility of healthcare avoidance behaviours, something that can have very serious consequences during an epidemic and is capable of worsening its course.

Stigmatisation caused during the public health response to an epidemic is therefore capable of creating negative affects that last long after the epidemic in question has subsided. These include not only a lesser motivation to seek healthcare, but also in areas such as education and employment.

One important aspect that has been identified with regards to stigmatisation is that it can occur even where there is no actual discrimination occurring. Stigmatisation can arise through human perception unaided by state or official organs, through ill-considered actions and expressions by the state can aggravate the situation.

Strategies: To avoid stigmatisation, those who plan public health responses must ensure that the provision of healthcare services is made on an equal basis to all, irrelevant of society's opinion on their moral status. This can be achieved primarily through legislative methods ensuring that such equal treatment is enshrined in law. It will also be necessary, during the context of epidemics, for public health authorities to engage

with groups to reinforce their own sense of self worth, allowing them to resist the stigmatizing pressures from other members of society. This will allow public health campaigns to take into consideration the sensitivity of such groups and also allow stigmatized groups to reinforce their own sense of self worth. The engagement of such groups could be optimized not only through the identification of such groups (where possible) long in advance of an epidemic but also through constructive dialogue with community representatives in the planning of a response to a potential epidemic. "

Modern social media technologies will provide an important opportunity for such authorities to monitor such perceptions and intervene if needed by the timely provision of accurate information. Given the serious nature of these negative effects the planners of public health responses to epidemics should seek to, where possible, avoid or at least minimize, creating new problems of this type or entrenching those that pre-exist amongst groups that are already stigmatized. Failure to do so may result in not only negative consequences during an epidemic but also after the epidemic in question has disappeared.

2.1.7 Conclusion

In agreement with the WHO (2010), risk communication should promote a positive social response to pandemic interventions. It should also aim at inducing preventive actions and an appropriate behavioural change in the population. The Strategies utilized during the 2009 influenza pandemic included 'speaking with one voice", involving academic experts and government officials in the effort, and targeting core groups of populations at risk .The activities included awareness campaigns, advocacy, call centers, on-line response capacities, BGO and private sector partnerships. However, during the European workshop in Brussels (2010) a number of participants reported that communication was a major and complex issue that needed further improvement. The challenges were to respond to the various public concerns and to achieve a high level of transparency over the disease burden. It was also emphasized that communication on vaccine issues should receive higher focus in pandemic preparedness, at all levels (EU Conference report, 2011; Ropero-Alvarez et al, 2012).

To manage this complexity, in Abraham's view (2009), a successful communication requires an understanding of the broader political, social and cultural environment in which communication occurs. Communicators need to explicitly develop tools to ensure the visibility and legitimacy of their message in a crowded political environment. The existing WHO outbreak communication principles of early announcement, trust and transparency achieve this to a certain extent. However, additional work is required to develop practices and principles to ensure visibility and legitimacy of communication. Choosing the best channels of communication, targeting primary audiences and finding spokespeople who provide legitimacy are some of the issues that need to be explicitly addressed. Communicators skilled in behaviour change communication and social mobilization own a variety of tools to deal with these issues and so they are often called on during outbreaks. It would be beneficial if these tools were incorporated into general outbreak communication principles (Abraham, 2009).

Finally, the new media tools and the novel information sources were also considered as the basis for an information revolution in public health, particularly in epidemiology and surveillance (i.e., biosurveillance) (Wysenbach, 2009). In the words of Khan et al (2010), this Internet revolution would lead to an increased availability of electronic health-related information. Improved information technology has given public health practitioners unprecedented access to novel streams of information and the ability to establish social networks for analysis and dissemination. Capitalizing on this opportunity will require the public health community to change its organizational culture so that the users of information will not be limited to traditional surveillance and direct notification. Instead, we must collectively learn to share information,

reward the sharing and reuse information across domains, and expand the boundaries of public health to multiple new sectors. This is also important for the public health communication, methods and evaluation.

2.2 Work Package 2 – New Challenges and New Methods Overview

The objective of work package 2 (WP2) was to identify new challenges and new methods for outbreak communication by emphasizing the multivariate nature of the network in which different stakeholders operate and the ever growing diversity of channels to communicate the information. The seven reports comprising WP2 tackle the issue of outbreak communication from different angles and outline new methods that should be used and new challenges that must be overcome to achieve an efficient information flow. In order to stress the complementary nature of the different reports in WP2, they are divided them into four sections, which can be seen as different stages in the process of outbreak communication. Analogous to any communication process that requires a sender, a message, and recipient, we begin by identifying the target population and its diverse communication requirements.

2.2.1 Stakeholder Directory and Map Description

The principle objective for this element of our research was to identify and categorise key actors or stakeholders in the field of risk and outbreak communications during a pandemic.

It is evident that, with the aide of mass media, social media and the World Wide Web, the general public are connected with an increasing number of sources from where information can be drawn on the pandemic, strategies and preventative measures – including specific communications about immunization. It is also the presence of the media and the internet that empower people to move in the opposite direction, and drastically influence decision-makers on a local, regional or even national level, based on the behavioural responses that become published through the various means of communication. Also it is apparent that an hierarchical structure exists and that it is respected on an international level in relation to communication and information involving policy making. There are also some standard procedures and clear links for incorporating the industry stakeholders in the process, while the EU umbrella organisations and associations have a clear role with reference to lobbying that takes place on an EU level.

More attention is required for local stakeholders and individuals who are part of a local community, who are perceived as having a dual role in outbreak communication.

Key stakeholders: The following organisations, institutions and agencies were identified as key stakeholders:

- World Health Organisation (WHO)
- European Commission – Directorate-General for Health & Consumers (DG SANCO)
- European Centre for Disease Prevention and Control (ECDC)
- European Medicines Agency (EMA)
- Ministrys' of Health and related Departments/Divisions
- National Surveillance Institute for Public Health
- National Medicines Regulatory Agency.

In addition, the stakeholders with medium and high levels of immediacy and having capacity to directly impact public perceptions, attitudes and/or behaviour in outbreak communication are the following:

- Non-Governmental Organisations
- General practitioners
- Healthcare workers and professionals
- Primary schools
- Ethnic / minority / religious groups
- Local political parties
- Opinion leaders
- Science journalists
- Media

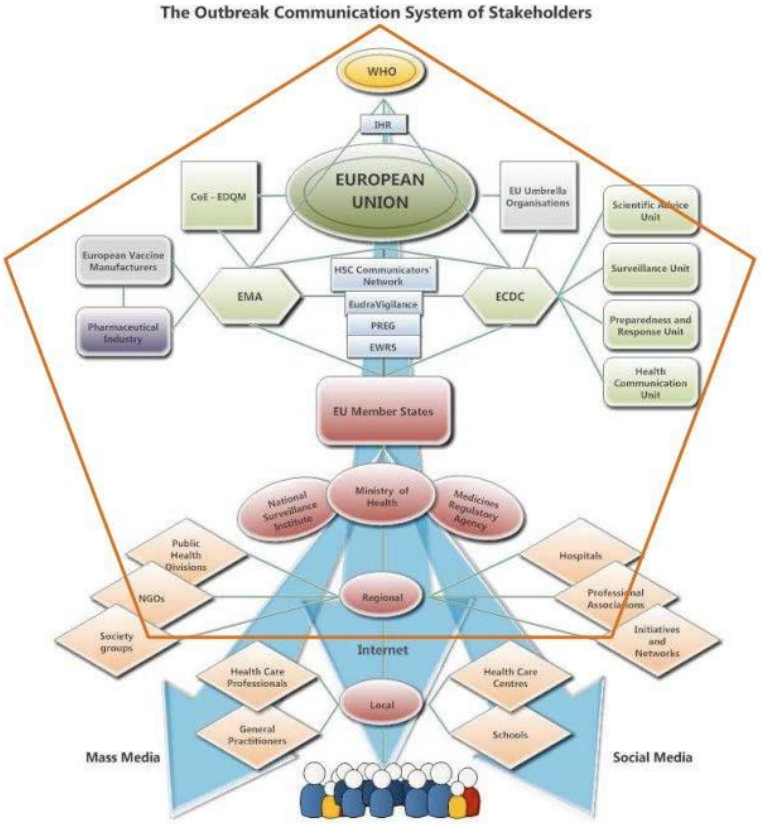
The stakeholder analysis in the frame of outbreak communication has not only been useful for understanding the dynamics and relationships between different stakeholders, but also important in order to understand the role and the potential each stakeholder has, for effectively becoming involved in the process. The challenge has been to identify stakeholders that usually are not exposed or do not appear in the front lines of outbreak communication, but nonetheless have enough power to influence the decisions or behaviours of policy-makers or the general public. To this extent, the need for national public health authorities to better make use of the possibilities provided in two-way communication with the public was recognized.

