



D5.1

Dissemination Report

2nd Reporting period
WP5 DISSEMINATION AND POLICY DIALOGUE
Responsible Partner: ZADIG
Contributing partners:

Due date of the deliverable: M36 (January 31st 2015)
Actual submission date: M36 (January 31st 2015)

Dissemination level: PU

PROJECT FULL TITLE	Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.
PROJECT ACRONYM	TELL ME
	Collaborative Project funded under Theme HEALTH.2011.2.3.3-3 “Development of an evidence-based behavioural and communication package to respond to major epidemics outbreaks”
GRANT AGREEMENT	278723
STARTING DATE	01/02/2012
DURATION	36 months

Document Management

D5.1 “Dissemination Report”

Task: 5.1

Leader: ZADIG – BMJ, HU

History of changes:

Vn	Status	Date	Organisation / Person responsible	Reason for Change
V1	Draft	17/2/2015	ZADIG/Roberta Villa	First draft
V2	Draft			
Vf	Final			

Table of Contents

1. Introduction.....	4
2. Executive summary	4
3. Objectives.....	5
4. Targets	6
5. Internal communication	7
5.1 Red Mine platform.....	7
5.2 In-person and virtual meetings.....	8
6. Cooperation with other projects and policy dialogue	9
7. Dissemination activities.....	18
7.1 Preliminary activities	18
7.1.1 Kick off meeting (minutes and videointerviews).....	19
7.1.2 Brand and presentation of the project (logo, video, brochure).....	19
7.1.3 First preliminary products (decalogue, glossary).....	20
7.2 Main dissemination activities	21
7.2.1 Website and Social Media.....	21
7.2.2 Press center and newsletters.....	36
7.2.3 Scientific publications and conference presentations.....	50
7.2.4 Final publishable summary report.....	59

1. Introduction

TELL ME devoted a whole work package (WP5), horizontally aligned within the project, to dissemination activities and policy dialogue. According to the DOW, the main objective of WP5 was to provide national health authorities and international organizations, the scientific community, the media and the general public with a clear understanding of the project's goals, methodology and findings, while allowing target groups to interact and directly participate by injecting their perspective into the project.

Accordingly, in the first reporting period, our communication strategy was mainly focused on **presenting the project and its goals**, and on reading into the news about infectious outbreaks in the light of the preliminary results of WP1 and WP2. These two WPs collected and assessed evidence about population behavioural response to infectious diseases outbreaks on the basis of 2009 A(H1N1) pandemic experience and investigated on different target groups communication requirements and new methods to meet them, respectively.

In the second reporting period, partners started to provide new contents and products to be disseminated and exploited. In this phase, further **scientific results and the TELL ME products** (notably the Framework Model for Outbreak Communication, the Online Courses, the proposal for a new pandemic Threat Index, the Communication Kit and the Social Simulation Model) became the main content of TELL ME dissemination and networking.

Since some of these products were not ready before the end of the project, some dissemination activities went on after its formal final term.

2. Executive summary

At the centre of TELL ME dissemination activities was the **TELL ME website**, whose number of visitors and visits increased in time, reaching 32,695 page views by 10,354 users in 2014.

Social network profiles (YouTube, Facebook, Twitter) helped to disseminate TELL ME contents and to get in touch with relevant opinion leaders and stakeholders.

The project as a whole was presented mainly by **specialistic websites** addressed to healthcare professionals, policy maker, stakeholders and public health experts, while some partners' scientific results and case-studies reached **mainstream media** as well.

A dedicated "Pandemic" section on the international website Scienceonthenet.eu often mentioned TELL ME project contents.

Zadig sent periodic **newsletters** to more than 1,200 European journalists, healthcare professionals, policy makers and other stakeholders updating them on TELL ME project progress and results. Other partners, such as UEMO and BMJ, helped to disseminate TELL ME through their website, blogs and bulletins as well.

Contacts with other EU funded projects (HProImmune, E-COM, ASSET) provided further tools of dissemination.

Through participation of some partners to both TELL ME and ASSET projects, TELL ME found support in dissemination by the International Management Society (TIEMS), partner of ASSET, and by the ASSET website as well.

Presentation of posters at the World Congress of Disaster Management in Toronto (WCDM 2014) and at the International Meeting on Emerging Diseases and Surveillance (IMED 2014) in Vienna were followed by dedicated **newsletter and mailing** to thousands of experts all over the world. At the same conferences, a **leaflet** on the increasing importance of social media in risk communication, based on TELL ME results, was given to delegates.

Scientific results were presented at Conferences and meetings by partners both in oral presentations and posters and members of the consortium participated and presented in **policy relevant conferences** as well.

Papers were published by partners on several peer-reviewed journal and a **Special issue** on TELL ME themes is being published online by Disaster Medicine and Public Health Preparedness journal. A paper issue could follow.

A **TELL ME book**, currently in process, collects main results produced by the project and will further disseminate TELL ME results, making them more easily accessible for future research.

In November 2014, a note summing up TELL ME results, as a **contribution to the EU response to ebola** crisis was provided by the consortium on request of the PO.

A short summary of TELL ME results useful to face the same outbreak in terms of communication was asked for, in order to be published on the website of the [EU Commission](#) in February 2015.

A **Final publishable summary report**, drawn at m36 by CEDARThree, included at the end of this report, offers a clear and synthetic vision of the project work and its results.

3. Objectives

According to the DOW, aim of WP5 was to communicate findings and outcomes of the project, coordinate efforts with similar projects, and network with relevant stakeholder organisations and international agencies, which is paramount in consideration of the global nature of pandemics. Potential future exploitation of the project's foreground were to be explored as well.

Networking and exploitation are object of two other reports ([D5.2](#) and D5.3), while this report will collect **all internal communication and external dissemination activities**.

As suggested by the communication strategy proposed by Zadig in April 2012 ([T5.1.2 Methodological paper on the strategy and main activities of the Press Centre](#), see TELL ME website) a first objective of communication was making of TELL ME a benchmark for balanced, independent and science-based reporting of controversial issues such as vaccines, microbes and pandemic outbreaks.

Internal communication was therefore aimed at merging different competencies and getting best cooperation among partners, taking advantage of the multidisciplinary of the consortium and making a fruitful working group out of it.

Contacts and communication with other related projects, health authorities and stakeholders, even if not included in formal **networking activities** scheduled by the DOW, improved the quality of TELL ME work and enhanced its dissemination, according to the principles of the [communication strategy updating](#) issued in May 2013 (see TELL ME website).

Dissemination had these purposes:

- to arouse the media's attention on pandemic-related issues and on the TELL ME project;
- to propose TELL ME consortium as a recognized speaker in the international debate on outbreak communication (*TELL ME website, social network and networking activities*);
- to propose TELL ME experts as opinion leaders in the field (*videointerviews*);
- to spread some acknowledged key points on risk and outbreak communication (*TELL ME decalogue*)
- to enhance public knowledge of issues related to outbreak communication (*Flu from A to Z glossary, video interviews, articles,..*)
- to disseminate the scientific results of TELL ME partners (*papers, posters and conference presentations*)
- to disseminate TELL ME products, also in view of any kind of economical and non-economical exploitation (the Framework model for outbreak communication, the Online courses, the Proposal for a new pandemic Threat index, the Communication kit and the Social simulation model).
- by all these means, to assist public health authorities in reducing either the risk or the impact of infectious disease outbreaks, supporting effective and correct information and counteracting misinformation.

4. Targets

Most people are concerned if an infectious disease is a threat to their lives and families. The spread of any infectious disease, on the other hand, depends on everybody's behaviour and attitudes, not only on public health officers and HCPs's decisions, actions and work.

General public is therefore an important target of communication about this issue, in which it is supposed to be very interested as well. That is why it was considered one of the main target of TELL ME communication.

Nevertheless, the experience of 2009 A(H1N1) pandemic, when something went wrong in institutional and media communication, severely impaired public trust in health authorities in this field, letting many people believe that alarms about infectious threats are moved by economic interests instead of common

good. This, and other previous cases, such as that of avian flu and SARS, brought many people to underestimate the risk of infectious diseases, as compared with other kind of risks. This caused less interest in the issue by the general public, that now often see any recommendation about the risk of pandemics as “crying the wolf”. Because of these circumstances, our efforts to involve a wider public in TELL ME dissemination were less effective than expected.

It must be remarked as well that TELL ME project focused on **communication issues**, not on preparedness as a whole: this of course made our contents of greater interest for public health experts and HCWs, who have the professional duty of giving information, while facing the challenge of managing fears, misconceptions and prejudice, than for common people, who are mainly recipients of these messages.

On the other hand, results from the project highlight the crucial role of healthcare workers in communication to the general public and in building trust. Targeting them could be therefore a good way to reach indirectly their patients.

Main targets of our communication proved therefore to be notably **HCWs, stakeholders, policy makers and experts** in different fields concerning epidemics and risk communication.

As the TELL ME outbreak communication framework model highlights, all of these target group are part of the public sphere as well, and in different conditions they can act as professionals, parents or as persons at risk.

5. Internal communication

The TELL ME consortium combines highest expertise in different fields of research, such as public health management, communication and media, risk and crisis communication, social and behavioral sciences, political science and law, ethics and software development: skills, knowledge and networks that needed to be shared. Therefore, **communication among partners** was of paramount importance during the project, in order to take advantage of this multidisciplinary. The result of the frequent and intense exchange the partners had in the 36 months of the project is in fact the creation of a strong and competent network that could survive beyond the end of the project (*See D 5.3 Updated plan for use and dissemination of foreground*). Partners communicated mainly, and almost daily, by e-mail, they had several face-to-face meetings but also the private area of the website – the so-called Red Mine platform - had a relevant role in this fruitful and continuous dialogue.

5.1 Red Mine platform

The private area of the TELL ME website (Red Mine) collected all the relevant documents concerning the project. It included a common section gathering guidance documents, templates for deliverables and

power point presentations, logos and other communication material, minutes of virtual and in-person meetings, documents to be discussed by partners and so on.

Each WP had a further dedicated file to collect work-in-progress, internal reports and documents to be circulated in the consortium only. Deliverables were published both in this area and on the main website, open to the public.

5.2 In-person and virtual meetings



In addition to the Kick Off Meeting (see below), the Final Conference (see [Final Conference report](#)) and to the 2 EAB meetings (see [D5.2 Networking Report](#)), attended by many partners, the TELL ME consortium met periodically in face-to-face meetings and in conference calls.

- 1st Board Meeting (1st March 2012)
- 1st Virtual Meeting (5th April 2012);
- 2nd Virtual Meeting (7th May 2012);
- 3rd Virtual Meeting (1st June 2012);
- 4th Virtual Meeting (11 July 2012);
- 2nd Board Meeting (Rome, 9 November 2012);
- 5th Virtual Meeting (10 December 2012);
- 6th Virtual Meeting (15 March 2013);
- 7th Virtual Meeting (11 June 2013);
- 8th Virtual Meeting (24 July 2013);
- Validation of the Framework Model and contribution to Social simulation model (Haifa, October 2013);
- Mid term review (Bruxelles, November 2013);
- TELL ME Consortium Meeting (Rome, 5-6 May 2014);
- TELL ME Final Workshop for Exploitation of the project's results (London, 23 January 2015).

6. Cooperation with other projects and policy dialogue

Other projects

TELL ME got in touch with other EU funded related projects, mainly with **E-COM** (*Effective Communication in Outbreak Management: development of an evidence-based tool for Europe*), that, despite relevant peculiarities, shares some objectives with TELL ME:

- analysis of past experience, especially of A(H1N1) pandemic;
- production of an evidence-based communication kit (even if with a different approach).

Roberta Villa, from Zadig, presented TELL ME project and possible ways of cooperation at the E-COM meeting in London on 20th March, 2014 and reported these perspectives to the TELL ME consortium at the TELL ME meeting in Rome on 5-6th May 2014. Jeff French, from Strategic Social Marketing, partner of ECOM project, was invited to present both at the TELL ME Final conference (see [Final conference report](#)) and at the Final Exploitation Workshop in London (on 23 January 2015).

Also Anna Kolliakou, from **PHEME** project, presented new possible use of social media in research at both meetings.

In the same meetings Valentina Possenti, from ISS, and Donato Greco, who were personally involved in both projects, highlighted the legacy between TELL ME and **ASSET** project: four partners from the former participate to the latter, that is supposed to take up some of the scientific results and practical products of TELL ME, literally bringing Science in Society.

ASSET project will further disseminate TELL ME contents, with [links to the website](#) and by the first issue of its Pandemic Preparedness Response Bulletin (ASSET T6.2).

Manfred Green, TELL ME scientific coordinator, also presented TELL ME at **HProImmune** project InfoDay in Athens (2014).

Attendance at the Final Conference

Within the TELL ME activities of policy dialogue is relevant the presence of Karl Ekdahl (ECDC) and Brian Mc Closky (PHE), both at the 2nd Advisory Board (see [D5.2 Networking report](#)) and at the Final Conference in Venice. This Final conference was attended by other relevant stakeholders as well, such as representatives from WHO, CDC and Israel Minister of Health (see also [Final conference report](#)).

Participants to the TELL ME Final Conference in Venice, 4-5 December 2014

SURNAME	Name	INSTITUTION	COUNTRY
BADHAM	Jennifer	University of Surrey	UK
BELLONE	Michele	Zadig	IT
BENELLI	Eva	Zadig - ASSET project	IT
BOWER	Claire	BMJ	UK
BRATTEKAS	Kjersti	Norwegian Defence Research Establishment	NO
BUORO	Annalisa	WHO - European Office for Investment for Health and Development	INTL
CANDIANI	Giulia	Zadig	IT
CARRA	Luca	Zadig	IT
DALLAS	Cham E.	University of Georgia	US
DIMITRIOU	Dimitris	Zadig	IT
DOWDALL	Nigel	UK Civil Aviation Authority	UK
DRAGER	Kare Harald	The International Emergency Management Society (TIEMS)	INTL
EKDAHL	Karl	European Centre for Disease Prevention and Control (ECDC)	INTL
FANTINI	Bernardino	Université de Genève	CH
FERRARA	Lorenza	Alessandria Local Health Agency (ASL)	IT
FRENCH	Jeff	Strategic Social Marketing	UK
GARROTE	Juan-Manuel	Consejo General de	ES

			Colegios Oficiales de Medicos	
	GESSER-HEDELSBURG	Anat	University of Haifa	IL
	GILBERT	Nigel	University of Surrey	UK
	GRECO	Donato	Zadig	IT
	GREEN	Manfred	University of Haifa	IL
	GROTTO	Itamar	Ministry of Health – State of Israel	IL
	GULLAND	Anne	BMJ	UK
	GUPTA	Kailash	The International Emergency Management Society (TIEMS) – India Chapter	INTL
	HAJNAL	Ferenc	European Union of General Practitioners (UEMO)	INTL
	HESAMI	Hessam	Université Grenoble Alpes	FR
	JAMES	James	National Disaster Life Support Foundation (NDLSF)	US
	KAMENSKA	Anhelita	Latvian Centre for Human Rights (LCHR)	LV
	KARNAKI	Pania	Institute of Preventive Medicine, Environmental and Occupational Health, Prolepsis - ASSET project	GR
	KOLLIAKOU	Anna	King's College London	UK
	LANGDON	Simon	CEDAR3	UK
	McCLOSKEY	Brian	Public Health England	UK
	MERLIN	Toby	Centre for Disease Prevention and Control (CDC)	INTL
	PACE	Alice	Zadig	IT
	PAPP	Renata	European Union of General Practitioners (UEMO)	INTL

PERELLI	Claudia	NHS – Venice Local Health – Prevention Department	IT
PETROVIC	Vladimir	Institute of Public Health of Vojvodina	RS
QUINN	Paul	Vrije Universiteit Brussel (VUB)	BE
ROBERTSON	Thomas	The International Emergency Management Society (TIEMS) – USA Chapter	INTL
RUSSO	Francesca	Regione Veneto - Venice Prevention Directorate	IT
STRINO	Francesca	Freelance - Communication & Human Factor	IT
TALBOTT	Alexander	BMJ	UK
TAMANG	Elizabeth	Regione Veneto	IT
TOZZI	Alberto	Bambino Gesù Children's Hospital	IT
VALETTO	Maria Rosa	Zadig	IT
VILLA	Roberta	Zadig	IT
VON BERGER	Giorgia	Zadig	IT
WOOD-HEATH	Moya	Community Resilience	UK
WROCZYNSKI	Mitali	BMJ	UK
ZAMBON	Francesco	WHO - European Office for Investment for Health and Development	INTL
ZANELLA	Francesca	Regione Veneto	IT

Visit to US CDC

The visit of TELL ME scientific coordinator, Manfred Green, to the US Centers for Diseases prevention and Control, **CDC**, in Atlanta on 24 October 2014 needs also to be mentioned. As described in his report below, he made a presentation on the TELL ME project to the personnel dealing with risk communication associated with pandemic influenza and other infectious disease crises (see Annex 1).

