D1.7

Population Behaviour in Epidemics Summary Report

1st Reporting period
WP1 Population Behaviour during epidemics

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TELL ME - Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence.Project co-funded by the European Commission within the 7th Framework Programme – HEALTH theme

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INTRODUCTION

The present Report summarizes the results of the TELL ME Project first Work Package "*Population Behaviour during epidemics*" which is aimed at collecting and assessing evidence about components and issues related to outbreak communication. Within this context, several aspects have been discussed in relation with behaviour adopted both by the general population and specific target groups during infectious diseases outbreaks. Furthermore, it has been studied how communication may affect human behaviour in that specific type of condition. This work is part of a more complex analysis towards a new communication strategy setting in order to improve the effectiveness of the preventive measures undertaken during epidemics. In particular, its main aim is the definition and design of a new framework model for outbreak communication.

Since this Summary Report is the final work (Deliverable due to the Task 1.7) within the Project TELL ME WP1 (POPULATION BEHAVIOUR DURING EPIDEMICS), it represents a comprehensive exercise containing the main findings and results of six Reports (Deliverables) which have been carried out by WP1 Partners, each of them having been assigned a single Task:

1. D1.1 ISTITUTO SUPERIORE DI SANITÀ- ISS (IT): a systematic review of studies addressing population behaviour during infectious outbreaks and review of outbreak communication in 2009 pandemic;
2. D1.2 CEDARTHREE LIMITED - CEDAR3 (U.K.): review of components and issues of outbreak communication;
3. D1.3 UNIVERSITY OF HAIFA- HU (ISRAEL): segmentation and specific communication needs of target groups;
4. D1.4 NATIONAL DISASTER LIFE SUPPORT FOUNDATION INC - NDLS (USA): vaccine acceptance/refusal and resistance to vaccination;
5. D1.5 CENTRE FOR SCIENCE, SOCIETY AND CITIZENSHIP - CSSC (IT): narratives and Urban Myths surrounding epidemics and vaccination;
6. D1.6 VRIJE UNIVERSITEIT BRUSSEL - VUB (BELGIUM): human rights, stigmatization and risk of discrimination against specific population segments and target groups.

Validation Process of the WP1 Summary Report

This Report has gone through an editing process, described as follows:

- received the finalized versions of six Reports by WP1 Task Leaders (Deliverables: D1.1, D1.2, D1.3, D1.4, D1.5, D1.6), it has been drafted reflecting their main findings, outcomes and recommendations (m9);
- then, it has been submitted to the Validation Workshop (m10);
- it has been finally revised, since the final version of the deliverable - including the partners' comments and the input from the whole Validation Process and the meeting - is due by December 31st 2012 (m11).

The meeting to validate WP1 Report represents the first milestone of the Project and has been convened by CSSC (m10). During the project's 2nd Board Meeting (that took place in Rome on November 9th), a second revised draft of the deliverable was distributed to WP1 Task Leaders for their comments; they suggestions on how WP1 tasks' outcomes had to be included in the Final WP1 Summary Report. Participants to the Rome meeting included: all TELL ME Project staff involved in the research, relevant EC services and agencies, target group representatives, critical reference group representatives.

In accordance with the DoW of TELL ME Project, participants received the WP1 Draft Summary Report in advance, and were asked to validate the report content on the basis of the objectives that had been already set out clearly from the beginning, i.e. the six objectives of WP1. In this context, through participants' responses effectiveness, conformity and alignment of the Summary Report have been measured as compared to the WP1 objectives it.

Making clear reference that a Validation Process was carried out for the WP1 Summary Report, this implied the collection of inputs and recommendations from external experts, as said before, previous the Rome WP1 Validation Meeting (i.e. the Validation Forms, the Validation Templates and Validation Points collected by participants) and in the context of that meeting (i.e. the Roundtables' List of Statements). The meeting participants/experts also provided their evaluations on specific areas of the Summary Report, from their own point of view and field of expertise. Those comments/feedback in the form of evaluations, views, perspectives came from different sources (e.g. statements, discussions, validation material), and they all have been taken into account in this final WP1 Summary Report. Then, it is important to note that this Summary Report has been validated across the four different criteria (they are formally explicated within Validation Templates: 1) comprehensiveness of the work, 2) scientific validity, 3) independence, 4) impact). The issues which have been more prevalent and crystallized better during discussions have been highlighted below.

Within the most updated and final draft of Report D1.7, integrated with the feedback received by partners and validation comments made by experts from the meeting, we aimed at searching for consensus whenever possible, so that the Report has been reorganized from the very beginning with regard both to its structure and contents in a more practical point of view. In fact now it includes two more factual chapters, since it has been judged to be too theoretical; Recommendations found in all Deliverables have been collected in the Annex. The chapter regarding communication has been enriched with several elements (a focus on social media and their potential has been made since they have been cited by all experts; the concept of trust has been strengthened). Aspects related to behavioural response have been added epidemiological information coming up from performed reviews. The consistency of Report has been upgraded: explanation of terms and methods which have been used has been made clearer and homogenous; the contrast between pro-vaccination and anti-vaccination has been graduated. In order to ensure a more effective reading, tables and figures have been added. On the other hand, it has not been possible to enter aspects related to travelling matter or specific quarantine actions, as school disclosure, because they have not been traced by the six Deliverables.

EXECUTIVE SUMMARY

The starting point of the Report is constituted by the description of outbreak communication components and issues with regard to Key concepts of crisis management and Components of Outbreak Communication (Sources, Media, Type, Timing, Trust building and Public Acceptance, Stakeholders, Coordination & Leadership). Dealing specifically with communication, the first chapter is divided in two parts, the second one takes into account several critical elements which might have negative effects on communication efficacy: human rights, stigmatization and the risk of discrimination; narratives and urban myths around epidemics, particularly related to the anti-vaccination movements and strategies fuelling the anti-vaccination discourse.

Then, the report goes on providing the epidemiological context for the behavioural response to infectious disease outbreaks among the general population and target groups. Vaccination (with trends in the United States and European Union) and Non-pharmacological interventions (NPIs) are the main objects of the second chapter. About vaccination, risk analysis stands before the study of compliance and factors affecting it among general population and particular target groups (healthcare workers - HCWs; elderly; chronically ill; pregnant women; paediatric population). Regarding NPIs, compliance and efficacy have been presented.

The third chapter is focused on those strategies and interventions needed to increase vaccination, in particular the effect that different types of outbreak communication (mass media, new media, personal) have on compliance with seasonal and pandemic vaccines.

In addition to this framework that has been built around the function of the population behaviour and communication during epidemics, some case studies are presented in chapter 4. They have been chosen taking into account aspects which are related both to behavioural elements and communication. Within cases of outbreak management, there are stories about BSE Crisis, H1N1, SARS. Being the most recent pandemic, the 2009 H1N1 is widely described with regard to communication topics: the use of new and social media, urban myths; beside case examples from the Anti-vaccination Campaign.

Finally, chapter 5 presents the lessons learnt together from exercises undertaken in various countries and by international organizations about the specific field of communication (internal; “with” the general public; to the media; on vaccination; elements to be effective; planning). In order to get a more practical and functional outline, “Areas for action” concludes the discussion, as well as recommendations are put in the Report according to the specific issue that is dealt with at that point.

1. COMPONENTS AND ISSUES OF OUTBREAK COMMUNICATION

Introduction

In the first part of this Summary Report, we identify the fundamental key components and issues needed to build an appropriate outbreak communication with regard to findings relating to outbreak communications issued in response to epidemics and pandemics that have affected Europe (Member States) in the last 10 years and in particular the 2009 flu pandemic[1].

This paper is intended to communicate the lessons learnt and the good practices identified and framed into a comprehensive 'tool set' to be used in future outbreak communication situations, and provide all necessary input for the design of the TELL ME Communication Kit and an Agent-Based Social Simulation. Several critical elements have also been considered due to their potential negative effects on communication efficacy: human rights, stigmatization and risk of discrimination and anti-vaccination movements, in the context of more general folk narratives and urban myths around epidemics. All these cultural aspects have been recognized and collected through appropriate reviews, with specific attention on the most recent infectious outbreaks.

PART I

1.1 Key concepts of crisis management

For the good understanding of what follows, it is necessary to provide some terminology and definitions and their meaning in this context:

- crisis management is the process implemented by local, national or international authorities to cope with all the aspects of a crisis, such as the safety of people, undertakings and infrastructure as well as media coverage;
- crisis communication is at the very heart of this process, being the bedrock on which crisis management is built (BSi, 2011);
- "risk communication is an interactive process of exchange of information and opinion on risk among risk assessors, risk managers, and other interested parties" (WHO, 2012), its aim is to help people at all levels of society make more informed decisions about the threats to health and safety (Vaughan and Tinker, 2009).

Risk communication differs from Crisis Communications in that it focuses on what might happen as opposed to what has or is happening. Risk and Crisis Communication also differ with regard to when the communication occurs. Whilst Risk Communication is an on-going process that takes place before an emergency occurs, Crisis Communication describes the messages that are delivered during an emergency event.

[1] In 2009, the H1N1 influenza appeared initially in Veracruz, Mexico, with the World Health Organisation declaring it a pandemic in June 2009. The H1N1 influenza is a respiratory illness that produces human-like flu symptoms in pigs and has, at times, sparked major health concerns when transmitted to humans. The strain H1N1 was implicated in the 1918 pandemic that was responsible for the deaths of millions around the world and a feared outbreak in 1976 resulted in a mass vaccination programme in the US, which was later discontinued due to safety concerns about the vaccine.

In the context of an outbreak situation, both risk and crisis communication play a key role in the success of Crisis Communications, which in turn are to some extent determined by the success of prior Risk Communication. The issues facing Health Risk Communicators are complex and do not only include medicine and epidemiology, but also ethics, politics, perception, psychology and culture, all of which influence the interpretation and impact of messages and the willingness of individuals to act as instructed (Menon, 2008). The development and implementation of effective health risk communication strategies before a crisis occurs are therefore vital for protecting public health when a crisis happens.

Since a pandemic is an epidemic occurring worldwide or over a very wide area, crossing boundaries of several countries, usually affecting a large number of people (WHO, 2007), it is certainly a crisis, which itself may be defined as 'an inherently, unstable and complex situation that represents a threat to the strategic objectives, reputation or existence of an organization' (BSi, 2011).

To consider the issues of crisis communications at the outbreak of a pandemic, it is useful to analyse the characteristics of a crisis or disaster: those caused by natural or man-made events are often unexpected and sudden. However, some crises develop over time, and a pandemic, which although initially is not so dramatic as a sudden crisis, can evolve remarkably quickly. Modern travel patterns may significantly reduce the time needed for pandemic influenza viruses to spread globally to a few months or even weeks (GlobalSecurity.org, 2012). Furthermore, the timing and location of a crisis may be unpredictable and its impact cannot normally be contained within boundaries.

Crisis management must therefore be aimed at making order out of chaos, providing a timely and effective response to ensure the safety of people, and returning the organisation to normality as quickly as possible. Organisations must be well prepared before the crisis – that is, now – and therefore the requirement is to have a strong-rehearsed plan based on effective communications.

While there is undoubtedly a risk of crises occurring, it is difficult to predict exactly what might happen, when or where. It therefore makes good sense to develop a generic crisis management plan to ensure that there can be a focused response to any type of crisis (which would include a pandemic) of whatever magnitude, whenever and wherever it might occur (UK Cabinet Office, 2011). This could be achieved by identification of similarities and emerging patterns between different types of crises, especially with regard to population behaviour, which could be used as cornerstone for constructing such management plan.

The two phases of crisis management

There are two clearly defined phases in crisis management – the immediate response and the recovery (BSi, 2011). A part of the first phase, the immediate response, is the identification and confirmation that a crisis is in fact occurring. This is not always as easy as it seems, as some crises appear to creep up almost unnoticed and are sometimes known as 'rising tide crises'. To counter this, it is good practice to use a Crisis Impact Table that quantifies the impact of an incident against pre-determined criteria under different headings such as Operations, People, Reputation, Legal and Finance. The table acts simply as a tool to inform the decision on when to invoke the crisis management plan. A common adage is 'If in doubt call it out!' that is, if undecided, invoke the plan

and call out the crisis management team, adopting a clear choice to take control in a timely way with positive, proactive action rather than trying to catch up after the crisis has fully developed.

The recovery, or second phase of the response, should start almost at the same time as the immediate response and runs parallel with it. Recovery is a project in its own right that requires planning and coordination. An early start will speed the return to 'business as usual'. As the immediate response tails off, the recovery will become the priority.

The key concepts of crisis management, which are based on the characteristics of crises or disaster, have relevance and a resonance to the issues concerned with outbreak communications and the preparation of crisis communication plans.

Model of crisis communication

Crisis and risk communication need to consider many different technical, psychological, sociological and cultural perspectives in order to understand, anticipate and respond to the needs of the public in relation to various risks. There are numerous complex and sometimes conflicting issues – interrelated or unrelated –that need to be considered by public health communicators. As expected, the development of conceptual frameworks and tools to assist with this process continues to be considered important.

The Centers for Disease Control and Prevention (CDC) have developed an integrated model, to provide health professionals with a framework for emergency communications. The tool is referred to as Crisis and Emergency Risk Communication (CERC) and was developed in response to the ever-increasing expectations and challenges that fall upon public health professionals for communications in a crisis situation (Veil et al, 2008). Whilst it is recognized by CDC that more work is needed to develop CERC, the model provides a systematic and structured approach to crisis and risk communication reflecting the closely interrelated nature of these two disciplines, and thousands of individuals have already been trained in CERC via a variety of methods. Not only does the model bring together a wide range of methodologies and approaches, it also recognizes the participatory nature of a crisis and the importance of giving people something to do in order to encourage self-efficacy and reduce feelings of anxiety and powerlessness. Importantly, it also sets out communication activities, strategies and outcomes that can be applied at a practical level by the health professional dealing with crisis communications. Another example of a model or models that strive to link both the technical assessment of risk with wider psychological, sociological and cultural perspectives of risk and risk perception in order to gain a better understanding of public response to risk is presented by Kasperson, et al (1988) who aim at providing a structural description of the 'The social amplification of risk'.

However helpful these or other similar models may be, it is nonetheless argued (Backer et al, 1992) that no one model will totally fulfil the needs of all public communication campaigns and can only be used as a guiding tool combined with, and validated by, practical experience.

Current pandemic plans

Crisis communication plans should be prepared as early as possible and staff trained and exercised in their use. However, in the event of a future pandemic, only few organisations, like CDC or NIH, have detailed crisis and risk communication plans in place. The crisis communication plan should be

developed as a separate task, but absolutely supportive of the actual crisis management plan. Within the plans, health authorities need to embrace new information and communication technologies, in particular social media, to allow and facilitate a two-way flow of information between officials and the public. This means authorities should not only look to use social media channels to broadcast their message but to use it as a valuable tool to understand sentiment and respond to concerns voiced on these platforms.

Understanding and addressing the needs of the stakeholders is vital for effective communication. It is also fundamental to have a strategic and planned approach for working with the media. In fact, plans need to be flexible to adapt to the sometime unpredictable and changing nature of an outbreak situation and they need to embrace the whole spectrum of communication channels and media available in order to reach the varying needs of the multi-cultural public audience. To do this effectively, greater coordination is required among the stakeholders to ensure the messages promulgated are not only based on the best available advice but are also consistent. Crisis communication plans should be developed as early as possible in preparation for a possible pandemic. The plans should therefore be based on the same principles of those developed for any crisis or disaster but should additionally include tasks based on the lessons learned and good practices identified from previous pandemics.

In addition, during a pandemic, the health authorities must take into account several critical elements which might have negative effects on communication efficacy, impairing the population compliance with both protective behaviours and vaccination. Some issues are of concern in this regard: human rights, stigmatization and the risk of discrimination [see sub-section 1.3]; narratives and urban myths closely related to the anti-vaccination movements [see sub-section 1.4].

Preparedness and flexibility

Based on the lessons of the H1N1 pandemic, when there was considerable uncertainty over the impact of the disease and the nature of the outbreak, Hine (2010) emphasises the importance of building greater flexibility into planning arrangements. Hine acknowledges that even with improvements in evidence gathering and scientific advice, as in many crisis situations: decisions will still have to be made without knowing the full facts of the situation, a key feature of crisis management. Moreover, in the UK, the H1N1 pandemic response was found to have been insufficiently flexible with arrangements very much focused on a worst-case scenario, which were difficult to scale back and adapt to the less severe situation that was unfolding.

Hine also suggests that there are two options available when responding to future pandemics: 1) responding based on the high end of the planning assumptions set out in the National Framework and then scaling back as more information is established or; 2) making calculated judgements based on the information and evidence available and resource the response accordingly. Whilst this would help to ensure a more proportionate response, underestimating the severity of the situation could leave the Health Service unable to cope.

The WHO (2010) also recommends that a generic plan framework, containing checklists appropriate not only for a worst-case scenario, is developed that can be applied flexibly to the situation as required, rather than developing extensively detailed documentation. It is suggested that this will

help responders to adapt to a changing situation as required. The principle of developing a generic plan that can be applied flexibly has long been recognised as a key tenet of good crisis management. Exercise simulations to achieve familiarity and facilitate plan development also need to be incorporate in planning activities (WHO, 2010).

There is a wide range of factors that could lead to decreasing levels of public trust in officials during an outbreak situation. Not least the uncertain and changing nature of the situation that may portray those in charge as incompetent. Preparedness plans should therefore also anticipate and prepare for the need to rebuild public trust, particularly with vulnerable populations (Vaughan and Tinker, 2008).

Another aspect to consider is highlighted in Dame Diedre Hine's (Hine, 2010) review of the UK response to the 2009 influenza pandemic, where it is reported that planning assumptions and worst-case scenario figures, which were publicly released to facilitate emergency planning activities, were wrongly assumed to be predictions rather than planning figures. Hine recommends that work should be carried out to review how planning scenarios are released and how they might be interpreted by public in the future to help ensure that balanced and realistic 'reasonable worst-case' scenarios can be developed. This may help to avoid any future perceptions of over-reaction or 'hyping-up' of the situation. Pandemic preparedness needs of course to be supported by appropriate funding to ensure that activities can be sustained (WHO, 2010).

1.2 Components of outbreak communication

One of the major challenges during infectious outbreaks has always been communicating with the population to influence behaviours, reduce the spread of disease and even avoid panic. It is vital to understand and improve the communication with the public, given that human behaviour significantly impacts disease transmission. Thus, the World Health Organization (WHO) believes it is now time to acknowledge that communication expertise has become as essential to outbreak control as epidemiological training and laboratory analysis (Lee, 2004; WHO, 2005).

According to WHO (2010), risk communication aims at promoting a positive social response to pandemic interventions and also at inducing preventive action and appropriate behaviour changes among populations. The aim of a good outbreak or crisis communications must be to successfully instruct, inform and motivate the public to adopt appropriate self-protective behaviours whilst also building trust and confidence in officials, dispelling myths and rumours and ultimately acting in partnership with the authorities' overall strategy. Outbreak communications in the event of a pandemic involve three distinct areas: a) the source i.e. those who develop messages, b) the media who channel those messages through, and c) the means by which the messages are communicated and the audience or public who receives them. Many issues or factors impact all three areas including some which may appear intangible at first but which are nevertheless of crucial importance, such as trust which is built on honesty, clarity, consistency and transparency and which meets the needs of the public. The type, tone and terminology used for the messages and the timing and means by which they are communicated also play their part as do new technologies such as social media.

Sources

The source of information in a crisis can impact the way in which communications are interpreted, perceived and accepted. Who communicates and the means used to provide the message have varying impacts. Furthermore, different individuals and groups will respond differently to various media. Health care providers, particularly local and regional physicians, remain a trusted source of information and NGOs are often considered more trustworthy than government officials. Messages delivered by television and radio are generally better regarded by members of the public than other sources of information. New technologies however, including social media and websites, are also being widely used by the public to gather health information and need to be integrated into the overall communication strateguies. The health communicators' strategies will benefit from using all the communication channels and media available in order to meet the varying needs of the public.

Media

When a major incident happens there are two 'versions' of it – one is how the organisation responds and the other is how the media reports how the organisation responds. The public is influenced by what is published and broadcasted by the media, with information not always pointing to the same direction. In some cases, the media's perception of what has happened leads to a one-sided interpretation of the reality that could become a kind of 'media driven event'. This is one of the areas where the lack of coherent information allow for misinterpretation of the facts and where transparency might be ensured.

There is a wide variety of different media available for communicating with the public: the health authority's selected strategy needs to be appropriate for and reflective of the diverse audiences for which it is intended. Whilst the mass media have an enormous impact on the public understanding and perception of a crisis choosing the right blend of media to ensure that messages reach those they are intended. Social media are becoming increasingly prominent and are a powerful means of leveraging large sections of the public. When used effectively, they will assist health authorities to fine tune with the actual information needs and requirements of their audiences.