Accountability: The issue of accountability has also been highlighted in this report. For this reason, it is paramount to better define the roles and relationships between the different institutions and agencies, as well as the national public health authorities, which on a second level could translate into redefining the role of the state in relation to different stakeholders and entities deemed to be particularly important in outbreak communication.

Key Recommendation: With regards to mapping stakeholders it is recommended to leave open the possibility that new entities or stakeholders might be introduced and be relevant in future pandemics. To achieve this, all different types of stakeholders need to be evaluated in terms of the specific requirements and needs that they might have.

2.2.2 Stakeholder Communication Requirements

TELL ME carried out exploratory research on stakeholder communication requirements that aimed to take a closer look into fundamental principles and various mechanisms underlying multi-layered outbreak communications between institutional actors on a national and international level, and non-institutional actors or stakeholder groups that operate on a local, regional or national level. Scrutiny of regulatory policies and mandates, technical reports and research studies, formed a comprehensive understanding of the stakeholder interconnections and the means used for the exchange of information at institutional level, in the event of an infectious disease outbreak. Based on this, further research was carried out to deepen understanding on the information needs and requirements for different types of stakeholders, the present risks and future challenges in outbreak communication, and general views on the different sources for communication of messages to the general public or specific stakeholder groups.



The analysis of the International Health Regulations (IHR) 2005, as per the mandated standards in communications between WHO and Member States, was indicative of the fact that on an international level sophisticated mechanisms are already in place for the exchange and flow of information.

Communication challenges are considerably more when national competent authorities need to take decisions for the general public and vulnerable populations under the (external) pressure and/or influence of the way an epidemic unfolds in other geographical regions and response measures taken in those cases. The clear-cut relationships and links that form part of international cooperation and partnerships are difficult to sustain on a national level, as the stakeholder groups involved in the outbreak communication process are significantly more, with diverse communication requirements and information needs.

In the national context, another key stakeholder group that plays a significant role in outbreak communications is the mass media.

The evidence suggests that social media is not yet considered to be a competent authority or health professional acting as the primary source for data collection, although any type of information that arrives directly from the community level is essential. For decision-makers at top level, focus should be shifted to better understand the information received from multiple sources at the local level, so that public health messages may be tailored for different populations and target groups. This requires national public health authorities to view the outbreak not only in its global dimension, but also in its local dimension.

Overall, the communication requirements at the level of collaboration between international organisations and national public health authorities are clearly framed through regulatory policies and mandates as described in the International Health Regulations (IHR 2005). Moving to the level of collaboration between national public health authorities and other national or local stakeholder groups, the requirements governing communications during an infectious disease outbreak become more blurred as the sources of information multiply as one moves from regional, to local and finally to the general public. It is apparent

that there are no great differences between the institutional and non-institutional actors in their views and perceptions about the type and value of information that is made available to the public, however a series of recommendations are made concerning the anticipated critical role of the new social media in future outbreaks.

Our research suggests that the plethora of existing surveillance and monitoring systems largely satisfy the information needs of institutional actors. It is the non-institutional actors that need to be better informed about how a disease develops and the associated risks through automated processes. There was general agreement between stakeholders that most essential information to be made available from the onset of an outbreak is that of risk assessments, which will be specific to the disease rather than a generic plan of response.

Stakeholders Engagement: Institutional actors focused on the need to engage more actively with healthcare workers, while the non-institutional actors perceived the journalists and media in general to be the priority. What becomes increasingly more critical in outbreak communication is the risk of exclusion of specific groups of society from the process. This is either as a direct consequence of the digital divide (in the case more information are made available through electronic means, e.g. the internet, social media etc.) or as an indirect consequence of failing to understand the actual information needs of marginalized or disadvantaged groups in society that have limited capacity to voice their concerns.

2.2.3 Health Care Professional Communication

In response to our research, participating GPs felt in general that national and local health authorities would have to handle the pandemic situation differently in the future. Misleading media communication was one of the main problems during the 2009/2010 pandemic flu. Patients were alarmed and GPs did not have enough information and tools to handle “hysteria”: doubts of the population about the pandemic situation and about the real need for vaccination. GPs from Eastern European countries complained about a communication gap i.e. a time delay in the information being passed to them by their health authorities. In contrast, British GPs felt that the communication overload in UK from different sources was at times overwhelming. In the United States non-vaccine preventative recommendations were widely adopted, but following the release of vaccines there was a mixed feeling regarding the handling of vaccinations.

GPs experienced many problems in the field of coordination among health care professionals (e.g. midwives, gynecologists and general physicians). There was a lack of effective cooperation between different levels of the PHC system, health authorities (national – regional – local) and between health authorities and GPs including the supply and distribution of the vaccine and protective wear.

GPs have a crucial role in preventative activities during pandemics. They possess high accessibility by the population and hold high levels of credibility and trust from the public. GPs serve to promote good health and due to their often personalized relationship with patients, they are able to target communication to at-risk groups who require a vaccination during a pandemic.

Recommendations for GPs focused on three main topics:

- **Communication**
    - Improve external communication regarding media campaigns and at the GP-patient relationship level
    - Improve internal communication between different health professionals, and between health authorities and health professionals

- **Collaboration**
    - Improve coordination between national and regional health government and GPs
    - Improve coordination among health care professionals
- **Organization, logistics and others**
    - Timely shipment of vaccines
    - Separate, reimbursed office hours for GPs to vaccinate
    - Weekend clinics for well patients
    - Improve access to flu lines e.g. widen the target of those who get vaccine free
    - Cheaper vaccine for people not belonging to a target group
    - Clear legislation or legal support

The overall feeling of British GPs was that the outbreak was well managed nationally and locally. A significant amount of practitioners found the "flu Tsar" Dr Maureen Baker's weekly bulletins invaluable *"one person of high standing made all the difference." (UK9).*

According to most of the participants in our research, health authorities and health organisations would have to handle the pandemic flu of 2009/2010 (they seemed more reactive than proactive) better in the future. The overall feeling of British and Danish/Scandinavian GPs was that the outbreak was well managed (but in the UK, the GP's often felt overwhelmed by the quantity of information from different sources). Italian GPs and doctors from Romania reported on their (mostly) negative experiences and inadequate handling of the pandemic, but we received a number of critical comments from Belgium and Hungary related to this question. Many respondents had 'mixed' opinions (partly good and partly bad views), and just very few participants (primarily from the UK) reported on absolute positive experiences.

In summary, GPs have a crucial role in preventative activities during pandemics. They possess high accessibility to the population and have high credibility in the public's view. Patients put trust in their GPs (a higher trust than in governmental communication). GPs serve as an example in their attitude to health prevention (the self-vaccination was found important in persuading patients). Thanks to the personal relationship and length of relationship, GPs could perform further personalized communications.

2.2.4 Technical, Legal and Scientific Feasibility of an Online Course for Primary Care Staff

Our research suggested that it could be possible to develop a protocol of E-learning, such as the TELL ME Project, that could be consistently applied in different countries. Most of the European Union countries have Continuing Medical Education (CME) systems with similar accreditation, recognize distance learning and have mutually recognized credits because they belong to a common system (UEMS).

The results of the second part of the research (technical) show that Moodle seems to be the open-source LMS platform that best meets the TELL ME project requirements.

The results of the last part of the research (scientific) support the adoption of a case-based e-learning approach in the TELL ME project as it allows 1) to rapidly and effectively disseminate and update critical information necessary to efficiently react to infectious disease emergencies in Europe, and 2) to promote active learning and skill acquisition by using clinical cases to recreate authentic and realistic clinical learning scenarios, which ultimately enable an effective transfer of the theoretical knowledge into practical problem solving.

2.2.5 New Social Media

Social media is built on the principle of user-generated content, which means that users can now contribute towards the collective body of information and knowledge developed during a crisis. This activity can be of use to authorities involved in crisis communication because it can alert them to concern or misinformation expressed by social media platforms and can help them prepare responses that reflect visible and quantifiable information needs. Furthermore, social media also appears to encourage pro-social behavior, which means that the medium often compels users to share useful information and resources with each other. This has the potential to be an important asset for those involved in crisis communication and the promotion of protective behaviours.

Organisations and individuals involved in crisis communication cannot afford simply to be reactive to messages shared and posted in this competitive environment, rather, they must take a proactive stance in establishing an authoritative presence on social media channels before and during a crisis. Whilst user-generated content can be a valuable resource to crisis communicators, there is strong evidence that the public rely on good quality information from 'official' sources to help cross-verify and make sense of the multitude of sources available on social media sites. Also, by building a community presence on social media before a crisis, organisations will be in tune with their audience's needs and can work to influence and shape the direction of discussions as they emerge.