Report on the Presentation of the TELL ME Project at the United States Centers for Disease Control and Prevention (CDC) – October, 2014

Manfred S Green MD,PhD – TELL ME Coordinator

Visit to CDC

On October 24, 2014, I visited the United States Centers for Disease Control and Prevention. My host was Dr. Sonja Rasmussen, Acting Director of Public Health Preparedness and Response.

The visit started with a welcome and briefing by Dr. Rasmussen on the CDC in general and the preparedness for pandemic influenza and the Ebola epidemic in particular. We were shown the Emergency Operations Center, currently dealing with the Ebola epidemic and how the CDC is participating in containing the epidemic.

I then made a presentation on the TELL ME project to the personnel dealing with risk communication associated with pandemic influenza and other infectious disease crises (see attached presentation). The discussion focused particularly on the issue of involving the public in risk communication (two-way communication). The CDC people showed great interest in the TELL ME project and are looking forward to seeing the final report. They have a large, highly qualified and experienced staff dealing with risk communication for issues such as pandemic and seasonal influenza and Ebola.

Following my presentation, I had separate meetings with the people involved in preparedness for pandemic influenza.

Some of the key people that I met were:

- Sam Graitcer, Pandemic Influenza Coordinator, Pandemic Influenza Vaccine Issues
- Carolyn Bridges, Associate Director for Science, National Center for Immunization and Respiratory Disease (NCIRD) Pandemic Influenza Vaccine Issues
- Jeanne Santoli, Branch Chief, Vaccine Supply and Assurance Branch (VSAB), Pandemic Influenza Vaccine Issues
- Kristine Sheedy, Associate Director for Communications Science, National Center for Immunization and Respiratory Disease (NCIRD) Seasonal Influenza Communications
- Erin Burns, Health Communications Specialist, National Center for Immunization and Respiratory Disease (NCIRD), Pandemic and Seasonal Influenza Communications

- Jeremy Sobel, Medical Officer, Center for Global Health, Division of Global Health Protection, Global Health Issues
- Eyal Lesham, Infectious Disease Specialist, currently staff with Division of Viral Diseases
- Jill Smith, Health Communication Specialist, Office of Public Health Preparedness and Response, Ebola Communications

In all the meetings, we had interesting discussions comparing the work that CDC does in the field of risk communication and what we have explored in TELL ME. All showed great interest in the work done in TELL ME and indicated that it could fill important gaps in the field.

The Institute for Disaster Management, University of Georgia

During my visit, I also met with Prof Cham Dallas, Director, Institute for Disaster Management, College of Public Health and others at the University of Georgia, Athens, Georgia, USA and updated them on the TELL ME project. Cham has been associated indirectly with TELL ME through his association with Dr. James James, director of the Society for Disaster Medicine and Public Health. They showed great interest in the TELL ME products and are looking forward to seeing the final reports and using the findings in the institute.

Conclusions

I believe that my visit to CDC was particularly useful in exposing key personnel at CDC to the work done in TELL ME. This will stimulate them to access the materials produced in TELL ME and promote networking with the partners in TELL ME and other European organisations.

Other policy relevant conferences

As far as participation in **policy relevant conferences** is concerned, a poster on compliance with influenza vaccination among healthcare workers, tailoring risk communication according to the factors affecting compliance, was presented by HU team at the **6th European Public Health Conference**, Brussels, Belgium (2013).



University of Haifa, School of Public Health
 מכללת חיפה, בית הספר לבריאות הציבור
 كلية علوم الصحة والوقاية وعلم الصحة مدرسة الصحة العامة

Compliance with Influenza Vaccination among Healthcare Workers (HCWs) – Tailoring Risk Communication According to Factors Affecting Compliance

Manfred S Green MD PhD¹, Noemie Groag Pri-or MPH¹, Emilio Mordini MD², Anat Geser-Edelsberg PhD³

¹School of Public Health, University of Haifa, Israel ²CSSC - Centre for Science, Society and Citizenship, Italy

Background

HCWs should be considered as the prime risk group for influenza vaccination for the following reasons:

1. They need to be protected in order to ensure that they are not absent from work when most needed
2. They can infect and be infected by patients
3. They can infect and be infected by their family members
4. They are in front of the communication chain to encourage vaccination of the population

Aims

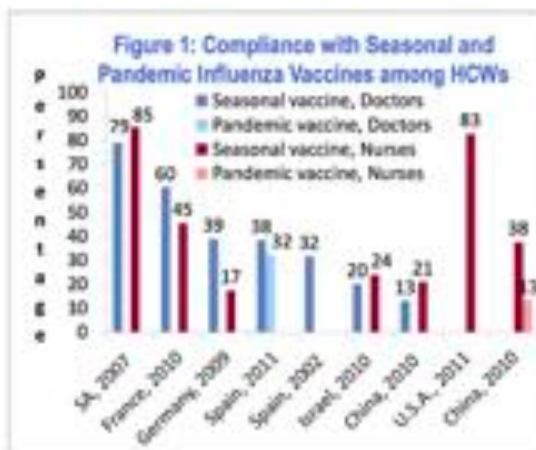
To identify the main factors affecting compliance in order to tailor risk communication for this population.

Methods

A comprehensive literature review on compliance and factors associated with compliance with influenza vaccination among HCWs.

Results

Compliance with vaccination against influenza among HCWs has always been extremely variable (see Figure 1).



Results

Major positive factors affecting compliance in HCWs include protection of self, patients and family (see Table 1). Major negative factors affecting compliance in HCWs include fear of side effects, skepticism about the efficacy and no fear of influenza (see Table 2).

Table 1: Positive Factors Affecting Compliance*

	Factors	Range (%)	Countries
Major	Self-protection	71-96	SP USA CH DE AU SA CA IR
	Desire to protect patients	63-98	SP USA CH AU IT DE SA CA
	Desire to protect family members	59-75	SP USA CH AU IT DE CA
Minor	Easy access to vaccine	58-68	DE USA IR
	Vaccine perceived to be effective	43-68	CH AU

Table 2: Negative Factors Affecting Compliance*

	Factors	Range (%)	Countries
Major	Fear of side effects of vaccine	29-54	DE USA UK CA SW GR
	Skepticism about efficacy of vaccine	14-45	CA USA UK GR
	No fear of influenza	18-32	DE UK USA SW IR
Minor	Inconvenience in accessing vaccine	8-24	IT DE GR UK

* Outliers excluded


Conclusions

There are both positive and negative factors affecting compliance with vaccination in HCWs. On the basis of numerous surveys, these can be divided broadly into major and minor factors. Failure to take into account adequately these factors may be the reason why many of the educational campaigns have been relatively unsuccessful. Thus it is essential that they should be taken into account when designing risk communication policy.

This work was completed as part of the TELL ME project (Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence), co-funded by the European Commission within the 7th Framework Programme – HEALTH theme.


An oral presentation at the **141st American Public Health Association (APHA) Annual Meeting**, Boston, MA, USA (2013) was given by AnatGesser-Edelsburg, HU, referring to the implementation of communication strategies during pandemics, based on the experience of the 2009 H1N1 influenza.

The [presentation of the simulation model](#) at **ESCAIDE (European Scientific Conference on Applied Infectious Diseases Epidemiology) Conference** in Stockholm 5-7 November 2014, by Jennifer Badham, University of Surrey, has to be mentioned as well.



Modelling Individual Protective Decisions within an Influenza Epidemic

Dr Jennifer Badham and Prof Nigel Gilbert
Centre for Research in Social Simulation, University of Surrey



The T@llm@e Project

The European funded T@llm@e project (Transparent communication in Epidemics: Learning Lessons from experience, delivering effective messages, providing evidence) is intended to provide advice about communication in response to influenza pandemics. Outputs from the project focus on effective communication, include a communications guide and online training to assist health authorities and health professionals to effectively provide information and advice. This is based on work already conducted by the project to collect evidence on attitudes concerning vaccination and non-vaccination behaviours, communication needs of health professionals, the role of social media, and other relevant issues.

The output presented here is the simulation model, which is to assist health agencies to compare the effect of different communication plans. It is currently under development and is expected to be released in January 2015.

Further information: www.tellmeproject.eu

Two Connected Submodels

Agent based model of behaviour: Simulated individuals make decisions to vaccinate or to adopt (or evade) protective behaviour such as hand hygiene or social distancing.

System dynamics model of epidemic: The country map is divided into grid cells, each of which tracks the number of people in different epidemic states (susceptible, exposed, infectious, removed).

Individuals → epidemic: Each grid cell is home to several (or many) simulated individuals. Their behaviour is considered representative of the population in the grid, and the force of infection (in the system dynamics model) is reduced according to the proportion adopting protective behaviour and the efficacy of that behaviour.

Epidemic → individuals: Simulated individuals consider the number of new nearby epidemic cases when making decisions about protective behaviour.

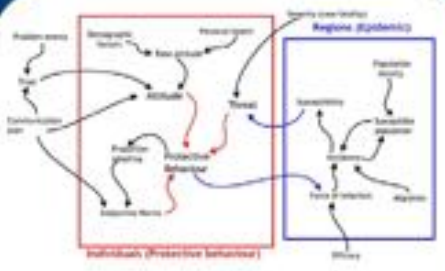
Model Logic

Agent based model: behaviour

At the start of the simulation, attitude scores (in 0-10) are randomly allocated, recognizing that attitude depends on demographic, perceived health, and other factors.

The individual adopts protective behaviour if the weighted average of attitude, perceived costs and perceived risk is higher than the threshold. Risk is the proportion of nearby individuals who have adopted protective behaviour. Risk is the cumulative nearby incidence, discounting older cases.

Communication plans are entered as sets of messages. Each message is described with a simplified language that details the media channel, target groups, and other properties. These messages change attitude or other behaviour influencers for simulated or target individuals exposed to the message.



Major influencers in the model behaviour rules. The red box contains the agent based model of individuals and their protective behaviour, and the blue box contains the spatial difference equations model of epidemic spread.

System dynamics model: epidemic

Standard SIR difference equations

$$\frac{dS}{dt} = -\beta SI$$

$$\frac{dE}{dt} = \beta SI - \lambda E$$

$$\frac{dI}{dt} = \lambda E - \gamma I$$


$$\frac{dR}{dt} = \gamma I$$

Some proportion of new infections in each grid cell are created at other locations, to represent mobility.

Individuals is adjusted to reflect the proportion of local agents who have adopted protective behaviour and the efficacy of that behaviour.

$$\beta = \beta_0(1 - P_e)$$

Prototype Model



Conclusion

There are excellent epidemic models that include detailed movement patterns and other important factors in epidemic progression. Some of these models also allow basic assumptions about behaviour such as social distancing. However, the T@llm@e model is the first to link these inherently connected components of the system of an influenza epidemic:

- Communication
- Personal protective behaviour
- Epidemic progress

The T@llm@e prototype model will be available January 2015, with user manual, exercises and other supporting documentation.

The prototype will assist planners to assess the implications of their understanding of effective communication in epidemic management. It implements that understanding in a formalized thought experiment that allows planners to explore scenarios and more deeply understand the complex and dynamic connections between communication and personal behaviour during an epidemic.

In the medium to long term, if predictive models are to be useful for communication planning, more and different data must be collected before, during and after epidemics. This prototype can guide the necessary data collection.

Contact: Jen Badham, jbadham@surrey.ac.uk

In the United States the TellMe project was presented by **NDLSF** at APHA, NDLSF, ASTHO, and several other meetings and will continue to be presented going forward.

As health care professionals and their organizations were identified as main stakeholder category, during the development of the framework model for outbreak communication, dissemination activities to these categories were considered as relevant as those targeted to public health professionals, epidemiologists and other stakeholders.

UEMO, as part of the network of the European medical organizations has presented TELL ME project in the meetings of CPME (European Standing Committee of European Doctors), UEMS (European Union of Medical Specialists), EMO (European Medical Organisations) presidents, EJD (European Junior Doctors) and FEMS (European Federation of Salaried Doctors). These organizations and groups meet at least two times a year each and their general assemblies, board meetings, etc. provide excellent forum for exchange of information about the main activities and projects of the so called sister organizations. UEMO president, secretary general, board members have taken chances while visited the sister organisations' meetings to take account about the actual advancing and preliminary results and messages of the TELL ME project, to let the host collegial community. UEMO president could use advantage to let the interested audience know at the **First international congress of GP/FM** organized in September 2014 (Bonn) and the **XIVth European Health Forum** (Bad Gastein) in October where inserted TELL ME developments and news, as well as UEMO activities in his presentations related to the TELL ME project.

Last, but not least the **General Assembly and Board meetings of UEMO** (in total 4 meetings a year) were used as forum of communication towards member organizations with the aim to spread the information in the home countries of the delegates as well.

The **UEMO General Assembly in November 2014** served as forum for presentation both of the online course and of the simulating software.

Contribution to response to Ebola crisis

In autumn 2014, when the Ebola crisis was escalating, TELL ME Consortium was asked by its PO if some of the project's results could be useful to tackle communication issues in the outbreak.

TELL ME work was mainly focused on communication about flu and similar airborne diseases possibly causing pandemics (such as SARS) from a European perspective. Partners were aware that communication strategies in African countries such as those mainly affected by the last Ebola crisis cannot be exactly the same as in the Western world, because of relevant differences in cultural backgrounds, levels of literacy, access to old and new media and to healthcare as well. Despite this discrepancy, the Consortium agreed that some results from TELL ME research could be transferred to that context as well.

A [note](#) summing up TELL ME results useful to face Ebola crisis was therefore drawn and provided as a contribution to the EU response to ebola crisis.

Again on request of the Policy Officer, a short summary of TELL ME results useful to face Ebola outbreak in terms of communication was provided in February 2015, with a view to be published on the webpage on EU-funded Ebola research of the [EU Commission](#):

[TELL ME project](#)

Aims

TELL ME project is a 7th Framework EU funded project aimed to develop evidence-based models for improved risk communication during infectious disease outbreaks. Even if conceived before the last Ebola crisis in 2014, some of the outcomes served for the response at communications level.