Social media (social networks, blogosphere, wikis, video sharing applications)

In contrast to traditional Web sites, which only allow communication of information to the public, social media allow not only the ability to provide information to the public, but also for the public to share information with the source. Users can create and disseminate information themselves, thus becoming more involved. As defined by Betsch, et al., (2010), Web 2.0 or social media are "Internet applications that enable users to create and upload new content, comment on existing content and share content with other users, e.g. discussion boards, web blogs and social media websites such as Facebook, Twitter, Wikipedia, LinkedIn and YouTube. That is, while 'Web 1.0' Internet websites typically allowed for one-way communication from the creator of the site to the user (e.g. static health portals), Web 2.0 enables a two-way and multi-way communication." An example of this interaction is demonstrated by a statement shared by the Centers for Disease Control and Prevention (CDC) on their Facebook page regarding vaccination on July 5, 2012: "When was your last tetanus shot? Tetanus vaccines can prevent this disease in children, teens and adults. Without the vaccine, you can get tetanus ("lockjaw") just by getting cuts, especially puncture wounds which become

infected with the bacteria." This statement received 100 "likes" and elicited both supportive statements such as "Mine was only a couple years ago, but it's good to know what it helps prevent. I've had this done twice already" as well as dissenting statements with links to other information.

Facebook is used "to stay connected with friends and family, to discover what's going on in the world, and to share and express what matters to them."[2] Users can "friend" other users, or "like" public figures and organizations which then allows them to follow their up-to-date information. According to its Web site, Twitter is a "real-time information network that connects you to the latest stories, ideas, opinions, and news about what you find interesting."[3] Users can follow a variety of organizations, public figures, and friends to stay up-to-date on news via "Tweets." YouTube "provides a forum for people to connect, inform, and inspire others across the globe and acts as a distribution platform for original content creators and advertisers large and small."[4] Users are able to upload videos for public viewing on this social media platform.

Social media also allow individuals to provide public support for organizations, individuals, and causes by "liking" on Facebook or "following" on Twitter. For example, the CDC has over 200,000 "likes" as compared to NVIC with 35,000. This is a simple way for an organization to draw attention to itself or to a cause. It also enables the sharing of information with a large audience. A link shared by an organization, individual, or cause, can be "shared" or "re-tweeted" to an individual's friends or followers, which can, in turn, lead to even greater shares or re-tweets. In this day and age, "going viral" is one of the fastest ways to facilitate the spread of information. One major advantage of social media is that they can share "real-time" information regarding a public health crisis or other emergency scenarios. For example, not only could a user receive information from an organization (e.g., CDC), a public figure, but also from their friends and associates.

CDC (2012) quote the Pew Internet & American Life Project report (2011) "Social Networking Sites and Our Lives", stating that nearly half of adults (47%) used at least one social networking site in 2010. It is thought that this proportion is continuing to grow rapidly. Whilst CDC has been praised for its use of various social media platforms others have been criticized for failing to follow this lead (European Commission DG SANCO, 2011). However, the European Commission's report on the Importance of Social Media during a Crisis (EC, 2011) emphatically outlines the many potential benefits of their use during a Crisis. In addition to providing the communicators with information that will help shape their messaging, Social Media also enable decision makers and communicators to identify trends, spot early-warnings and communicate with far reaching audiences in addition to target groups. In their report, the EC clearly set out the need for Member States to embrace Social Media as part of their crisis response stating that "It is no longer possible to simply communicate offline via information sheets, press conferences and press releases". (EC, 2011, p.9).

As said before, unlike many other forms of mass communication, Social Media allow for a two-way conversation in which the audience can react and ask questions, in effect giving the public a voice. This provides communicators with greater insight and understanding of the audiences they are targeting (WHO, 2005a). Because the individuals self-selects the source of their own information,

[2] Facebook – Key Facts. http://newsroom.fb.com/content/default.aspx?NewsAreaId=22. Accessed July 27, 2012.
[3] Twitter – About. http://twitter.com/about. Accessed July 27, 2012.
[4] YouTube – http://youtube.com. Accessed July 27, 2012.

they are able to determine the sources that they most trust, or alternatively like or know (e.g., friend or celebrity). Such sources are likely to shape beliefs, attitudes, and behaviours. While this is great for sharing information, it can also be challenging, since people will be getting their information from the same types of places, which may not be reputable. They may also receive conflicting information, which can lead to mistrust and confusion. Furthermore, individuals can easily receive information from "friends" or "followers." Simply sharing or tweeting "Should I vaccinate my child?" could provide an array of responses – both positive and negative – which could potentially influence an individual's decision making process.

On the other hand, it is relatively easy for messages to get distorted or used out of context. For example, for each "retweet" or "share," the original message can potentially be modified or added to by the user. While the initial source of information (e.g., Web site) will remain the same, the commentary/interpretation on such initial source of information can be altered drastically. Because of this, misinformation can rapidly spread amongst social media sources, leading to such sources as Snopes (www.snopes.com), a well-known resource for validating and debunking "social media legends." Frighteningly, social media users can "share" or "re-tweet" misinformation just as quickly and easily as accurate information. For example, an image shared on the NVIC page on July 1, 2012 stating "If you caused a 6,000% increase in autism wouldn't you try to cover it up, too?" which was shared 94 times by followers. Two-way communication, while listed as strength of social media, can also be used negatively to further perpetuate misinformation. For example, the National Vaccine Information Center recently shared the article Another Fabricated Pandemic like the Swine Flu?(http://articles.mercola.com/sites/articles/archive/2012/07/07/pandemic-swine-flu-vaccines.aspx) on July 8, 2012. Fifty one people "liked" this article, with the following selected comment: "Of course but they will wait a couple of years before the next one so that maybe we will forget how H1N1 was not the threat they said it was [...] except from the vaccine itself." While social media avenues are great for getting information out quickly, they are not always well-suited to sharing complex or substantial amounts of information. Most social media outlets only allow limited lengths of communication. For example, "tweets" are limited to less than 140 characters, which often precludes sufficient evidence or explanation being provided. Therefore, the use of social media should be included in a wider communications strategy.

Type

The type, tone and terminology used for communications in a crisis should be appropriate to the understanding and knowledge of their intended audience. Health authorities must communicate with empathy and understanding. It is vital that they are open and address the needs and concerns of the public. Speculative and inaccurate reporting will only increase public fear and scepticism. Trust and credibility need to be nurtured and can be eroded through inappropriate communications. In particular, it is crucial that messages, preferably from a variety of sources, do not conflict and be consistent with one another. Symbolism, as an aid to communication, can be used in a positive way to enhance messages. However care must be taken to avoid the use of inappropriate symbols creating a negative effect. In addition, official announcements need to be enforced by on-going public awareness campaigns and core messages need to be repeated often if they are to be widely accepted.

Timing

Early detection and decision-making are crucial in managing an outbreak situation. Similarly, any announcements from the health authorities need to be made as early as possible. Informed and accurate communication should also continue throughout all phases of a pandemic and on a frequent basis in order to avoid speculation and false reporting. However, authorities need to be mindful of information fatigue generated by repeated and unfulfilled scares.

Trust building and public acceptance

Public acceptance and behavioural response will differ depending on the audience, their culture, faith, their trust in the authors of advice, their knowledge and understanding of a pandemic and its real or perceived risks. The influencing factors are many and at times counterbalancing, so that the Health Communicator's strategy will benefit from not only taking into account these several and varied influencing factors, but also by using all the communication channels and media available in order to meet the varying needs and interests of the public, which have to be readily identified and understood.

Trust is one of the most significant factors related to successful crisis communications and will affect people's judgements and subsequent acceptance of recommended measures. Trust needs to be built up over time and can be eroded by ineffective communications. In this regard, it is important for health authorities to be open and honest and to acknowledge uncertainty. It is also vital for health authorities to understand the needs and interests of the public. Fears and concerns need to be acknowledged however mistaken they might be. Health communicators must understand and meet the needs and challenges of specific groups, too. It is clear that media reporting can significantly influence public perception and therefore working closely with the media can help the health authorities to improve message accuracy and public understanding. Factors increasing/decreasing Public Trust in Crisis Communication are shown, respectively, in the following figures (Fig. 1,2).

Figure 1. Factors that increase public trust in crisis communication

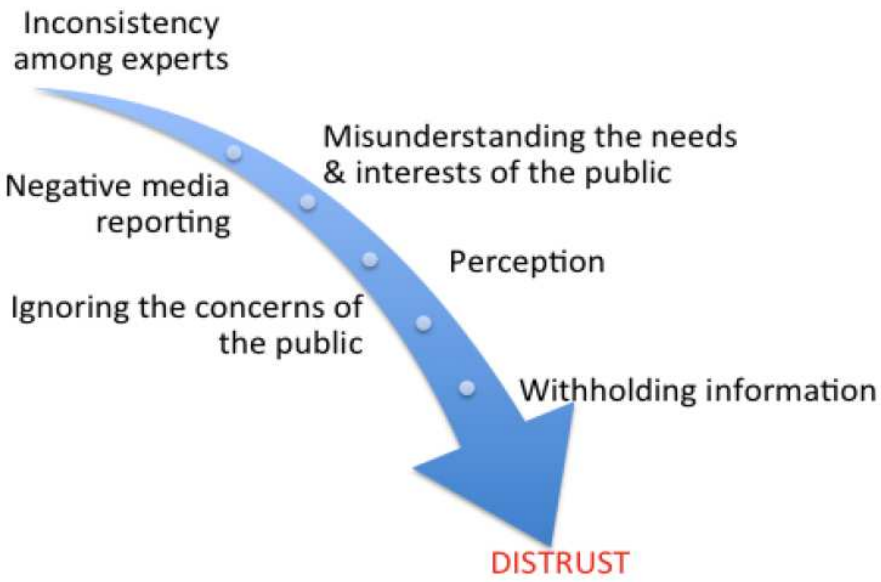


Figure 2. Factors that decrease public trust in crisis communication

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 no matter how good they are need also to consider the life circumstances and communication needs that influence decision making and behaviour (Vaughan and Tinker, 2008). In order to achieve this, stakeholders need also to be represented during the planning process (WHO, 2010).

For instance, it is argued that during the BSE crisis, the government did not understand the different stakeholders that needed to be involved in the communication strategies. To address this, Harris and O'Shaughnessy (1997) emphasise the need to build on the principles defined by Grunig and Repper (1992):

- Identifying, analysing and mapping strategically important stakeholder relationships.
- Identifying those stakeholder groups who are affected by, or whose actions may affect, the organization, and who are affected by the issue.
- Anticipating the likely emergence of issues that may arise out of the organization's relationship with its various stakeholders."

Coordination and Leadership

A major outbreak situation, such as an influenza pandemic, requires significant and prolonged central government coordination. Beyond this, it also requires multisectoral and international coordination (Hine, 2010). Strong leadership is required not only during a pandemic response, but also during the pandemic planning stage. Multisectoral engagement and co-ordination are also required (WHO, 2010) with international planning and interoperability between countries and regions to achieve consistency and coordination. EMA has also identified that communication activities need to be

better coordinated among the main EU stakeholders" (EMA, 2011). This coordination should include the development of key messages to help achieve consistency of messages (WHO, 2010).

PART II

1.3 Stigmatization and human rights principles during infectious diseases outbreaks

1.3.1 The risk of stigmatisation

Although stigmatisation is an ancient concept, a modern academic study of the concept began in the second half of the twentieth century with the seminal work of Goffman and within the decades the conceptual has been refined taking into account several phenomena.

Stigmatisation is an important socio-cultural issue especially during and after an epidemic pbecause of its propensity to bring about a range of negative effects, which can include:

- Health care avoidance;
- Cardiovascular health problems as a response of long term stress;
- A lack of motivation to seek the necessary goods in life;
- Physician Bias.

With particular regard to epidemics, some groups of people are more prone to suffer stigmatisation than others, such individuals are those:

- with readily identifiable traits which can be linked to characteristics that are given negative moral connotations;
- occupying inferior positions in relationships of power;
- belonging to ethnic minorities;
- having a perceived connection with the geographic / animal origin of the outbreak;
- members of the medical profession;
- who are part of pre-stigmatised groups e.g. the poor, homeless, immigrants, the elderly, individuals with conditions that result in a reduced immunity;
- who actually become infected themselves;
- to be vaccinated.

The problem of stigmatisation can be reduced by ensuring that discriminatory practices are not permitted and by fostering communication and improving the positive collaboration with associations or representatives of groups that have the potential to be stigmatised. Communication between public health response planners and the representatives of such groups should be facilitated in advance of an epidemic.

This issue is not only of moral or ethical concern. In the context of an epidemic, in fact, stigmatisation can impact not only in the area of healthcare, but also in other areas such as education and employment. This is the main reason why the planners of public health responses to

epidemics should seek to avoid, where possible, or at least minimise the creation of new problems or the intensification of pre-existing ones. Those who plan public health responses should implement two principal strategies to avoid unnecessary stigmatisation: ensuring that the provision of healthcare services is made on an equal basis to all, and reinforcing the stigmatised groups own sense of self-worth, allowing them to resist the stigmatising pressures from other members of society. Moreover, in the planning of a response to a potential epidemic, a constructive dialogue has to be built up with these indicated subjects.

The respect of human rights principles

In the regulation of responses to epidemic situations, a valuable role is played by human rights, whose systems have begun to challenge the traditional role of medical ethics as the dominant system for deciding upon the provision of care in many settings. Many countries are bound however – both by international and national laws, regulations and codes – to respect an arrayof human rights principles which vary from very precise duties upon states to act to prevent and deal with epidemics to other more general principles that will inevitably apply in such contexts, associated with several types of rights (civil and political, social and economic), such as:

- the right to life;
- the right to health (often conceived of as a right to access healthcare);
- the freedom from inhuman and degrading treatment (important in the context of compulsory treatments);
- the right of liberty and security of person (important in the context of the potential use of quarantine);
- the right to a family and private life (important requirements concerning patient data);
- prohibitions on discrimination.

It is important to remark that during an epidemic human rights principals are useful in protecting the fundamental rights of individuals but cannot be used to completely prevent stigmatization. This is because there is doubt over whether the mere release of health advice is capable of engaging human rights and even if it was any consequent stigmatisation would likely be seen as a proportional effect in the context of an epidemic.

The right to life

The right to life concerns primarily negative duties upon states not to take the lives of individuals (except in exceptional circumstances like war), whilst case law in some countries (usually developing) interprets the right to life as providing a positive duty upon states to provide healthcare.

The right to health

A positive duty to provide healthcare finds for itself a more natural home within ‘the right to health’. This social and economic right foresees a duty upon states to provide healthcare for individuals in need of such services. However, the use of such a right, however, comes with several caveats. A most notable caveat is the relative nature of such a right – it provides not for the absolute duty to

deliver a certain level of healthcare but a duty to move as far as possible in that direction as much as available resources permit. It is therefore not likely that individuals will be able to make use of the right to health to compel states to make vaccinations, testing and treatments available where the priority in their preparedness plans for a serious epidemic would envisage targeting certain valuable or vulnerable groups for vaccination. Indeed it may even be impossible for public health authorities to provide treatment, such as vaccinations, to anyone who might want such an intervention as the availability of such treatments may be limited (or not even exist) at the time an epidemic strikes.

The right to freedom from inhuman and degrading treatment

The right to freedom from inhuman and degrading treatment provides important guarantees to individuals regarding their bodily integrity. In the area of medical practice, this right has been closely linked to the concept of informed consent that has to be present before treatment. However it does not sit easily with the potential use of several procedures in the context of a pandemic: quarantine, compulsory testing, treatment and vaccination. Such powers are recognised at national level by many states in their national law and also at international level in inter alia the International Health Regulations (IHR, 2005). In addition, states may carry out treatments on individuals without their consent if such individuals do not have the capacity to consent and the treatment in question is indeed a medical necessity. However public health authorities should be cautious in relying upon the use of compulsory treatment measures, being able, where they do, to clearly demonstrate that other, less severe, courses of action were not available.

The right of liberty and security of person

Engagement with the right of liberty and security of person is also a significant possibility during a serious epidemic. The right envisages freedom for individuals from arbitrary detention. There is an obvious scope for conflict of such a right with techniques such as quarantine which have been employed for many years during serious epidemics. However the detention of individuals under public health powers may be permissible, but only if certain strict conditions are met. Firstly, such detention must be necessary and proportional, meaning that the detention or quarantine must actually serve a purpose and secondly it must be the least severe method available to achieve that purpose.

The right to a family and private life

The right to a private and family life will also represent an important concept for those tasked with planning public health responses to epidemics. In the context of healthcare it has been linked to both positive and negative obligations. In terms of positive obligations, a state can be required to act where such action is likely to protect an individual's private or family life. Negative duties envisage however an obligation upon states to desist from acts that may prevent individuals from realising this aim. Like the right to liberty and security of person, this one is usually not perceived of as an absolute right. It can be engaged by states in order to secure the protection of public health, but only where once again the methods in question meet the concepts of necessity and proportionality.

The data protection regime provides important requirements which public health planners should comply with in several ways, but mainly through the use of anonymised data or relying upon the data subject to give their express consent for the use of non anonymised data. This last requirement may

be present in the context of an epidemic, especially in the initial stages, when processing data without individual consent would be done under the public interest exception. Such processing must be clearly described by law. It is therefore necessary for states to have the necessary legislation in place allowing such processing before an epidemic takes place.

Prohibitions on discrimination

If such a situation shows up, individuals cannot be denied their rights under the European Convention of Human Rights because they belong to one of the groups in question. Health status has been taken to fall with the miscellaneous category of 'other group'. This right of non-discrimination applied to a range of groups such as race, ethnicity and religion, has been more recently accepted by those who have a different health status (e.g. those who are HIV positive). Discrimination occurs where members of one of these groups are treated differently from other persons in an analogous situation without an objective and reasonable justification. This right could also be used by individuals who are denied access to other (non healthcare related) public services because of their health status. This could conceivably occur where individuals have become (or have been) infected during a pandemic. Human Rights Instruments provide important protection against discrimination for vulnerable and stigmatised groups. States that whish to treat such vulnerable groups differently must show compelling reasons for needing to do so.

1.3.2 Stigmatisation and discrimination

Stigmatisation can result in various negative effects, even where stigmatised individuals are not the result of direct discrimination. This can be through indirect structural discrimination for example that is often difficult to prevent, through health care avoidance by those that are stigmatised, through the negative health effects of long term stress, through perceived physician bias and even through a reduced motivation to strive for the necessary benefits of a successful life. Whilst human rights tools can not eradicate stigmatisation, ensuring respect for human rights principles would reduce stigma, allowing benefits in terms of prevention and treatment. Whereas, as is often the case in public health campaigns, the prevention of mortality or serious morbidity, it is likely that in most cases where stigmatisation occurs, that this would not be deemed sufficient to render the measures taken as disproportionate.

1.4 Narratives and urban myths around epidemics

At this point it is essential to describe urban myths and narratives surrounding epidemics and vaccination with regard to the role of the folk narratives and rhetorical devices used in communications with the general public, and the level of impact these have in shaping attitudes and behavioural responses. While all different cultures in the world have had past experiences of infectious disease outbreaks, epidemics or pandemics, there are certain qualitative elements for each culture that produced various responses towards the disease, and such events were 'embodied' differently in the traditions of each culture. Globalisation, as experienced in our days, also produces, among other things, – via developments in the field of Information and Communication Technologies (ICT) – hybrids of cultures that exceed geographical boundaries through synchronisation of individuals' behaviours, emotions, attitudes or even concerns that are shared in the global communities. However, this might lead to detachment from local traditions and collective

experiences of the past, creating gaps that can allow for 'imported' urban myths and legends to grow, and for conspiracies to take a more global dimension.

The urban myths, and generally folk narratives, influence primarily the perceptions of risk and behavioural responses of the public towards an infectious disease outbreak, and, as an extension, the attitudes towards vaccination and other preventive measures put forward by national public health authorities.

The role of myths in older, as well as modern, societies is an element that could explain in part the population behaviour during epidemics, since 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. 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 a 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 globalisation era, which is mostly characterised by the revolution in the field of 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.

A wide array of narrative motifs and urban myths exist, having a direct impact on public perceptions and attitudes in response to an infectious disease outbreak. Perhaps the most complex problem is the fact that during an infectious disease outbreak, people are confronted with an immense amount of information, which is very often controversial or contradictory. This creates confusion and uncertainty as to which would be the best way to act, and this would be a case where people find retreat in the familiarity and comfort of urban myths.

Thus, a number of recommendations for effective communication of information to the public can be provided, by taking under consideration qualitative aspects of urban myths and narratives in the event of infectious disease outbreaks. Urban myths could be in fact used as indicators to evaluate or predict the behavioural responses of the public in the implementation of a vaccination programme.

1.4.1 The anti-vaccination movements and strategies fuelling the anti-vaccination discourse

During the major disease outbreaks of the last two hundred years, one of the priorities for governments has been to secure public health through administering vaccines for the general population. This, inevitably leads some sceptics to generate and diffuse rumours, conspiracy theories and/or myths concerning the related vaccine. In fact, some of the urban myths and contemporary legends appear to be stubbornly resistant in time, with the mass (mainstream) media playing a central role in this, like TV broadcasts, as well as the internet.