Currently, use of social media in crisis situations is often applied inconsistently, owing to Organisation's varying priorities and resources. Our research highlights the benefits of using social media as crisis communication tool, as well as identifying potential challenges in integrating it into formal communication strategies.

It is recommended that further research should be undertaken to analyse the dynamics of the social networks in order to understand more about how information spreads through them. It is also recommended that organisations should do more to analyse the data posted on social media sites in a more scientific way, by categorizing the types of messages being posted, in order to quantify actual needs expressed, rather than perceived needs. By assessing these two aspects of social networks in more depth, crisis communicators could build a data drive and transparent approach to crisis communication.

Social media has been used in a variety of ways by organisations that aim to protect public health during an emergency. However, most organisations have not embraced social media as a key communications tool during a crisis, and remain unsure of how to harness it to achieve their strategic aims.

It is important for authorities to 'establish ownership' and authority over crises discourses, particularly online, where information and sentiment can change so quickly. Organisations should aim to build a social media presence before a crisis happens by keeping members of a community regularly informed of what it is involved in, as well as providing advice on protective behaviours. It may also be worthwhile nominating several people within the organization to have access to the social media accounts to help monitor and respond to comments.

For health care professionals to feel comfortable using social media during a crisis, they need to know that their employer has sanctioned its use and also be in possession of verified information that they can pass on.

As well as setting up organization accounts to disseminate information, organisations could also identify the most connected individuals within their social network and ask them to help spread a particular messages or resource more widely.

2.2.6 Digital Resources for Disease Detection

The availability of digital resources using both formal and informal methodology for monitoring infectious diseases has grown rapidly during the last decade. The impetus for developing such methodologies was initially driven by the desire to reduce the time taken for detecting infectious disease outbreaks. There is limited evidence to show that such resources actually help to detect outbreaks earlier than conventional methods. However, it has become increasingly clear that these resources provide important information for managing such outbreaks by increasing the situational awareness. They also provide essential information for risk communication.

Based on the fundamentals of the natural history of the diseases and on simulated outbreaks, both syndromic-type surveillance and non-formal digital methods are unlikely to detect infectious disease outbreaks, prior to clinical and laboratory diagnoses of the early cases. However, there is evidence that they can be useful as decision-support tools for control of the outbreak. They can provide critical, timely information on the location and spread of the outbreak and predictions on its ultimate extent, making them invaluable for managing the epidemic. They can also play a crucial role in providing timely and valid information for risk communication. Emphasis should be place on this aspect when developing or deploying such systems.

Surveillance systems for infectious disease outbreaks will need to be flexible and adapted to the characteristics of the potential biological agents. Surveillance systems will also have to be sustainable, without long-term burnout. It is clear that health professionals will need to play a much more active role in disease surveillance than in the past.

In summary, syndromic-type surveillance systems, with sophisticated statistical algorithms, are of limited value in the early detection infectious disease outbreaks. The first cases probably will be identified when they are serious enough to be diagnosed by alert physicians. However, syndromic surveillance can play an important support for controlling the outbreak once it has been detected.

There has been impressive progress in the development of informal digital systems for disease surveillance. Informal digital systems are widely used by the general public, as well as by health officials. Currently there is little prospective evidence that existing informal systems are capable of real-time early detection of disease outbreaks.

The challenge is to present critical information clearly and concisely. Another important challenge is to establish a response system to early warnings. With the lack of such a system, early warning is not useful, as no practical action is followed by the publication of the information. Such a response system may include triggers and decision criteria, which would lead to an appropriate and proportionate response to the threat (Morse, 2012).

2.2.7 The New Global Health Security Regime

International public health cooperation is essential to mitigate the spread of epidemics. In order to prevent or minimize harm from emerging infectious diseases in the future, it may be necessary to impose measures that constrain national sovereignty. The trend towards a global health security regime is likely to change the traditional approaches to outbreak communication. However, there are still many questions that remain unanswered regarding whether the WHO eventually will be legitimate as a supranational public health authority.

The findings show that the revised IHR provide an important mechanism for controlling international infectious disease crises and significantly improve the coordination between the WHO and member states than was apparent prior to their implementation. However, it seems that while these channels worked on the international level, more specific instructions and guidance were needed on the national level. The instructions are mostly "top-down", and there seems to be a need for more attention to be dedicated to their implementation in individual member states. There is some evidence that the states need more feedback on their concerns regarding lack of information or misunderstanding and adaptations required at the local level. Many countries have not yet been able to achieve the core capacities required by the revised IHR. This may require assistance from resource rich countries to those that possess fewer resources.

Four main conclusions and recommendations:

1. The first recommendation relates to the necessity of establishing the goal of the vaccination program as the first essential step in formulating effective communication strategies in order to clarify that the vaccination program has two main purposes one for protecting the individual and one for protecting the public.
2. The second refers to the importance of using the most up-to-date theoretical literature and theoretical dimensions in planning communication strategies. These theoretical dimensions should be transformed to practical applications and implemented in different programs.
3. The third conclusion relates to the gap between the instructions on the international level and their implementation in the member states. Therefore, in future epidemics, it is recommended not just to give general instructions on building local guidelines, but to be more involved in their implementation.
4. The last conclusion refers to the flow of communication as part of the strategy. Most of the communication process that was found in the reports, both between the international organisations and the member states and between them and the healthcare workers and the public, was one-way. Therefore, it is recommended to give more emphasis to the two-way flow of communication and its value in informing communication strategies.

2.2.8 Conclusion

We have outlined the various new challenges faced in outbreak communication in the 21st century, and suggest several new methods that can be used to facilitate the flow of information among different stakeholders. We began by suggesting a concrete definition for the concept of "stakeholder" in order to establish a more comprehensive and accurate outbreak information net, which emphasizes the specific communication needs of different level stakeholders. Consequently, new methods for a rapid and effective dissemination of critical information were introduced, including E-learning, social media, formal and informal surveillance systems.

It is safe to say that the notion that resonates most strongly throughout the different reports is that the concept of "outbreak communication" in the process of containment of a pandemic has developed (together with the communication technologies) to such as extent that it almost threatens to overshadow the pure healthcare aspect of Virus containment.

Mass communication can be portrayed as a double-edged sword (although it can be argued that silence is not an option here, not anymore). While new methods for outbreak communication better accommodate the requirements of different stakeholders, their indirect effect is a growing digital divide that marginalizes source-limited stakeholders. Moreover, social media facilitate the process of democratization of information, helping users to access a wide plethora of sources and get a broader understanding of the crisis but simultaneously it gives a pseudo-authorised stage for misinformation.

2.3 Work Package 3 – New Communication Strategies

Work package three focused on developing strategies to support vaccine uptake with special focus on new communication strategies for health professionals/agencies to engage with vaccine-resistant groups. The general aim was to "develop the TELL ME Communication Kit that will offer an **integrated, participatory model for crisis communication**, on the basis of which messages can be produced for **different sub-populations in different countries**, addressing new and emerging communication challenges.

The main objective of this element of the project was to define and design a new framework model for outbreak communication. Broadly speaking, the model focuses on four crucial elements that shape the distribution of information in outbreak communication:

1. WHO: which actors are called for involvement at which stage?
2. HOW: which communication channels are best to be used by those actors to achieve objectives?
3. WHEN: which time is best to communicate messages, prior, during or after an epidemic?
4. WHAT: which risk communication theories and tools ought to be considered in producing messages, for more effective involvement of the public and a better level of immunisation, also keeping ethics in mind?

2.4 Key Scientific and Technical Findings of Deliverables

2.4.1 New Framework Model for Outbreak Communication

The proposed model is not based on a hierarchic, linear structure. It is not an attempt to shape or funnel reality into clear, linear spreadsheets, as some guidelines do. The New Framework Model envisages a different approach whereby the public (i.e. the end targets of communicative effort) are placed at the center of the framework, and placed in a more dynamic position where they will be able to interact with public health agencies through community representatives and stakeholders. The New Framework Model recognizes the existence of a much more homogeneous public in terms of a target audience, including members of the medical profession. In addition, through the use of stakeholders and community representatives the new framework model foresees a much more dynamic two-way communication process where messages are distributed and altered according to feedback, before, during and after an epidemic. Such a set-up allows important information to be gathered concerning the efficacy of particular communication strategies long before a pandemic would arise. In addition, it would allow important lessons to be learned from subsequent pandemics.