State of Play

In November 2014 a document with the project's contribution to Ebola response was submitted to the European Commission, with a set of proposed actions. Meanwhile a dedicated [e-learning course](#) for primary care professionals was adopted by the Italian Associations of Doctors and Nurses respectively, reaching about 30,000 Italian health professionals, including a dedicated course on Ebola. The TELL ME [Communication Kit](#) also offers practical guidance at different levels which can be useful to consider in order to overcome communication obstacles in the context of the Ebola crisis.

7. Dissemination activities

The TELL ME consortium carried out dissemination activities during all the period of the project. At different phases, dissemination strategies ranged from mainly passive (by collecting and commenting news on communication issues related to flu, vaccines and infectious threats) to mostly active, when TELL ME main outcomes were ready to be presented to stakeholders and to the public.

7.1 Preliminary activities

In the first phases of the project, most dissemination activities were aimed at communicating **TELL ME project's** characteristics and peculiarities, trying to make it acknowledged, since the beginning, as a recognized speaker in the international debate on outbreak communication (Kick Off Meeting). Content of these first phases of communication was also previous consolidated knowledge about health risk communication (Decalogue) and information about flu and other infectious disease outbreak issues (Glossary).

7.1.1 Kick off meeting

The TELL ME project's Kick-Off Meeting was held on 1-2 March 2012 in Rome. All partners in the consortium were represented by one or more people. An overview of the context and of the project were given prior each WP presentations.

At a first level, the purpose of this meeting was to review carefully the project's objectives and the scheduled activities, fine-tune the work between partners and clarify any scientific or administrative issues, where necessary. Each partner had the opportunity to present their institution and role in the project, while the wider context of the TELL ME project was discussed more in-depth in the presence of the TELL ME Project Officer, Christian Desaintes.

During the meeting, the TELL ME vision and mission statements were presented by CSSC to the rest of the consortium. Following the meeting, these statements were further refined and unanimously agreed upon by partners. Vision and mission statements were then presented on TELL ME website.

Several [videointerviews](#) to partners were recorded and uploaded on the website.

7.1.2 Brand and presentation of the project (logo, video, brochure)

A TELL ME logo was chosen during the KOM to better identify the corporate image.



Accordingly, templates for deliverables and powerpoint presentations were created.

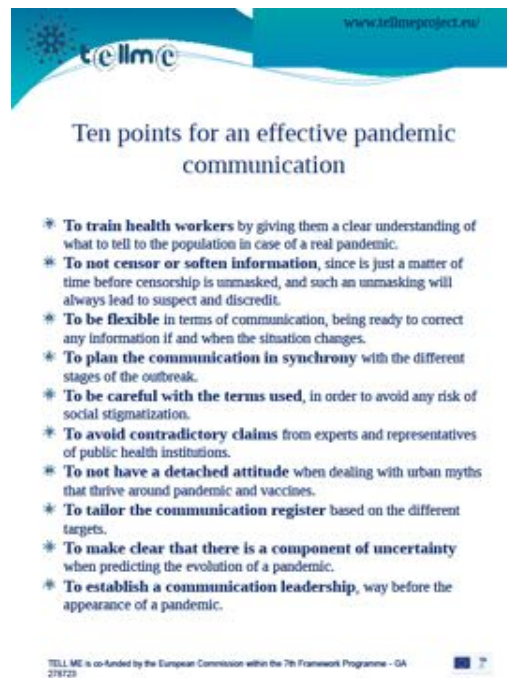
A brochure was disseminated, summing up the project's characteristics, its context and the questions to which it was going to answer.



Also a [video](#), published on the website and spread by social media, presented the project, its vision and mission.

7.1.3 First preliminary products (decatalogue, glossary)

In the first months of the projects, while partners were still working on their first tasks and subtasks, Zadig staff produced a decatalogue of communication, based on current evidence as a basis for discussion in the issue of pandemic and communicating this kind of risk.



A [glossary \(Flu from A to Z\)](#) , to explain to the public many terms related to epidemics, pandemics, flu, vaccination and so on, was created as well.

All these products were published on the website and spread by social media (Facebook and Twitter).

7.2 Main dissemination activities

7.2.1 Website and Social Media

The [TELL ME website](#), set up in the early phase of the project, 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.

In accordance with the Annex I of the DOW, the TELL ME project website was set up by ZADIG 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).



Website contents

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
 - o [Viewpoints](#)
 - o [News from the world](#)
 - o [News from TELL ME](#)
 - o [Multimedia gallery](#)
 - o [Press Review](#)
 - o [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 piling results and products by the project itself.

In the last year of the project, as requested by the mid-term review, each deliverable was presented by an **executive summary** and **linked to 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 on 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.



In the last months, connection **with Twitter** was broadened with additional keywords to cover the public discourse on related issues better and it was used to make **analysis** of prevailing sentiments and actors on the social network, notably about the H7N9 and Ebola crisis.

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

The website was enriched with **videointerviews** 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 Center for Epidemiology, Surveillance and Health Promotion, National Institute of Health (ISS), Italy
- **Agoritsa Baka**, Hellenic Center 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 interaction between veterinary field and human health (the latter requested by mid-term review) were also expressed in articles by experts as:



- **Donato Greco**, past Director of the Italian National Center 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 Center for Diseases at the Human - Animal Interface.

VUB experts provided reflections on [human right](#) principles related to epidemics and on the [risk of stigma](#) in case of outbreaks like ebola.

Both [UEMO](#) and [NDLSF](#) contributed with links from their website and by their social media accounts to disseminate our contents to European and US doctors.

Monthly bulletin, banners and links of the project and its deliverables were placed on the UEMO website. Actual news and messages from the TELL ME project were included in the regular and opportunistic e-mails sent out to the delegation of the member organizations.

For a long time TELL ME website had been hosting in its homepage a questionnaire that UEMO submitted to European family doctors in Hungary, Italy, UK, Romania and Belgium, while BMJ disseminated it online.

Between m8 and m12 158 GPs took part in TELL ME Qualitative Research:

- 32 GPs from Hungary,
- 29 GPs from the UK,
- 29 GPs from Italy,
- 25 GPs from Romania
- 20 GPs from Belgium
- 23 GPs mostly from Denmark.

62 participants took part in focus group discussions in the period m8-m9. Individual interviews for 73 GPs were undertaken during the period (m9-m11) and 23 online questionnaires were processed in the period m11-m12. Answers were used to draw the D2.3 Report on Health Care Professional Communication Requirements deliverable.

The TELL ME website was also cited by the WHO in the report [Health and environment: communicating the risks](#), in 2013.

Links with other EU projects

As requested by the mid-term review, **links with related projects** were highlighted in home page and E-COM video on communication in outbreaks was shared.

Related EU projects

<p>PHEME</p> <p>Computing Veracity – the Fourth Challenge of Big Data Starting date: 1 January 2014 Duration: 36 months</p>	<p>FLURESIP</p> <p>Cost-effectiveness assessment of european influenza human pandemic alert and response strategies Starting date: 1 April 2011 Duration: 36 months</p>	<p>FLUMODCONT</p> <p>Modelling the spread of pandemic influenza and strategies for its containment and mitigation Starting date: 1 June 2008 Duration: 36 months</p>
<p>ECOM</p> <p>Effective communication in outbreak management: development of an evidence-based tool for Europe Starting date: 1 March 2012 Duration: 48 months</p>	<p>M-Eco</p> <p>Medical ecosystem – personalized event-based surveillance Starting date: 1 January 2010 Duration: 30 months</p>	<p>AsiaFluCap</p> <p>Health system analysis to support capacity development in response to the threat of pandemic influenza in Asia Starting date: 1 May 2008 Duration: 36 months</p>
<p>HPImmune</p> <p>Promotion of immunization for health professionals in Europe Starting date: 1 September 2011 Duration: 36 months</p>	<p>EPIWORK</p> <p>Developing the framework for an epidemic forecast infrastructure Starting date: 3 October 2008 Duration: 48 months</p>	<p>EuroMOMO</p> <p>European monitoring of excess mortality for public health action Starting date: 1 February 2008 Duration: 39 months</p>

Follow us on: Twitter, YouTube, Facebook

Join our mailing list: Name, E-mail

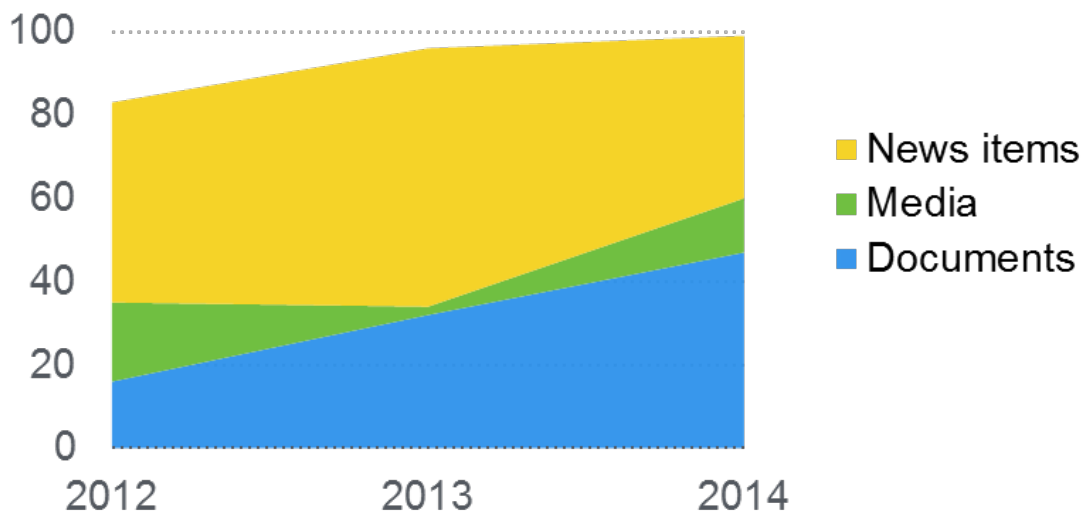
BMJ Going Viral

Service links: Search, Contact, Credits, Disclaimer

This project has received funding from the European Union's Seventh Framework Programme for research, technological

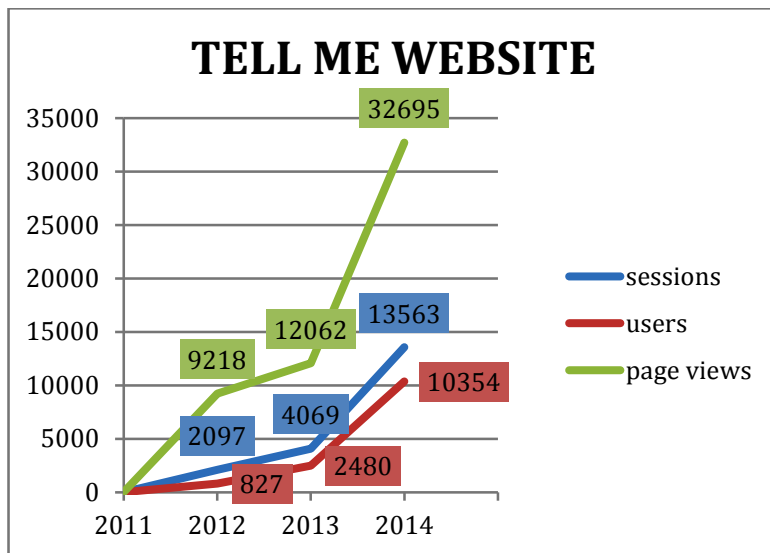
Website statistics

From 2012 to 2014, **about 300 contents** were uploaded on the TELL ME website: in the 2nd reporting period, accordingly to the different strategy adopted, number of news from the world decreased, while TELL ME documents and their pickups by media increased.

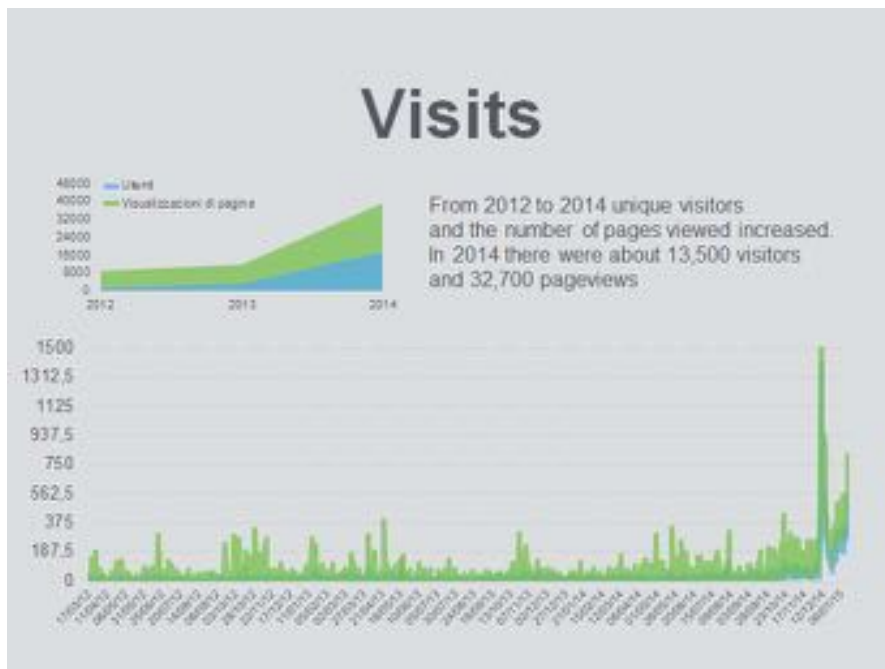


In the last year of the project, the **number of visitors and visits increased as well: from 2013 to 2014, visitors passed from 4,069 to 13,563 and page views from 12,062 to 32,695**, with a peak around and after the Final Conference. This was both due to the press releases about the Conference

itself and to the spread of the Ebola online course made by about 30,000 Italian HCWs, who might have looked for information about the project in the website.



	Sessions	User	Page Views
2012	2097	827	9218
2013	4069	2480	12062
2014	13563	10354	32695



Social networks



As underlined by the [second report on TELL ME Communication Strategy](#) (May 2013), **social media** can attract a high number of followers. Thus we implemented a stable and permanent activity on these platforms, including sharing and commenting related contents not produced by the project, but relevant in term of communication, vaccines, flu or other infectious outbreaks.

This active presence on social media, mainly on Twitter, is useful either to gauge trends and public narrative relevant to TELL ME areas of interest, and to promptly react during events and periods when the media are more sensitive towards flu symptoms and vaccination (i.e. during autumn/winter period and infectious disease outbreaks) or when scientific news sparks public interest in the topics.

Social networks were useful especially to engage relevant stakeholders, journalists, researchers and opinion leaders in the fields of public health, infectious diseases, preparedness and pandemics. Most of our followers belong to one of these categories.

During the project, TELL ME accounts were therefore created on YouTube, Twitter and Facebook.

On the **YouTube channel** all videos were uploaded and shared.

Video title	Views	Upload date
TELL ME PROJECT	324	4 Apr 2013
TELL ME Project: Nigel Gilbert	105	18 Jun 2012
TELL ME Project: Manfred Green	102	20 Jun 2012
Are we prepared for pandemics? Pete Doherty and Rolf Zinkernagel	98	28 Oct 2013
TELL ME Project: Donato Greco	83	19 Jun 2012
TELL ME Project: Emilio Mordini	65	20 Jun 2012
TELL ME Project: Valentina Possenti	46	20 Jun 2012
Vaccination is also a matter of communication: Stefania Salmaso	43	15 Jul 2014
Karl Ekdahl interview in Venice	38	16 Dec 2014
Pier Luigi Lopalco interview in Venice	33	16 Dec 2014
MERS is a threat. Not only for the Middle East: Manfred Green	24	30 Jun 2014
TELL ME Project: Simon Langdon	20	20 Jun 2012
Protect Europe from polio without stigma: Agoritsa Baka	21	15 Jul 2014
Toby L Merlin interview in Venice	17	16 Dec 2014

Twitter and Facebook accounts were created on 1st March 2012.