Properly, anti-vaccination movements began in the United Kingdom with the approval of compulsory vaccination acts between 1840 and 1867. In 1898, a clause was introduced that allowed parents an exemption to a compulsory vaccine based on conscience, thus introducing the notion of "conscientious objector." The anti-vaccination movement subsequently spread to the United States

in reaction to the smallpox vaccination effort. A comparison of the current anti-vaccination movements with those of the late 19th century reveals remarkable similarities and common themes (Wolfe and Sharp, 2002). One century later, the names of infectious diseases and the narrative discourse may have changed, however the core ideology of the anti-vaccination movement continues to live on.

In addition to individual protests and initiatives opposing vaccination on the grounds of political rights and religious beliefs (with examples of parents also 'using' religion to avoid vaccination), there are also cultural perspectives that need to be taken into account. For instance, China during the SARS outbreak in 2003 developed theories about a 'Western plot' which aimed at the depopulation of the country by conduct of biological warfare. The result was a growing suspicion and mistrust for vaccines in many other South-East Asian countries also.

Nowadays, controversies over the efficacy, safety and morality of compulsory immunisation stem from the longstanding tension between the two, sometimes divergent, goals: protecting individual liberties and safeguarding the public's health. It is the efficacy and safety of vaccines that seems to generate great concern for the general public, especially as new stories come to the surface, while moral issues also form part of the discourse. The strongest anti-vaccination movements tend to appear in places where usually there is some history of vaccine-related disasters (Kitta, 2012). For instance, places like the UK, Japan and Scandinavian countries, closely followed by the US, Canada and Australia have among the lowest vaccination rates.

To this end, there are some 'emblematic' figures that seem to be leading the anti-vaccination movement (especially in the US), which currently focuses mostly on the 'MMR vaccine causes autism' debate, finding their way through the mass media and the internet for communicating messages. Especially in the time of major disease outbreaks during the last 200 years, one of the priorities for governments has been to secure public health through administering vaccines for the general population. This, inevitably leads some sceptics to generate and diffuse rumours, conspiracy theories and/or myths concerning the related vaccine. In fact, some of the urban myths and contemporary legends appear to be stubbornly resistant in time, with the mass (mainstream) media playing a central role in this, like TV broadcasts, as well as the internet. To this end, there are some 'emblematic' figures that seem to be leading the anti-vaccination movement (especially in the US), which currently focuses mostly on the 'MMR vaccine causes autism' debate, finding their way through the mass media and the internet for communicating messages. Projection through the media also gives people a falsely perceived credibility and veracity in the claims made. Today's culture of exposure to mass media, social media and the internet makes it easy to understand why the anti-vaccination movement continues to grow, with much of the debates on public health issues remaining open. Due to this flood of information presented by the media about the (positive or negative) impact of vaccines on health, whether these are based on scientific data or purely on urban myths, people have started becoming more sceptical and actively engaged in a search of 'reliable' sources and 'insider's' type of information to support their decision for choosing to vaccinate or not.

The internet and social media networks then, have proven to be a two-edged sword in medicine as they allow individuals' access to specialized medical scientific information previously available only to health professionals and have the power both to adequately inform and deceive or confuse online

users. During the 2009 H1N1 pandemic, the anti-vaccination movements spread doubts about the safety and effectiveness of pandemic influenza vaccines and the low safety of vaccines was raised regarding the 2009 H1N1 vaccine also in anti-vaccination websites. A recent article analysed the contents of 25 anti-vaccination sites showing that one specific theme did not appear in previous analyses. This included assertion of a manufactured or exaggerated threat to boost vaccination. "The H1N1 outbreak of 2009 and the campaign to promote widespread vaccination of vulnerable populations were deemed as manufactured threats. This new theme, emerging as a specific reaction to the H1N1 influenza vaccination promotion, was present on 44% of the sites in the current study, though it was absent from any of the earlier studies" (Bean, 2011). Bean's study (2011) also showed that the other themes which appeared on the anti-vaccination websites concerned the safety and effectiveness of vaccine. About 76% of all websites included content that asserted that vaccine causes damage, illness, or death. An issue about poisons, additive, and ingredients was present on 80% of the sites. Also, 84% of the websites mentioned a conspiracy theory. 52% of sites made reference to the idea that vaccination was promoted only for financial reasons. About 44% of the websites also noted that vaccine mandates were an example of excessive government control. And finally, alternative treatments, like homeopathy, chiropractic, and further alternative vaccination, were mentioned by 20% of this websites.

Some examples of the narrative discourse used by the anti-vaccination community online are well known, but it would be much useful at this point to present the findings of a study conducted by Kata (2012), who identified most of the common tactics (i.e. actions undertaken to spread messages) and tropes (i.e. oft-repeated mottos and phrases) used by the anti-vaccination movement.

With regard to the tactics used by the anti-vaccination movement, these are classified as follows (Kata, 2012):

- Skewing cience (i.e. denigrating and rejecting science that fails to support anti-vaccine positions; endorsing poorly-conducted studies that promote anti-vaccine agendas)
- Shifting hypotheses (i.e. continually proposing new theories for vaccines causing harm; moving targets when evidence fails to support such ideas)
- Censorship (i.e. suppressing dissenting opinions; shutting down critics)
- Attacking the opposition (i.e. attacking critics, via both personal insults and filing legal actions)

Following these tactics, Kata continues to present a number of tropes which are commonly used by the anti-vaccine activists, usually as points of arguments when they are challenged by the scientific community. These tropes are (Kata, 2012):

- I'm not anti-vaccine, I'm pro-safe vaccines.
- Vaccines are toxic.
- Vaccines should be 100% safe.
- You can't prove vaccines are safe.
- Vaccines didn't save us.

- Vaccines are unnatural.
- Choosing between diseases and vaccine injuries.
- Galileo was persecuted too.
- Science was wrong before.
- So many people can't all be wrong.
- You're in the pocket of Big Pharma.
- I don't believe in coincidences.
- I'm an expert on my own child.

These tropes and tactics might comprise the core of the anti-vaccine activism discourse, but it is important to note that tropes like the above can have a great effect on people's perception, even for those who claim to be in favour of vaccination (Downs et al, 2008).

1.4.2 To contrast urban legends and myths

Urban myths could be used as indicators to evaluate or predict the behavioural responses of the public in the implementation of a vaccination programme. In order to obtain the efficacy of the preventive interventions, Public health authorities need to:

- develop a deeper understanding of the unconscious social drivers that 'push' people to generate (or circulate among the community) urban myths about infectious disease outbreaks and vaccinations;
- make a methodical assessment of the rationale and impact for each urban myth separately, as these emerge during an infectious disease outbreak;
- focus mostly on the facts that need to be communicated to the public, and avoid systematic debunking of urban myths that emerge for the duration of the outbreak;
- consider making more frequent use of *pathos* (appeal to emotion) when communicating messages to the public;
- ensure transparency at all stages and engage more actively the public in the decision-making process;
- communicate with patients in a language that is easily understood;
- take care that patients are not overloaded with information, in order to avoid generating ambiguities;
- encourage patients to construct their own narratives, so that they could better contextualise their personal experience around the disease;
- be well prepared for answering questions about the disease and long-term side effects (if any) that vaccine could have, i.e. be open and honest to the public.

On the other hand, the media need to:

- redefine their role as regards the reporting and coverage of an infectious disease outbreak;
- evaluate more carefully the information communicated to the public, as erroneous information and reproduction of urban myths could have a serious impact on the public health authorities' efforts to control the disease.

A wide array of narrative motifs and urban myths exist, having a direct impact on public perceptions and attitudes in response to an infectious disease outbreak. Perhaps the most complex problem is the fact that during an infectious disease outbreak, people are confronted with an immense amount of information, which very often are controversial or contradictory. This creates confusion and uncertainty as to which would be the best way to act, and this would be a case where people find retreat in the familiarity and comfort of urban myths.

Conclusions

After introducing the key concepts of crisis management (the two phases of Crisis Management, model of crisis communication, the importance of planning with the description of Current Pandemic Plans, closely linked to the importance of preparedness/flexibility), we have provided readers with fundamental components and issues needed to build an appropriate outbreak communication: sources, media, with a particular focus on social media (social networks, blogosphere, wikis, video sharing applications), type, timing, the process of trust building and public acceptance, stakeholders identification and the issue of coordination impaired with that of leadership.

Then, we tried to outline a comprehensive framework of those critical elements which could affect negatively communication efficacy during epidemics: first human rights and principles, stigmatization and risk of discrimination; then anti-vaccination movements, in the context of more general folk narratives and urban myths. In addition to the presentation of these cultural aspects -which were recognized and collected through appropriate reviews from a theoretical point of view- they are described in more detail in the form of practical case studies within the fourth chapter of this Summary Report.

2. BEHAVIOURAL RESPONSES TO INFECTIOUS DISEASE OUTBREAKS

2.1 Vaccination

2.1.1 Epidemiology of vaccination and disease

To better understand discrepancies in vaccination acceptance rates in different populations, we must first understand the profile of those that are and are not getting vaccinated. Working exclusively within the United States (US) and European Union (EU) contexts provides a unique perspective from many other vaccine-related epidemiological assessments, in that it assumes a standard of health care, level of access to care, stability of infrastructure, and ability for resource allocation that is more typical of the developed world than of the developing one. While areas of low coverage in the US and EU may very well be areas that lack the resources and infrastructures of similar jurisdictions, most areas will be well above the standard found in cities and countries in which vaccination interventions are traditionally focused.

Looking beyond barriers associated with infrastructures and supply, it is not always easy to discern the reasons for low vaccination rates. A closer look at the US and the EU as large but discrete units, can also be challenging, as both are made up by many smaller, semi-autonomous units (Federal States in the US and Member States - countries in the EU) each having its own healthcare policies and recommendations, unique healthcare delivery systems, varying levels of governmental support, and differing socioeconomic characteristics. Because a multitude of epidemiological surveillance data on vaccination rates exists for both the US and the EU, it is possible to run countless analyses using many scale units and all of these factors and the like. The intention here is rather to present broad and basic trends in vaccine coverage between and across the US and EU contexts. This paragraph offers a descriptive epidemiology, which may help lay the groundwork for identifying the places and people that are not currently meeting vaccination goals. It is not meant to derive conclusions regarding the reasons for high or low vaccination coverage, nor does it attempt to draw any statistical significance among variables. These figures have not been controlled for income level, education, insurance status, or any other potential confounding variables. Data are limited to a subset of vaccine-preventable diseases, which have been selected, because the vaccines are relatively ubiquitous in most US and EU populations. Data are represented in their raw form and are purely observational. Time trend data are available elsewhere, as are data on additional vaccinations.

The United States

Tables 1 through 5 present coverage levels in the US population at both national and state levels. Tables 1, 2, and 3 display data that specifically addresse US vaccination coverage among different age groups. Special attention is paid to vaccination rates among children since data are most robust for this population, and because vaccination rates among children are often an indicator of vaccination rates in the American population at-large. Vaccination rates of children aged 19-35 months in the US are used as a case study example of the type of analyses that are available for each age group. Within this population, factors such as socioeconomic status, urbanicity, race, and provider type have been controlled, with the intention of identifying sub-populations that are less likely to be vaccinated than others.

Table 1. Estimated Vaccination Coverage with Individual Vaccines and Selected Vaccination Series Among Children by State, US 2011

	3+Polio[5]	1+MMR[6]	3+PCV[7]	4+PCV[8]	3+Hib[9]	Hib-PS[10]	Hib-FS[11]
0-24 months of age	92.6±0.7	89.9±0.8	92.6±0.7	81.7±1.1	91.8±0.8	92.3±0.7	69.6±1.3
19-35 months of age	93.7±0.7	91.7±0.8	93.2±0.7	84.4±1.0	93.1±0.7	93.4±0.7	76.2±1.2

The data in Table 1 are derived from the US Centers for Disease Control and Prevention National Immunization Survey (Centers for Disease Control and Prevention - CDC, 2011b; CDC, 2011c). While rates of Hib vaccine coverage are generally high, rates of the full series are lower than those of the other two categories. As expected, vaccination coverage among children aged 19-35 months is higher than coverage in children 0-24 months.

Table 2. Estimated Vaccination Coverage with Selected Vaccines Among Adolescents Aged 13-17 Years

						Females Only		
	≥ 1 Td or Tdap[12]	≥ 1 Tdap[13]	≥ 1 MenACWY[14]	≥2 MMR[15]	≥ 3 HepB[16]	≥ 1 HPV[17]	≥ 3 HPV	HPV 3 dose[18]
Age 13-17	81.2 (80.2-82.2)	68.7 (67.5-69.8)	62.7 (61.5-63.9)	90.5 (89.6-91.3)	91.6 (90.8-92.4)	48.7 (46.9-50.5)	32.0 (30.3-33.6)	69.6 (66.8-72.2)

The data in Table 2 are derived from the US Centers for Disease Control and Prevention National Immunization Survey Teen[19] (CDC, 2011d), and shows coverage levels of 5 commonly recommended or mandated vaccinations for teenagers in the US according to the 2010 NIS-Teen survey. Vaccination rates for the second MMR dose are high, reaching 90.5%, and exceed the estimates for herd

[5] 3 or more doses of any poliovirus vaccine

[6] 1 or more doses of measles-mumps-rubella vaccine.

[7] 3 or more doses of pneumococcal conjugate vaccine (PCV)

[8] 4 or more doses of PCV.

[9] 3 or more doses of Haemophilusinfluenzae type b (Hib) vaccine.

[10] Primary series Hib: ≥2 or ≥3 doses of Haemophilusinfluenzae type b (Hib), depending on brand type.

[11] Full series Hib: ≥3 or ≥4 doses of Hib vaccine depending on product

[12] ≥1 dose of tetanus toxoid-diphtheria vaccine (Td) or tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis (Tdap) since the age of ten years.

[13] ≥1 dose of tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis (Tdap) since the age of ten years.

[14] ≥1 dose of meningococcal conjugate vaccine or meningococcal –unknown type vaccine.

[15] ≥ 2 doses of measles-mumps-rubella vaccine.

[16] ≥3 doses of hepatitis B vaccine.

[17] ≥1 dose of human papillomavirus vaccine, either quadrivalent or bivalent. Percentages reported among females only (n=9,220).

[18] Percent of females who received three doses among those who had at least one HPV dose and at least 24 weeks between the first dose and the interview date.

[19] Adolescents in this population were born during January 1992 – February 1998. Vaccination coverage estimates include only adolescents who had adequately complete provider-reported immunization records, which limits the generalizability of the data to the greater population, as they may be more likely to have been vaccinated than other children.

immunity. Coverage rates for the meningococcal conjugate or meningococcal-unknown type vaccine, however, are relatively low, with just 62.7% of respondents having been vaccinated.

Table 3. Estimated Vaccination Coverage Among US Adults, 2007

	Influenza, 2006-07	Pneumococcal, ever	Tetanus in past 10 years
18-49	37.3% (29.6, 45.7)	32.8% (27.1, 39.0)	57.2% (54.0, 60.5)
50-64	42.2% (39.0, 45.)	-----	57.2% (53.8, 60.5)
65+	68.8% (65.9, 71.6)	65.6% (62.6, 68.6)	44.1% (40.7, 47.6)

Recommended vaccinations for adults are different than those for the younger age ranges (CDC, 2008). However, in general, vaccination rates for recommended vaccines among adults are much lower than among children and rates are higher among older adults than their younger counterparts.

As shown in Table 3, the 65+ population has higher levels of influenza and pneumococcal vaccination than the 50-64 year old and 18-49 year old age groups. Pneumococcal vaccine coverage was twice as high for the over 65 group than for the 18-49 year olds, but the pneumococcal vaccination rates for adults aged 50-64 years were unavailable. Influenza vaccinations were underutilized in all age groups, especially in the younger groups, with vaccination coverage being almost twice as high in the 65+ group than in the 18-49 group. In contrast, adults aged 65 and older had fewer tetanus vaccinations in the last 10 years than the other two groups.

Table 4. Estimated Vaccination Coverage with Individual Vaccines and Selected Vaccination Series Among Children 19-35 Months of Age by US State

	3+Polio	1+MMR	3+PCV	4+PCV	3+Hib	Hib-PS	Hib-FS
US National	93.7±0.7	91.7±0.8	93.2±0.7	84.4±1.0	93.1±0.7	93.4±0.7	76.2±1.2
Alabama	94.5±2.9	94.4±2.5	95.7±2.4	87.0±4.2	94.5±2.9	96.5±2.2	78.4±5.2
Alaska	91.6±3.8	89.7±4.0	91.1±4.0	78.1±5.6	88.8±4.3	93.5±3.4	80.9±5.2
Arizona	94.4±2.8	89.2±4.7	93.6±3.1	82.8±5.3	93.9±3.2	94.8±2.8	76.5±6.4
Arkansas	96.0±2.2	93.5±3.2	92.9±4.3	77.4±6.5	93.6±4.1	93.9±4.1	70.9±7.1
California	92.4±3.4	90.9±3.9	92.8±3.4	82.0±5.4	92.9±3.3	92.9±3.3	76.7±5.5
Colorado	93.3±2.8	89.9±3.5	90.6±4.3	82.5±5.5	92.7±3.4	92.9±3.3	78.1±5.7
Connecticut	95.6±3.1	95.0±2.9	95.6±2.8	87.8±4.6	94.4±3.3	94.4±3.3	82.0±5.3
Delaware	93.2±3.9	91.7±4.2	95.0±3.3	87.2±5.0	94.9±3.4	94.9±3.4	79.5±5.5
Dist. of Columbia	93.8±3.6	92.3±4.9	96.8±2.2	90.5±4.4	94.9±3.5	94.9±3.5	84.5±5.9
Florida	97.8±1.5	96.3±2.2	96.1±3.0	88.7±4.6	94.7±3.6	94.9±3.6	81.8±5.8
Georgia	96.0±2.9	91.3±4.3	95.7±3.1	88.2±5.1	92.8±3.9	93.2±3.9	66.1±7.1
Hawaii	94.7±2.8	91.7±3.7	93.0±4.4	83.8±5.8	91.7±4.6	92.6±4.5	78.9±5.8
Idaho	89.6±4.8	86.7±5.3	87.2±5.1	78.9±6.0	85.8±5.3	85.8±5.3	59.0±7.4
Illinois	95.0±2.4	90.5±3.3	93.5±2.7	86.0±3.9	93.8±2.7	94.1±2.7	77.5±4.7
Indiana	95.1±2.7	93.7±2.9	94.6±2.8	84.2±5.1	94.2±3.2	94.2±3.2	77.7±5.7
Iowa	92.7±4.4	89.4±5.0	93.2±4.2	86.8±5.7	92.0±4.5	92.5±4.5	76.6±7.0
Kansas	92.1±4.2	85.8±5.4	90.9±4.4	82.5±5.9	91.7±4.2	91.7±4.2	75.1±6.4

Kentucky	96.1±2.8	92.1±3.9	95.1±2.9	89.3±4.2	94.7±3.1	95.0±3.1	78.3±5.8
Louisiana	95.7±2.8	90.0±4.1	93.1±3.9	83.1±5.8	94.1±3.5	95.0±3.3	75.7±6.4
Maine	94.7±3.2	92.5±3.6	94.0±3.3	88.8±4.5	93.0±3.7	93.9±3.4	71.4±6.3
Maryland	95.0±3.2	92.2±3.7	91.4±4.3	86.9±4.8	94.7±3.1	94.8±3.1	79.3±5.6
Massachusetts	94.1±3.9	93.3±4.1	95.3±3.6	88.5±5.2	94.9±3.8	94.9±3.8	84.2±6.0
Michigan	93.3±3.9	88.4±4.6	90.8±4.5	84.1±5.6	91.0±4.5	91.4±4.4	72.0±6.7
Minnesota	94.0±4.7	93.5±4.9	96.4±3.9	89.7±5.7	94.6±4.4	94.6±4.4	77.9±6.8
Mississippi	93.8±3.4	91.2±3.7	94.0±3.4	82.3±5.4	93.6±3.4	94.2±3.2	75.0±5.9
Missouri	91.8±3.6	89.7±4.1	88.7±4.3	78.4±5.6	90.8±3.8	90.8±3.8	73.2±6.0
Montana	88.7±4.5	90.6±3.8	87.4±4.6	79.8±5.4	87.5±4.6	88.7±4.1	73.7±5.9
Nebraska	94.0±3.3	94.4±2.9	94.1±4.3	89.4±5.1	90.2±5.1	90.7±5.1	81.9±5.8
Nevada	91.0±4.1	89.1±4.5	90.5±4.4	77.6±6.1	90.7±4.3	90.7±4.3	72.5±6.6
New Hampshire	97.2±2.4	92.9±4.1	97.1±2.5	93.8±3.8	97.8±2.3	97.8±2.3	86.6±5.5
New Jersey	92.3±3.6	91.8±3.9	94.7±3.1	87.7±4.5	95.5±3.3	95.5±3.3	79.4±5.6
New Mexico	93.1±3.1	89.0±4.0	90.6±4.0	81.5±5.2	93.1±3.2	93.9±3.0	73.4±6.0
New York	91.8±3.1	91.0±3.1	90.9±3.2	80.0±4.3	90.8±3.2	90.8±3.2	70.2±5.0
North Carolina	93.3±4.4	91.1±4.7	93.0±4.4	83.9±5.6	91.1±4.8	92.4±4.5	66.6±7.1
North Dakota	95.2±2.9	92.7±3.4	95.9±2.7	88.0±4.4	92.4±3.5	92.4±3.5	79.4±5.4
Ohio	93.4±3.7	92.0±4.0	91.2±4.5	80.2±6.5	93.9±3.6	93.9±3.6	79.6±6.3
Oklahoma	92.4±3.9	92.5±3.7	90.9±4.0	76.9±5.8	91.0±4.1	91.2±4.1	72.4±6.1
Oregon	93.5±3.5	92.4±3.3	95.7±2.5	87.5±5.2	93.0±3.7	94.3±3.2	71.4±6.9
Pennsylvania	95.1±2.3	91.6±3.0	94.4±2.3	85.9±3.7	95.5±1.9	95.6±1.9	79.6±4.3
Rhode Island	98.4±1.6	97.5±2.0	96.9±2.5	92.1±3.9	96.5±2.7	98.4±1.5	76.4±6.8
South Carolina	94.9±2.7	94.0±2.8	94.0±3.1	86.7±4.8	93.3±3.2	93.3±3.2	72.0±6.2
South Dakota	95.5±3.0	90.0±5.2	90.9±4.5	76.8±6.7	89.8±5.0	90.4±4.9	70.9±7.1
Tennessee	94.7±3.3	91.9±3.8	93.2±3.7	83.8±5.2	92.5±4.6	92.5±4.6	82.4±5.8
Texas	93.1±2.4	93.9±2.1	93.4±2.4	85.8±3.2	93.3±2.3	93.4±2.3	77.0±4.0
Utah	90.2±4.9	88.5±4.5	90.7±4.3	75.5±6.8	91.9±4.0	91.9±4.0	76.1±6.4
Vermont	98.3±1.3	95.6±2.3	94.7±3.1	87.8±4.5	96.9±2.0	96.9±2.0	73.8±6.4
Virginia	91.6±4.8	88.8±5.0	91.6±4.9	83.0±5.8	91.7±5.2	91.7±5.2	72.8±6.8
Washington	91.5±3.5	90.4±3.6	94.0±2.9	88.8±3.9	92.8±3.2	92.8±3.2	78.3±5.1
West Virginia	92.0±3.5	90.1±3.6	90.5±3.6	78.8±5.2	92.0±3.4	92.0±3.4	70.4±5.6
Wisconsin	94.0±3.5	92.9±3.5	95.3±3.0	91.6±4.1	95.8±2.9	95.8±2.9	84.7±5.2
Wyoming	93.9±3.0	92.9±3.4	93.8±3.2	76.0±6.9	94.3±4.3	94.7±4.2	77.2±6.7

Vaccination coverage varies by both state and vaccine (CDC, 2011c). As shown in Table 4, Hib-FS and 4+PCV have some of the lowest coverage rates across all states, while 3+Polio, Hib-PS, and MMR

have some of the highest. Interestingly, Alaska has high coverage rates of Hib-FS and relatively low coverage of 1+MMR and 4+PCV, which have high coverage rates in most other states.