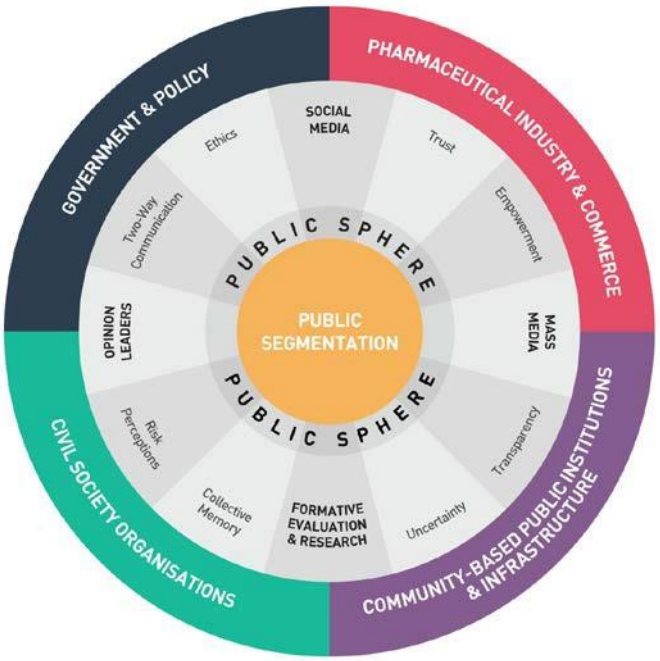


Figure 4: Framework Model

The significance of the proposed risk communication framework model is that it integrates relevant concepts and theories with a practical approach. The contribution of this model is that it can be adapted to many specific risk situations through simulations in which the ideas can be developed into concrete plans. Although it provides some details on certain aspects, it is not meant to serve as a communication kit per se, but as the foundation for such a kit, and also for further research.

2.4.2 A New Model for Risk Communication Health

The TELL ME Communication Kit has been developed in response to a call made by the European Commission in the context of the 7th Framework Programme (HEALTH 2011.2.3-3), in the aftermath of the 2009 influenza (H1N1) pandemic. The TELL ME Communication Kit is the outcome of a collaborative effort made by TELL ME partners and experts, to further improve risk communication and the management of public health threats at different phases of an influenza pandemic.

The TELL ME Communication Kit offers a wide spectrum of practical recommendations and tools to support the development of evidence-based messages, tailored for different sub-populations and target groups across various cultural contexts with the aim of minimizing deviations between perceived and intended messages in the communication process. The guidelines have been developed by considering the dynamic nature of infectious disease outbreaks where priorities shift and information needs vary according to situational or contextual factors that characterize each phase of the outbreak.

It is envisaged that for the communication strategies, practical tools and templates found in the guidance documents will be considered in the development of future preparedness and response plans elaborated by public health authorities, as part of a wider strategy to counteract an infectious disease outbreak – namely an influenza pandemic- both on the local and international level.

The TELL ME Communication Kit comprises four different guidance documents;

1. **New communication strategies for healthcare professionals and agencies.**
2. **New communication strategies for working with different sub populations/at-risk groups.**

3. **New communication strategies for institutional actors.**
4. **New communication strategies for preventing misinformation.**

Target Audience: The TELL ME communication Kit has been developed as a support tool to assist public health officials in the development of a communication strategy within the wider framework of a national or international preparedness and response plan for major infectious disease outbreaks. The document is geared towards health communicators and healthcare professionals who are required to communicate risk and uncertainties to the general public, with special attention to individuals who resist the uptake of protective measures, such as vaccination.

Validation Process: The guidance documents were reviewed internally by consortium partners and at the second stage by a panel of external stakeholders. A total of 21 stakeholders from 13 countries participated as reviewers. All four guidance documents were received positively with the majority of reviewers expressing their overall satisfaction with the scientific robustness and comprehensiveness of the guidance documents.

2.4.3 Prototype Online Course For Primary Care Staff

Based on the results of D2.4 Study of Feasibility of an online course for primary care staff, an online prototype has been developed. The interactive e-learning course is to help healthcare professionals to get acquainted with the TELL ME issues of transparent communication in epidemics, before a new pandemic would occur. The main target of this course is healthcare professionals, notably GPs, but also nurses, midwives, health assistants, etc.

The interactive course allows therefore healthcare professionals to prove themselves in daily situations, after studying three documents in which all requested information is included:

- Dossier 1 – Epidemics and pandemics: what health professionals need to know
- Dossier 2 – Talking about prevention in case of pandemics: information and strategies for healthcare professionals
- Dossier 3 – Stigmatisation and discrimination: a guide for healthcare workers.

It is mandatory to read all of the three sources before tackling the interactive activities.

The course can be done in several sessions, by logging on at different times.

It is divided in 6 case histories, each divided in steps with multiple-choice questions with only one correct answer.

At the end of each step, one gets his/her score; the step is passed if at least 80% of answers are correct.

When a case history is passed, an explanation of right answers is given. At this point, it is possible to return to the course's activities summary or proceed to the next case via the navigation menu.

At the end of each case, a forum for discussion is open. A certificate can be achieved when all case histories have been passed.

2.4.4 Legal Ethical Political Implications

The focus of this stage of our research aimed to highlight prominent legal, ethical and political issues that will surround the use of the TELL ME NEW Framework Model (the NFM). The NFM, unlike previous models, is accordingly not based on a hierarchic, linear structure and incorporates the active participation of a range of non-public health bodies that are capable of representing a range of possible interests in society, and each capable of communication with a section of the public in a unique manner. Such stakeholders can represent diverse groups and interests ranging from the pharmaceutical sector, to the groups representing medical professionals and even groups representing certain sections of the population e.g. ethnic minorities.

The organization of public health communication activities in such a manner raises numerous issues of the type this document is concerned with. In particular, these include:

- International Obligations and the NFM
- The consequences of the Non-Engagement of Important Systems of Law Designed to Protect Individuals Who Suffer Negative Consequences
- The Potential Application of Data Protection and Freedom of Information Laws to the NFM
- Ethical and Political Issues Surrounding the Use of Private Stakeholders

2.4.5 Guidance For Assessing WHO Threat Index

TELL ME examined different revisions of the WHO threat index, from its first version in 1999 until its most recent modification in 2013. We defined each threat scale in terms of its meaning, its rationale, the way it is used, to what extent it can confuse, and most importantly its implications for outbreak communication.

Based on lessons learned from H1N1 2009 pandemic, we presented three alternative risk communication scales; WHO revised pandemic phases (2013), CDC Pandemic Severity Index (2007) and Sandman's risk Scale (2007). The potential of each scale to construct effective channels with different stakeholders is discussed; from the level of the Member State to the level of the individual. Most importantly, we stressed the complementary nature of these scales.

In summary, we recommend to connect the three scales to a united integrative pandemic communication phases' threat index. The integrated threat index will be designed to consider geographical threat, severity and public risk perception. This comprehensive index might be the solution for the shortcomings of the current WHO threat index, that does not defects its many advantages. It offers the most practical tools for outbreak communication with different stakeholders, and it takes into consideration international, national and local risk assessments.

Figure 9 demonstrates the complementary nature of Sandman's threat index with WHO six-phase influenza system and CDC pandemic severity index.

Pandemic communication phases		
Communication phase	**WHO pandemic phase**	**CDC pandemic severity**
1. Pre-pandemic cold	1 or 2	
2. pre-pandemic warm (little public attention)	3	1
3. pre-pandemic hot (teachable moment)	3 or 4	1
4. pandemic imminent	4 or	2 or 3
	5	2 or 3
5. pandemic elsewhere	6	4
6. pandemic here	6	5
7. pandemic elsewhere (again)	6	4
8. post-pandemic	1 or 2 or	1
	3 or even 4 (for different strain)	

Figure 9- Integrated WHO Threat Index

2.5 Work Package 4 – Agent Based Social Simulation.

The agent-based social simulation component of the TELL ME project (WP4) developed prototype software to assist communication planners to understand the complex relationships between communication, personal protective behavior and epidemic spread. Using the simulation, planners can enter different potential communications plans, and see their simulated effect on attitudes, behavior and the consequent effect on an influenza epidemic.

2.5.1 Architecture Technical Specifications and Validation Criteria

The social simulation component of the TELL ME project (WP4) started in February 2013. An initial report was produced setting out the intended architecture and validation process. Other elements of the model design were also presented in their then current form in order to provide context.

The model is to provide decision support for health agencies (and other official information providers). More specifically, it is to allow a comparison of options for communication strategies.

The focus question for the TELL ME model is:

- Given a specific communication strategy, what proportion of the population is infected over the duration of the epidemic?

This question focuses the design requirements on the relationship between communication and total infected population, which provides for intermediate relationships with behaviour.

Architecture The modeling technique used for the TELL ME project is agent-based modeling (ABM). This method has three characteristics that are important for the TELL ME social simulation.

Firstly, the model is composed of autonomous and heterogeneous agents. That is, there are many simulated individuals with different properties and decision-making rules. In TELL ME for example, properties include geographic location and access to media, and rules include epidemic prevalence at which the individual will seek vaccination.