As at 31st January 2015, TELL ME followers on **Twitter** are 342 (+71,2% compared to 2013), mainly experts and stakeholders, and 267 like TELL ME page on **Facebook** (+32,5% compared to 2013).

This can be considered a good result in engaging experts and stakeholders, while some difficulties were met in reaching a wider public. Reaching the general public through social networks, in fact, requires a long-term daily intense work, for which more human resources are needed.

For this reason, in the last months of the project, a journalist was engaged to develop the communication on social networks and send more than daily tweets in order to disseminate the project's contents. Though not completely satisfying, this effort slightly increased the number of followers on Twitter (Aug 2014: 284 followers- Dec 2014: 342) and the number of likes on Facebook (Aug 2014: 223 likes- Dec 2014: 267).

Even if not scheduled by DOW, Zadig performed some **Twitter analysys** as well, to identify opinion leaders and trends in the public perceptions about vaccines and emerging infectious diseases:

- **a hashtag-based Twitter analysis of the H7N9 virus Chinese crisis in April 2013;**

In spring 2013, as it happened during the 2009 pandemic, the emergence of a new avian flu virus in China, spreading in humans, was intensely followed and commented about on the Internet, particularly on the social media.

Even if the H7N9 outbreak was mainly confined within Chinese borders, and was never considered a “pandemic”, it brought back such a risk to the public attention, unerestimated in previous years, after the 2009 A(H1N1) was perceived by great part of the public as a false alarm.

Zadig experts performed then a hashtag-based search on Twitter, in order to collect quantitative and qualitative information.

As shown in Figure 1, the number of tweets containing the hashtag **#pandemic**, low in the previous year, peaked after the H7N9 virus started spreading in China.

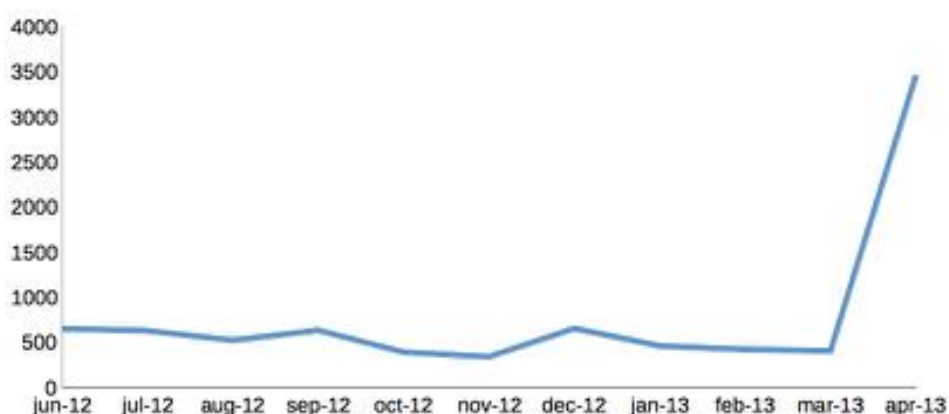


Fig. 1

Zadig staff performed a **content and “sentiment analysis”** as well, identifying the informative and emotional content of the tweets related to the H7N9 virus in the period from 2nd to 22nd April 2013. Tweets were then grouped into five categories:

- **NEUTRAL:** messages aimed to spread information, usually with links to statistics and scientific or media articles;
- **ALARM:** messages expressing emotionality, mainly in terms of fear;
- **REASSURANCE:** messages aimed to hinder possible panic reactions with reassurances and practical advices;
- **CONSPIRACY:** messages suggesting conspiracy theories;

- **DISTRUST**: messages expressing distrust over authorities and experts.

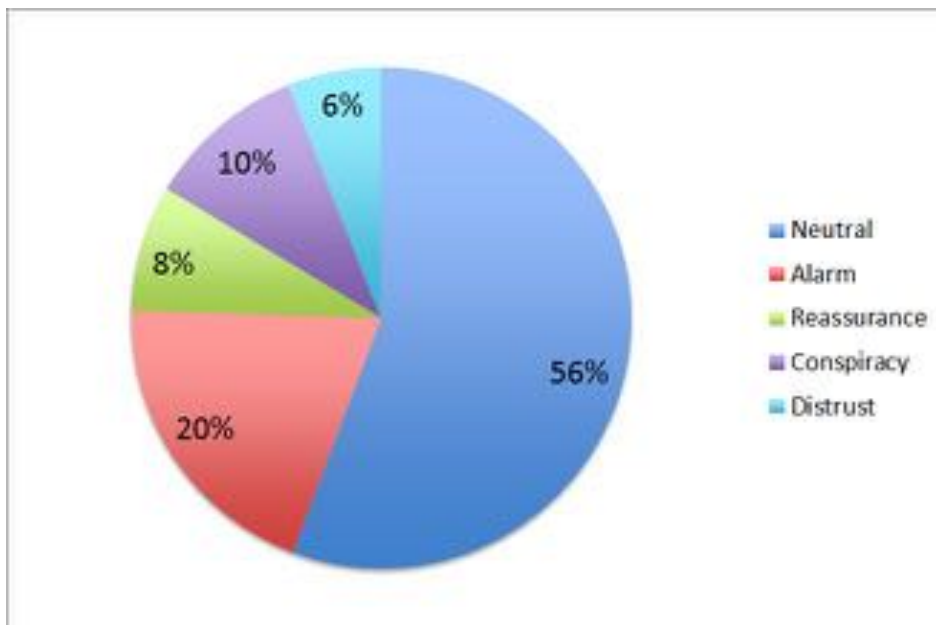


Fig. 2

The analysis carried out by the TELL ME experts and shown in Fig.2 revealed that, in comparison with 2009 A(H1N1) pandemic, the authorities seemed to have learnt how to take better advantage of the new technologies, notably social network’s power of quickly spreading information.

The WHO, for instance, immediately and explicitly chose Twitter as a privileged tool for their update about the number of new cases, thus proving to have understood the significant advantages of this social media in terms of risk communication:

- 1) it is aimed directly to the reader;
- 2) the 140 character limit dictates the use of short messages that are more likely to be understood;
- 3) it helps sharing and disseminate these messages.

This sober kind of communication avoided alarms on the one hand and offered transparency – even when remarking what is still unclear – on the other. In this way, it managed to ward off the accusations of plots and conspiracies that often follow this kind of situations.

This response was anyway mainly addressed to Western public, since Twitter was blocked in China. A relevant role in the management of the outbreak both by the public and by Chinese authorities had in that country Weibo, a similar social media, popular in China, that as the beginning of 2015 counts 66.6 million daily active users and 143.8 million monthly active users.

Spreading the news of first cases, it pushed the government to admit an outbreak was on, and to communicate with people. When rumours of conspiracy started to circulate, a correct information spread through the social contributes to turn them off as well.

The overall response to the appearance of the new avian flu virus H7N9 in China by local and international health authorities seemed anyway to be more proper, transparent and adequate than in previous crises.

In a [press release](#) sent on April 24th 2013 TELL ME experts communicated these positive results, while warning that there was still room for improvement: communication plans involving health workers had to be established, and institutions could be more active in reporting and explaining facts also at the national level, in order to hinder conjectures and exploitations, at the same time monitoring what is going on in the blogosphere.

This work was picked up by [Cordis](#) (Community Research and Development Information Service) on 8th May 2013.



Pandemic flu 2.0: what to do

The cases of human infection with influenza A(H7N9) virus reported in China cannot be called a pandemic. Up to now, there are no signs of human-to-human transmission, as reported by the World Health Organisation (WHO). Nevertheless, there is a pandemic which is actually ongoing: we could call it web pandemic 2.0. And it is something that does not come without risks.

Exactly as it happened during the previous pandemic, in 2009, the Chinese avian flu was intensely followed and commented about on the internet, particularly on social media. As evidenced by an hashtag-based search on Twitter, the informative and emotional content of the tweets related to the H7N9 virus in the period from 2nd to 22nd April may be grouped into five categories: neutrality, alarm, reassurance, conspiracy, distrust. Also, the trends of the number of tweets containing the hashtag 'pandemic' in the last year and in the last twenty days are related with the spread of the H7N9 virus (more details about this analysis may be found here: <http://tel.me/project.eu/content/tell-me-press-release-24th-april-2013>).

In 2009, a series of communication mistakes from healthcare authorities cost much in terms of trust and reliability, and left the field clear for the suspect that the pandemic was just a machination arranged by pharmaceutical industries to sell more vaccines. A suspect that shattered the credibility of those institutions that are expected to plan efficient preventative measures in case of a real pandemic. "Now it is important not to ignore the flow of information that runs through the social media and that may influence the population's behavior and, as a consequence, the course of the pandemic," declare the experts of TELL ME, a consortium of the main research centers around the world dedicated to elaborate new rules for an effective 'pandemic communication'.

In these days, both the World Health Organization (WHO) and the ministers of health from several countries have activated daily online updates on the evolution of the Chinese situation. Despite some early issues, the analysis carried out by the TELL ME experts revealed that these authorities seemed to have learnt how to take advantage of the potential of the new technologies. The WHO, for instance, immediately and explicitly chose Twitter as a privileged tool for their update about the number of new cases, thus proving to have understood the significant advantages of this social media in terms of risk communication: 1) it is aimed directly to the reader; 2) the 140 character limit dictates the use of short messages that are more likely to be understood; 3) it helps sharing and disseminate these messages. This subtle kind of communication avoided alarms on the one hand and offered transparency - even when republishing what is still unclear - on the other. In this way, it managed to ward off the accusations of plots and conspiracies that often follow this kind of situations. Until now, those movements that are used to see Big Pharma's hands behind every move made by healthcare authorities had not so much room on the social network.

The TELL ME study concluded that the response from healthcare authorities to the appearance of the new avian flu virus H7N9 in China has been more proper, transparent and adequate than in 2009. "But there is still room for improvement," insisted the TELL ME experts. "Communication plans that involve health workers should have been already established, and institutions should have been already active on the main channels - like Facebook, Twitter, YouTube - to report and explain facts also at the national level, to hinder conjectures and exploitations, and at the same time to monitor what is going on in the blogosphere."

Related information

Programmes	• FP7-HEALTH
Countries	• Belgium, France, Israel, Italy, Latvia, United Kingdom

Contact
 Carra, Luis
 Tel.: +39075261354
 E-mail: luis.carra@tel.me

- **a hashtag-based Twitter analysis of the ebola African crisis in autumn 2014**

At the end of summer 2014, concern and fear about the Ebola outbreak in West Africa quickly spread around the world. Social media are a fertile ground for similar feelings, as well as for the circulation of information, be they correct, distorted or totally wrong. In order to understand which were the main actors and topics related to Ebola on social media, Zadig staff carried out an another Twitter-based analysis. Using **#ebola** as the main query, and English as language, the authors of the analysis collected 632,712 tweets and 17,023 hashtags between September 5th and 11th 2014.

According to an algorithm that counted the number of followers, posts and retweets, TELL ME analysis identified the **five top influencer on Ebola topics** (see table 1). It is interesting to note that four of them are organizations, while the only single person is Sue Desmond-Hellmann, CEO of the Bill & Melinda Gates Foundation, which also appears in the list. Curiously, CDC is not amongst the top five, surpassed by the WHO, the breaking news service from BBC and Médecins Sans Frontières.

ACCOUNT	FOLLOWERS	POSTS
@WHO	1.56 Mln	42
@BBCBREAKING	11.4 Mln	4
@SUEDHELLMANN	7.199	5
@MSF	6.326	11
@GATESFOUNDATION	1.28 Mln	14

Table 1 – Top five influencer.

The most used hashtags in addition to #ebola were then investigated, thus revealing that the most used was #usaheadlines, with more than 30,000 citations, the second being #liberia with a bit more than 7,000. This clearly reflect the impact of fear in the US regarding the potential diffusion of the virus within American borders.

The relevance of the #liberia hashtag is related with the regional interest shown by the count of searched geographical keywords. Table 2 shows a list of locations with their relevance expressed as a percentage compared to the most searched one, which is indeed Liberia. This is not a surprise, since at the time Liberia was the country that most suffered from the Ebola outbreak.



Table 2 – Trend for regional keywords searches.

The skills acquired through the social media use in TELL ME will be transferred to ASSET project (G.A. 612236), in which Zadig is leader of the T5.1 Social media mobilization task.

@nhssm and #fluscenario

In July 2012, the Tell Me project produced a report on the past and previous uses of social media during pandemics ([D2.5 New Social Media](#)). One of the chapters focused on stakeholder engagement of healthcare professionals who have an interest in using social media and its role in healthcare communication. Project partners BMJ conducted two hour-long Twitter chats in collaboration with @nhssm (NHS social media), a Twitter community dedicated to NHS staff who are interested in discussing the uses of social media in healthcare.

The first chat was entitled: Social media and emergency planning –what has worked in the past?

For the second chat, BMJ staff worked with Dr Chloe Sellwood (Pandemic Influenza Resilience Manager and Horizon Scanning Lead at NHS England) and Alex Talbott, who founded and organises @nhssm, to devise a #fluscenario blog. The purpose the blog was to understand how healthcare professionals would react on social media to an unfolding flu pandemic.

#fluscenario was adapted at the University of Dundee by Dr Ellie Hothersall, Consultant and Undergraduate Teaching Lead for Public Health, to help medical students learn and think more about the role of social media in pandemic communication.

Four scenarios were posted on a blog (www.dundeepublichealth.wordpress.com), and were discussed mostly during private study periods during the weeks the scenarios were running. A publicly accessible website was used so that members of the public could follow or join in the conversation. Staff and students from outside the medical school were also encouraged to take part. Using an online, interactive scenario gives students insight into pandemic influenza and emergency planning; areas that historically do not get much coverage within the curriculum (although every doctor needs to understand them).

In January 2014 Ellie Hothersall reported this experience [on the TELL ME website](#).

7.2.2 Press center and newsletters

During the project, Zadig performed **Press Center activity**, in order to promote the project on European media, and issued **periodical newsletters**, updating a mailing list of European journalists, healthcare professionals, policy makers and other stakeholders on TELL ME project progress and results.

A team composed by experienced scientific journalists by Zadig had been collecting and adding further and further relevant contacts to the **mailing lists**, reaching, at the end of the project, a total of 1273* addresses all over Europe:

- Journalists 634
- Stakeholders 523
- Members of consortium, EAB and related projects 62
- Doctors 144
- Others 87

* This number does not exactly correspond to the sum of groups, due to some duplications in lists.

Press centre

In the first part of the project the TELL ME Press Centre tried notably to stay on the news, following events related to flu, vaccines and emerging diseases, taking any possible chance to talk about the TELL ME project and to highlight the importance of communication issues in such case-studies.

In the second part, while TELL ME results and products were provided by partners, they became the main object of communication and of the Press Center activity.

In the whole, the Press centre issued **seven Press releases** and organized **one in-person Press conference**.

General presentations of the **project** and its objectives were published mainly by websites addressed to healthcare professionals, policy maker, stakeholders and public health experts, while some partners' **scientific results** and **case-studies** reached mainstream media as well.