States with the lowest vaccination coverage include Idaho, Montana, Missouri, Utah, Alaska, and South Dakota. States with the highest vaccination rates include New Hampshire, Rhode Island, Florida, Wisconsin, Vermont, Pennsylvania, New Jersey, Massachusetts, Louisiana, Kentucky, Indiana, DC, Delaware, and Alabama.

For each vaccine, coverage ranges are as follows:

- 3+Polio: 98.4% in Rhode Island, 88.7% in Montana
- 1+MMR: 97.5% in Rhode Island, 85.8% in Kansas
- 3+PCV: 97.1% in New Hampshire, 87.2% in Idaho
- 4+PCV: 93.8% in New Hampshire, 75.5% in Utah
- 3+Hib: 97.8% in New Hampshire, 85.8% in Idaho
- Hib-PS: 98.4% in Rhode Island, 85.8% in Idaho
- Hib-FS: 86.6% in New Hampshire, 59.0% in Idaho

The European Union

Tables 5 and 6 illustrate vaccination coverage in the EU context. Data are presented both by country (where data were available) and by particular disease. Data in Table 5 were drawn from the World Health Organization (WHO)/UNICEF estimates of National Vaccination Coverage (World Health Organization - WHO/UNICEF, 2012). In most countries, administrative coverage data monitor the number of vaccine doses administered to the target population. This number is divided by the total estimated target population, which is used as an estimate of the percentage immunization coverage. WHO and UNICEF request from countries their best estimate of coverage (administrative or survey data) and this figure is reported as the official coverage estimate**.** Based on the data available, consideration of potential biases, and contributions from local experts, WHO and UNICEF have attempted to determine the most likely true level of immunization coverage.

Table 5. WHO and UNICEF estimates of national vaccination coverage percentage by country, European Union 2011

	3+Polio	MCV	MCV2	HepB3	3+Hib	DTP3	PCV3
Total Average	89	88	91	88	88	89	73
Albania	99	99		99	99	99	
Andorra	99	99	82	99	99	95	
Armenia	96	97	98	95	95	83	
Austria	83	76		83	83	74	
Azerbaijan	80	67	98	48	38	98	
Belarus	98	99	99	98	21	98	
Belgium	98	95	83	97	98	88	
Bosnia and Herzegovina	89	89	88	88	85	95	

Bulgaria	95	95		96	95	96	94
Croatia	96	96	98	97	96	99	
Cyprus	99	87		96	96	99	
Czech Republic (the)	99	98	98	99	99	91	
Denmark	91	87	86	94	91	93	90
Estonia	93	94	95	65	93	99	
Finland	99	97		92	99	99	
France	99	89		93	97	94	89
Georgia	90	94	77	95	92	99	
Germany	95	99	92	95	93	99	15
Greece	99	99	77	99	83	99	
Hungary	99	99	99	96	99	96	84
Iceland	96	93		99	96	95	
Ireland	95	92		96	95	94	90
Israel	94	98	88	91	93	96	
Italy	96	90		95	96	99	
Kazakhstan	99	99	99	95	95	96	
Kyrgyzstan	94	97	98	82	96	94	
Latvia	94	99	91	99	93	92	78
Lithuania	92	94	94	91	92	99	
Luxembourg	99	96		98	99	96	86
Malta	96	84	85	97	96	99	
Monaco	99	99		96	99	95	
Montenegro	95	91	97	96	90	97	
Netherlands (the)	97	96	93	97	97	94	96
Norway	94	93	94	86	95	99	92
Poland	96	98		89	99	98	
Portugal	97	96	96	99	97	93	
Republic of Moldova	96	91	97		78	89	
Romania	89	93	91	97	89	97	
Russian Federation (the)	97	98	97	96	85	86	
San Marino	86	83	84	90	91	91	
Serbia	91	95		96	99	99	
Slovakia	99	98	99	97	96	96	99
Slovenia	96	95		21	97	97	
Spain	97	95		99	98	98	
Sweden	98	96	95	99	95	95	60
Switzerland	95	92	82	99	96	96	

Tajikistan	97	98	96	95	89	95	
The former Yugoslav Republic of Macedonia	95	98		83	97	97	
Turkey	97	97		48	71	97	93
Turkmenistan	97	99	99	98	26	50	
Ukraine	58	67	56	97	95	95	
United Kingdom & Northern Ireland	95	90	88	88	99	99	90
Uzbekistan	99	99	99	96	99	99	

Like the US, vaccination coverage within the EU varies by country and by immunization. However, whereas in the US there are states which clearly have higher rates of all vaccinations, in the EU it is much more common to see countries with high levels of one vaccination and low levels of another.

In terms of each vaccine, polio coverage is fairly ubiquitous, with the exception of the countries of Ukraine (58%), Azerbaijan (80%), Austria (83%), San Marino (86%), and Romania and Bosnia and Herzegovina (89%), which fall below the 90% estimated coverage rate for herd immunity. Hib vaccination coverage is generally above the 70% estimated threshold for herd immunity, with the exception of Azerbaijan (38%), Belarus (21%), and Turkmenistan (26%). Measles vaccination coverage is generally above the 83-94% threshold, with the exception of Azerbaijan (76%) and Austria (76%). Andorra (82%), Georgia (77%), Greece (77%) and Switzerland (82%) have the lowest rates of MCV2.

Data in Table 6 are derived from the HEIDI (Health in Europe: Information and Data Interface) data tool; health services indicators, vaccination coverage in children (European Commission, 2012). Childhood coverage rates are defined as the percentage of infants reaching their first birthday in the given calendar year who have been fully vaccinated against diphtheria (3 doses of DPT or DT), tetanus, pertussis, poliomyelitis (3 doses), haemophilus influenzae type b or Hepatitis B and those reaching their second birthday in the given calendar year who have been fully vaccinated against measles (1 dose), mumps and rubella.

Table 6. Childhood coverage rates of vaccine-preventable diseases in the European Union, 2008-2009

	Diphtheria	Tetanus	Pertussis	Poliomyelitis	Haemophilus B	Hepatitis B	Rubella	Measles
Maximum	99.8	99.8	99.8	99.8	99.9	99.0	99.0	99.8
Average	95.4	95.4	95.4	95.1	92.1	87.6	91.8	93.2
Minimum	73.0	73.0	73.0	73.0	48.9	15.7	76.0	76.0

As shown in Table 6, for each vaccine, there are countries that have very high coverage levels, with the maximum for each vaccine at or above 99%. Across all countries, the average coverage is highest for diphtheria, tetanus, and pertussis (95.4%) and lowest for haemophilus B (92.1%), rubella (91.8%), and hepatitis B (87.6%). For some vaccines, there is a shockingly low coverage in certain countries. Hepatitis B coverage falls as low as 15.7%, and haemophilus B coverage falls as low as 48.9%.

Countries falling at the high and low ends of coverage are as follows:

- Diphtheria: Hungary is on the high end (99.8%) and Malta is on the low end (73%), 2009.
- Tetanus: Hungary is on the high end (99.8%) and Malta is on low end (73%), 2009.
- Pertussis: Hungary is on the high end (99.8%) and Malta is on the low end (73%), 2009.
- Poliomyelitis: Hungary is on high end (99.8%) and Malta is on low end (73%), 2009.
- Haemophilus B: Hungary is on the high end (99.9%) and Macedonia is on the low end (48.9%), 2008.
- Hepatitis B: Slovakia is on the high end (99%) and Sweden is on the low end (15.7%), 2008.
- Rubella: Slovakia and Finland are on the high end (99%) and Austria is on the low end (76%), 2009.
- Measles: Hungary is on high end (99.8%) and Austria is on low end (76%), 2009.

Trends: vaccination coverage in the United States compared to the European Union

Rates of whole population vaccination in the US are slightly higher than those in the EU, with both maintaining relatively high overall rates of vaccination for most vaccines. There is a greater discrepancy in vaccination rates from vaccine-to-vaccine in the US than there is in the EU. Average coverage rates in the EU were similar across the board (with the exception of PCV3), whereas in the US, coverage rates for the full series of PCV and Hib were much lower than for other vaccines; this may indicate difficulty in fulfilling multi-visit vaccinations in the US.

Rates of childhood vaccination in the EU were more variable than were their overall population rates, perhaps due to the recent decrease in vaccine acceptance. The lowest rates of childhood coverage were for rubella and Hepatitis B.

In the United States, vaccination coverage varied significantly from state to state. While some states had very low vaccination rates for some vaccines and high rates for others, others had consistently high coverage rates for all vaccines. This observation was mirrored in the EU context, where some countries had particular vaccination rates as low as 15%, and others had high rates across the board.

Trends: disease incidence rates in the United States and European Union

Disease incidence rates vary from state-to-state and country-to-country, with some vaccine-preventable diseases more prevalent than others. The data substantiate the many news reports regarding increased incidence of measles. France was the hardest hit, with about 15,000 cases. Germany, Romania, Ukraine, and the UK also saw over 1,000 cases. In the US, pertussis accounted for more of the disease burden, with over 27,000 cases. Israel, Norway, Poland, San Marino, Ireland and Ukraine also experienced a relatively large number of measles cases.

Interestingly, the incidence of mumps was relatively high in the US in 2011, despite the fact that most people in the US get a combination vaccine that protects against both measles and mumps. Incidence of mumps was also high in Bosnia and Herzegovina, Ukraine, Uzbekistan, the UK, the Czech Republic, and Tajikistan.

Data indicate that it is difficult to make "blanket" conclusions regarding who is and is not getting vaccinated in the US and EU. In both contexts, rates vary based on geographical location, particular vaccines, and demographics; this variation may support the notion that there is a wide variety of factors that are likely to influence population and individual decisions on whether to vaccinate.

The epidemiological approach is essential in helping to identify populations and areas which may need additional attention in order to improve vaccination rates. It does not, however, provide much information as to *why* these areas and individuals in particular do not meet vaccination levels of other places and people. Because epidemiology is a population-based science, it also does not lend to drawing conclusions at the level of the individual. In order to make better sense of the epidemiological landscape presented here, it is essential to take into consideration individual risk-benefit decision-making processes and understand that exploration must go beyond the predominantly quantitative approach derived by surveillance and statistics.

Validity of available datasets

Investigators who administer large public health surveys, such as those referenced in this report, invest much efforts and money to ensure the survey results are valid, representative, and with minimal sampling error (Luman, Sablan, Stokley, McCuley, and Shaw, 2008). Data presented were primarily derived from two sources, the US Centers for Disease Control and Prevention National Immunization Survey (NIS), and the World Health Organization's Expanded Program on Immunization (EPI).

2.1.2 Risk analysis: real, perceived, and theoretical risk

Vaccine risk and risk perception play significant roles in vaccination acceptance by health organizations, government policy makers, health practitioners and individuals. Attempting to determine acceptable risks for the individual versus society is an ethical challenge complicated by the elusive nature of risk conferred by vaccines and vaccine preventable diseases. The actual risks are continuously changing and very difficult to calculate. Finally, the interpretation and the understanding of risk – perceived risk – vary widely, as it is an individual or organization's composite risk assessment affected by information, background, environmental and social influences, personal experience and individual personality traits. The perceived vaccination risk can be corrupted by misinformation, reasoning flaws, social influences and mistrust, potentially leading to poor risk assessment and decision making.

Acceptable risk varies among groups and individuals, and there is no standardized definition or universal threshold for acceptable risk levels in vaccination. Some tenets, however, are consistent within the risk/benefit analysis.

The most widely agreed upon requirements for immunizations given to otherwise healthy individuals is that they must infer minimal risk of serious adverse effects, including death, and they must be effective at reducing risk imposed by the targeted disease (Grabenstein and Wilson, 1999; Calreus, 2010). On the organizational and personal levels, active intervention confers greater responsibility and therefore greater accountability than not intervening to prevent an undesirable outcome (Jacobson, 2007; Meszaros et al, 1996). Therefore, taking into account that routine vaccinations are prophylactic and not therapeutic measures, the vaccine-associated risks must be considerably lower

than the predicted risk of not vaccinating for one to choose vaccination.

The individual acceptability of vaccination increases with (1) increasing severity of risk associated with the correlating vaccine preventable disease; (2) one's susceptibility to that disease; and (3) vaccine efficacy (van der Weerd, Timmermans, Beaujean, Oudhoff and van Steenbergen, 2011; Kok, Jonkers, Gelissen, Meertens, Schaalma and de Zwart; 2010; Brewer et al, 2007; Bults et al, 2011). However, even if an individual's risk from vaccine preventable disease – whether perceived or actual – is negligible, making the risks of vaccination appear unacceptable to that individual, this small individual risk would be acceptable in the broader societal context, as it significantly lowers risk for the population expecially for those who are susceptible and more vulnerable (Diekema and Committee on Bioethics, 2005). While the risk associated with vaccine injury is personal, the other side of the balance should weigh disease severity and susceptibility for the individual as well as others in society, including those at high risk of increased morbidity and mortality from infectious diseases (Diekema and Committee on Bioethics, 2005).

This apparent conflict in acceptable risk as determined from an individual versus a societal perspective appears to be the source of much of the disagreement concerning acceptable risk, as providers and lay individuals focus their risk analysis on individual outcomes, whereas governing and public health organizations analyse risk according to population trends and the greater common good. When addressing risk of less severe side effects from vaccines, acceptable risk is higher, particularly for diseases perceived as severe or relatively common and associated with extended morbidity. This applies particularly to acceptable risk as determined by caregivers for their children (Wischnack et al, 1995).

The risk that individuals perceive from vaccine-preventable diseases is often underestimated, and the risk of vaccine harm is often overestimated (Maldonado, 2002; Bellaby, 2003). This can cause individuals to assess vaccine risk as unacceptable based on perceived risks that do not accurately reflect actual risks.

For example, in healthy individuals the perceived risk from disease is often underestimated or even dismissed (Grabenstein and Wilson, 1999) leading to a low acceptance of even mild side effects from vaccines, as demonstrated among low vaccination rates of healthy children and adults to seasonal influenza (Tosh, Jacobson and Poland, 2010). Those with a higher perceived risk from influenza, including those with chronic medical problems and older adults, find the mild side effects an acceptable risk likely explaining the higher influenza vaccine uptake observed in the US and Europe among these groups (Loerbroks, Stock, Bosch, Litaker and Apfelbacher, 2012; Blank, Freiburghaus, Schwenkglenks and Szucs, 2008; de Andres et al, 2007, Foster and Nevin-Woods, 2011).

Acceptable risk for vaccinations produced and distributed in the event of a pandemic is similarly predicated on vaccine efficacy and safety and perceived severity and susceptibility to the targeted disease (Rubin, Amlot and Wessely, 2009; Kok et al, 2010; & Bults et al, 2011). however, more attention is given to potential disease risk in a pandemic event than to vaccine risk (Liao, Cowling, Lam and Fielding, 2011), supporting the historical pattern of increased vaccine uptake corresponding to increased disease incidence.

There are overwhelming data to support the general safety of routinely recommended immunizations. The vast majority of vaccine adverse reactions are considered mild. These include local reactions that can manifest as pain, redness, or swelling at the injection site occurring in approximately 50% of those vaccinated. Mild systemic reactions such as low grade fever, soreness, fussiness, fatigue and transient influenza-like illnesses are vaccine-specific, ranging from almost non-existent with the inactivated polio vaccine to over 30% risk of fever and fussiness in infants given the pneumococcal conjugate vaccine. These risks do not generally affect the perceived safety of a vaccine, as they do not induce long-term harm and rarely require intervention (Maldonado, 2002).

Moderate to severe reactions do rarely occur and must be considered in an evaluation of vaccine risk. Anaphylactic reactions occur in approximately 1/1,000,000 vaccine doses administered (CDC, 2012) according to another retrospective review where anaphylactic reactions incidence was observed to be 0.65-1.53/1,000,000 doses without associated deaths (Bohlke et al, 2003).

However, there are also other vaccine-specific risks that must be considered. There is a documented risk of idiopathic thrombocytopenic purpura (ITP) associated with MMR vaccination, (0.087-4 cases per 100,000 vaccine doses) where cases spontaneously resolved within 6 months with no documented recurrence of ITP after additional vaccine doses (Mantadakis, Farmaki and Buchanan, 2010). Encephalitis has also been documented with MMR vaccination at a rate of 1 case per 1,000,000 vaccine doses (CDC, 2012). DTaP immunization is associated with seizures in 1/14,000 doses administered and fever of 40.5 degrees C or higher in 1/16,000 doses. The occurrence of permanent brain damage has been suggested but remains unproven (CDC, 2012). Inactivated influenza vaccine might cause Guillian Barré Syndrome at a rate of 1-2/1,000,000 vaccine doses administered. This risk has not been definitively established, but if actual, it appears to affect vaccine recipients aged 50+ using particular variants of the H1N1 influenza vaccine (DeWals, 2012). There is even some evidence to suggest that the risk of Guillian Barré Syndrome is higher following influenza infection than following influenza vaccination (Tosh, et al., 2010).

The actual risks assumed by declining vaccination are more difficult to quantify, as disease prevalence changes in response to natural cycles, vaccination rates, global interconnectedness, environmental changes and clinical disease occurrence is mitigated by more advanced medical practices which could conceivably result in lower morbidity and mortality rates.

There is, however, plenty of evidence to indicate significantly lower individual and societal risk with higher levels of vaccine acceptance. Globally, paediatric vaccinations alone account for an estimated 3 million lives saved annually (Maldonado, 2002). A comparison of 13 vaccine-preventable illnesses prior to and following vaccine programmes in the US shows a greater than 92% decrease in cases and a greater than 99% decrease in deaths due to the specified illnesses (Roush, 2007).

More recently, many outbreaks of vaccine preventable illnesses were observed that have been directly correlated with decreased vaccination: pertussis outbreaks in the United States (Omer, et al., 2008); a number of measles outbreaks in Europe, including Switzerland, and the 20 fold increase in the incidence of measles in the 9 years in United Kingdom following the published suggested link between MMR vaccination and autism (Callreus, 2010). One study also demonstrates an increased risk of pertussis in children with parents who refuse vaccination (Glanz et al, 2009).