Secondly, these agents interact within an environment. That is, the individuals are able to perceive the situation in which they find themselves, take that situation into account in their decision and take actions that affect the environment. In TELL ME, an important aspect of the environment is epidemic risk; how close is an agent to areas in which the epidemic is active?

Finally, ABM is a computational method that simulated interactions over time. Simulations allow 'what if' questions to be tested quickly, cheaply and without the ethical problems of setting up experiments.

The simulation uses NetLogo, a specialist agent-based modeling application with its own programming language. This is to enable model users to input communication strategies and also to manipulate other parameters that are relevant for planning such as the country to be considered and the infectivity of the disease.

Validation Various validation tests were planned to check the accuracy and functionality of the model code or translation. These focused on accessibility of the models for users and reasonableness of the model's behaviour.

Effective model design and development relied on appropriate inclusion of expertise from several relevant subject matter areas such as communication, psychology, public health and epidemiology. This was accessed through workshops and on-going communication with two groups: stakeholders in epidemiology management in the United Kingdom and TELL ME project partners.

The model was to be assessed by two separate groups of public health and health communication professionals who have not previously been exposed to the TELL ME model.

2.5.2 Software Design

The second report on the social simulation component of the TELL ME project (WP4) details the intended design of the simulation model expanding upon, and superseding, the material presented in D4.1.

Specifications The design document describes a two-layer model. One layer consists of simulated individuals that receive communication messages, adjust their attitudes accordingly, perceive their situation and make decisions about whether to adopt (or cease) protective behavior. This behavior is founded on a hybrid psychological model that includes attitudes, subjective norms and perceived threat. The other layer is a spatial epidemic simulation. The layers interact with each other; epidemic progress is the major element of an individual's perceived threat, force of infection through transmissibility of the epidemic.

The connection and mutual influence of the communication, personal protective behavior and epidemic progress is a substantial theoretical advance over existing models. The key benefit of the TELL ME simulation is to assist health authorities to understand their complex decision making environment and stimulate a broad perspective.

Interface The intended use of the model imposes three requirements on the interface. There are two broad types of input, the communication plan to be assessed and the situations in which that plan is intended to be used. Separately the model output must provide information necessary to assess and compare communication plans, particularly the impact of the plan being assessed.

Communication Plan: The simulation must describe the most basic elements of the messages constructed by health agencies and intended to encourage protective behaviour by individuals. A communication plan (or campaign) will involve one or more tactics. Messages that make up a communications plan each have several properties and each property has a specific value. In describing a communications plan to the

model, each message will need to be fully specified, with a particular value selected for each property. The objective for the set of properties is therefore to have the smallest possible number of properties (to limit the number of description required) while including the details required to apply the message to modeled entities. For each property, the set of values should be as small as possible (to minimize the number of rules) but include all the values that lead to different effects.

The language to describe messages to the simulation has six properties:

- trigger: the type of conditions under which the message occurs, such as a set period after an epidemic is declared;
- trigger parameter: the value associated with the trigger event, such as the specific number of days;
- delivery channel: the media type used for the message, such as social media;
- target group: the population group who would respond to the message if it reaches them, such as those people in target groups;
- content: the message that is actually delivered, such as promoting the benefits of adopting protective behaviour; and
- behaviour: which behavior (vaccination or nonvaccination) is the subject of the message.

Input: Epidemic Situation As well as the communication plan to be addressed, the model inputs include details of the situation in which the plan is to be delivered. This includes key characteristics of the population potentially affected by the hypothetical epidemic and details about the infection itself.

Output: Simulation Results There are two types of results provided by the model output: adoption of protective behaviour and epidemic progress. Further, the output is to be provided in several ways: a map to display spatial information, plots of time series, and reporting of specific numbers.

Interaction Rules In an ABM, logical if-then statements or equations are required to connect circumstances to agent actions, encoding the influences between properties and decisions of different types of agents. . For the TELL ME model, rules are required for many aspects of message reception, attitude change, behaviour and disease transmission, connecting the inputs to the outputs ensuring that the way that the model is to respond to different communication plans and epidemic situations is moderately realistic. The model design document included a discussion of broad model logic and proposed detailed rules. The rules were developed from findings earlier in the TELL ME Project, specific additional literature analyses, and a stakeholder communication process involving experienced epidemic response managers and other key personnel.

2.5.3 Prototype Software

The prototype software was released in January 2015. The model and the software to run the model are both freely available from the TELL ME website. Installing the TELL ME simulation is relatively simple but does require several steps. Documentation for the prototype software has been developed and can also be accessed from the TELL ME Website.

The major component of the documentation is the user guide. This provides instructions on how to set up the software, some training scenarios to become familiar with the model operation and use, and details about the model control and output.

The final technical reference contains two parts. The first is a guide for advance users who wish to run multiple simulations and analyse the results. The second is to orient programmers who wish to adapt or extend the simulation model. This material is not suitable for general users.

The connection and mutual influence of the communication, personal protective behavior and epidemic progress as embodied in the simulation is a substantial theoretical advance over existing models. The key benefit of the TELL ME simulation is to assist health authorities to understand their complex decision making environment and stimulate a broad perspective.

However, data is not available to accurately parameterize the model. That is, the model will be sufficiently precise and accurate to directly compare potential communication plans. Nevertheless, it can also guide future data collection efforts, the structure is based on relevant psychological theories and the model parameters can be adjusted as more data becomes available.

3 TELL ME Project Impact, Dissemination and Exploitation

3.1 Impact

The TELL ME project has developed a number of products already available via the **TELL ME website** and which are being disseminated to public health agencies, the media, academy, policy makers, and civil society organizations. The products are interrelated and have been developed through intensive evidence based research by the consortium using their considerable and wide experience. The F**ramework Model for Outbreak Communication** crucially places the public at the heart of the communication process underlining the importance of a continual dialogue between the Health Care Professionals, other major stakeholders and those who need protecting from the risks at each stage of an outbreak.

The practicalities of the processes inherent in the framework model are made clear and accessible in the **TELL ME Communication Practical Guide**. Further training in the application of the recommended outbreak communications strategies and tactics are available via the **Online E-learning Course for Primary Care Staff**. In the future further research and the maturing of these strategies and tactical processes may be developed through use of the **Agent-based Simulation Model**.

TELL ME has also produced a **Guidance for using the WHO Threat Index**.

Outbreak communications is a “live” subject that needs to continually adapt and develop as situations change. The following products developed and refined as the TELL ME project progressed will do much to ensure that the beneficial impacts of the project will continue to be felt for years to come.

1. TELL ME Website
2. Framework model for outbreak communication
3. TELL ME Communication Practical Guide
4. Online e-learning course for primary care staff
5. Agent-based Simulation Model
6. Guidance for using the WHO Threat Index

3.2 TELL ME Website

The TELL ME website was targeted at the general public, professionals and policy makers, providing information on the issues related to the project (flu, vaccines, emerging infectious diseases and communication strategies in these fields) and updating on progress and results of the project itself.

The main purpose of the website was for internal and external communications, as well as for management and reporting activities within the project. A beta version of the TELL ME website was released in March 2012 (M2), to become fully operational in April 2012 (M3).

The website provides information on the project, updates on progress and results, while hosting news and features about the issue of infectious outbreak communication.

The main sections of the public web portal are:

- Project (summary, vision, mission, partners, EAB members)
- Documents (deliverables, presentations, publications, other outputs)
- Media centre (with Viewpoints, News from the world, News from TELL ME, Multimedia gallery, Press Review, Newsletter and Press Releases)
- A glossary (Flu from A to Z)
- A human rights section (devoted to case law and regulations concerning flu pandemics and vaccination, managed by VUB)

During the project, the website underwent several updating, in order to adapt it to evolving needs: in the 1st reporting period it was mainly focused on giving general information and on reading into the news about flu, vaccine and emerging infectious threats, always highlighting communication issues; in the 2nd period, it was mostly dedicated to collect and disseminate mounting results and products by the project itself.

The website acted as a principle source of information for research and a repository for the many papers and deliverables. Each deliverable was presented by an **executive summary** and **linked to the homepage**, in order to be more visible, accessible and usable. For the same purpose, **red tags** highlighting the main TELL ME products (E-learning course, Health Risk Communication New Framework Model, Proposal for a New Threat Index, Practical guide for Health Risk Communication, Social Simulation Model) were created and easily visible at the top of the home page.

A special section was created to present the **TELL ME Final Conference**, where all presentations and recordings from the event can be found.