TELL ME project as a whole was presented on **DOC2DOC blog** (Connecting Doctors Worldwide), by BMJ, on **CORDIS website** (EU Community Research and Development Information Service), on **EPICENTRO** (Epidemiological website of the Italian Institute of Health) and on an Italian printed journal for doctors (**Torino medica**).

TELL ME project was mentioned more than once by Italian main Italian newspapers (**Corriere della Sera**, **la Repubblica** and **Pagina 99**) in articles concerning communication challenges in flu, pandemics

and Ebola and when a poll was asked for, by TELL ME experts, on attitudes towards vaccines of Italian people after a flu vaccine withdrawal in 2012 (see [Press Review on TELL ME website](#)).



Pensa la salute
di **Riccardo Renzi**

L'«astensionismo» nelle vaccinazioni

Non c'è solo l'antipolitica. L'astensionismo sta coinvolgendo anche il mondo delle vaccinazioni, almeno quelle contro l'influenza. Così come gli scandali nazionali e regionali creano un clima di sfiducia nella politica, anche le cattive notizie relative a blocchi e ritiri di partite di vaccini antinfluenzali, perché risultate contaminate ai controlli, stanno incrementando le schiere degli scettici della salute. E quanto emerge da un'indagine, realizzata dall'Ispo di Renato Mannheimer, che verrà presentata il 9 novembre. La ricerca è stata commissionata da Tell Me, progetto finanziato dalla Commissione europea, che ha l'obiettivo di "insegnare a comunicare" durante le epidemie influenzali. I risultati ci dicono che il 5% degli italiani ha deciso di non immunizzarsi

“
La diffidenza sarebbe causata dal "fallimento comunicativo"

dopo le prime notizie di vaccini "avariati", e che il 14% ha espresso dubbi sull'opportunità. Se aggiungiamo un 18% di persone che già era contrario alla vaccinazione e l'ampia quota di chi si dichiara disinteressato al problema (diciamo così, le "schede bianche"), scopriamo che l'astensionismo supera la metà della popolazione. Come alle elezioni siciliane. La causa della diffidenza crescente viene indicata nel "fallimento comunicativo", al modo allarmistico o poco trasparente con cui sarebbero state date le notizie sui problemi dei vaccini. Sarà anche vero. Ma questo "fallimento comunicativo" non vorremmo che assomigliasse molto al "fango mediatico" di cui parlano di solito i politici indagati.

An interesting **paper about ambivalent risk perception in healthcare workers**, published in the [American Journal of Infection Control](#) by HU team, was picked up by many media, both in Israel and in

the world: it was cited by [The Jerusalem Post](#), [San Diego Jewish World](#), [Times of Israel](#), [Infection Control Today](#), [International Biosecurity Intelligence system](#) and [Science Daily](#), an important international website collecting news from research, selected from hundreds of sources from around the world.

Science daily is one of the Internet's most popular science news web sites, which targets students, researchers, healthcare professionals, government agencies, educators and the general public around the world. With more than 3 million monthly visitors, it generates nearly 15 million page views a month.

A dedicated "Pandemic" section was created on [Scienceonthenet.eu](#), a site funded by Italian Minister of University and scientific research in order to disseminate the Italian research in the world. It picked up several contents from the TELL ME website and underlined some relevant contents from the [Final Conference](#).

News about the **Final Conference** were picked up also by [BMJ](#), [CORDIS](#) and [Epicentro](#) again.

The [article](#) by Anne Gulland on **BMJ** following the TELL ME final conference [has been accessed](#) by more than 1,000 qualified readers.

A [post](#) in BMJ blog about social media in epidemics, mentioning TELL ME documents and the final conference, got 721 page views.

The image shows a screenshot of a BMJ Blogs article. The URL in the browser is blogs.bmj.com/bmj-journals-development-blog/2015/01/05/social-media-during-epidemics-a-poisoned-chalice/. The page features a blue header with the 'BMJ Blogs' logo and a search bar. Below the header, the article title 'Social media during epidemics: a poisoned chalice?' is displayed, along with the author's name 'Claire Bowler, Digital Content Manager, @clairebowlr' and the date '5 Jan, 16'. The article text discusses the prevalence of social networking sites and their role in crisis communication. A cartoon illustration depicts a man with a speech bubble saying 'EBOLA!!!' while holding a burger, a cigarette, and a can of beer. Text next to the cartoon lists 'OBESITY: 300,000 DEATHS PER YEAR', 'TOBACCO: 450,000 DEATHS PER YEAR', and 'ALCOHOL: 86,000 DEATHS PER YEAR'. The right sidebar contains a 'SUBMIT YOUR PAPER' button, a 'BMJ Open Gastroenterology' section, and a list of tags including 'altmetrics', 'Apps', 'Article-level links', 'Article functionality', 'Article metrics', 'Blogs', 'BMJ', 'bmj.com', 'BMJ Supportive & Palliative Care', 'Citations', 'Emergency Medicine', 'Facebook', 'Google+', 'HighWire Press', 'homepage', 'Impact factor', 'iPad', 'iPhone', 'Kindle', 'Libraries', 'Mendeley', 'Mobile', 'New website', 'Open access', 'Open Science', 'Personalisation', 'QR codes', and 'Scientific'. There is also a 'Follow me on Twitter' section with the handle '@clairebowlr' and a 'Visit bmjopen gastro.bmj.com TO LEARN MORE' link.

New **Asset project** website referred of the meeting in homepage, highlighting the torch passing between the two projects.

General public in Italy was informed through a popular Italian health website (**Healthdesk**) that in 2014 had 1,7 millions total visitors and 920,000 unique visitors. Healthdesk newsletter is sent to 15.000 registered recipients. Finally, people was reached by this article also by social networks, since 5.000 people like HealthDesk on Facebook and 1.500 follow it on Twitter.

When **TELL ME Practical guide** was ready, it was presented to millions of readers by **Medical News Today**, a website in the top 5,000 global websites, as reported by Alexa.com, which receives more than 9 million monthly visits, has 10 millions unique visitors and got 12 millions monthly page views (Statistics from Google Analytics).

The screenshot shows a news article page with a blue header containing the MNT logo, navigation links (A-B, C-D, E-G, H-L, M-O, P-R, S-Z), and social media icons. The main headline is "Practical guide to improve communication during disease outbreaks launched". Below the headline, there are social media share buttons for Facebook (2), Twitter (12), and a total of 14 shares. A sidebar on the left lists categories: Infectious Diseases / Bacteria / Viruses, Bird Flu / Avian Flu, and Flu / Cold / SARS. The article text begins with "A practical guide for healthcare professionals to help improve communication during major disease outbreaks was launched Monday 2 February 2015." It then describes the TELL ME project, a collaborative effort between BMJ, CEDARthree, Istituto Superiore di Sanità, and Zedig Srl, which developed evidence-based models and tools for improved risk communication. The guide offers practical recommendations and tools for evidence-based messages tailored to different populations. A quote from Mitali Wroczynski, Business Development Manager at BMJ, states: "Since the outbreak of the H1N1 or 'swine flu' virus, communication has become a central issue for managing risk." Another quote says: "Communication is strengthened when institutions, healthcare professionals, and other community groups - who form part of the wider social network - engage in constructive, open and transparent dialogue. This guide provides clear, practical advice that can be adapted to specific risk situations to help effective information exchange during a public health crisis." The article concludes with a link for more information: <http://tellmeproject.eu/>. On the right side, there is a "Spotlight on: Infectious Diseases / Bacteria / Viruses" section with a sub-heading "What is Pneumococcal Disease?" and a small image of a globe.

Press releases

Press Office activity included **press releases**, issued to inform about keystones in the project (such as the Final conference) or taking cues from events in the news, in order to make case-studies.

Two **case-studies**, notably, performed by Zadig staff, were disseminated by Press releases during the course of the project:

- the first, in 2012, about the withdrawal of flu vaccine in Italy and other European countries;
- the second, in 2013, regarding the Twitter analysis performed about H7N9 crisis.

2012: withdrawal of flu vaccines

On Oct 17th, 2012, on the verge of the 2012 seasonal flu vaccine campaign, the Italian Ministry of Health suddenly announced the recall of 2.3 million doses of the Inflexal V flu vaccine, produced by Dutch producer of the vaccine, Crucell. "Potential danger" to health was claimed for the recall. This news rapidly spread with alarm. The Ministry of Health reassured the population that security problem should not be expected because no dose was put into circulation.

However, a few days after, on Oct 24th, 2012, the Italian Ministry of Health prohibited also the use and sale of other four influenza vaccines produced by the pharmaceutical company Novartis. In a statement circulated with urgency, Italian citizens were asked not to buy or use these vaccines until further notice. The Italian Medicines Agency (AIFA), the national authority responsible for the regulation of drugs in Italy, explained that the documentation submitted by the pharmaceutical company needed to include more safety checks and more details on the safety and quality of their vaccines. Withdrawals followed in several other European countries.

TELL ME project identified in this series of events an extremely interesting case study to investigate the mutual interplay between medical evidence, institutional information, public health campaign, public opinion. ZADIG therefore commissioned the **Italian Institute for Studies on Public Opinion (ISPO)** – a company specialised in polls, an **instant poll** about the impact of these facts and communication on people's attitude towards flu vaccination.

A quantitative research was carried out through telephone interviews (CATI SYSTEM) on a sample of **802 individuals**.

The sample, selected randomly, was representative of Italian adult population (i.e. population aged over 17), for gender, age, professional occupation, educational qualifications, geographic area of domicile, size of the domicile centre. The poll had a response rate of 38,7%.

46% referred being either vaccinated or responsible for others' vaccination (children, not autonomus relative, and so on); this rate increased with age and was higher in big cities and in the central areas of Italy. From answers emerged that the doctor's advice is decisive in the choice of vaccinating.

A relevant conclusion of the poll was that more than 1 out of 4 responders (28%) was skeptical about flu vaccines, thinking that they entail more risks than benefits.

Persons who were most critical against flu vaccines are those who do not vaccinate and those who were not responsible for other persons.

Almost **20% of people referred that their opinion about vaccines was influenced by the news about vaccine withdrawal**. This relevant minority, mainly constituted by young adults (25-34y), workmen and housewives, shows the importance of communication, especially in crisis.

For further information, see Annex 2.

Since the survey had been conducted in Italy, two press releases were sent to Italian journalists (see [Newsletter and Press releases](#) on TELL ME websites).

The first, sent on 17/10/2012, warned about the risks of mistakes in communication in such cases, anticipating that a survey had been commissioned.

The second, sent on 6/11/2012, referred about the results of the poll.

Both press releases invited journalists at the **Press Conference** to be held at Hotel NH Leonardo Da Vinci in Rome on November 9th. In the agenda, in addition to the results of the survey, some preliminary findings from TELL ME research were presented to the press:

- Analysis of people's behaviour in past pandemics, and notably 2009 A (H1N1), depending on information provided;
- Analysis on information about flu and vaccines provided by traditional and new social media;
- Analysis of false myths and urban legend about flu and vaccines
- TELL ME questionnaire on Communication requirements for European family doctors.

The survey was picked up by several Italian websites ([Fondazione Veronesi.it](#), [Tribuna Italia](#), [Wellme.it](#), [Benessere Blog](#), [You-ng](#), [Mamme domani](#), [Altopascio.info](#), [Lo schermo.it](#), [Sindacatomediciitaliani.it](#), [Il moderatore.it](#)) and by the two main Italian newspapers:

- [La Repubblica](#) (9/11/2012)
-
- Corriere della Sera, in two different articles both in its print (4/11/2012) and online (5/11/2012) editions

2013: H7N9 new flu virus emerging in China

Another press release was sent to European journalists on 24 April 2013, analyzing communication in H7N9 new flu virus emerging in China, in comparisons with experience from the past, such as that of 2009 A(H1N1).

It included some results from the Twitter analysis performed by Zadig staff and described before, in the 6.2.1 Website and social media section.

TELL ME Final Conference in Venice was both anticipated and followed by **press releases** in English and Italian picked up by Italian and international websites, as described before.

In the same days, another Press release informed the Italian press of **the adoption of TELL ME Ebola course by Italian Associations of doctors and nurses**.

This product that can be considered an exploitation of TELL ME results gave a further opportunity to disseminate the project as well, notably among Italian doctors and nurses.

List of main media pickups

	media	institution	title	date of publication	target
DOC2DOC (Connecting Doctors Worldwide)	blog	BMJ publishing	<u>Introducing... TELL ME</u>	20/4/2012	Doctors and other HCPs
Corriere della Sera	newspaper	main Italian newspaper Mainstream press	<u>L"astensionismo" nelle vaccinazioni</u>	4/11/2012	General public
Corriere della Sera	News website	main Italian newspaper Mainstream press	<u>Vaccini, il 14% degli italiani ha dubbi sulla loro utilità. E il 5% ha deciso di non vaccinarsi</u>	5/11/2012	General public
La Repubblica.it	News website	main Italian newspaper Mainstream press	<u>Rimosso divieto utilizzo vaccini Dall'Aifa il via libera a Novartis</u>	9/11/2012	General public
CORDIS (Community Research and Development Information Service)	Institutional website	EU Commission	<u>How to talk about epidemics: the TellMe project</u>	4/3/2013	Policy makers, experts, other projects' members, journalists
EPICENTRO (epidemiological website of the Italian Institute)	Institutional website	Italian Minister of Health	<u>La comunicazione in caso di epidemia: il progetto Tell Me</u>	20/5/2013	Public health experts, healthcare professionals, policy maker, stakeholders

of Health)					and health journalists
CORRIERE.IT	News website	Corriere della Sera, main Italian newspaper Mainstream press	<u>Influenza A, l'eccessivo allarmismo di chi aveva interessi (economici) in gioco</u>	20/11/2013	General public
TORINO MEDICA	local medical journal (printed edition)	<u>Turin Medical Association</u>	<u>TELL ME project: la comunicazione efficace in caso di pandemia</u>	December 2013	Doctors
Pagina 99	Italian weekly newspaper (printed edition)	Mainstream press	<u>La comunicazione vale come un vaccino</u>	27/9/2014	General public
The Jerusalem Post	News website	Israel main newspaper Mainstream press	<u>Ministry urges taking preventive measures against West Nile virus</u>	10/8/2014	General public
Science Daily	Science news website		<u>When a health risk is close to home, health care professionals base their positions on vaccines on their own emotions, personal experiences</u>	24/8/2014	Scientists, healthcare professional, science journalists
San Diego Jewish World	News website		<u>Health workers may become less objective if threat near</u>	24/8/2014	General public
Infection Control	Medical		<u>Healthcare</u>	25/8/2014	Doctors,

Today	website		<u>Workers Base Their Positions on Vaccines on Their Own Emotions and Personal Experiences</u>		infectivologists, public health experts
The Times of Israel	News website		<u>Health workers too close to make vaccination call: study</u>	26/8/2014	General public
International Biosecurity Intelligence System	Specialized website	<u>Centre of Excellence for Biosecurity Risk Analysis at the University of Melbourne</u>	<u>Healthcare Workers Base Their Positions on Vaccines on Their Own Emotions and Personal Experiences</u>	26/8/2014	Security, environment, biology, climate, sociology, epidemiology experts
CORDIS (Community Research and Development Information Service)	website	EU Commission	<u>TELL ME, Tell You: Bridging theory and practice for effective communications during infectious disease crises</u>	5/11/2014	Policy makers, experts, other projects' members, journalists
Epicentro (epidemiological website of the Italian Institute of Health)	Institutional website	Italian Minister of health	<u>La comunicazione in caso di pandemia: il progetto TELL ME</u>	27/11/2014	Public health experts, healthcare professionals, policy maker, stakeholders and health journalists
BMJ	Medical journal	BMA	<u>Quarantining health workers returning from Ebola affected countries is "bad</u>	8/12/2014	Healthcare professionals, policy maker, public health experts, health journalists

			<u>science,” says public health adviser</u>		
Healthdesk	Italian health website		<u>Quando i virus infettano la comunicazione</u>	9/12/2014	General public
BMJ	blog	BMA	<u>Social media during epidemics: a poisoned chalice?</u>	5/1/2015	Healthcare worrkers, health journalists, experts in risk and health communication
Epicentro (epidemiological website of the Italian Institute of Health)	Institutional website	Italian Minister of health	<u>Il Progetto TELL ME dà i suoi frutti</u>	29/1/2015	Public health experts, healthcare professionals, policy maker, stakeholders and health journalists
Medical News Today	International medical news website		<u>Practical guide to improve communication during disease outbreaks launched</u>	4/2/2015	Healthcare professionals, policy maker, public health experts, health journalists
AboutPharma	Pharmaceutical industry journal		<u>In press</u>		Pharmaceutical industry stakeholders

Newsletters

TELL ME newsletters were thought as a main tool of dissemination. They were sent to the mailing lists previously described, reaching more than 1,000 journalists, experts and stakeholders in Europe and the world. Their contents changed during the course of the project, as described before: being in the beginning more focused on the project in general and on news regarding pandemic issues, in the following phases they were more dedicated to disseminate the TELL ME results and products.