The risks associated with declining vaccination for more common infections such as influenza are also evident. Approximately 10% of adults experience influenza illness each year. Although only 2-4/10,000 healthy young adults will be hospitalized with influenza, approximately 1/3 of adults with influenza will visit their doctor and many more will miss work. In addition to the increased personal risk of influenza when declining vaccination, an increased risk on society is also imposed. Although the influenza vaccination is only 60-90% efficacious, immunization programmes targeting children, high risk individuals, the elderly and medical staff working with the elderly have all effectively reduced hospital admissions, outpatient visits, missed work/school days, antibiotic use and mortality among high risk populations during outbreaks of influenza (Neuzil, Griffin and Shaffner, 2001) and a 42-80% reduction in illness among household contacts, 70% reduction in missed school days (Tosh et al, 2010). In addition to known risks from vaccine refusal and vaccine acceptance, one must acknowledge additional, yet unidentified actual risks,some of which are theoretical and others are only apparent due to unrelated events temporally linked to vaccination times. This introduces the problem of theoretical risk into assessing vaccine safety. The best recognized of these proposed vaccine risks that have failed to be substantiated are the suggested link between MMR vaccination and autism; the assertion that immunizations can cause autoimmune disorders such as diabetes mellitus, asthma and atopic dermatitis; and the proposed causal relationship between hepatitis B vaccination and multiple sclerosis. Studies have failed to support any of these associations (Chen et al, 2001).

Additional theoretical vaccine risks entail extrapolating potential harm from vaccine ingredients that can be toxic in large quantities. No such toxicity has ever been demonstrated by the tiny amounts of ingredients such as aluminium and formaldehyde in vaccines, but the idea of trace toxins causing some insidious level of harm remains popular (Chen et al, 2001).

Finally, there are theoretical epidemiological risks that have been proposed with particular vaccinations the concern about selecting more virulent strains of pneumococcus by inhibiting the most common, less severe strains (Weinberger, Malley and Lisitch, 2011.): the theory that lower vaccine efficacy rates might increase the frequency of mild influenza infections (Bemejo-Martin, 2009); the concern that children immunized against current strains of influenza will not develop heterosubtypic immunity and therefore will be more vulnerable to new pandemic strains (Heikkenen and Peltola, 2009). Analysis of the actual risks from vaccination versus the benefits, or risks of not vaccinating, clearly indicates that vaccination provides the lowest risk option. However, this conclusion does not take into account perceived risk, or the risk that individuals believe they incur with a particular choice. When perceived risk becomes distorted and no longer reflects actual risk, reasonable analyses can lead to poor decisions due to invalid premises. The most common reasoning errors were classified according to Thomas Gilovich's taxonomy of common reasoning flaws seen in contemporary society, by splitting common reasoning flaws into cognitive determinants and motivational/social determinants. (Jacobson, Targonski and Poland, 2007).

The first flaw, one's natural desire to find order and predictability in random data, can explain the erroneously held belief that a causal relationship occurs between DTaP vaccination and sudden infant death syndrome (SIDS), the most common cause of death in infants older than 1 month.

The second common reasoning flaw, difficulty in detecting and correcting biases in incomplete and unrepresentative data, applies to two common anti-vaccine movement misconceptions resulting in an underestimation of perceived risk: diseases against which we vaccinate were already declining before immunizations, and vaccine-preventable diseases are no longer threats: people interpret low incidence to mean low risk.

The third cognitive flaw is an eagerness to interpret ambiguous and inconsistent data to fit theories and expectations. Anti-vaccine movements ascribe the fact that many of those who get vaccine-preventable illnesses are immunized to low vaccine efficacy. However, in a universally, or even highly vaccinated population, everyone would be likely to be immunized. A very low vaccine failure rate would allow some low incidence of disease among vaccinated individuals when introduced into a community. The fact that the majority of those who contract the illness have been vaccinated only indicates a high vaccination rate.

This same behavioural/social reasoning flaw allows parents to believe the commonly held notion that children receive too many vaccinations at once, and these vaccinations interfere with natural development thereby allowing them to rationalize a decision that appeals to their desire to avoid painful experiences.

Gilovich (2010) identifies the second common reasoning flaw stemming from motivational/social determinants as pit-falls of second-hand information and miscommunication including mass communication. Jacobson, Targonski and Poland (2007) ascribe the thimerosal scare to this reasoning flaw. The voluntary removal of thimerosal by manufacturers from the hepatitis B vaccination due to theoretical potential risks to low birth weight infants resulted in the miscommunication that the thimerosal was a dangerous component of that vaccine.

The final reasoning flaw described by Gilovich is exaggerated impressions of social support. Individuals who decline vaccination find validation in this decision through identifying with others who forego vaccination. Other reasoning problems have also been cited for the often-skewed perception of vaccine risk. A recurrent concern is the particular difficulty with understanding relative risks and conditional probabilities. When vaccine and disease risks are communicated using these statistics, underestimation and overestimation of actual risk can result in perceived risk from vaccination that is much higher than the actual risk (Gigerenzer and Edwards, 2003). There is even a tendency to give disproportionate consideration to extremely rare eventsThis allows to overemphasize a 2/1,000,000 risk of developing GBS after influenza vaccination while disregarding the significantly higher number of influenza related hospitalizations and deaths (Edwards, Elwyn and Mulley, 2002).

Surveys during the H1N1 pandemic of 2009 identify additional factors that influence risk assessment during a pandemic. Significant anxiety was associated with increased intentions to comply with public health recommendations such as immunization, as were perceived vulnerability, self-efficacy and government trust (Rubin et al, 2009, Raude and Setbon, 2009 and Kok et al, 2009). Interestingly, the perceived increase in risk relates to perceived severity more than susceptibility (Raude and Setbon, 2009). As perceived disease risk diminished, so did individuals' willingness to comply with protective measures (Bults et al, 2011), leading to maladaptive behaviours and noncompliance with recommendations (Raude and Setbon, 2009).

Vaccine risk is a complicated but crucial issue. In order to maintain and increase vaccine acceptance, vaccine manufacturers, governing bodies, public health authorities, and medical providers must work to continuously reduce actual risk associated with vaccination; align perceived risk with actual risk; and be ready to demonstrate and counter common cognitive and behavioural biases that lead to potentially harmful decisions to avoid vaccination.

2.1.3 Pandemic influenza vaccination and compliance among general population

Pandemics have occurred periodically to limit the spread of disease, and WHO recommends the use of non-pharmaceutical interventions (NPIs), as well as and vaccination. However, a compliance approach is based on community understanding of required control measures as well as their important role in disease mitigation. When an outbreak of pandemic influenza finally occurs, the understanding of those factors that could influence the people's behaviour and thus lower the risk of infection, transmission, and disease severity, is highly relevant. This information represents the most precious source needed to implement health policies communication strategies aimed at minimizing both the impact and spread of the disease. Important useful results came from several studies carried out during recent epidemics such as Severe Acute Respiratory Syndrome (SARS), Avian influenza and H1N1.

Methods

Research was selected only if based on a cross-sectional study design which included the main infectious outbreaks that occurred during the last ten years, in accordance with WHO Global Alert and Response (GAR). A systematic search was performed in the: MEDLINE; Cinahl; EMBASE and the Cochrane Central Register of Controlled Trials (*Cochrane Library*). The search was conducted from June 2012 to July 2012, though initially no language restriction was used. In total 60 relevant papers were included.

Among the 60 articles of this review, 23 of them focused on factors related to vaccination or the intention to be vaccinated. Most of the studies were concentrated on H1N1 vaccination (n=20), one study was on avian influenza and two were about a hypothetical pandemic influenza vaccination. Twelve were about both H1N1 and seasonal influenza vaccination. The studies were carried out in the following countries[20]: Australia (n=4), USA(n=6) France (n=2), Germany (n=1), Greece (n=1), Italy (n=2); Netherlands (n=2), UK (n=1), Israel (n=1), India (n=1), Hong Kong (n=3), Malaysia (n=1), and China (n=1) [21].

Data synthesis began with a narrative overview of the findings in the form of a table gathering the extracted results systematically.

The data gathered have shown how the compliance to vaccination, particularly against the H1N1 pandemic influenza, remains very low, as it is the availability (intention) to be vaccinated.

The following socio-demographic and psychological variables were found to foster the vaccination acceptance among the general population in the event of a pandemic:

- Previous history of the seasonal influenza vaccination uptake

[20] In alphabetical order.
[21] These add up to more than 23 as some studies were conducted in more than one country.

- Receiving advice/information from primary care physicians
- Being elderly people
- Perceived safety of the vaccine
- Perceived efficacy of the vaccine
- Perceived susceptibility to the disease
- Perceived severity of the disease
- Trust in authorities
- Presence of children in the household
- Cost of the vaccine

By contrast, other factors negatively affected the vaccination acceptance:

- Being female
- The fear that the vaccine could cause disease or side effects

Among the socio-demographic factors, age is associated with a higher intent to get vaccinated. Even if a study conducted in the U.S and two Australian studies gave proof that young people are more likely to be vaccinated, old people generally appear to be more willing to get vaccinated (Garlace et al, 2011; Seale et al, 2010 and Eastwood et al, 2009). Gender factors can be as well linked to the intention to be vaccinated: women were less willing to get vaccinated than men. Another variable associated with vaccination is the presence of children in the household. The roles of ethnicity, educational level, and income level, from the literature analysed in this review, are instead controversial. On the other hand it is also clear the influence of past behaviour, in fact those who have been vaccinated in the past against seasonal influenza were more likely to be vaccinated against pandemic influenza. In agreement with the above-mentioned theories, perceived severity and – above all - perceived vulnerability were positively linked to the intention to adopt protective measures and to accept vaccination; such a correlation was also highlighted in a recent systematic review on this topic. (Brewer et al, 2007).

Beliefs in the effectiveness of the vaccine are strongly associated with influenza vaccination or with the intention to get a vaccination. Many studies have focused on the safety and efficacy of the vaccine as the most important factors in the decision to be immunized (Wong et al, 2010; Lau et al, 2009; Eastwood et al, 2010).

On the other hand, the low acceptance of pandemic vaccination showed great fears about the safety of the H1N1 vaccine and general mistrust of new vaccines. In particular, public attention focused on the potential adverse effects of the vaccine. Trust and institutional communication therefore are the fundamental keys in vaccination. Finally, many studies have shown that behaviours, attitudes, and advice from primary care physicians were strongly associated with their patients' immunization behaviour for seasonal influenza or with the intention to get a vaccination (Maurer et al, 2009; Schwarzinger et al, 2010; Seale et al, 2010; Ferrante et al, 2011; Jehn et al, 2011; Walter et al, 2012). However, most respondents in these studies were not advised to get vaccinated. Healthcare workers

(HCW) reported a very low uptake rate while they usually were the first priority group to access pandemic vaccines *(See Appendix 2. Tab 1. Factors associated to protective behaviour among general population)*.

2.1.4 Compliance with influenza vaccination and factors affecting the compliance among target groups

Historically, the compliance of some target groups (healthcare workers, the elderly, the chronically ill, pregnant women and the paediatric population) with vaccination against seasonal and pandemic influenza has been extremely variable. The understanding of the factors involved is therefore of main importance in order to improve effective vaccination strategies *(See Appendix 2. Table 2. Summary of factors associated with the compliance with influenza vaccination by target group)*.

Methods

Relevant articles were identified by an electronic search. For the electronic searches, we reviewed Pubmed and the CDC website. We did not make any primary restrictions regarding the trials language or year of publication. The search was conducted during April 2012. We included all studies found, irrespective of their publication year. We placed special emphasis on articles related to the 2009 H1N1 influenza pandemic. The key words we used for the search included: Influenza, seasonal, pandemic, vaccination, immunization, vaccine, adjuvant, adverse events, compliance, coverage, acceptance, barriers, refusal, risk groups and their different combinations.

The primary search yielded 59 articles and documents concerning health care workers' compliance, 25 articles and documents concerning elderly people's compliance, 43 articles and documents concerning chronically ill people's compliance, 7 articles and documents concerning pregnant women's compliance and 26 articles and documents concerning the paediatric population's compliance.

Findings from the selected articles were extracted and summarized graphically. Data was grouped and presented according to country and year of the study performance. A summary of all the data together was not possible due to the great variety of study populations and methods.

Factors affecting compliance among healthcare workers (HCWs)

The countries represented in the studies include Australia, Brazil, Canada, China, France, Germany, Israel, Italy, Morocco, Saudi Arabia, Spain and the United States. Compliance among HCWs varied widely between and within countries. The compliance rates also varied widely by HCW category (physicians, nurses, ancillary workers, medical students etc.). The compliance rates varied from very low (less than 10%) to around 40-50%. No clear pattern can be distinguished.

A number of factors have been found to affect vaccination compliance among HCWs.

- Desire for self-protection
- Desire to avoid infecting patients
- Desire to avoid infecting family members
- Perceived safety of the vaccine

- Perceived efficacy of the vaccine
- Perceived seriousness of the disease
- Perceived risk of the disease
- Perceived seriousness of complications from the disease
- Access to the vaccine (convenience- for example the *existents of mobile carts*)
- Cost of the vaccine
- Fear that the vaccine could cause disease (a negative effect).

In a study of HCWs in Brazil (Takayanagi et al, 2007), older age, believing that most departmental colleagues had been vaccinated and having cared for patients suffering from severe influenza, were all associated with greater compliance with vaccination. Another study in Brazil found that working in a paediatric unit and the years in the job significantly increased compliance (Cavalcante Rde et al, 2010). Factors such as age and sex were shown to be associated with compliance in several studies (CDC, 2011). In a study performed in Australia, Seale et al, (2010a) reported that 81% of physicians and 68% of allied and ancillary workers felt that the vaccine was safe. 74% felt it was important to get vaccinated to protect patients, and 68% that it was important to protect their families. Despite this, only 22.5% were vaccinated.

In France, Kelly et al (2008) found that five of the six reasons for being vaccinated were altruistic, such as avoiding transmission to patients and to family. The same study also found a strong correlation between compliance and previous influenza infection. The reasons for not receiving the vaccine included a feeling of invulnerability, being too young and in good health. Van den Hoven and Verweii (2003), from the Netherlands, discussed the moral reasons for nursing home professionals to accept vaccination. In another study from the Netherlands, (Hopman et al, 2011), predictors of compliance included a sense of duty to do no harm and to ensure continuity of care. Virseda et al (2010) found in a study in Spain that self-protection and protection of the patients were the most common reasons for compliance. In the same study, compliance with the seasonal vaccine predicted compliance with the pandemic vaccine. In the U.S. beliefs in the safety and effectiveness of the vaccine, as well as believing that HCWs should be vaccinated each year, were factors associated with greater compliance (Hakim et al, 2011; Rebmann et al, 2012a; 2012b).

A study in Israel found that compliance was strongly associated with knowledge related to the vaccine (Nativ et al, 2010). A CDC study in 2011 found that beliefs that the time and expense of being vaccinated were worthwhile, and these beliefs were strongly associated with compliance, as well as the beliefs in the effectiveness of the vaccine in protecting the HCW himself and the people around (CDC, 2011). Rebmann et al (2012a) in a study in the U.S. found that determinants of compliance included occupational health encouragement and on-site access.

In Germany, Wicker et al (2011) found that predictors of non-compliance included a belief of a low risk of infection, fear of side-effects, the belief that the vaccine may trigger an infection and scepticism about the effectiveness of the vaccine. Piccirillo and Gaeta, (2006), found that concern that the vaccine could cause illness was a significant factor causing refusal of vaccination. According to Cavalcante Rde et al (2010), compliance may decline with time at work. Baron-Eppel et al (2012),

in a study in Israel, found that trust in the health authorities after the H1N1 pandemic was low and affected the willingness to be vaccinated.

Esposito et al (2007), found a low level of knowledge among Italian HCWs regarding the vaccine. In a study in Morocco, Tagajdid et al (2011), found that media controversy during the influenza pandemic reduced compliance with the seasonal vaccine. In China, only 13.3% planned to receive the pandemic vaccine compared with 37.5% for the seasonal vaccine. The main reason for receiving H1N1 vaccine was for self-protection and the reasons for rejection included fear of side-effects, and belief in the ineffectiveness of the vaccine and the mild nature of the disease (To et al, 2010).

Factors affecting compliance among the elderly

Most of the studies concerning the compliance of the elderly to influenza vaccination were conducted by the CDC, and discuss the compliance rates in the U.S.. According to those studies, there has been a constant increase in the compliance rates of the elderly (65+) in the United States that started in 1973 and continued at least until 2004 (CDC, 1995; 2005; 2006). When data were examined according to race and ethnicity, it was found that the increase was constant for non-Hispanic whites and blacks, but that for Hispanics the trend was opposite (CDC, 2005).

The main factors affecting compliance rates with influenza vaccines among the elderly in both Europe and the U.S. are the number of visits the person pays to a physician during the year (Avelino-Silva et al, 2011; CDC, 1995; 2003a; 2005). One reason for the major effect of this factor on compliance is the advice given to the elderly by their physicians (Avelino-Silva et al, 2011; Evans and Watson, 2003; Kaufman and Green, 2003).

Major reasons for non-compliance with influenza vaccination among the elderly include disbelief of this group in the efficiency and safety of the vaccine and fear of side-effect or influenza resulting from the vaccine (CDC, 2004b; Avelino-Silva et al, 2011; Evans and Watson, 2003).

Factors affecting compliance among the chronically ill

Compliance rates of the chronically ill with influenza vaccine in the U.S. are greater than those of healthy people and have been increasing over the years (CDC, 2007; 2008). In contrast, compliance rates among the chronically ill in Europe are relatively low (Fernandez-Ibiea et al., 2007).

Most of the factors affecting the compliance with influenza vaccinations among the chronically ill are the same as those affecting compliance among the healthy elderly population, and include the number of visits to a physician and the acceptance of the physician's advice as positive factors, and the fear of side effects and disbelief in the vaccine effectiveness as negative factors (CDC, 2007; 2008; Jimenez-Garcia et al, 2005; Mohseni-Zedeh et al, 2010; Naseem and Saravana, 2011; Printza et al, 2010, Stavroulopoulos et al, 2010).

Factors affecting compliance among pregnant women

Most of the studies we found on the compliance of pregnant women with influenza vaccines were carried out in the United States. According to a study by Rasmussen (2008), planning for a future influenza pandemic should include specific considerations for pregnant women, as they are at increased risk for influenza-associated illness and death, and there might be severe effects on the foetus health in case of a maternal influenza infection, associated fever, and agents used for

prophylaxis and treatment. The same study assumes that pregnant women might be reluctant to comply with public health recommendations during a pandemic because of concerns regarding the effects of vaccines or medications on the foetus.

In accordance with those assumptions, a number of studies in the U.S. have found that pregnant women tend to comply better with the seasonal influenza vaccine than with the pandemic vaccine (CDC, 2010; 2011; Fisher et al, 2011). The rates of compliance with the seasonal influenza vaccination among pregnant women in the U.S. are increasing yearly.

The study conducted in the U.S. by Fisher et al (2011), showed that the main reasons for pregnant women not to receive the influenza vaccination were lack of knowledge of the importance of the vaccine and where to get it, and concerns for the effects of the vaccine on foetal and maternal health. Another factor found to influence vaccine uptake by pregnant women is their health care provider recommendation (CDC, 2010; 2011; 2012).

Factors affecting compliance among the paediatric population

There is a big difference in the compliance rates to influenza vaccines between the different countries in the United States and throughout the years. If this trend also exists in Europe it may point to a need in state specific programs to enhance compliance rates (CDC, 2004a; 2007a). Also, the compliance of chronically ill children with the vaccine is greater than that of healthy children (CDC, 2004b). This may point to a need to emphasise the importance of vaccination to the population of healthy children's parents. Finally, the percentage of children getting one dose of the vaccine is greater than the percentage of fully vaccinated children. This may point to a need in enhancing the adherence of children and their parents with the full immunization program.

Factors that affect the rates of children's influenza vaccination in the U.S. are mostly connected to their parents' health behaviour. Factors that were found to have a positive effect on vaccination rates of children include the child’s influenza vaccination in the previous year, the child’s receipt of all recommended immunizations, the child’s uninterrupted health insurance coverage, and the mother’s unmarried status (CDC, 2011b).

Factors that were found to have a negative effect on vaccination rates of children include using a family doctor rather than a paediatrician for well-child visits, parents belief that the vaccine was unneeded or that their child was getting too many shots, and parents having a hard time obtaining the vaccine (CDC, 2004b; 2011b).

2.2 Non-pharmacological interventions (NPIs)

2.2.1 Protective behaviour against infectious diseases outbreak and compliance among general population

A number of non-pharmacological interventions (NPIs) are recommended both for the primary prevention of influenza and as a complement to vaccination to prevent the spread of the disease. The non-pharmacological interventions include personal hygiene, social distancing, the use of face masks, school closures and limitation of travel. Effective risk communication is a priority in order to achieve high compliance with these interventions. In order to convey credible messages to enhance

compliance, there is a need for good evidence to support the efficacy of the various interventions proposed.

Methods

The studies were selected only if based on a cross-sectional study design including the main infectious outbreaks occurred during the last ten years, in accordance with WHO Global Alert and Response (GAR). A systematic search was performed in the: MEDLINE; Cinahl; EMBASE and the Cochrane Central Register of Controlled Trials (*Cochrane Library*). The search was conducted from June 2012 to July 2012, though initially we did not use a language restriction. On the whole, 60 relevant papers were included.