The **connection with Twitter** was broadened as the project progressed with additional keywords being added to more effectively cover the public discourse on related issues. Twitter was also used to make a more in depth **analysis** of the prevailing sentiments and actors within the social network, and most notably the information and ongoing dialogue concerning the H7N9 and Ebola crisis.

The Ebola crisis was an important bench-test for the application of the communication guidelines developed by the project: thus, the consortium agreed to use the guidelines as the basis for developing **an e-learning course** specifically focused on this issue. The Ebola e-learning course was uploaded onto the website and available through the TELL ME e-learning platform.

The website was enriched with **video interviews** by relevant experts and stakeholders, deepening several aspects of preparedness and response to infectious outbreaks, notably about the communication issues:

- Nobel prizes **Rolf Zinkernagel and Peter Doherty**, author of "Pandemics"
- **David Quammen**, author of "Spillover"
- **Marc Sprenger**, director of ECDC
- **Pierluigi Lopalco**, Head of the Vaccine-Preventable Diseases Programme, ECDC
- **Karl Ekdahl**, Head of the Public Health Capacity and Communication Unit, ECDC
- **Toby Merlin,** Director of the Division of Preparedness and Emerging Infections, US CDC
- **Stefania Salmaso**, Head of the Italian National Centre for Epidemiology, Surveillance and Health Promotion, National Institute of Health (ISS) , Italy
- **Agoritsa Baka**, Hellenic Centre for Disease Control and Prevention, Greece
- **Manfred Green,** University of Haifa Public Health Schools

Relevant point of views about the news on flu, Ebola and about the interaction between the veterinary field and human health were also expressed in articles by experts including:

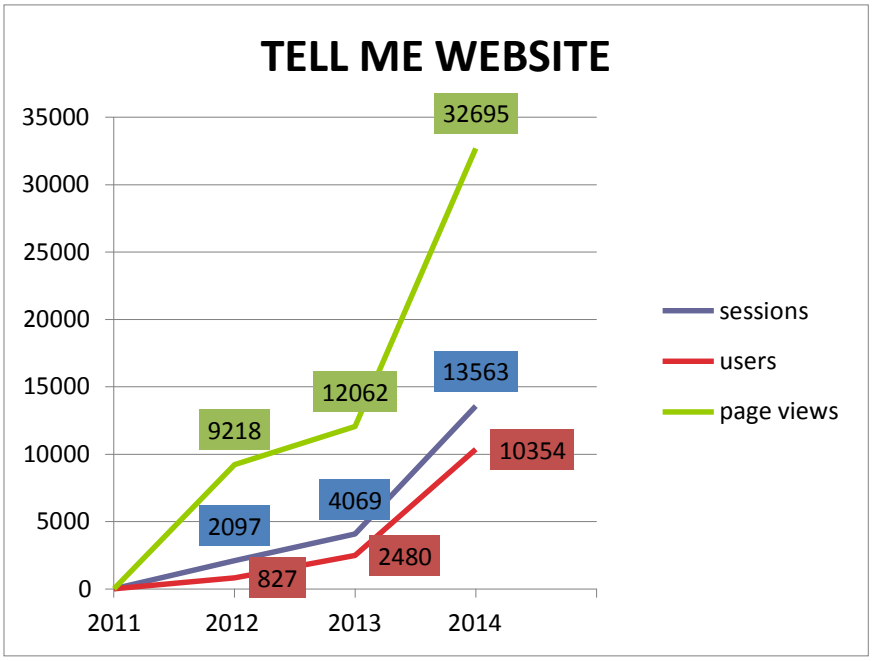
- **Donato Greco**, past director of the Italian National Centre for Epidemiology, Surveillance and Health Promotion, ISS, now in charge with WHO European Regional certification Commission for Poliomyelitis Eradication

- **Ilaria Capua**, Head of the Division of Comparative Biomedical Sciences (DSBio) at the Istituto Zooprofilattico Sperimentale delle Venezie (IZSVe), Legnaro (Padova - Italy) and Director of the FAO/OIE and National Reference Laboratory for Avian Influenza and Newcastle Disease, OIE and National Collaborating Centre for Diseases at the Human - Animal Interface

Both UEMO and NDLSF contributed with links from their website to disseminate our contents to European and US doctors. VUB provided reflections on human right principles related to epidemics and on the risk of stigma in case of outbreaks like Ebola.

Links with related projects are highlighted in home page and an E-COM video on communication in outbreaks was shared.

From 2012 to 2014 **about 300 papers, articles and documents** were uploaded on the TELL ME website: in the second reporting period, due to the different strategy adopted, the number of views from the world decreased, while TELL ME documents and their pickups by media increased.



3.3 Framework Model for Outbreak Communications

The potential role of emerging communication technologies and in particular social media were researched to assess the potential benefits of immediate public participation in outbreak communications under crisis situations. The framework model was developed to demonstrate the way in which public concerns and beliefs flow back into the decision-making of health organizations and how the interaction between health organizations and citizens can best be handled in order to maximize the effectiveness of the coping mechanisms. The various levels of participation in decision-making were defined in the different aspects of the descriptive scheme together with illustrative descriptor scales. The illustrative descriptor scales, plus other descriptors and indicators produced during the project (e.g, stakeholder survey, expert interviews, etc.) are available to users of the model in a data bank of descriptors created in the project web site. Relevant ethical, legal, and cultural issues are also addressed.

The framework model has enabled the development of crisis communication plans, templates for communication management, SOPs that define roles and responsibilities for the different levels management and stakeholders and guidelines for the efficient early warning communication of major epidemic risks. Two basic principles were adopted whilst this process was applied: 1) that communication has to be based on scientific evidence; and 2) that risk communication has to be integrated into risk management (This requires a training program for technical staff). Inter alia, the following are addressed 1) lack of information; 2) reliability of information; 3) conflicting information; 4) lack of clarity; 5) perceived risk vs. actual risk

3.4 TELL ME Communication Practical Guide

The TELL ME Communication Kit is the outcome of a collaborative effort made between four TELL ME partners (Zadig Srl – BMJ – Istituto Superiore di Sanità - CEDARthree) and comprises in essence a set of *four guidance documents* geared towards risk communication professionals, crisis managers and public health officials at national or international level. The principal objective of the Guide was to develop and present new communication strategies to support the risk communication process and the management of public health threats at different phases of an influenza pandemic. At core, the four guidance documents and the Communication Kit as a whole, sought to address the key research questions of the TELL ME project.

The Communication Kit was designed to offer a set of practical recommendations, evidence-based communication tools and templates to support the development of messages, which could be tailored for different sub-populations and target groups across various contexts, with the goal to minimise deviations between perceived and intended messages in the communication process.

The objectives for each of the guidance document of the Communication Kit are summarised below:

ST3.2.1 New communication strategies for healthcare professionals and agencies. This guidance document aims to help healthcare communicators and healthcare professionals (HCPs) responsible for drafting and delivering communication strategies in outbreak situations, to develop appropriate messages for their local populations to increase the uptake of preventative behaviours and vaccination. The document has a specific focus on vaccine resistant groups on both the patient and HCP sides. Moreover, the document sets out the key areas to understand and consider when developing the messages and provides a summary of the best practice available. Finally, the document sets the foundation from which healthcare communicators and HCPs can set to work on developing effective messages for each phase of an outbreak.

- **ST3.2.2 New communication strategies for working with different subpopulations/at-risk groups.** This guidance document aims to assist health communicators, operating at decision-making level, who are responsible for drafting and delivering communication strategies in outbreak situations, with the practical tools that will help them to develop appropriate messages. The document seeks to provide very much a visual aide-memoire of the issues to be considered and addressed when drafting communications to the key 'at-risk groups' at each stage of an outbreak.

- **ST3.2.3 New communication strategies for institutional actors**. This guidance document aims to assist institutional actors to help them contribute in the trust-building process and the overall communication strategy. The document offers a description of the perspective, role and responsibilities of institutional actors in the communication process, and includes a "toolbox" with supporting material and operational tools for institutional actors to use in communications with their widely diversified audience during epidemics and – even – pandemics

- **ST3.2.4 New communication strategies for preventing misinformation**. This guidance document aims to support public health officials, risk communicators and decision makers, to prevent the emergence and/or handle the widespread diffusion of misinformation in the course of a major infectious disease outbreak. The document presents a methodological framework to describe the conditions under which misinformation is generated and spread, and offers key recommendations to deal with complexity and uncertainties in various contexts, and across different phases of the outbreak, to ultimately produce messages that have the desired outcome.