TELL ME DOW scheduled three newsletter per year. As a matter of fact, one was sent in the first year, two in the second, four in the last year and one at the end of the project, reflecting the increasing amount of contents to disseminate:

Newsletter TELL ME 2012-09-25

Newsletter TELL ME 2013-04-24

[Newsletter TELL ME 2013-10-31](#)

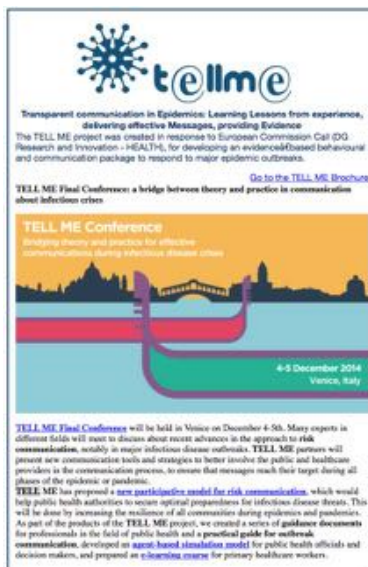
[Newsletter TELL ME 2014-05-22](#)

[Newsletter TELL ME 2014-07-04](#)

[Newsletter TELL ME 2014-10-20](#)

[Newsletter TELL ME 2014-11-20](#)

[Newsletter TELL ME 2015-2-20](#)



In addition to the eight TELL ME newsletter just mentioned, several others disseminated TELL ME content through other channels to thousands of people all over the world.

The project was in fact also disseminated by:

- BMJ bulletin (May 2014, addressed to **300 CEOs, clinical directors, societies and trade press**)



TELL ME PROJECT

We are participating in an exciting EU funded, collaborative project which aims to provide evidence and to develop models for improved communication during infectious disease crises. One of the major problems during infectious outbreaks has always been communicating with the population in order to influence behaviours, reduce the spread of disease and avoid panic.

The TELL ME project will answer three distinct research questions:

How can the general population be persuaded through public health communication to take effective preventative actions (e.g. vaccination, antiviral therapy, hygienic norms, etc.)?

What are the most appropriate communication methods to deal with complexity, uncertainty, ignorance, information asymmetries, overwhelming information, biased information, misinformation and malicious information?

What are the best communication strategies to support vaccine uptake, and to assist health professionals and agencies to engage with vaccine-resistant groups?

TELL ME is currently developing a communications toolkit for use when planning pandemic flu communications. Part of the process of development is to have the toolkit validated by practitioners and experts. The validation phase will start at the beginning of June.

We are putting together a list of experts to help validate the toolkit. If you are interested in participating or have skills or background related to healthcare communication, commissioning (particularly CCGs), public health, healthcare policy or emergency planning, we would like to hear from you. The total time required would be around 2.5 hours to skim through the toolkit and fill out a feedback form. Unfortunately, there is no remuneration on offer.

If you are interested in participating with the toolkit validation or would like further information about the project or would like to be involved in any future activities, please do not hesitate to contact:

Mitali Wroczynski
Business Development and Marketing Manager
mwroczynski@bmi.com

- TIEMS newsletter (August 2014, more than 36,000 experts of emergency management worldwide

TELL ME Project: A Summary

Background Information and Context

From the onset of an infectious disease outbreak, public health communication is a critical component for influencing population behaviors toward an effective containment of the disease. The continuous growth and development of information and communication technologies (ICT), with the public health education to break through traditional barriers and shift away from the conventional top-down, representative governance approach, which makes use of a number of behavioral models to convey protective messages to the public. In the effort to meet the ever-growing information needs and requirements by the general public, urgent research in evidence-based communication should explore new pathways and strategies, towards a participatory governance approach, to effectively address general public concerns and their ever deeply interrelated beliefs that have an effect on the uptake of protective measures in the event of an outbreak.

The recent developments in ICT have triggered changes in the communication dynamics between public health authorities, the media and the general public, leading to a major trend in the "democratization of information" as various stakeholders take an active role in the outbreak communication process. By taking into account opportunities and challenges posed by ICT developments and increasing interconnectivity as a result of globalization, it becomes imperative to create a suitable and innovative framework to address new challenges and explore the huge potential that the information society can offer in terms of participatory communication in preparation and response phase of an epidemic. This is the general concept that drives the TELL ME project, backed up by the action that open and transparent communication is the element in the process, which requires following of evidence-based strategies, involvement of citizens and health professionals in decision-making processes and representative two-way dialogue with public health authorities.

Figure 1 - The TELL ME concept

Research Questions and Objectives

TELL ME set as its overarching goal the establishment of an integrated research project providing a range of inputs on social and behavioral sciences, communication and media, health professionals and representatives from civil society organizations to develop an evidence-based behavioral and communication package to respond to major infectious disease outbreaks, amidst the pandemic. To such a context, the project aims to address the following three distinct research questions regarding communication during infectious disease outbreaks, to better articulate the TELL ME concept:

- RQ1: How can the general public be better educated or positively influenced to take effective protective measures during the outbreak?
- RQ2: Which are the most appropriate communication methods to deal with the complexity, uncertainty, uncertainties and multiple outbreaks?
- RQ3: What are the best communication strategies to maximize vaccine uptake, and to avoid health professionals and agencies to cope with vaccine-averse groups?

To address these questions, which have been set to define the scope of the project, research in TELL ME concentrates on key focus areas, such as: (i) the investigation of behavioral beliefs and their that factors influence infectious disease transmission, vaccine acceptance or refusal, and network theory; (ii) responses to the general population during a health crisis; (iii) development of appropriate communication methods, especially regarding complicated messages and advice based on socio-economic and cultural differences; (iv) evaluation of knowledge and attitude research, vaccination for a better understanding of the level of acceptance and its correlation in relation to the perceived cost of disease.

In essence, the project comprises three main stages (Figure 1) and by use of mixed-method research techniques (e.g. focus groups, expert interviews, stakeholder surveys, qualitative meetings etc.), TELL ME seeks to meet the following four objectives, with each objective pursuing a scientific Work Package (WP):

1. To collect and discuss evidence about population behavioral responses to infectious disease outbreaks, and ways in which different types of communication can affect human behaviors (Objective 1 - WP1).
2. To identify and assess existing challenges and new methods for public health communication with respect to infectious disease outbreaks (Objective 2 - WP2).
3. To develop an integrated evidence-based communication package (TELL ME Communication Kit) - based on a general leading framework model that will offer a new participatory model for outbreak communication - comprising a series of product documents for health professionals and agencies to respond in effective engagement with vaccine-averse groups during infectious disease outbreaks (Objective 3 - WP3).
4. To design and conduct a model prototype (Agent-Based Simulation Model) to test the effect of new communication strategies developed in TELL ME, by simulating the

Review and interpretation of infectious disease-related matters within a virtual environment in the event of an epidemic outbreak (Objective 4 - WP4).

Potential Impact

The TELL ME project will provide public health agencies, policy-makers, and civil society organizations with a state-of-the-art assessment of best practices in such communication and an enhanced understanding of communication problems that have occurred in previous infectious disease outbreaks. Communication strategies to support vaccine uptake will be developed, as well as a series of product documents will be created for health professionals and agencies to support an effective engagement with vaccine-averse groups and groups at risk of stigmatization and discrimination. Furthermore, the TELL ME project will provide policy makers, public health agencies, and communication with an innovative package model for outbreak communication, on the basis of which messages can be produced for different sub-populations across different countries. The model will offer guidelines for the coordinated ways to work with different sub-populations of health professionals and their partnerships with them to best optimize behavior, towards an effective intervention during a crisis. With the prototype model will be possible to test public response and impact of messages communicated in the event of an infectious disease outbreak.


To maximize awareness between perceived and intended messages as the course of a pandemic, the TELL ME project will focus efforts to thoroughly investigate information detection and revealed information dissemination gaps between intended and perceived messages etc. It is expected that the TELL ME project will make valuable contributions on theoretical, conceptual, analytical and types of information during the outbreak. On the practical side, the TELL ME project is expected to provide communication and officials with an effective simulation tool of that can help to test and evaluate in advance, with the aim to make any refinements for dissemination of messages between perceived and intended messages.

Contributors and TELL ME entities

1. Unacademy (UNACAD)	7. Latvian Child Health Centre Riga (LACH)
2. British Medical Journal Publishing Group (BMJPG)	8. Uppsala University Research Centre (URC)
3. (E)Health (EHEALTH)	9. National Disaster Life Support Foundation (NLSF)
4. University of Sussex - CRISIS (CRISIS)	10. University of Bath - School of Public Health (SPH)
5. Centre for Health Systems Research (CHSR)	11. Gdynia (GDYNIA)
6. Uppsala University (Uppsala University)	

Scientific Co-ordinator: Matt of Green (University of Bath)
Administrative Co-ordinator: Oliver de Borchsenius (Unacademy)
TELL ME Website: www.tellmeproject.org

- a dedicated newsletter about TELL ME sent following participation at World Congress of Disaster Management (Toronto, June 2014) to **about 7,000 experts all over the world.**



**Transparent communication in Epidemics: Learning Lessons from experience,
delivering effective Messages, providing Evidence**

The TELL ME project was created in response to European Commission Call (DG Research and Innovation - HEALTH), for developing an evidence-based behavioural and communication package to respond to major epidemic outbreaks.

[Go to the TELL ME Brochure](#)

TELL ME, a Collaborative Project that aims to provide evidence and develop models for improved risk communication during major infectious disease outbreaks, has combined public health, social sciences, behavioural sciences, political sciences, law, ethics, communication and media, in order to develop a set of original communication strategies and approach to outbreak communication. **At the WCDM in Toronto we presented a poster on the importance of Social Media.**

Learning from the experience of 2009 A(H1N1) pandemic, TELL ME experts have developed new tools to improve preparedness in case of infectious outbreaks, such as a new model of outbreak communication. From this model, **a practical guide for outbreak communication is currently being developed** which is geared toward decision makers, institutional actors and healthcare professionals.

The model has provided the basis for the development of an e-learning course that any **healthcare professionals can access [here](#)**. For the moment, the e-learning course is available as a pilot, so any comments or views on the course would be highly appreciated.

Another important resource is a **social simulation model based on a software modelling of protective behaviour decisions**. The objective of this simulation model is to provide guidance for health authorities regarding the usefulness and effectiveness of different communication strategies prior, during and after an influenza epidemic.



In addition, we are in the process of finalising a number of guidance documents which will be freely accessible.

Stay in touch with TELL ME

- Join the mailing list to receive TELL ME e-Newsletters by contacting us [here](#)
- Follow us on [Twitter](#)
- Get informed about TELL ME news and events on [Facebook](#)
- For more information, please visit the TELL ME web portal at www.tellmeproject.eu.

For further information, contact Mitali Wroczynski at mwroczynski@bmj.com

2012 TELL ME is co-funded by the 7th Framework Programme of the EC
Project No. 278723

- a mail was sent to **60,000 people following IMED 2014** in Vienna

Infectious disease outbreak preparedness: access FREE guidance, e-learning and tools

TELL ME, a Collaborative Project that aims to provide evidence and develop models for improved risk communication during major infectious disease outbreaks, has combined public health, social sciences, behavioural sciences, political sciences, law, ethics, communication and media, in order to develop a set of original communication strategies and approach to outbreak communication.

Learning from the experience of 2009 A(H1N1) pandemic, TELL ME experts have developed new tools to improve preparedness in case of infectious outbreaks, such as a new model of outbreak communication. From this model, **a practical guide for outbreak communication is currently being developed** which is geared toward decision makers, institutional actors and healthcare professionals.

The model has provided the basis for the development of **an e-learning course that any healthcare professionals can access [here](#)**. For the moment, the e-learning course is available as a pilot, so any comments or views on the course would be highly appreciated.

Another important resource is **a social simulation model based on a software modelling of protective behaviour decisions**. The objective of this simulation model is to provide guidance for health authorities regarding the usefulness and effectiveness of different communication strategies prior, during and after an influenza epidemic.

In addition, we are in the process of finalising a number of guidance documents which will be freely accessible.

Stay in touch with TELL ME

- Join the mailing list to receive TELL ME e-Newsletters by contacting us [here](#).
- Follow us on [Twitter](#).
- Get informed about TELL ME news and events on [Facebook](#).
- For more information, please visit the TELL ME web portal at www.tellmeproject.eu.

For further information, contact Mitali Wroczynski at mwroczynski@bmi.com

7.2.3 Scientific publications and conference presentations

Scientific publications

During the project, papers by several researchers involved in the project and joint papers were submitted to journals in respective relevant disciplinary areas, reaching and overcoming the average of at least two papers requested by the DOW.

Between month 1 – 6 of the project, BMJ, leader of ST5.1.4, analysed the various outputs and deliverables of the TELL ME project in order to identify research carried out by project partners that could be developed or submitted as research to academic journals. A list of potential collaborations between project partners was devised and partners asked for feedback as well as the specific journals they would like to submit to. Once collected this feedback, BMJ designed the publication schedule for the

project which documents the journal papers and their titles to be submitted, as well as schedules for submission.

Furthermore, BMJ and NDLSF lead the initiative of publishing a special issue in the [Disaster Medicine and Public Health Preparedness journal](#), devising a list of suitable articles and themes for this issue that was agreed could substitute the ISSN paper series mentioned in the DOW.

The University of Haifa School of Public health also took care of collecting ideas and results in a **TELL ME book** that will be further disseminating TELL ME contents, making them even more easily accessible for future research.

As requested by the DOW, the consortium prepared two **joined main articles**:

- the first was published on Disaster Medicine and Public Health Preparedness in April 2014 (*Risk Communication Recommendations and Implementation During Emerging Infectious Diseases: A Case Study of the 2009 H1N1 Influenza Pandemic*);
- the second is still in process, collecting all the experience of the work made within the TELL ME project, with this preliminary title: *Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence (TELL ME) - Project Description*.

Additionally, individual papers were authored by one or more partners:

University of Haifa

HU partners were notably active in publications during the whole project. Their first work in TELL ME project, regarding HCPs compliance in flu vaccination depending on communication received, was published by the [European Journal of Public Health](#) in October 2013.