From the 57 papers included in this review, a total of 40 studies focus on preventive behaviours and their related factors. The studies concern different outbreak diseases of the last ten years; in particular, 16 studies were about the A/H1N1 pandemic, six studies were on pandemic avian influenza, 14 concerned the SARS epidemic, and four studies were relevant to an hypothetical pandemic influenza. Nineteen studies were conducted in Asiatic regions (China n=1, Hong Kong n=12; India n=1; Singapore n=2; Taiwan n=3), one in Saudi Arabia, four studies in the US, five in Australia and eight studies were carried out in Europe (Germany n=2; Italy n=2; Netherlands n=3; UK n=1), while only three were international studies.

Data synthesis began with a narrative overview of the findings in the form of a table gathering the systematically extracted results and highlighting relevant behaviours during a pandemic such as preventive and avoidant vaccination or disease behaviours management.

Understanding the socio-demographic characteristics together with the psychological factors influencing people's protective behaviour is fundamental in order to plan any effective communication strategy that could reduce both the spread and the impact of infectious pandemic outbreaks. In particular, some conceptual frameworks, as the Theory of Planned Behaviour (TPB), Health Belief Model HBM), the Protection Motivation Theory (PMT), and the Extended Parallel Process Model (EPPM) are useful to understand and make a theoretical analysis of the psychological factors involved.

Some factors were demonstrated to be of a particular relevance:

- Being elderly people
- Being woman
- Having a high education level
- Perceived efficacy of the behaviour
- Perceived susceptibility to the disease
- Perceived severity of the disease
- Perceived self-efficacy to adopt a behaviour
- Trust in the authorities
- Having a high level of knowledge

- Having a high level of anxiety

Regardless of the socio-cultural different responses to pandemic diseases, some similar factors have influenced the behaviours and/or the intentions of the population at large. Some of the socio-demographic variables have been associated with the action of preventive and avoidant behaviours. More specifically, studies have found that women are more inclined to put those preventive behaviours into practice.

Age factor is another precious element: old people are more likely to adopt protective measures than the young. Only one study - among those we considered - has found a positive correlation between being young and preventive behaviours such as more hand washing, cleaning surfaces more or getting a flu friend (Rubin et al, 2009). On the contrary, a study conducted in Australia gave proof that age is not a predictive factor (Eastwood et al, 2009).

People having a high education level are more likely to adopt preventive or avoidant behaviours, though two studies have shown that no direct correlation could be found between education and such positive behaviours during the SARS epidemic (Tang and Wong 2003; Blendon et al, 2004).

Some psychological factors were associated with protective behaviours. Evidence has been found that perceiving oneself to be more susceptible to SARS, avian flu, H1N1, or pandemic influenza can be associated with undertaking preventive and avoidant behaviours to protect oneself. There is also evidence that the perceived severity of a disease is associated with carried out preventive and avoidant behaviours. These results can be better explained if related with the above-mentioned models, particularly the HBM, the PMT, and the EPPM describing the important role of threat perception in determining behaviours.

A factor, closely associated with the adoption of protective behaviours, is the perceived effectiveness of the same measures whose practice can be fostered by the real capability of producing the desired results. This review has also given evidence of a high level of anxiety associated with the implementation of preventive/avoidant behaviours. Also knowledge seems to be correlated to the implementation of such measures, together with the willingness to comply with home quarantine.

Finally, a key factor for putting into practice the preventive behaviours as a whole is the trust for institutions and the satisfaction with the received communications about the disease. Trust and effective communication are of particular importance especially in the case of a pandemic fatality when the role of the institutions is to provide information on the progress of the epidemic itself, on the measures to be put in place and on the available health treatments *(See Appendix 2. Tab 1. Factors associated to protective behaviour among general population)*.

2.2.2 Compliance with non-pharmacological interventions to prevent the spread of influenza among target groups

There are few studies on the compliance with non-pharmacological interventions and factors associated with compliance. There are almost no studies focusing on specific target groups. It seems that compliance with increased frequency of hand washing is relatively low in the general population.

In general, the studies on HCWs show relatively low compliance with NPIs. Factors that have been associated with increased compliance include a sense of duty to protect patients and family and occupational health services encouragement as well as easy access to the vaccine. The health belief model is a traditional model used to explain attitudes and behaviour regarding vaccine compliance.

2.2.3 Efficacy of non-pharmacological interventions

Studies on the efficacy of non-pharmacological interventions to prevent influenza transmission in different target groups

In general, only a few of the non-pharmacological methods have been systematically evaluated. The most prominent are hand-washing and the use of face-masks. Jefferson et al (2011) carried out a review of studies on the effectiveness of physical measures to reduce the spread of respiratory infections, not necessarily influenza. Meta-analysis of six case-control studies suggested that hand washing, wearing face masks, wearing gloves, wearing gowns, and all these measures combined, reduced the spread of severe acute respiratory syndrome. The combination was also effective in interrupting the spread of influenza within households. They found that the highest quality randomised trials suggested that spread of respiratory viruses can be prevented by hygienic measures in younger children and within households. The incremental effect of adding virucidals or antiseptics to normal hand washing to reduce respiratory diseases remains uncertain. Global measures, such as screening at entry ports, were not properly evaluated. Evidence was limited for social distancing being effective, especially if related to risk of exposure.

Bin-Reza et al, (2011) carried out a review of the literature. In six of eight randomized controlled trials they found no significant differences between control and intervention groups (masks with or without hand hygiene). In one household trial, face masks together with hand sanitizer use reduced secondary transmission of URI/ILI whereas hand sanitizer alone resulted in no reduction. In one hospital-based trial among HCWs, there was a lower rate of clinical respiratory illness associated with non-fit-tested N95 respirator use compared with medical masks. In eight of nine retrospective observational studies, they found that mask and ⁄ or respirator use was independently associated with a reduced risk of severe acute respiratory syndrome (SARS), although they stressed that the findings may not be applicable to influenza.

Trials of the efficacy of physical interventions

Hand washing

In general, there appeared to be a trend in lower rates of infection in the hand washing groups, although the evidence is not clear-cut. The following are highlights from some of the main studies on hand-washing to prevent the transmission of influenza-like illness (ILI). Larson et al (2010) found that the hand sanitizer group was significantly more likely to report that no household member had symptoms, but there were no significant differences in rates of infection by intervention group in multivariate analyses. Knowledge improved significantly more in the hand sanitizer group. Despite the fact that compliance with mask wearing was poor, mask wearing as well as increased crowding, lower education levels of caretakers, and index cases 0–5 years of age (compared with adults) were associated with significantly lower secondary transmission rates.

Aiello et al (2010) carried out a trial of hand-washing and face masks and the transmission of influenza. They found significant reductions in ILI in the mask and hand hygiene group, compared with the control group, ranging from 35% (CI 9%–53%) to 51% (CI, 13%–73%), after adjusting for vaccination and other covariates. Face mask use alone showed a similar reduction in ILI compared with the control group, but adjusted estimates were not statistically significant. Neither face mask use and hand hygiene nor face mask use alone were associated with a significant reduction in the rate of ILI cumulatively.

Cowling et al (2009) carried out a randomized control trial on hand-washing among contacts in households that had confirmed influenza virus infection, in the 7 days after intervention. Hand hygiene with or without facemasks seemed to reduce influenza transmission, but the differences between the intervention and control groups were not significant. In 154 households in which interventions were implemented within 36 hours of symptom onset in the index patient, transmission of confirmed influenza was reduced, an effect attributable to fewer infections among participants using facemasks plus hand hygiene (adjusted OR=0.33; 95% CI, 0.13 to 0.87).

Johnson et al (2009) have reported that there is no evidence that hand hygiene or other interventions prevent the transmission of influenza. However, this ignores much evidence that does support a role for hand hygiene in decreasing the likelihood of acquiring a respiratory tract infection (RTI) presented in a 2007 Cochrane Review.

The use of face masks

For the general public there is no clear evidence in the reduction of influenza in the face masks groups. Nevertheless, some studies did find evidence of the efficacy of face masks. Aiello et al (2012) found a significant reduction in the rate of ILI in the face mask group, with a maximum reduction of 75% during the final study week (rate ratio RR=0.25; 95% CI, 0.07 to 0.87). There was a cumulative reduction in rates of influenza over the study period, although results did not reach statistical significance. They stressed that generalizability was limited to similar settings and age groups.

In a study in Hong Kong et al (2009), hand washing and facemasks helped to prevent spread of influenza when people started using these measures within 36 hours of their family member becoming sick. The researchers could not prove that hand washing and use of facemasks prevented spread of influenza if these measures were begun after that time.

Evidence of the efficacy of interventions in target groups

There is no clear evidence of the efficacy of any of the non-pharmacological interventions to prevent the spread of influenza in the general population. The most widely studied is hand-washing with some studies on the use of face masks. Despite the lack of clear evidence, there are almost universal recommendations on the importance of hand washing. This may be due to the relative ease of implementation, low cost and apparent usefulness for the prevention of the spread of disease in general, including enteric diseases. There is much less consensus about the efficacy of the use of face masks in the general population.

Among healthcare workers, hand washing is considered to be essential in the control of infectious diseases in general. It is not clear whether it reduces the spread of influenza, although physical data provides some support. There is some evidence (not necessarily clinical trials) to support the use of

face masks to protect healthcare workers when caring for patients with influenza. However, it is a general recommendation. The type of face mask remains controversial.

There are few studies that have focused on the efficacy of any of the non-pharmacological interventions in the elderly. While hand washing is recommended, there is no clear evidence that face masks should be used when going to public places. Without clear evidence, there may be some support for limited social distancing, although it may be particularly problematical for elderly living alone.

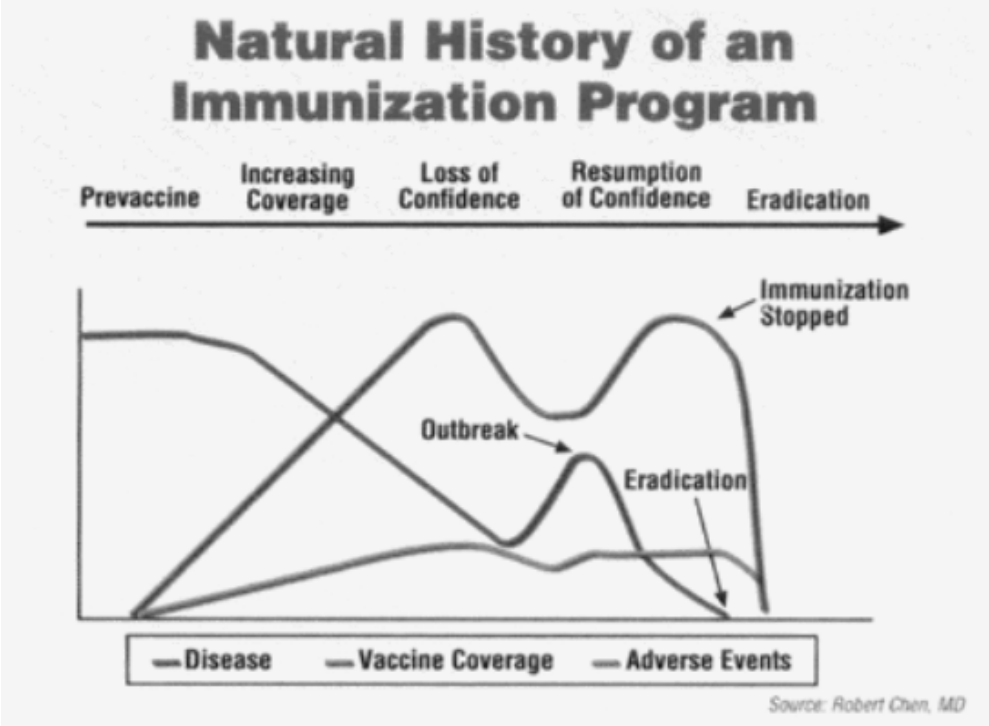
As for the elderly, there is no clear evidence for the NPIs in the chronically ill. Face masks may be considered at the peak of epidemics. For infants and small children, hand washing appears to reduce the transmission of respiratory infections in small children. Face masks may not be practical. For pregnant women there is no clear evidence of the efficacy of NPI's. Staying away from work at the peak of the epidemic may be practical, when the workplace requires contact with numerous people.

While there is no specific evidence on the NPIs for patients with flu-like illness, hand washing and the use of masks at home are general recommendations. The recommendation for patients with ILI to remain at home are almost universal.

3. STRATEGIES AND INTERVENTIONS TO INCREASE VACCINATION

3.1 Strategies to increase vaccination

In a broad sense, there are three approaches to increase the uptake of vaccines in a population (Offit, 2011). The first is taken from a graph prepared in 1998 by Robert Chen (Figure) at CDC that demonstrates the natural cycle of increased vaccine uptake → decreased incidence of disease → decreased vaccine uptake → increased incidence of disease and finally increased vaccine uptake to start the cycle over (Infectious Diseases in Children Specialty Forums, 1999). Vaccine uptake is motivated by an increase in disease morbidity and mortality. The effectiveness of this strategy is amply demonstrated in Dr. Offit's work for many vaccine disease entities, most markedly for smallpox and pertussis, both in England and the United States. However, the magnitude of the resultant consequences of decreased vaccine uptake in terms of morbidity and mortality makes this an unacceptable medical and/or public health strategy.



The second general solution is to enforce mandated vaccination requirements. Vaccination mandates have played an important role in increased vaccination uptake in the US and EU. However, religious and philosophical exemptions exist to some extent in all 50 states in the US and in most countries in Europe. Elimination of non-medical exemptions is one strategy that could increase vaccination uptake. Dr. Offit sums up his estimate as to the viability of this strategy in these words: "the notion that US courts would eliminate religious exemptions to vaccination, when they haven't eliminated religious exemptions to lifesaving medicines, is fanciful" (Offit, 2011). This sentiment might be overly pessimistic, however, especially in light of the United States Supreme Court's 1944 ruling in Prince vs.

Commonwealth of Massachusetts, which states, “the right to practice religion freely does not include liberty to expose the community or the child to communicable disease or the latter to ill health or death” (Prince v. Massachusetts, 1944). While individual and religious liberties are held as sacrosanct in the US and EU, even more so are the rights of the public, and our children in particular, to enjoy the state’s protection from preventable disease and loss of life.

The right of states to require vaccination has since been repeatedly upheld in the US, and most European countries maintain the right to mandate and enforce vaccination. Throughout the history of vaccination, however, enforced mandates have been met with passionate opposition and resistance, even rioting and violence. Philosophical and political objections to mandated and compulsory vaccination warrant careful deliberation regarding individual and state rights.

The distinction between mandatory and compulsory vaccination must be made. Compulsory vaccination allows the enforcement of a legal requirement to vaccinate that can result in individuals being vaccinated by force. There is a long history of compulsory vaccination, especially associated with smallpox; unfortunately, the first anti-vaccine movement also resulted from these programmes.

In contrast to this, a mandated vaccination programme is one in which an individual can refuse vaccination, but refusal entails a penalty, usually the denial of a social privilege such as attending school or working in a hospital. Vaccine mandates have tended to elicit strong negative reactions from subsets of the population, and, over time, the concerns of these groups have led to the allowance of medical, religious and philosophical exemptions to vaccine mandates, eroding their effectiveness. Mandates have, however, been responsible for improved vaccine uptake in many instances, conferring significant benefit to the public, or population good.

The World Health Organization (2007) has no official policy on mandatory vaccinations, but Alison Brunier, communications officer for Immunizations, Vaccines, and Biologicals at the WHO has recently written: “While it is preferable that high community demand and acceptance make community vaccination programmes unnecessary, WHO understands that some countries may wish to move in that direction when faced with declining vaccination rates and outbreaks of disease” (Walkinshaw, 2011). This stance underscores the great problem with vaccine mandates: they are an imperfect solution to a very serious problem. One possible approach to making mandates more acceptable would be the formation of a multi-national commission to better delineate individual vs. societal rights and propose model legislative remedies to better address this complicated, multi-faceted issue.

Dr. Offit’s third strategy sees the health professions becoming more actively involved in this issue of vaccination acceptance. He proposes that health care professionals improve vaccine acceptance by becoming better informed, influencing behaviours on the part of both care providers and the general population and finally engendering an increased “trust” with regard to the knowledge, motivations, abilities and commitments of those involved in developing, producing, approving, distributing, administering and monitoring vaccines. This strategy, while the least clearly defined, is the basis of vaccination efforts that target individual vaccine reluctance and resistance. While philosophically and politically based vaccine opposition can be difficult to change, vaccine resistance based on personal and societal health decisions and risk analysis is believed to be less rigid and more open to influence. Within this group, trusted health professionals can improve vaccine acceptance through personal

example; unequivocal vaccination recommendations based on scientific evidence; accurate and clearly explained information with a preparedness to counter common misconceptions and cognitive errors; and using effective timing strategies to take advantage of heightened vaccine acceptance in various settings and emotional states.

Dr. Offit (2011) fully recognizes the inherent difficulties in achieving such a level of trust in medical professionals, especially given the virulence of anti-vaccine groups globally and their liberal and deliberate use of misinformation, disinformation and outright falsifications, delivered through hostile and personally demeaning attacks from popular media platforms and expanding Web 2.0 outlets. However, strategies to improve health professional support and delivery of vaccinations have the potential to significantly improve vaccine uptake, especially within the context of highly vaccinated communities whose trends are towards greater vaccine resistance.

Medical professionals play a crucial role in vaccine efforts that attempt to avoid relying on coercion or increased disease morbidity and mortality to motivate vaccine uptake. It is therefore important to look at current beliefs, knowledge, practices, participation and recommendations of health care professionals regarding vaccination and vaccine efforts.

Eventually, many additional strategies have been recommended and implemented in an effort to increase vaccine uptake. There are literally thousands of reports documenting vaccination efforts by individual practitioners and researchers as well as by institutions and government agencies from the local to the national level. Some of the reports can be found in the traditional peer-reviewed literature, but more are documented in what is termed the gray literature, which includes agency reports and articles taken from the popular, non-peer reviewed literature. Web 2.0 modalities and web sites such as Wikipedia serve as important resources for information outside of the peer-reviewed literature that is relevant to vaccination efforts. The quality of the data covers the spectrum from anecdote through empiricism and descriptive epidemiology through analytical and case control methodologies. Unfortunately, but of necessity, the anecdotal and empirical reports far outweigh the analytical and outcome ones. Further complicating the review are the unreported data, those data derived but for a multitude of reasons, not reported.

Given the admixture and volume of inputs, a complete review of vaccine uptake strategies would be impossible without unlimited resources, and a cogent meta-analysis would yield little in terms of useful information due to a lack of uniformity across reports. However, the data and information that are available are valuable; a great deal of fine work has been done across the US and the E.U. in regards to developing effective vaccination strategies. What follows is a review of a representative number of reports that recommend strategies for improved vaccine uptake, roughly in chronological order.

The first report offers the 10 strategies defined by the CDC convened “Task Force on Community Preventative Services” (CDC, 2010). The strategies derived were:

1) Standing orders – pre-prepared written orders with appropriate criteria for use in multiple practice settings. This has been found to be the single most effective tool for increasing vaccination uptake. Multiple studies document this, including one that demonstrated that 40% of in-patients with standing orders received a flu shot versus 10% without.

2) Computerized record reminder – computer generated vaccination reminders linked to patient records. This strategy is effective for those with medical contacts but misses others. In one practice, vaccination rates increased from 29% to 86% for pneumococcal vaccine.

3) Chart reminders – they can use a variety of formats but are again linked to medical records and do not reach the general population. One report showed an increase in influenza vaccination from 18% to 40% using this approach.

4) Performance feedback – retrospective evaluation of provider performance compared to a set goal or standard with built-in incentive to attain a goal. One report documented achieving an overall influenza vaccination rate of 66% (6% higher than the national goal) versus 34% in a control group.

5) Home visits – this approach can range from mail and telephonic contacts to the actual delivery of vaccination services to the home environment. This can be well targeted to higher risk groups but can be resource intensive. Several studies have shown a modest overall benefit to include one that showed a 20% increase in influenza vaccination comparing older people with mobility problems in the U.K.

6) Mailed/telephone reminders – best adapted to stable, managed care practices that have electronic medical record capabilities. A study showed an influenza vaccine uptake of 37% in the reminders group versus only 9.8% in a randomized control group (McDowell, 1986). Mailed and telephone reminders have been found to be equally effective.

7) Expanding access – multiple possible approaches such as expanded hours, setting up more convenient vaccination sites, reducing administrative barriers, etc. This strategy can broaden target population to include higher risk individuals but at increased levels or resource requirements. A doubling in overall vaccination rates was accomplished by increasing availability of vaccine plus a telephone reminder.

8) Patient education – this strategy was narrowly defined to educational material being given to individuals during a clinical contact. In the limited context defined this can be a very effective intervention. Pneumococcal and influenza vaccine uptake rates of 75% and 78% were reported utilizing a hospital pre-discharge educational programme as compared to a control group with 0% uptake.

9) Personal Health Records (PHRs) – PHRs, not official medical records, that contain recommended vaccination information are issued to patients. This, unfortunately, can be a complex intervention as it is dependent on the adoption and creation of a PHR within a practice unit. However, when used, it has been shown to be an effective strategy, with one report showing an increase in pneumococcal vaccination rates from 4.8% to 20.5% with provision PHRs.