3.5 The Online Course (e-learning)

The interactive e-learning courses are aimed at educating healthcare professionals in providing a correct risk communication to the public before, during and after epidemics and pandemics. Based on

the TELL ME Practical guide and other tools, the TELL ME Consortium intends to develop new e-learning courses and to offer them to an European audience composed by Healthcare professionals and Agencies, such as GPs, but also nurses, midwives, health assistants, public health workers, medical specialists (such as virologists, vets) etc, since one of the main lessons learnt from the experience of 2009 A(H1N1) pandemic is their crucial role in such cases, especially about vaccination. One partner of TELL ME consortium - Zadig, which set up the e-learning system - could develop and market this application.

After having studied the legal and technical feasibility of this kind of online course for health professionals (http://TELL MEproject.eu/content/d24-technical-legal-and-scientific-feasibility-online-course-primary-care-staff), a fully functioning TELL ME e-learning platform (in open source moodle system) has been set up (http://elearn.TELL MEproject.eu) with a course about management of the influenza epidemic. *The prototype course* designed in TELL ME Project (http://TELL MEproject.eu/content/d33-prototype-online-course-primary-care-staff) provides reliable information based on TELL ME research, but also other sources (WHO, ECDC, CDC). The course focus on preventative measures (from hygiene to vaccination), and communication skills, with a particular focus on risk of stigma, in case of influenza epidemic and pandemic. (The following are links to the Dossiers: Dossier 1: http://TELL MEproject.eu/content/dossier-1-epidemics-and-pandemics-what-health-professionals-need-know; Dossier 2: http://TELL MEproject.eu/content/dossier-2-talking-about-prevention-case-pandemics-information-and-strategies-healthcare; Dossier 3: http://TELL MEproject.eu/content/dossier-3-stigmatisation-and-discrimination-guide-healthcare-workers

3.6 The Simulation Model

One of the tools developed within the TELL ME project is prototype software: an agent-based social simulation to assist with communication planning. The simulation is intended to assist relevant officials in health agencies (and other information providers) to understand the complex problem of communicating effectively before, during and after an influenza epidemic. More specifically, it is to allow comparison of options for communication plans, with the user to enter a communication plan and explore some of the key effects on behaviour and consequently on the progress of the epidemic.

The basic question for the model is, given a specific communication plan and epidemic parameters:

- What proportion of general population and specific target groups adopt protective behaviour?
- What proportion of the population is infected over the duration of the epidemic?

3.7 Guidance for using the WHO Threat Index

We critically examined the WHO threat scale, what it means, how it is used and to what extent it can confuse and on the basis of the framework model and the other findings, develop guidance for its practical usage. The new framework will be the basis for the design of the new communication package.

We designed, constructed and tested a prototype of a computational method for simulating the actions and interactions of autonomous decision-making entities using the TELL ME Communication Kit within a virtual environment during an epidemic outbreak. The Communication Kit shows, through the cooperative research with the population of health professionals, the assumptions, professional background, opinions and perceptions about the organization of the experts in the health organizations, which affect the way they manage the risk and communicate it to the public. Our assumption is that revealing the considerations and interests of the public of "experts" will provide us with principles and even guidelines for the experts' work with the public and the media. Furthermore, the participatory communication package offers

guidelines for working with different sub-populations of health professionals, in order to recruit them as opinion leaders for the messages of the government organization.

The model also proposes guidelines for working with different sub-populations in the general public, through simulations that will check how different messages are received by the public. The model offers different strategies and tactics for working with the media in conditions of uncertainty, while providing tools for working after the peak of a crisis and preparing for the next publicized crisis. The Communication Kit includes: Guidance document on new communication strategies for health professionals/agencies. Owner: BMJ Guidance document on new communication strategies for working with different subpopulations/ target groups.

3.8 Dissemination

A number of different channels have been deployed for the dissemination of the TELL ME Communication Kit, with the aim to reach out to various groups of stakeholders in the field of risk and outbreak communication.

Zadig Srl considered a variety of options for raising awareness about the TELL ME Communication Kit across different stakeholder audiences. The following TELL ME resources were exploited for this purpose:

- **TELL ME Stakeholder Directory:** Key representative stakeholders from national public health authorities and international agencies received a notification email about the release of the Communication Kit from the TELL ME website.

- **TELL ME October/January 2015 Newsletter:** More than …..[number] stakeholders/subscribers to the TELL ME newsletter received announcement about the official release of the Communication Kit.

- **TELL ME Social Media platforms:** The Communication Kit and sample content from the four guidance documents was publicised via TELL ME Twitter and Facebook accounts.

The TELL ME Communication Kit was also promoted via external online platforms, such as the **BMJ**, and more specifically the @BMJ_company Twitter account, which numbers more than 19,000 followers, as well as the **Medical News Today**[1], the largest independent medical and health news site on the web - with over 11,000,000 monthly unique users and 16,000,000 monthly page views it is ranked number one for medical news on Google, Bing and Yahoo! The **SciDev.Net** also expressed interest to present the TELL ME Communication Kit on their website.

The four guidance documents that comprise the Communication Kit will form part of the **TELL ME Book** – a TELL ME initiative to consolidate the scientific outcomes of the project in a book format – with a dedicated section on new communication strategies for infectious disease outbreaks and international public health threats. The TELL ME Book is edited by Prof. Manfred Green, University of Haifa, and will be published later in 2015.

Finally, Prof. Karl Ekdahl, Head of Public Health Capacity and Communication Unit and member of the TELL ME External Advisory Board, took initiative to disseminate the Communication Kit to institutional actors at EU level, to public health officials, policy makers and members of the EC Health Security Committee.

[1] Medical News Today (4 February 2015): Practical Guide to improve communication during disease outbreaks launched. Available from <http://www.medicalnewstoday.com/releases/288886.php>

3.9 Exploitation

We can say that all these results are the durable heritage of TELL ME project. All this has ignited an important scientific activity with some papers published or in progress, and conferences, but also some attention by lay media

TELL ME messages raised also the interest of major National and International Health agencies as US CDC, ECDC and WHO. Their members took part to our meetings, also collaborating to validate and refine these tools, and express interest for their exploitation. It is the case - just to name a few - of World Health Organization (WHO: http://www.who.int) which considered our e-learning course on Ebola a good example for its trainees. This course has been already delivered to around 30,000 Italian MD and Nurses - through their professional Federations - with excellent results (*see section B*). Also The International Emergency Management Society (TIEMS: http://tiems.info) wanted to adopt this kind of online courses. The European Centre for Disease Prevention and Control (http://www.ecdc.europa.eu/en/Pages/home.aspx) is willing to network with projects like TELL ME to face risk and crisis communication challenges, and to uptake its guidelines.

Other example of exploitation of the general competences of TELL ME is, for instance, the collaboration with the World Health Organization for the publication "Health and environment: communicating the risk", namely the report of the workshop held in Trento, Italy in 2013 together with the WHO Regional Office for Europe (http://www.euro.who.int/en/publications/abstracts/health-and-environment-communicating-the-risks). Although not in the context of risk communication during infectious outbreaks, the latter document does develop some concepts outlined by TELL ME, especially with regards to the use of social media and to some mechanisms that can hinder fair and proper forms of communication (*particularly pp. 22, 24*). The said report, originally written in English and later translated into Italian and Russian has been distributed by the WHO European Office for Investment for Health and Development in approximately 250 copies reaching all WHO regional offices in Europe and a great number of stakeholders too.

Agent-based modelling (ABM) is the most appropriate technique where both heterogeneity and interaction are important. Heterogeneity means that simulated individuals with different characteristics (such as attitude or access to media) may behave differently when faced with the same situation. Furthermore, the same simulated individual may have different behaviours in different situations (such as close to or far from the epidemic front). Interaction means that an individual's behaviour influences, and is influenced by, their environment (that is, the interaction between the two model layers).

It was developed by researchers at the Centre for Research in Social Simulation (CRESS) at the University of Surrey. The model file is freely available, with no intellectual property rights claimed for the simulation. Documentation and appropriate links are available from the TELL ME and CRESS websites.

The simulation was developed in NetLogo, open source specialist agent-based modelling software. CRESS developed the eXtraWidgets extension for NetLogo to allow additional interface screens, which was important in making the TELL ME simulation easy to use. Both NetLogo and the extension must be installed on any computer that is to be used to run the simulation. NetLogo and the eXtraWidgets extension are freely available under GNU General Public Licenses.

It should be noted that while the TELL ME project was conceived and constructed around communication issues associated with influenza outbreaks, the Communication Kit and respective guidance documents may also find some applications on other type of communicable disease outbreaks, where there is a need to communicate risk and/or plan a public health campaign to raise awareness about an infectious disease, influence positive behavioural responses, and further support the take-up of protective measures.