A further paper, published in the [American Journal of Infection Control](#) in August 2014, on the ambivalency of risk perception in HCPs, has already been mentioned since it was widely picked up by media.

A third paper, about parents' attitude to vaccinating their children, was published on the [Journal of Risk Research](#) on 12 December 2014.

One paper has already been accepted for publication on Disaster Medicine and Public Health Preparedness TELL ME Special Issue:

Gesser-Edelsburg, A., Mordini, E., Billingsley, M., Stoloro, N., James, J.J., Green, M.S. (Forthcoming). Risk communication during the 2009 H1N1 influenza outbreak: literature review (2009-2013) of the methodology used for EID communication analysis. Disaster Medicine and Public Health Preparedness.

In addition, HU team have four scientific manuscripts that are either in preparation, submitted, or under review.

Under Review for Publication in TELL ME Special Issue:

Gesser-Edelsburg, A., Walter, N., Shir-Raz, Y., Mordini, E., Dimitriou, D., Green, M.S. The public sphere in EID communication: Recipient or active and vocal partner? Disaster Medicine and Public Health Preparedness.

Under Review:

Gesser-Edelsburg, A., Shir-Raz, Y., Sassoni Bar-Lev, O., Green, M.S. Outbreak or epidemic? How Obama's language choice transformed the Ebola outbreak into an epidemic. Global Health Communication.

Submitted:

Gesser-Edelsburg, A., Shir-Raz, Y., Haiek, S., Sassoni Bar-Lev, O. What Does the Public Know about Ebola? The Public's risk perceptions regarding the current Ebola in an as-yet uninfected country. American Journal of Infection Control.

In Preparation:

Gesser-Edelsburg, A., Shir-Raz, Y. Science vs Fear: the Ebola quarantine debate as a case study that reveals how the public perceives risk.

Zadig

Zadig reported the experience of T2.4 Technical, legal and scientific feasibility of an online course for primary care staff in a paper published in Creative Education in May 2014.

Another paper on the Ebola course conceived within the TELL ME project was submitted to be included in a Ebola special issue of Disaster Medicine and Public Health Preparedness (DMPHP) journal: Dri P., Saita T., Valetto MR., Bellone M., Villa R. Ebola outbreak: use, acceptance and utility of an e-learning course for health professionals in Italy.

Vrije Universiteit Brussels, VUB

VUB wrote one paper on stigmatisation and human rights issues in relation to public information campaigns. This paper further built on and developed on several themes created in task T1.6. The paper was submitted to the International Journal of Discrimination and the Law, which published it in March 2014.

Centre for Research in social simulation - (University of Surrey)

CRESS planned 4 journal articles:

- two have been submitted in February (model design, and calibration): their tentative titles are respectively:
 - o Badham J., Gilbert N. Protective Behaviour During an Epidemic: A Modelling Framework
 - o Badham, J., Jansen, C., French, T., Shardlow, N. Calibrating with Multiple Criteria: Protective Behaviour During an Epidemic.
- one is expected to be submitted in March (based on the CSS/ECCS conference presentation);
- a final paper will report the results and uses of the model. This is not expected to be submitted until April.

National Centre for Epidemiology, Surveillance and Health Promotion, CNESPS (Italy)

ISS staff is working on several papers. The most advanced (even not submitted yet) are:

- Cattaneo C., Possenti V., De Mei B., Rizzo C., Bella A., Lattanzi A., Bassi C., Di Mario S., Moro M.L., Salmaso S. Analysis of factors associated with compliance in accepting influenza vaccination during infectious outbreaks and pandemics. A systematic review. *Targeted journal: Annali ISS*
- Possenti V., De Mei B., Dimitriou D., Talbot A., Wroczynski M et al. Integrated outbreak communication strategies for Institutional Actors” [or something like: “Developing a strategic communication plan by a public health institution”]. *Targeted journal: Health Communication*

European Union of General Practitioners, UEMO

UEMO drafted a scientific article with the aim to present the results of the research done to identify and describe opinions – positive or negative – experiences of GP/FP about handling of the pandemic, including their suggestions and proposals for solutions. The article shows the understanding of the views and perceptions of the GP/FP about communication requirements in case of outbreak communication and investigates reasons of mistrust or poor compliance with vaccination in 2009 pandemic. The article went through internal review and after fine tuning is going to be submitted for publication in a scientific journal related to the subject.

All of these are not expected to be published until several months after submission.

Links to all journal publications will be included on the TELL ME website as they are published.

Disaster Medicine and Public Health Preparedness (DMPHP) journal Special issue

A special issue in the Disaster Medicine and Public Health Preparedness (DMPHP) journal, with a focus on communication in pandemic and seasonal influenza and vaccination, was in fact planned since the first phase of the project, with BMJ, CSSC and other partners cooperating with NLDSF in the task.

Since June 2013 (m17) BMJ has been working with consortium members to devise a list of suitable articles and themes. Aim of this issue is to bring together the most relevant research from two EU-funded projects – TELL ME and E-COM – which are currently investigating the factors that impact on and influence communication strategies and their relative effectiveness during a pandemic.

It will focus into the following main issues:

- Crisis preparedness framework
- Tools for outbreak communication
- Models for outbreak communication
- Information management and access
- Public involvement in communications
- Governance and policy issues
- Ethical and legal issues
- Socio-cultural contexts
- Vaccination campaigns
- Social marketing
- Business continuity
- Mass media / Social media
- Training and education
- Risk and uncertainty.

Planned for February 2014 (m25), it was postponed to the end of the project in order to collect all the results coming out from the project and it is scheduled for April 2014.

A call for papers was disseminated since June 2014, asking for research regarding the role of communication in public health preparedness measures and response to pandemics, with particular reference to infectious disease outbreaks.

Disaster Medicine and Public Health Preparedness Call for Papers – Special Issue

Call description

The journal for [Disaster Medicine and Public Health Preparedness](#) is publishing a special issue in 2014 on **the role of communication in public health preparedness measures and response to pandemics**, with particular reference to infectious disease outbreaks.

Within the scope of the 7th Framework Programme, the European Commission has funded two projects (TELL ME and Ecom@EU) which are currently investigating the factors that impact on and influence communication strategies and their relative effectiveness during a pandemic. This special issue aims to bring together the most relevant research from these projects, as well as invite other contributors who have an interest in this area.

We welcome paper submissions from a variety of disciplines for this special issue. Submissions for research, editorials, commentaries that fit the theme of this special issue will also be considered. Please contact dmp@journal@gmail.com if you have any questions regarding submission.

Submission guidelines

Full instructions on how to prepare a submission can be viewed at <http://mc.manuscriptcentral.com/dmp>.

Guest Editors

Prof. Pier Luigi Lopalco, MD
Head of Scientific Assessment Section
European Centre for Disease Prevention and Control (ECDC)

Litjen (LJ) Tan, MS, PhD
Chief Strategy Officer
Immunization Action Coalition



Thematic areas

Contributions are welcomed in the following thematic areas (but not limited to):

- Crisis preparedness framework
- Tools for outbreak communication
- Models for outbreak communication
- Information management and access
- Public involvement in communications
- Governance and policy issues
- Ethical and legal issues
- Socio-cultural contexts
- Vaccination campaigns
- Social marketing
- Business continuity
- Mass media / Social media
- Training and education
- Risk and uncertainty

Important dates

Call for Papers open	February 28, 2014
Deadline for Submission	June 30, 2014
Print Publication	October, 2014



It is ongoing now and it will continue to accept, review and publish online accepted papers. A paper supplement can be published later on.

List of papers

At the end of the project, the following scientific papers have been produced by project partners in the context of TELL ME:

1. Green MS., Groag Prior N., Geser-Edelsberg A. (2013). Compliance with influenza vaccination among healthcare workers – tailoring risk communication according to the factors affecting

compliance. *The European Journal of Public Health*. Vol. 23: 180.

<http://dx.doi.org/10.1093/eurpub/ckt123.083>

2. Gesser-Edelsburg, A., Mordini, E., James, J., Greco, D., Green, M.S. (2014). Risk communication recommendations and implementation during EID: The case study of the 2009 H1N1 influenza pandemic. *Disaster Medicine and Public Health Preparedness*. Vol. 8: 158-169.
<http://dx.doi.org/10.1017/dmp.2014.27>
3. Saita, T., Dri, P. (2014). Evaluation of Continuing Medical Education (CME) Systems across the 27 European Countries. *Creative Education*. Vol.5 (9): 682-689.
<http://dx.doi.org/10.4236/ce.2014.59080>
4. Gesser-Edelsburg, A., Walter, N., Green, M.S. (2014). Healthcare workers as part of the system or part of the public: Ambivalent risk perception in healthcare workers. *American Journal of Infection Control*. Vol. 42(8): 829-833. <http://dx.doi.org/10.1016/j.ajic.2014.04.012>
5. Quinn, P., De Hert, P. (2014). Self respect—A “Rawlsian Primary Good” unprotected by the European Convention on Human Rights and its lack of a coherent approach to stigmatization? *International Journal of Discrimination and the Law*. Vol 14 (1): 19-53.
<http://dx.doi.org/10.1177/1358229113509734>
6. Gesser-Edelsburg, A., Shir-Raz, Y., Green, M.S. (Published online 2014). Why do parents who usually vaccinate their children hesitate or refuse? General good vs. individual risk. *Journal of Risk Research*. <http://dx.doi.org/10.1080/13669877.2014.983947>
7. Gesser-Edelsburg, A., Mordini, E., Billingsley, M., Stolerio, N., James, J.J., Green, M.S. (Forthcoming). Risk communication during the 2009 H1N1 influenza outbreak: literature review (2009-2013) of the methodology used for EID communication analysis. *Disaster Medicine and Public Health Preparedness*. Accepted for publication in TELL ME special issue.
8. Gesser-Edelsburg, A., Walter, N., Shir-Raz, Y., Mordini, E., Dimitriou, D., Green, M.S. (Forthcoming). The public sphere in EID communication: Recipient or active and vocal partner? *Disaster Medicine and Public Health Preparedness*. Under review for publication in TELL ME special issue.
9. Quinn P., De Hert P. Ebola, Discrimination, and Stigmatization. Familiar Social Problems Produced in the Context of an International Health Crisis. *Disaster Medicine and Public Health Preparedness*. Under review for publication in TELL ME special issue.

10. Dri, P., Saita, T., Valetto, MR., Bellone, M., Villa, R. Ebola outbreak: use, acceptance and utility of an e-learning course for health professionals in Italy. Submitted to *Disaster Medicine and Public Health Preparedness* for publication in TELL ME special issue.
11. Badham, J., Gilbert, N. Protective Behaviour During an Epidemic: A Modelling Framework. (Under review for publication)
12. Badham, J., Jansen, C., French, T., Shardlow, N. Calibrating with Multiple Criteria: Protective Behaviour During an Epidemic. (Under review for publication).
13. Gesser-Edelsburg, A., Shir-Raz, Y., Haiek, S., Sassoni Bar-Lev, O. What Does the Public Know about Ebola? The Public's risk perceptions regarding the current Ebola in an as-yet uninfected country. Submitted to the *American Journal of Infection Control*.

Posters and oral presentations

During the project, **11 posters** have been presented and **several oral presentations** have been given at **international or national scientific conferences and policy meetings** by project partners on behalf of TELL ME project.

Most of this activity, as well as oral presentations in similar contexts, took place in the second reporting period of the project, when main TELL ME results and products were available to be disseminated.

In these events TELL ME project could reach thousands experts and policy makers from tens of countries. The audience in different conferences included many different stakeholder profiles in Europe and North America, but coming also from other continents: infectivologists, epidemiologists, healthcare workers, public health experts, risk and health communication professionals but also air transport people, risk managers, and so on.

List of posters presented at conferences and meetings

1. Avi Magid, Anat Gesser-Edelsburg, Manfred S. Green. *Are informal digital surveillance systems currently capable of detection disease outbreaks in real-time?* International Meeting on Emerging Diseases and Surveillance (IMED 2013). Vienna, Austria. February, 2013.
2. Emilio Mordini, Manfred Green, Donato Greco, Barbara De Mei, Roberto Satolli, Nigel Gilbert. For an effective communication during infectious outbreaks. XVth International Congress of Immunology. Milan, Italy. August, 2013.
3. Manfred S. Green, Noemi Groag Pri-or, Anat Gesser-Edelsburg. *Factors associated with compliance to immunization against influenza among healthcare workers.* European Public Health Association. Brussels, Belgium. November, 2013.
4. Anat Gesser-Edelsburg, Manfred S. Green. Implementation of communication strategies during pandemics: The case of the 2009 H1N1 influenza. 141st APHA Annual Meeting. Boston, USA. November, 2013

5. Manfred S Green MD, Noemie Groag Pri-or, Emilio Mordini, Anat Geser-Edelsberg. Compliance with influenza vaccination among healthcare workers - tailoring risk communication according to the factors affecting compliance. 6th European Public Health Conference, Brussels, Belgium. November, 2013.
6. Mitali Wroczynski (BMJ) and Roberta Villa (Zadig) on behalf of the TELL ME Consortium. Risk Communication: The Power of Social Media. World Conference on Disaster Management. Toronto, Canada. June, 2014.
7. Barbara De Mei (ISS). La vaccinazione tra diritto e dovere (ITA). Meeting regionale sulle vaccinazioni. Pescara, Italy. October, 2014.
8. Anat Gesser-Edelsburg (School of Public Health, University of Haifa). Transforming the dynamics of Emerging Infectious Disease (EID) communication: an innovative integrative framework. International Meeting on Emerging Diseases and Surveillance (IMED). Vienna, Austria. Oct/Nov 2014
9. Mitali Wroczynski (BMJ). Risk Communication. The Power of Social Media. International Meeting on Emerging Diseases and Surveillance (IMED). Vienna, Austria. Oct/Nov 2014
10. Roberta Villa (ZADIG). E-Learning: how to tackle infectious disease outbreaks. International Meeting on Emerging Diseases and Surveillance (IMED). Vienna, Austria. Oct/Nov 2014
11. Jennifer Badham and Nigel Gilbert (University of Surrey). Modelling Individual Protective Decisions within an Influenza Epidemic. European Scientific Conference on Applied Infectious Disease Epidemiology (ESCAIDE). Stockholm, Sweden. November, 2014.
12. Riccardo Scalco and Sergio Cima. Discover Twitter influential user by means of Markov chains models, a computational approach. TELL ME Final Conference. Venice, Italy. December, 2014

List of oral presentations

1. Luca Carra. "Pandemia 2.0 L'uso dei social media nell'informazione scientifica" (ITA) at "Come raccontare l'epidemiologia in un mondo 2.0", Bologna, Italy. May, 2013.
2. Anat Gesser-Edelsburg and Manfred Green. Implementation of communication strategies during pandemics: the case of the 2009 H1N1 influenza. 141st American Public Health Association (APHA) Annual Meeting. Boston, USA. November, 2013.
3. Roberta Villa. TELL ME Possible cooperation with E-COM project. E-Com Meeting. London, UK. March, 2013.
4. Roberta Villa. Comunicare la pandemia (ITA). Convegno ISDE Comunicazione: salute e ambiente. Verona, Italy. March, 2014.
5. Roberta Villa. Vaccinazioni e social media at "Il rifiuto vaccinale: ragioniamo insieme?", Bologna, Italy. May, 2014.
6. Barbara De Mei. Come aumentare la consapevolezza dell'importanza della vaccinazione tra gli operatori sanitari (ITA) at "La promozione della vaccinazione negli operatori sanitari: National info day del progetto HProImmune". Roma, Italy. June, 2014.
7. Gesser-Edelsburg, A. Walter, N. Shir-Raz, Y., Mordini, E., Dimitriou, D. & Green, M.S. New framework model for outbreak communication. 12th International Conference on Communication, Medicine & Ethics (COMET). Lugano, Switzerland. June, 2014.