10) Measuring and Tracking Rates for Most Strategies – Two approaches are recommended to assist in standardizing the measures used to evaluate the effectiveness of a given vaccination strategy.

    These are:

- To compare vaccination rates pre- and post-implementation of the strategy, and
- To set a vaccination goal prior to implementing the intervention and track the immunization level over time.

In developing and evaluating strategies for vaccination programmes, it is imperative to identify the purpose of the vaccination programme – to control the spread of an epidemic/pandemic or to prevent individual cases of a given infectious disease. This is critical within the context of TellMe, because depending on the individual disease/vaccine parameters for a given event, the approach might be significantly different when seen from individual case reduction vs. control of epidemic/pandemic spread. A clear definition of the vaccination programme goal at the outset is essential to developing appropriate, effective strategies. If we don't accomplish this, we will continue to foster the uncertainties and programmatic conflicts that crippled the pandemic H1N1 campaign.

It must also be taken into consideration that the available literature about vaccination efforts and resistance is largely comprised of historical data and studies looking at traditional, fairly universal paediatric immunization programmes, seasonal influenza vaccination, and 2009 – 2010 pandemic influenza experiences. The lessons learned from this information may not be directly applicable to the attempts to control the pandemic or epidemic spread of an emergent infectious agent. The decision of a caregiver to accept vaccination on behalf of her child, under no perception of immediate threat, is likely motivated by very different factors than an individual's decision to protect himself and others when faced with the outbreak of a dangerous disease. Likewise, a different level of intervention would be required in order to motivate individuals to accept a vaccine for an apparently mild disease versus vaccine for a highly virulent disease actively spreading within the community. Therefore, the extent to which information presented can be applied to preparing for a novel organism that may well be potent and able to cause widespread fear and concern must be considered.

3.1.1 Improve vaccination acceptance

Increasing vaccine resistance is a problem throughout the European Union and the United States. Poor vaccine uptake of influenza vaccine among the general population and healthcare workers in the E.U. and US is also a source of concern, as is the documented poor uptake of the pandemic H1N1 vaccine during the 2009 influenza pandemic. The use of information and experience derived from almost 200 years of vaccination efforts and vaccine resistance, however, enable us to better develop informed strategies and achieve various vaccination objectives relating to the aforementioned areas of concern, i.e., the increasing resistance to childhood vaccinations; the universally poor uptake of seasonal influenza vaccination; and preparedness to use vaccination as an effective intervention to curb potential epidemic and pandemic events. Strategies will vary according to the specified goals of the different vaccination efforts. Recommendations are therefore divided into three different sections.

There are, however, two highly effective strategies that will first of all apply to each of the vaccine efforts. The first strategy concerns targeted messaging and interventions. Following Pareto's principle, for each vaccination effort it will be necessary to specify the population groups for which resources and interventions would be the most effectively and efficiently applied. Influences on

vaccination acceptance vary among population groups. The identification of a specific subset of the population on which to concentrate efforts will enable the consideration of influences, information resources, and other important characteristics unique to that group. This will result in targeted messaging and interventions that are highly effective for the key strategic groups and most likely to achieve an overall vaccination success.

The second strategy universally applicable to all vaccine efforts is an improved healthcare provider support and participation. This is crucial for many reasons. The literature clearly indicates that a recommendation from a healthcare professional has perhaps the strongest influence on vaccine acceptance. Healthcare providers also play a role in the delivery of vaccines and can affect vaccine accessibility, convenience, quality of experience and proper distribution. Furthermore, healthcare workers who accept vaccination for themselves play a critical role in reducing disease transmission and in influencing patient vaccine acceptance. For these reasons, it is strongly recommended that the knowledge of healthcare professionals about the vaccines be improved, and that measures be taken to improve support of vaccine efforts by all healthcare workers. Healthcare workers should actively promote vaccinations in all healthcare settings, as currently modelled within paediatrics.

Possible strategies include:

- Vaccine education and promotion should be included in training courses.
- To target vaccine-promoting literature to professional association publications and newsletters.
- To increase partnership between public health organizations and clinicians.
- To make updated vaccination information a part of a lifelong medical education training and provide licensing requirements.
- To consider the creation of a WHO endorsed “vaccination supporter” logo to be used on identification tags, office signs, practice advertisements, etc. The logo could serve as public promotion for vaccination and could induce some peer pressure on individual healthcare workers and medical practices to comply with recommended vaccinations and demonstrate public support of vaccines overall.
- To develop multi-pronged programmes to address misinformed, erroneous vaccination recommendations from health care professionals.
- To enforce high standards for acceptance to peer-reviewed literature, requiring more rigorous review of reported data, methods and conclusions.

3.1.2 Improving acceptance of childhood immunizations

Recommended strategies to decrease resistance to childhood immunizations:

- Local and national governments should take whatever actions are necessary to ensure that all children have equal access to routine immunizations.

- Health providers should include the positive aspects of vaccination in informed consent papers and in obtaining informed consent. Informed consent should not only focus on risks from vaccination, but on risks of not vaccinating as well.
- Efforts should be made to minimize discomfort during and after vaccination using measures such as ice, analgesics, massage and distraction.
- Healthcare providers should work with vaccine resistant caregivers, avoiding strategies that will alienate them. Aim for incremental success if full vaccination cannot be persuaded. Acknowledge concerns and be prepared to address them using accurate information. Do not abandon vaccine resistant patients; continue to provide care, and take advantage of every opportunity to further educate about the benefits of vaccination.
- To give healthcare providers the suggested counter-arguments to common misconceptions and fears regarding vaccines.
- To give positive feedback to caregivers praising their efforts to protect their children and community.
- To use positive messaging by means of cartoons, celebrities and trusted authorities, easy-to-understand and accurate information, and guidance in the context of informed decision-making.
- To avoid the use of difficult-to-interpret statistics such as relative risks and probabilities that involve very large or small numbers.
- To encourage individuals and civic groups within pro-vaccination efforts and outreaches to enlist the support of celebrity spokespersons.
- To utilize the same communication outlets as vaccine opponents.
- To monitor common Internet search engine results for key terms, and look into ways to ensure that the top results are not anti-vaccination web sites.
- To consider an official endorsement logo of WHO-approved web sites, so that caregivers seeking information on vaccination can feel confident about the information on those sites and potentially avoid biased anti-vaccine sites.
- To increase public awareness of the continued reality of vaccine preventable illnesses. To consider fundraising campaigns to fight vaccine preventable illnesses in countries where they remain a problem, potentially increasing visibility of the diseases and aiding in vaccine programmes around the world.
- To encourage vaccine manufacturers to avoid advertising and to keep vaccine costs as low as possible.
- To encourage vaccine developers to try, when possible, to avoid using highly controversial ingredients such as aluminium, mercury, formaldehyde, and cells derived from human stem cells.

- To advocate for federally/nationally funded vaccination development and administration. If vaccines can be mandated on the premise of public protection, then governing bodies have the obligation to ensure that such public protection is available and provided.

3.1.3 Improving seasonal influenza vaccination programmes

School-based vaccination programmes have been very successful at achieving high vaccination rates in children. It is strongly recommended, therefore, that seasonal influenza vaccination efforts target children using school programmes.

Some suggestions for this targeted approach are:

- To employ local, state, national, and regional health authorities to enlist the cooperation of schools and childcare centres.
- To try and use the fact that individuals prefer to commit acts of omission. When obtaining informed consent from caregivers for in-school vaccination, to require that parents who do not want their children vaccinated sign a declination form stating that they understand the risks to their child and community by refusing vaccination.
- To consider using intranasal vaccine to avoid a traumatic experience at school and eliminate the possibility of unintentional needle sticks and bleeding.
- To consider incentives for receiving vaccination.
- To educate the children prior to vaccination using age-appropriate material, so that they will more likely be supportive of the programme.

Based on these general findings, the following recommendations and suggestions are aimed at improving seasonal influenza uptake among healthcare workers:

- To encourage healthcare facilities and organizations to offer free influenza vaccinations to employees.
- To urge professional organizations to issue support statements for health care professional vaccination, including ethical, medical, and practical reasons for this support.
- To make influenza vaccination easily accessible at work.
- To offer a choice between injection and intranasal spray.
- To encourage healthcare facilities to use incentive programmes for healthcare worker vaccination.
- To consider using peer tactics such as inter-departmental competitions, or rewards based on reaching various goals for vaccine coverage rates.
- To ask insurance companies to consider offering incentives for influenza vaccination of healthcare workers.
- To require healthcare workers and medical and nursing students who refuse influenza vaccination to sign declination statements.

3.1.4 Preparedness for a novel epidemic or pandemic event

From the perspective of the TELL ME project, the most important set of strategies and derivative messages are those that will be used in the face of an outbreak resulting from a novel pathogen, one for which a vaccine is not available and must be developed. In the event of such an outbreak, 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.

Clearly, accomplishing this is a challenge of great complexity and magnitude. 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. Only then will we be able to identify needed pharmacological countermeasures, and, in the absence of such medical interventions, implement effective, non- pharmacological public heath countermeasures.

It has been demonstrated that vaccine resistance, while present, is not a significant barrier in an epidemic or pandemic situation in which the disease is perceived as severe and exposure as likely. More significant are communication and timing issues. 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 on-going disease threats as vaccine is made available and throughout the vaccination effort, until the desired goals are reached. This will be easier to do 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. Efforts should be made to coordinate global efforts in vaccine development and manufacturing in order to make discovery, synthesis and distribution as efficient and rapid as possible.

The following are recommendations for the implementation of these strategies:

- The development and maintenance of an effective global health surveillance system is critical.
- With identification of a potential pandemic agent, aggressive genetic and epidemiological assessment must be made.
- In an initiative coordinated through the WHO, nations should be divided according to particular strengths and capabilities regarding vaccine development and manufacturing. Specific tasks required for vaccine development and distribution should be assigned to nations or groups of nations according to capabilities. This would save time in vaccine development by minimizing redundant efforts between countries. It would also allow nations

to allot appropriate funding and resources to maintain expertise and readiness in their assigned tasks, potentially providing an overall improvement in global capabilities.

- Messages must be coordinated and consistent. Consideration should be given to an agreement among nations to provide multi-media public communications disseminated by the WHO with a frequency warranted by the pandemic or epidemic.
- Messages should be factual. They must address both what is known and what is unknown.
- When possible, messages should give people something proactive to do, such as frequent hand washing.
- Messages must be current, and therefore updated frequently.
- Messages must be attuned to changes overtime, especially as to changing risks, perceived and real, as well as to projections for availability of medical countermeasures.
- Messages should be communicated through all available media.
- To have a communication system, including networks, in place. If possible, build on a system already in place. If communicators, outlets, and spokespersons have to be identified and incorporated de novo, consistent message communication within a political unit is unlikely, and virtually impossible globally.
- Special emphasis needs to be given to stigmatization issues in characterizing and naming infectious agents. For example, labelling by place of geographic origin will promote defensiveness and be counterproductive to achieve the global openness required by the circumstance.
- As soon as enough information about the infective agent is learned, a strategic goal should be defined identifying personal disease prevention or community protection, and a plan should be accordingly developed.
- To incorporate all stakeholders as early as possible. Eventual policies and programmes may be scientifically informed, but they must be politically supported and publicly acceptable.

3.2 Effect of outbreak communication on with the uptake of seasonal and pandemic vaccines

During a disease outbreak the media play a key role in moving the public to action. However, in light of the large gaps discovered in various health crises between the intentions and plans of the WHO and their extensions and the way the public in different countries receives their health messages, the role of the media does not appear to be given adequate attention. Nor do overall flu prevention and treatment efforts in the various countries appear to include the role of the media adequately into their plans. A systematic review of English-language studies from 1974 to 2012 was conducted, and 118 of them were analysed in order to examine how the professional literature studies the reciprocal interactions between the media and the public (*See Appendix 2. Table 3. Factors associated with type of communication*).

3.2.1 The effects of the mass media on risk perception and with the uptake of seasonal and pandemic vaccines

The mass media are still considered a popular force in many countries and the most important and used tool to spread information about seasonal and pandemic vaccines (Garrett, 2001; D. C. Glik, 2007; May, 2005). The importance of studying the mass media is justified by three important roles of the media: providing information (Breban, 2011; Duncan, 2009; Dutta- Bergman, 2004; Dutta, 2007), fostering attitude formation towards vaccines and pandemics (Krishna, Balas, Boren and Maglaveras, 2002; Maurer and Harris, 2010; Stockwell, Kharbanda, Martinez, Lara et al, 2012; Yoo, Holland, Bhattacharya, Phelps and Szilagyi, 2010) and influencing the decision to take the vaccine, including shaping risk perception (Abeysinghe and White, 2011; K. Holland, R. W. Blood, M. Imison, S. Chapman, and A. Fogarty, 2012; Holmes et al, 2009; Walter et al, 2012). Analysing the role of the mass media during a threat of an infectious disease outbreak can help us understand their effect on the public and the public's response to it, since media coverage usually defines the situation for the public and influences risk perception and attitudes towards this issue (Smith, Burkle, Holman, Dunlop, and Archer, 2009; Smith, 2006).Nonetheless, healthcare providers still underestimate the power of the media to help promoting health issues, while they fear their power to instil fear and irrational behaviour among the public (Garrett, 2001; Glik, 2007; May, 2005).

Holmes et al. (2009) claim that the mass media play an important role in emerging infectious disease (EID) coverage. Dutta-Berman (2004) showed that active communication channels, such as print media and internet communication, can serve as primary tools for health information sources, but mainly for health conscious and informed individuals. Yoo et al. (2010) showed that the timing and annual receipt of the influenza vaccination are influenced by media coverage.

In the field of mass media and risk perception, Kristiansen (2007) concluded that the mass media play an important role in risk perception of influenza pandemics. However, while Kristiansen (2007) showed a high perception of risk, in the case of the H1N1 influenza pandemic in 2009, Maurer and Haris (2010) showed that the vaccine uptake was lower than the seasonal vaccine, due to the fact that the population perceived it to be less safe, relying on different information sources, including the mass media. Walter et al (2012) added that in addition to the low level of safety that was attributed to the H1N1 influenza vaccine, the perceived low risk of the disease was also one of the main barriers that contributed to the low vaccination coverage.

The effect of the mass media is not measured just by its provision information but also by threat levels and risk perception and communication (R. D. Smith, 2006). The SARS pandemic, which dealt with the fear of possible bio-terrorism, is a good comparative example that shows how the threat and fear affect the public. In this case, although the pandemic had been feared to cause disastrous health effects, only 1,000 people died. However, the fear level and threat that the public felt were much higher. According to the professional literature on strategies of intimidation (Person, Sy, Holton, Govert, and Liang, 2004), this is caused by many factors and media strategies, among them emphasis on death incidents, conflicting messages and metaphorical framing. This leads to the conclusion that sometimes while the pandemic potential is low, the fear potential remains high – because the media perceive the risk and threat as much higher than they actually are (Griffin, Dunwoody, and Zabala, 1998; Mansotte, 2004; Rezza, Marino, Farchi, and Taranto, 2004; Smith,

2006). May (2005) adds that the media portrayal of health crises can create public perception and cause irrational behaviour that threatens the effectiveness of vaccination programmes.

Dutta (2007) claims that even though research in the last decade focused on the unhealthy effects of television, in recent years there has been an increase in the amount of scholarly research seeking to investigate the positive health effects of television. Taking the motivation-based approach to learning health information from television, the author argues that health orientation influences the amount of health information individuals learned from television, by demonstrating that individuals who gained health information from the television were more health-oriented than others.

However, mass media are not just television. While most studies showed that traditional vaccine reminders have a limited effect on low-income populations (Abeysinghe and White, 2011; Glik, 2007; Holmes et al, 2009; Smith et al, 2009; Walter et al, 2012), 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, Kharbanda, Martinez, Lara et al, 2012; Stockwell, Kharbanda, Martinez, Vargas et al, 2012).

3.2.2 The effects of new media on risk perceptions and with the takeup of seasonal and pandemic vaccines

The new media are a new development in the digital world. They open new opportunities for their users that weren't available before. It is common to differentiate between two types of spreading of information: Web 1.0 and Web 2.0 (Bernhardt, Mays, and Kreuter, 2011; Han, 2010; Harrison and Barthel, 2009; Hesse et al, 2011). Most studies cited here deal mainly with spreading the information using web 1.0 techniques. They also dealt with the questions of what kind of information is being published and where, but not with the question of who is looking for information. What do people look for? What are they expecting to find on the web, regarding seasonal and pandemic vaccines (Bass et al, 2006; Bernhardt et al, 2011; Dutta-Bergman, 2004; Krewski et al, 2012; van Noort et al, 2012)?

The best known definition of Web 2.0 is O'Reilly's (2005, 2006), as technologies intended to be interactive and consumer-centred, while enabling users to interact with others, create and share content and have control over their use. Although it has been a major feature of our daily life, there have been very few research studies and projects of the new media as a tool for communicating health issues, with an emphasis on risk perception and compliance with seasonal and pandemic vaccines (Bass et al, 2006; Bernhardt et al, 2011; Dutta-Bergman, 2004; Krewski et al, 2012; van Noort et al, 2012).Bernhardt, Mays and Kreuter (2011) explain that one of the reasons for lack of evidence-based health programmes and services in the new media is a continuous failure of dissemination, when implementing practices. Failure of dissemination is caused by many factors, such as a significant gap in current processes to implement effective programmes and the lack of systems and infrastructure to facilitate the distribution of scientific research products to potential users, practitioners or the public.

There are four known strategies to promote dissemination and implementation of research evidence in practice, and each of them can be improved by leveraging Web 2.0 technologies to enhance dissemination (Kreuter and Bernhardt, 2009): to increase scientists' dissemination efforts, to

assemble inventories of effective programmes, to build partnerships for dissemination, and to increase demand among practitioners for evidence-based approaches. All of the strategies above require Web 2.0 training (Bernhardt et al, 2011; Kreuter and Bernhardt, 2009). Another approach to the new media is the health communication media choice model which is based on the migration of consumers to the web, health information strategies and effective evidence-based campaigns (Blumler and Katz, 1974; Duffy and Thorson, 2009; Eysenbach and Kohler, 2002; Palfrey and Gasser, 2009; Peterson, Aslani and Williams, 2003).

Summing up the above findings, Gesser-Edelsburg (in preparation) concludes that it is important to enhance dialogue with the public on health websites, while creating a wide forum for public representation. Inclusive dialogic websites, according to the author, help to communicate with subpopulations during crises and tailor personal message for them, addressing their linguistic, cultural and normative frames of reference. Gesser-Edelsburg also adds that some multidisciplinary models and inclusive approaches should be implemented on the website: risk communication and social marketing, interactive technological tools, credibility and attractiveness.

3.2.3 The effects of personal communication on risk perceptions and with the takeup of seasonal and pandemic vaccines among healthcare workers and the public

While the mass media, and in a certain sense the new media as well, deal with communicating with the masses with "one size fits all" messages or "personal messages" tailored to subpopulations, in the case of the new media, personal communication allows primary care providers and policy makers to overcome common barriers and achieve better goals in risk perception and compliance, among healthcare workers and the public (Gene Badia, Pane Mena, Sais Curus and Maicos, 1990; Lasser et al, 2008).

Goldstein, Kincade, Gamble and Bearman (2004) claim that efforts should be personally tailored to the individual healthcare worker and adopted to the institution and healthcare system where he or she works. In a study of healthcare workers in institutions which serve the elderly population, the authors found health policies to be very uncommon, while most of the mechanisms used to increase vaccinations were voluntary. On the side of the public, personal communication was found to be efficient to enhance compliance and risk perception of seasonal and pandemic vaccines (Lasser et al, 2008; Maurer and Harris, 2010; Moran, Nelson, Wofford and Velez, 1992).Lasser et al (2008) add that encounters between personal care providers (PCP's) and elderly patients can help improve their compliance with the influenza vaccination. Sharing power and responsibility, the use of empathy, and treating the patient like a person were found to be important factors of personal communication in improving compliance. Personal communication also helped to cope with cultural competence, introduction of the vaccine, revisiting the topic, rapport and trust between the patient and PCP and the vaccination process itself.

4. CASE STUDIES

In this fourth chapter of this present Summary Report, we have focused on case studies about the main infectious outbreaks that occurred during the 21st century, with particular attention to what happened during 2009 pandemic (H1N1). The experiences selected were collected in six reports due to the Work Package 1 "Population Behaviour during epidemics" and were here divided in two main paragraphs: the first regarding cases of outbreak management and the second one about the specific topics of crisis communication.

4.1 Cases of outbreak management

4.1.1 Case study of the UK Government's handling of the BSE crisis

In Harris and O'Shaughnessy's (1997) analysis of the UK Government's much criticized handling of the BSE Crisis, it is suggested that a key element in the failure of its communication to the public was that the Government believed and tried to sell the crisis as a technical problem with a technical solution. In doing this, they misjudged public feeling and interpretation of the situation, which only served to intensify feelings of mistrust and suspicion.

During this crisis, the overriding concern amongst the public was that the disease could pass from cattle to humans unless successfully proved otherwise. This widely held theory was repeatedly denied by various government officials, an approach that failed to win over public opinion and only resulted in casting the authorities in an increasingly suspicious light and eroding the public's trust.