3.10 Exploitation of the Online Course

During the 2014 Ebola emergency the TELL ME consortium was alerted by the European Commission on this new outbreak threat, and TELL ME promptly responded with the proposition of a dedicated online course. The course, based on the TELL ME online course, was adapted and titled "**How to Communicate During an Ebola Crisis**". The course was immediately submitted by the TELL ME partner in charge of the online course (Zadig) to the Italian Federation of Medical Doctors (FNOMCEO) and the Italian Federation of Nurses (IPASVI), with excellent results. The results of the course in Italy were most successful: Approximately 30,000 Italian health workers (updated to 23/01/2015) have undertaken the Ebola course**.** The income generated by the course has been (up to 23/01/2015) approximately 12,000 Euros (2,000 euro from FNOMCEO + 2,000 euro from IPASVI + 25-30 cent for every participant, up to 50,000 participants, any participants beyond this number are free of charge). Among the more than 28,000 questionnaires of customer satisfaction filled by participants, effectiveness, quality and importance of the course was considered very high (>97%). Over 9,200 comments by participants were left on the platform, 98% of which were positive.

3.11 Developing the Online Course

The aim of Zadig is to market online courses about communication issues related to infectious diseases epidemics and pandemics all over the European Union. Zadig (www.zadig.it) developed the TELL ME online platform and the courses. Zadig is a national CME provider in Italy and has developed several e-learning technological platforms (www.fadinmed.it, www.goal.snlg.it, www.saepe.it, www.formars.it). To date over 300,000 Italian healthcare professionals have participated in Zadig's e-learning courses. Zadig has developed a specific andragogical model of case history that is more appropriate for the education of professional health workers. For this reason, the 2 e-learning courses of TELL ME are focused on case histories or vignettes.

The positive experiences of these online courses has convinced Zadig to plan a further set of online courses (approximately four courses) focussed on risk communication in epidemics and pandemics from 2015 to 2018. E-learning represents an ideal tool to achieve the primary aims of the TELL ME project. There is the real prospect of developing an E-learning system for health care workers capable of efficiently disseminating information across all 27 European Union countries at the time of an infectious disease emergency.

3.12 Further exploitation of the Simulation Model

As an academic partner, the University of Surrey plans to exploit the simulation in further research. The rigour of developing the TELL ME prototype simulation has identified gaps in the knowledge about the connections between communication and personal behaviour. Two of these are substantial: the contribution of different influences to personal decisions to adopt or cease protective behaviour; and the effect of different types of communication on these influences. Both are suitable for investigation with targeted research programmes that involve academic researchers from different disciplines and practitioners. In addition, the experience of developing the TELL ME simulation will support research in more general behaviour modeling. These opportunities will be pursued by developing health and modeling consortia and submitting collaborative research bids.

There are additional ways in which the model could be used that require some work before they could be exploited. This work could be undertaken by the University of Surrey, as the developer of the prototype, or by other organisations with the support of the University of Surrey. Three such uses have been identified:

1. Customisation and extension of the simulation: The prototype simulation can be customised by users with parameter values that are appropriate for their own situation. However, additional customisation of behaviour or amendment of model rules require specialised skills. University of Surrey would be able to provide such customisation services, including progressive development toward a full planning tool.
2. Improved educational programmes: Degree programmes and short courses in communication and public health could use the simulation to enhance the learning of students, providing practical experience to complement theoretical material. University of Surrey would work with interested education providers to develop a package of scenarios, training materials and discussion guide. The University could also provide lecturers or workshop leaders to deliver the educational materials.
3. Adaptation as a game for education or entertainment: The behaviour engine within the simulation could be used as the basis of a game. University of Surrey could provide assistance to developers who wish to pursue these opportunities.

3.13 Connections with other projects

Throughout the whole project, the TELL ME consortium has already made a significant impact in many ways. First, it has created a new European project with some of its partners (Zadig, Haifa University, Absiskey, ISS), that is to say the ASSET initiative. The latter is meant as a continuation of TELL ME, since it will try to implement the main scientific outcomes of TELL ME (e.g. the Framework Model).

As declared by members of the ASSET project TELL ME and ASSET share four Partners (ABSISKEY, HU, ISS, ZADIG. Many TELL ME deliverables can be ASSET utilities: from communication strategy, to literature reviews to vaccine story to myths, etc". ASSET has also shown some interest in the Network TELL ME is going to create, and to invest some resource on it.

Also, the connection with the "twin" project E-com (http://www.ecomeu.info) has resulted in a very positive exchange of information and good practices. E-com (which will run until 2016) is keen to utilize some of the synergies established with TELL ME, first and foremost the TELL ME website, whose informative features have been greatly appraised.

3.14 The TELL ME Network

TELL ME has outstanding potential in terms of exploitation of its outcomes and competencies – something that should be fully maximized through the creation of a dedicated Network bringing together all of its partners, ASSET consortium and maybe other partners as well. ECDC declared its interest to have a connection with this Network as a competent source for issues related to risk communication. This is what was discussed in the meeting held in London on 23rd January 2015, during the final days of the project. The need for a Network specialized in risk communication and health topics and outbreaks comes about mainly from the multifaceted nature of TELL ME - bringing together all the main disciplines in the field: epidemiology (ISS, School of Public Health, Haifa University); journalism and training (BMJ Group, Zadig); risk communication (Cedar3); human rights (VUB); groups representing the cultural and professional interests of doctors (UEMO) and risk management during health crises (NDSLF).

To this aim, a first analysis of what has already been done in terms of Health Risk Communication (*see the presentation by Donato Greco. Reference*) was conducted, concluding that very few scientific societies and journals have focused on this topic. At the London conference, the ECDC has also stated its interest in using the Network to decide on specific guidelines and future projects for collaboration on communication of health risks. This is surely a crucial endorsement for TELL ME and a useful starting point for future initiatives.

The TELL ME Consortium will then proceed with the following steps forward:

- Defining what partners are really interested in the Network and in taking an active role in it
- Stating the corporate purpose and mission of the Network
- Completing the market analysis
- Understanding the economic feasibility of the products and services to offer
- Identifying which legal form the Network can have
- Designing a multi-year development plan

3.15 List of foreground that might be exploited

List of foreground that might be exploited (i.e. that might have commercial or industrial applicability) including its description, sector of application and IP protection:

The main foregrounds of TELL ME include the following:

Foreground	Involved Partner
The Communication kit	Zadig, Haifa University, ISS, Cedar3, BMJ
The Simulation Model	University of Surrey
The Online courses	Zadig
The Framework Model	Haifa University
The Guidance for using the WHO Threat Index	Haifa University
The Book of TELL ME	Haifa University and all partners

3.16 The Book of TELL ME

During the course of the TELL ME project, a large amount of high quality documents were produced. These documents would be an invaluable resource to anyone dealing with risk communication during infectious disease crises. It was thus decided to organise the documents into the form of a book. The main sections of the book include an introduction to communication and infectious disease crises and a history of pandemics. Other sections include the impact and relevance during pandemics of risk communication, social media, population behaviour and compliance. There are also sections on pandemic communication strategies and preparedness and the issues surrounding stigma and human rights. The TELL ME Model, the Communication Guide and the prototype Online Course are also included. The book will be published as an online version and possibly later in a print version.

3.17 Scientific Publications

The following is a list of scientific publications:

Title	Authors	Publication
Why do parents who usually vaccinate their children hesitate or refuse? General good vs. individual risk	Anat Gesser-Edelsburg, Yaffa Shir-Raz and Manfred S. Green, MSc, MBChB, MPH, PhD	Journal of Risk Research, 2014
Risk communication during the 2009 H1N1 influenza outbreak: literature review	Gesser-Edelsburg, A., et al.	Submitted to Health, Risk & Society, under review
Health care workers-part of the system or part of the public? Ambivalent risk perception in health care workers	Anat Gesser-Edelsburg, PhD, Nathan Walter, MA, Manfred S. Green	American Journal of Infection Control, August 2014
Evaluation of Continuing Medical Education (CME) Systems across the 27 European Countries	Tommaso Saita, Pietro Dri	Creative Education, May 2014
Risk Communication Recommendations and Implementation During Emerging Infectious Diseases: A Case Study of the 2009 H1N1 Influenza Pandemic	Anat Gesser-Edelsburg, Emilio Mordini, James J. James, Donato Greco and Manfred S. Green	Disaster Medicine and Public Health Preparedness, April 2014
Self respect—A "Rawlsian Primary Good" unprotected by the European Convention on Human Rights and its lack of a coherent approach to stigmatization	Paul Quinn, Paul De Hert	International Journal of Discrimination and the Law, March 2014
Compliance with influenza vaccination among healthcare workers – tailoring risk communication according to the factors affecting compliance	MS Green, N Groag Prior and A Geser-Edelsberg	European Journal of Public Health, October 2013

4 TELL ME Website and Contact Details

4.1 TELL ME Website

The TELL ME website is at www.tellmeproject.eu

4.2 TELL ME Consortium Contact Details

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