8. Manfred Green. TELL ME Project (Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence). HrpImmune EU Info Day, Athens, Greece (2014).
9. Riccardo Scalco. Evaluate data streams by means of Markov Chains models, a computational approach. 3rd International Conference on Digital Disease Detection, Florence, Italy May, 2015.

7.2.4 Final publishable summary report



Table of Contents

Executive Summary.....	62
1 TELL ME Project Context and Objectives.....	63
1.1 Participants	63
1.2 Objectives.....	63
1.3 Research Questions.....	64
1.4 Major Issues	65
1.5 Key Subjects Addressed	65
1.6 Outcomes.....	65
2 Key Scientific and Technical Findings of Deliverables.....	66
2.1 Work Package 1 – Population Behaviour During Epidemics Overview	66
2.1.1 Population Behaviour During Epidemics	66
2.1.2 Components of Outbreak Communication	67
2.1.3 Segmentation and Communication Needs of Target Groups	68
2.1.4 Vaccine Acceptance/Refusal to Vaccination	68
2.1.5 Reports on Narratives and Urban Myths.....	70
2.1.6 Human Rights, Stigmatisation and Risk of Discrimination	58
2.1.7 Conclusion.....	59
2.2 Work Package 2 – New Challenges and New Methods Overview.....	73
2.2.1 Stakeholder Directory and Map Description	73
2.2.2 Stakeholder Communication Requirements.....	74
2.2.3 Health Care Professional Communication	76
2.2.4 Technical, Legal and Scientific Feasibility of an Online Course for Primary Care Staff....	77
2.2.5 New Social Media	78
2.2.6 Digital Resources for Disease Detection.....	79
2.2.7 The New Global Health Security Regime	79
2.2.8 Conclusion.....	80
2.3 Work Package 3 – New Communication Strategies.....	81
2.4 Key Scientific and Technical Findings of Deliverables	81
2.4.1 New Framework Model for Outbreak Communication.....	81
2.4.2 A New Model for Risk Communication Health.....	69
2.4.3 Prototype Online Course For Primary Care Staff.....	83
2.4.4 Legal Ethical Political Implications.....	83
2.4.5 Guidance For Assessing WHO Threat Index.....	84
2.5 Work Package 4 – Agent Based Social Simulation.....	85

2.5.1	Architecture Technical Specifications and Validation Criteria.....	85
2.5.2	Software Design.....	86
2.5.3	Prototype Software.....	87
3	TELL ME Project Impact, Dissemination and Exploitation	88
3.1	Impact.....	88
3.2	TELL ME Website.....	89
3.3	Framework Model for Outbreak Communications.....	91
3.4	TELL ME Communication Practical Guide.....	91
3.5	The Online Course (e-learning).....	79
3.6	The Simulation Model	93
3.7	Guidance for using the WHO Threat Index.....	93
3.8	Dissemination.....	94
3.9	Exploitation.....	95
3.10	Exploitation of the Online Course	96
3.11	Developing the Online Course	96
3.12	Further exploitation of the Simulation Model	97
3.13	Connections with other projects	97
3.14	The TELL ME Network.....	98
3.15	List of foreground that might be exploited	98
3.16	The Book of TELL ME.....	99
3.17	Scientific Publications.....	99
4	TELL ME Website and Contact Details.....	100
4.1	TELL ME Website.....	100
4.2	TELL ME Consortium Contact Details	100
	References.....	101

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 Epidemics: **L**earning Lessons 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 exponential 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. Complementing 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 **Innovative 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
- ISTITUTO 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 behavioural responses** to infectious disease outbreaks, and ways in which different types of communication can affect human behaviour.
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 outbreak communication.
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 affects 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.

Factors That Increase Public Trust in Crisis Communications



Figure 2 – Factors that increase public trust

Factors That Decrease Public Trust in Crisis Communications



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)
- Ministries' 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

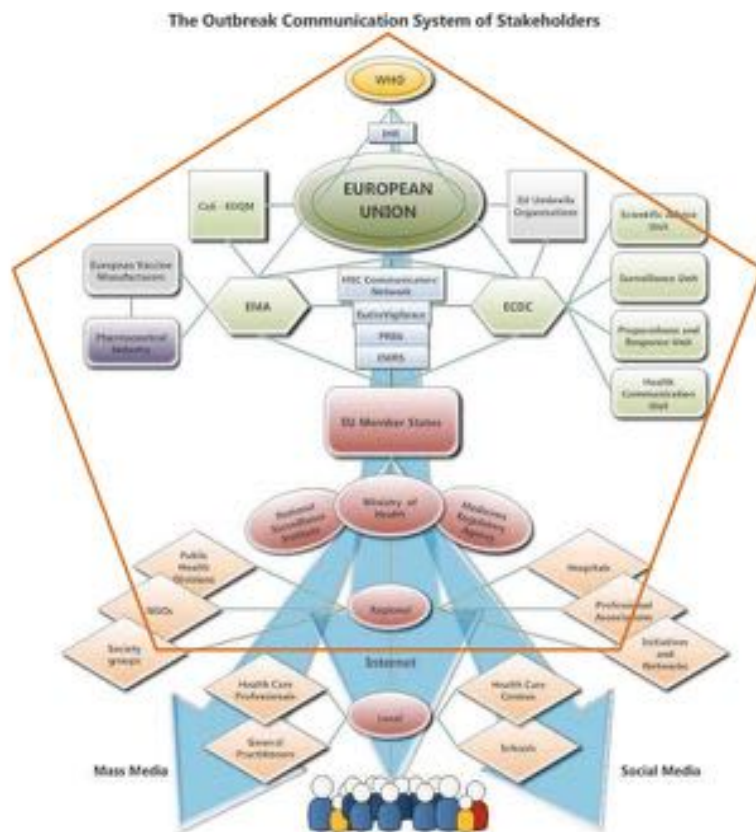
The stakeholder analysis in the frame of outbreak communication has not only been useful for understanding the dynamics and relationships between different stakeholders, but also important in order to understand the role and the potential each stakeholder has, for effectively becoming involved in the 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 driven 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 placed 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 of 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 an 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 5	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 3	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 **Framework 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

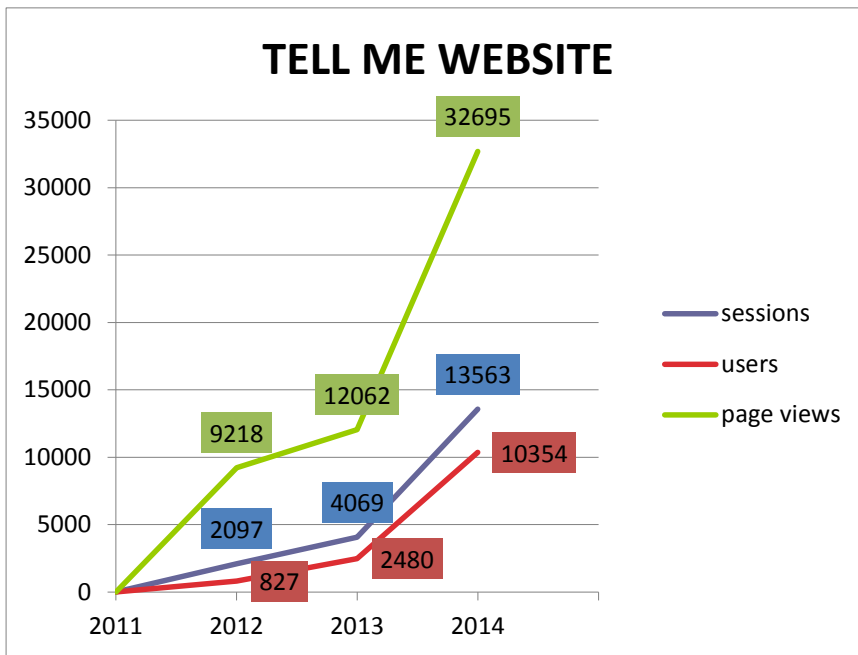
Relevant point of views about the news on flu, Ebola and about the interaction between the veterinary field and human health were also expressed in articles by experts including:

- **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
- **Iliaria 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 (NDSLFL).

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

Partner	Point of Contact	Email Address
ABSISKEY FRANCE (previously VITAMIB SAS (VITAMIB))	Youssefa Tahirou	y.tahirou@absiskey.com
BMJ PUBLISHING GROUP (BMJ) UNITED KINGDOM	Mitali Wroczynski Alexander Talbot	mwroczynski@bmj.com alexander.j.talbott@gmail.com
CEDARTHREE LIMITED (CEDAR3) UNITED KINGDOM	Simon Langdon	simon.langdon@cedarthree.co.uk
UNIVERSITY OF SURREY (SURREY) UNITED KINGDOM	Nigel Gilbert Jennifer Babham	N.Gilbert@surrey.ac.uk j.badham@surrey.ac.uk
ISTITUTO SUPERIORE DI SANITA (ISS) ITALY	Valentina Possenti Barbara De Mei	valentina.possenti@iss.it barbara.demei@iss.it
UNION EUROPEENNE DES MEDECINS OMNIPRATICIENS/MEDECINS DE FAMILLE AISBL (UEMO) BELGIUM	Ferenc Hajnal	hajnal.ferenc@med.u-szeged.hu
LATVIJAS CILVEKTIESIBU CENTRS BIEDRIBA (LCHR) LATVIA	Anhelita Kamenska	angel@humanrights.org.lv
VRIJE UNIVERSITEIT BRUSSEL (VUB) BELGIUM	Paul Quinn	paul.quinn@vub.ac.be
NATIONAL DISASTER LIFE SUPPORT FOUNDATION INC (NDLSF) UNITED STATES	James James	james.james@sdmph.org
UNIVERSITY OF HAIFA (HU) ISRAEL	Manfred Green	mgreen@univ.haifa.ac.il
ZADIG SRL (ZADIG) ITALY (NB. Took over from CENTRE FOR SCIENCE, SOCIETY AND CITIZENSHIP (CSSC) ITALY)	Dimitris Dimitriou Roberta Villa Roberto Satolli	dimitriou@zadig.it robi.vil@hotmail.it satolli@zadig.it

References

- Abraham T, (2009). Risk and outbreak communication: lessons from alternative paradigms. *Bulletin of the World Health Organisation*, 87, 604-607
- Duffy, M. E., & Thorson, E. (2009). Emerging trends in the new media landscape. In J. C.Parker & E. Thorson (Eds.), *Health communication in the new media landscape*. New York: Springer Publishing Company
- Ferrante G, Baldissera S, Moghadam PF, Carrozzi G, Trinito MO, Salmaso S. (2011). Surveillance of perceptions, knowledge, attitudes and behaviors of the Italian adult population (18-69 years) during the 2009-2010 A/H1N1 influenza pandemic. *European Journal of Epidemiology*, 26 (3), 211-219.
- Garrett, L. (2001). Understanding media's response to epidemics. *Public Health Reports*, 116 Suppl 2, 87-91.
- Gesser_Edelsburg, A. (Forthcoming). Strategies of persuasion for effectively communicating with the public using websites and social media during emergencies and disease outbreak. In M. Green & E. Mordini (Eds.), *Internet-Based Intelligence for Public Health Emergencies & Disease Outbreak: Technical, Medical & Regulatory Issues*. U.N.: Nato Science for Peace and Security Programme.
- Gidengil, C. A., Parker, A. M., & Zikmund-Fisher, B. J. (2012). Trends in risk perceptions and vaccination intentions: A longitudinal study of the first year of the H1N1 pandemic. *American Journal of Public Health*, 102, 672-678.
- Gilk, D. C. (2007). Risk communication for public health emergencies. *Annual review of public health*, 28, 33-54
- Hine, D., (2010). The 2009 Influenza Pandemic, An independent review of the UK response to the 2009 influenza pandemic. Retrieved from http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/416533/the_2009influenzapandemic-review.pdf
- Jehn M, Kim Y, Bradley B, Lant T. (2011). Community knowledge, risk perception, and preparedness for the 2009 influenza A/H1N1 pandemic. *Journal of Public Health Management and Practice*, 17 (5), 431-438.
- Krishna,S., Balas, E. A., Boren, S.A., & Maglaveras, N. (2002). Patient acceptance of educational voice messages: a review of controlled clinical studies. [Research Support, Non-U.S. Gov't
- Maurer J, Uscher-Pines L, Harris KM. (2010). Perceived seriousness of seasonal and A(H1N1) influenzas, attitudes toward vaccination, and vaccine uptake among U.S. adults: does the source of information matter?. *Preventive Medicine*, 51 (2), 185-187.
- Morse S. S. (2012). Public health surveillance and infectious disease detection. *Biosecurity and Bioterrorism: Biodefence. Strategy, Practice and Science*, 10(1)
- Ropero-Alvarez AM, Whittembury A, Kurtis HJD, dos ST, Danovaro-Holliday MC, Ruiz-Matus C. (2012). Pandemic influenza vaccination: lessons learned from Latin America and the Caribbean. *Vaccine*, 30(5), 916-921.
- Schwarzingler M, Flicoteaux R, Cortarenoda S, Obadia Y, Moatti JP. (2010). Low acceptability

- of A/H1N1 pandemic vaccination in French adult population: did public health policy fuel public dissonance? *PLoS One*, 5 (4), e10199.
- Seale H, Heywood AE, McLaws ML, Ward KF, Lowbridge CP, Van D et al. (2010). Why do I need it? I am not at risk! Public perceptions towards the pandemic (H1N1) 2009 vaccine. *BMC Infectious Diseases*, 10, 99.
 - Stockwell, M. S., Kharbanda, E. O., Martinez, R. A., Lara, M., Vawdrey, D., Natarajan, K., et al. (2012). Text4Health: impact of text message reminder-recalls for pediatric and adolescent immunizations. [Research Support, U.S. Gov't, P.H.S.]. *American journal of public health*, 102(2), e15-21.
 - Stockwell, M. S., Kharbanda, E. O., Martinez, R. A., Vargas, C. Y., Vawdrey, D. K., & Camargo, S. (2012). Effect of a text messaging intervention on influenza vaccination in an urban, low-income pediatric and adolescent population: a randomized controlled trial. [Multicenter Study Randomized Controlled Trial Research Support, U.S. Gov't, P.H.S.]. *JAMA : the journal of the American Medical Association*, 307(16), 1702-1708.
 - Vaughan, E., Tinker, T. (2009). Effective Health Risk Communication About Pandemic Influenza for Vulnerable Populations, *American Journal of Public Health*, 2 (99), 324-332.
 - Walter D, Bohmer M, Reiter S, Krause G, Wichmann O. (2012). Risk perception and information-seeking behaviour during the 2009/10 influenza A(H1N1)pdm09 pandemic in Germany. *Euro Surveillance*, 17(13), pii: 20131.
 - Wikipedia. (2012). Basic reproduction number. Retrieved from http://en.wikipedia.org/wiki/Basic_reproduction_number
 - Witte K, Allen M. (2000). A meta-analysis of fear appeals: implications for effective public health campaigns. *Health Education & Behavior*, 27, 591–615.
 - World Health Organisation (WHO), (2010). Recommendations for Good Practice in Pandemic Preparedness, Identified through evaluation of the response to pandemic (H1N1) 2009. Retrieved from http://www.euro.who.int/data/assets/pdf_file/0017/128060/e94534.pdf

Annex 1