It is also suggested that the UK Government's approach to communications during the BSE Crisis was further undermined by 'scientific tentativeness' and an inability to communicate in a language the public understood (Harris and O'Shaughnessy, 1997). It is argued that during a crisis the public desire clarity and brevity and that their understanding of 'proof' may be totally at odds with the scientific interpretation of a situation. Public behaviour and cooperation are key to controlling an outbreak of infectious disease. However, as surprising as it might seem, merely telling people that their behaviour is putting them at risk is not enough to make them change their habits (De Zwart, 2008).

4.1.2 Documented experiences of stigmatisation in epidemic situations: H1N1, SARS

Several prominent outbreaks of infectious disease on an international scale which occurred in the last decade (SARS outbreak of 2004, the outbreak of Avian Influenza in 2005 and the H1N1 pandemic of 2009) provide useful study cases for many aspects of the epidemiological strategy including the possible stigmatising effects of communications strategies designed to confront such epidemics. Research on instances of discrimination and stigmatisation, as a result of these crises, have helped to illuminate some of the issues that have arisen as result of the communication strategies designed to contrast these outbreaks. Hindsight has shown that in each of these instances the perceived threat proved not to be as severe as had initially been feared. Often, during the early stages of epidemics the lack of official information creates a gap that can be filled by rumour and misinformation. This environment creates fertile conditions for stigmatisation effects for certain categories of individuals and also examples of detrimental effects that occur as a result of such stigmatisation.

In such conditions, where there is a lack of official reliable information, individuals seem likely to grasp at whatever is available, even though the reliability of such information may be questionable.

One study for example showed YouTube to be a prominent source of information for the general public during the H1N1 epidemic of 2009. Whilst this provided a useful medium for agencies such as the CDC to distribute accurate information, it also provided a medium for the dissemination of inaccurate information. In this study, 21% of videos on YouTube were found to be misleading (Pandey et al, 2010). Such easily available information accommodates an instinctual desire of individuals to create categories of 'others'. This can be seen as a negative effect of the positive ability individuals have to identify common interests with other individuals and to engage in co-operation with such individuals. Often the sense of solidarity that such individuals feel with each other comes at the expense of those who are not perceived to share the same interests. This can be seen in the way that popular media often demonises individuals who come from other countries and are seen to be profiteering unjustly from public health care services.[22] In these situations, the common sense of solidarity between individuals that can identify with each other is reinforced by efforts to isolate those who fall outside this group. With HIV, for example. an 'us' and 'them' mind-set has often been described (Maywar et al, 2010). This need to isolate outsiders, those who are not perceived to share the same interests can also extend to those perceived to be a threat in terms of communicable diseases. In such situations, society as a whole may feel threatened by groups or categories of individuals that are perceived to be a greater threat in terms of communicable diseases. Often moral culpability may be attached to conditions where lifestyle factors can play a part. Threats of this kind can be perceived as emanating from a wide range of individuals. These can range from the obvious, i.e. those suspected of acutely carrying an infectious disease and exhibiting the requisite symptoms to others who are deemed more likely, because of their pre-existing health status or their behaviour, to be susceptible to infection. Such individuals could be those who live or work in close proximity to those who might be infected or those that emanate from a region where the disease in question is more prevalent. The stigmatisation that these and other groups may be exposed to as a result of epidemics is described below.

In 2009, during the H1N1 pandemic, the worldwide Mexican community was the subject of unwelcome attention due to the fact that Mexico was perceived as being the origin of the new virus. The outbreak came to be called the Mexican flu in many states because it was thought to have first originated there and despite the fact that this fact would have little to do with the future propagation of the virus (Gallagher, 2009). Information on the possible origin of an infectious agent is often the source of fear and anxiety. This was evidenced during the H1N1 outbreak in 2009 by ships refusing to dock in Mexican ports, even in areas where there had been no incidence of infection, but which were willing to dock in US areas where infections had actually occurred. Haitian officials decided that turning back a Mexican ship carrying humanitarian food aid was warranted because of H1N1 fears.[23] Whilst there is undoubtedly a logical purpose in outlining where an outbreak is occurring so that individuals can be vigilant and, in appropriate circumstances, avoid unnecessary travel to the affected region, this information led to Mexican individuals experiencing numerous

[22] See for example the article in the UK's Daily Telegraph of 19 March 2011. This article was in response to concern that too many foreigners were coming to the UK merely to gain access to the health service there. http://www.telegraph.co.uk/news/uknews/immigration/8391274/Health-tourism-why-the-NHS-became-popular-destination.html

[23] Mexico City Businesses Reopen, But International Fears Persist, *CNN* May 6, 2009- http://edition.cnn.com/2009/HEALTH/05/06/swine.flu.mexico/index.html

problems around the world and even in their own country. The identification of Mexico as ground zero of the emerging pandemic justified many instances of repressive policies against Mexicans in other countries such as the employment of unnecessary quarantine procedures (Perry and Lenhoff, 2010). Mexican citizens were for example confined by Chinese health officials despite having no flu symptoms or any other illness in the cities of Shanghai, Hong Kong, Beijing and Guangzhou.[24] Reports indicated that quarantine measures in Beijing were extended even to Mexicans who lived in Beijing and who had not recently visited Mexico.[25] In the US, conservative media personalities on many occasions blamed Mexican immigrants for spreading the disease across the border, continuing their scapegoating of immigrants.[26] In a national survey on swine flu in April 2009, 17% of respondents reported "avoiding Mexican restaurants or stores" out of concern over swine flu.[27] The stigmatisation and discrimination of Mexicans led to statements of condemnation by the Anti-Defamation League[28] and Human Rights Watch.[29]

The H1N1 Influenza virus was also popularly known as the 'Mexican flu' or the 'swine flu'. This resulted not only in negative outcomes for humans but also for pigs and the agricultural sector involved in producing pork. Numerous media stories were reporting the connection between the virus and the porcine industry. This resulted in a reduced consumption of pork and also fear of those individuals such as pig farmers who worked in close proximity to pigs. These reactions likely caused considerable economic damage to individuals and regions that depend heavily upon the pork industry. This also appeared to provide fuel to religious prejudices against the pork industry in lands such as Egypt where the prevailing religion amongst the majority deems the consumption of pork to be unacceptable. This lead to the slaughter of the entire pork stock in that country. This was despite the fact that there was no real danger from exposure to pork whether it was dead or alive. Whilst the virus in question had likely arisen from a recombination of various genetic materials in an infected pig, this was a one-time event. As a consequence, pigs presented no running health risks to humans despite the name 'swine flu' being commonly used.

It appears therefore to be necessary for health authorities to be very careful when attributing origins to outbreaks of an infectious disease. Such information can risk stigmatisation of individuals that originate from the region concerned. This is especially true when describing the virus itself. Care should be taken not to use a language that could lead to emotive and irrational inferences. References such as 'Mexican flu' or 'swine flu' should be avoided in favour of a more technical language.

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[24] Mexico City Businesses Reopen, But International Fears Persist, *CNN* May 6, 2009- http://edition.cnn.com/2009/HEALTH/05/06/swine.flu.mexico/index.html

[25] Human Rights Watch, Swine Flu Measures No Excuse for Abridging Rights, May 18, 2009 http://www.hrw.org/news/2009/05/18/swine-flu-measures-no-excuse-abridging-rights

[26] Allison Tom, Paranoia Pandemic: Conservative Media Baselessly Blame Swine Flu Outbreak on Immigrants, *Media Matters for America* April 27, 2009, http://mediamatters.org/research/2009/04/27/paranoia-pandemic-conservative-media-baselessly/149558

[27] Blendon RJ, SteelFisher GK, Benson JM, Weldon KJ, Herrmann MJ: Influenza A(HIN1)/Swine Flu Survey III. http://www.hsph.harvard.edu/news/press-releases/files/Swine_Flu_Topline_7.15.09.pdf

[28] ADL Condemns Demonizing of Mexicans for Swine Flu Outbreak, 1 May 2009, http://www.adl.org/PresRele/DiRaB_41/5516_41.htm

[29] Human Rights Watch, Swine Flu Measures No Excuse for Abridging Rights, May 18, 2009 http://www.hrw.org/news/2009/05/18/swine-flu-measures-no-excuse-abridging-rights

In addition, highly visible infection control measures used against individuals that have recently travelled from high risk areas (such as compulsory examinations) can, in the mind of the general public, act to focus attention upon immigrant groups that are trying to enter another country. The very act of naming a country of origin appears to aid individuals and mainstream society in focusing on a group perceived as being outsiders or different than mainstream society. As described above, such a notion is central to many conceptions of what stigmatisation entails. The identification of a small minority group that is likely to pose a risk to the other members of a society is therefore likely to lead to stigmatising effects. Caution should therefore be taken where health communication strategies intend to identify one minority as posing more of a risk than the rest of society as a whole. Negative reactions to such identification appear more likely if the group in question is already the subject of stigmatisation or discrimination.

During the SARS outbreak for example, the general American population's distaste of some Chinese eating habits appeared to manifest itself in a Newsweek article that stated the Chinese should question their habits of eating raw meat (Eichelberger, 2007). This was despite the lack of evidence at the time that there was any connection with Chinese dietary habits in the US and the spread of the disease. Even individuals who have no connections with affected countries can find themselves subject to such stigma. This can be the case where an unfamiliar host culture casually groups different minority cultures into one. This occurred in the SARS outbreak for example where not only the Chinese community felt itself the subject of stigmatising attitudes but also other south east Asian groups that were present as minorities in western societies (Schram, 2003). In one incident, the Vietnamese owner of a Chinese restaurant read a completely mistaken report in the local press that he had succumbed to the syndrome. In the SARS outbreak a non-scientific message of an airborne agent that was spread by the Asian community was prevalent amongst the general Canadian public. In Canada, visits by non-Chinese individuals to Chinese restaurants plummeted, real estate agents were told not to bring potential buyers of Chinese ethnic origin to see properties. An intense panic had taken hold around the Toronto area, much of it focused around the Asian community because one woman had brought SARS in Toronto from a trip to Hong Kong. This was despite the fact that no official advice had been issued stating that the Chinese community in general was a cause for concern and that public advice in Canada was focused around avoiding contact with hospitals where possible. This demonstrates the ability for groups to become stigmatised even where no official sources have given valid reasons to suspect that the group concerned poses more of a danger than any other group. Usually such responses are not rational as the individuals who are members of such minorities may have been living in the host country for many years without having travelled back to their country of origin. Such individuals will be no more likely to infect others than other members of the general population. Other individuals may have travelled back to other regions of the state of origin or may have had no contact with anybody likely to be infected. This situation therefore presents a positive role for medical authorities to act during epidemics by dispersing accurate information in order to dispel urban myths that may be both false and harmful.

4.2 Specific topic of communication related to epidemics

4.2.1 H1N1 and the uses of new and social media

In response to the H1N1 pandemic, some health agencies decided to use the social media. The CDC in particular used any kind of news media: it started with podcast, RSS feeds, Facebook, MySpace, Flickr, and Twitter, then increased its action to offer buttons and badges, a pilot mobile texting program, YouTube videos, widgets and pilot syndicate Web pages (Reynolds, 2010). A video about the "Symptoms of H1N1 (Swine Flu)" uploaded on YouTube on the 28th of April was viewed by 2,130,028 people, most of the visits were during the same uploading day though there were only 140,349 viewers for an educational video called "Clean hands to prevent flu".

However a general consideration can be made: sometimes these new advanced tools are used accordingly to old-traditional communication strategies. The NHS published on YouTube a video called "Catch it. Bin it. Kill it", viewed by 12,787 people. Most of the people viewed this video during the first day of publication: (30th April 2009). On the other hand, a parody version uploaded in the same day by a YouTube user got 138365 viewers, almost fifteen times more than the original one. This does not mean that the best way to communicate is to provide funny videos during a crisis time but to find a key for more effective strategies for communicating and responding on web 2.0 channels. To this regard, it is paradigmatic what Barbara Reynolds (the crisis communication senior advisor in the Office of the Director, Centers for Disease Control and Prevention) said: "CDC made the conscious decision to maintain its scientific integrity in its messaging through these new media (e.g., it used simple but still formal language, not jargon) and also respect the norms of the social networks it joined" (Reynolds, 2010).

The H1N1 was finally "the first pandemic with a blogosphere and other rapid communication tools that were impossible to ignore" (ECDC, 2010). New and social media were used both to disseminate information and to monitor the issues of concern of the population, with the aim, for example, to identify the concerns that pregnant women had about vaccination. Their use was different among countries and the best practice of their application comes from to CDC. In the UK Facebook, Twitter and YouTube were used primarily to re-direct people to National Health Service website rather than to engage in discussion (Hine, 2010). However, in other countries the use of new media, and social networks in particular, is limited. For the future, the WHO declared that the use of new information technologies, including social networks, should be an essential part of strategic communications planning, including research, training and guidelines for Member States (WHO, 2011).

4.2.2 Myths about the 2009 (H1N1) pandemic

In June 2009 the declaration of a pandemic was subject to much criticism and claims that the WHO advisors had links to major pharmaceutical companies, and so it was compromised by a conflict of interest in stressing the potential severity of the outbreak. The H1N1 flu vaccinations also became subject of suspicion, with other 'natural' cures offered as alternatives.

Rumours and contemporary legends spread 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. From the announcement of the H1N1 influenza in Mexico, each stage of the flu outbreak was couched in controversy, urban myths, contemporary legends and accusations of

malpractice. Claims that Mexico had attempted to cover up the outbreak of the H1N1 influenza (same as it happened with China during SARS), eventually gave way to claims that the threat of pandemic had been exaggerated by the World Health Organization. Much of the fear relating to the H1N1 influenza was its (prolaimed) similarity to the flu that caused the pandemic of 1918. Nonetheless, the narrative constructed to support claims that the H1N1 influenza could become the 'new' 1918 flu pandemic was rather misleading, as some commodities (e.g. access to clean water, antiviral drugs etc.) of the present had not been around back then; absence of such commodities can indeed have facilitated (or facilitate) the spread of the illness.

One of the most frequently recurring contemporary legends surrounding the H1N1 influenza (or the so-called Swine Flu) is that it was created in a laboratory. Much of the impetus for this comes from a journalist named Jane Burgermeister. In April, 2009, Burgermeister filed charges with the FBI against Baxter International, accusing them of shipping batches of vaccine contaminated with the 'Avian Flu' virus. Her blog site, *birdflu666.wordpress.com*, now focuses on the dangers of vaccine and accusations of abuse against major pharmaceutical companies[30]. She has also filed a case in Austria on behalf of those who claim they developed narcolepsy as a result of the H1N1 influenza vaccine, the links of which were identified by the Helsinki Sleep Clinic[31]. Burgermeister's background as a contributor to The Guardian, the British Medical Journal and Nature gave weight to her claims, as did her announcement that she had been fired from her position as the European correspondent of the Renewable Energy World, an online magazine offering daily international news. As such, she became a high profile opponent to vaccinations, though her case against the H1N1 influenza vaccine has meant that she has become strongly tied to contemporary legends surrounding the cause of the illness and the dangers of the vaccine against it.

Burgermeister's claims went beyond allegations of negligence, extending into the realm of conspiracy and tying into other rumours and contemporary legends surrounding the pandemic. At the most extreme, were claims that the outbreak was linked to the 'Illuminati', the 'Bilderberg Group' and other secret societies. According to some legends, 'The Elite', the umbrella name for the secret societies and powerful corporations created Swine Flu (or the vaccine, depending on the source), to manage or cull populations, either for financial gain or for the sake of the planet[32.] This outbreak was released on unsuspecting populations, to the financial benefit of the 'Big Pharma', major pharmaceutical companies who are making billions of dollars in revenue manufacturing vaccines that are ineffective at best, but dangerous at worst. Only few months after the H1N1 influenza was declared a pandemic, it was reported in the UK media that according to estimates this pandemic was expected to give an economical boost of around £1.5 billion to the pharmaceutical corporations GSK and Astra[33], while countries' economies 'become strangulated' as the financial

[30] More information about the case available from <http://birdflu666.wordpress.com/>
[31] The Independent – *Swine flu jab linked to narcolepsy*, 29 March 2012, available from <http://www.independent.ie/health/health-news/swine-flu-jab-linked-to-narcolepsy-3065112.html>
[32] Information retrieved from the Centre for Research on Globalization in Canada <http://globalresearch.ca/index.php?context=va&aid=14513>, Alex Jones' Prison Planet <http://www.prisonplanet.com/swine-flu-attack-likely-a-beta-test.html>, and the Healthy Wyze Report <http://healthwyze.org/index.php/the-man-made-swine-flu.html>
[33] The Telegraph - *£1.5bn swine flu vaccine boost for GSK and Astra*, 25 October 2009, available from <http://www.telegraph.co.uk/finance/newsbysector/pharmaceuticalsandchemicals/6432931/1.5bn-swine-flu-vaccine-boost-for-GSK-and-Astra.html>

costs for purchase and storage of vaccines was particularly high. The link between the vaccine and narcolepsy was also picked up on by mainstream media, causing concern among the general public that the vaccination for the illness carried more risks than the illness itself, particularly in Ireland, where a government report was commissioned to examine the link[34].

Outside of rumours, legends and accusations surrounding the cause and intent of the 2009 (H1N1) pandemic, cures and treatments flowered on the internet, offering relief or protection from the causes and symptoms of the virus. Anti-virals such as Tamiflu and Relenza were recommended by health boards, as well as the use of paracetamol to relieve the symptoms[35.] Other remedies, using herbs and minerals were also claimed to hold the secret of the cure from the H1N1 influenza, including apple cider vinegar and a mixture of garlic, onion, vinegar and hot sauce[36]. Other natural methods involved the use of 'Ayurveda' medicine, which claimed to source cures through methods over five thousand years old and offered a variety of concoctions and recipes for cures, as well as recommending the practice of yoga[37].

Many of the myths surrounding the H1N1 influenza and its vaccine share similarities, but may differ in the explanations of the intentions of those involved, or the underlying reasons for how events unfolded. However, in the wake of the 2009 (H1N1) pandemic, two claims surrounding the pandemic emerged and circulated, not just within the circles of those who cried conspiracy, but also within the mainstream media and press. The first was that the dangers of the pandemic were exaggerated by the World Health Organisation, that the pandemic that was declared never materialised and the announcement ultimately cost governments millions in preparation. This extended to claims that WHO was unduly influenced by vaccine manufacturers, who stood to profit greatly from vaccine sales on the back of a pandemic being declared[38]. The declaration of a pandemic was further criticised when a study carried out by the Journal of the American Medical Association found that the Swine Flu had been no more severe on children and young adults than seasonal flu, despite WHO having previously cited younger demographics as being more likely to suffer complications following infection[39].

Much like SARS before it, the 2009 (H1N1) pandemic, and the debate over whether it was even indeed so a pandemic, damaged the credibility of both the World Health Organisation and the various government health agencies who prepared for an emergency that, in the eyes of the public, never materialised. This criticism came not only from groups that would traditionally be hostile or suspicious of vaccination, but also from medical journals and government officials. As a result, terms

[34] The Irish Times – *Narcolepsy linked to flu vaccine in 25 children*, 19 April 2012, available from <http://www.irishtimes.com/newspaper/ireland/2012/0419/1224314925694.html>
[35] Irish Health – *Swine Flu Q&A* by J. McCarthy , available from <http://www.irishhealth.com/article.html?id=15853>
[36] HowToDoThings.com – *Curing the swine flu: Influenza facts and remedies*, available from <http://www.howtodothings.com/health-fitness/how-to-cure-swine-flu>
[37] NowPublic – *H1N1 swine flu cure by Ayurveda and homeopathy*, 24 August 2009, available from <http://www.nowpublic.com/health/h1n1-swine-flu-cure-ayurveda-and-homeopathy>
[38] The Telegraph – *Swine flu treatment: Antiviral drug stocks, antibiotic use and pandemic planning*, 1 May 2009, available from <http://www.telegraph.co.uk/health/swine-flu-information/5258424/Swine-flu-treatment-Antiviral-drug-stocks-antibiotic-use-and-pandemic-planning.html#>
[39] Bloomberg News – *Swine flu found no more severe than seasonal virus*, 7 September 2010, available from <http://www.bloomberg.com/news/2010-09-07/swine-flu-in-children-is-no-more-severe-than-seasonal-virus-study-finds.html>

like pandemic and emergency became tainted in the eyes of the public, bringing back to mind the Aesop's fable of 'the boy who cried wolf'.

To better summarise the most common myths and contemporary legends that emerged, diffused and circulated among the general public at rhe time of the 2009 (H1N1) pandemic and vaccines, three groups have been identified and categorised – appearing in the form of statements – which relate to public perceptions and compliance with preventive measures: Myths about 1) the 2009 (H1N1) Influenza (Swine Flu); 2) H1N1 vaccines and preventive measures; 3) use of alternatives to H1N1 vaccines and preventive measures. It is worth noting that the narrative discourse accompanying each of these most popular urban myths and contemporary legends of the time, here presented in form of statements, could have negatively affected public compliance with preventive measures as put forward by competent authorities and healthcare professionals. The following statements have been collected from various online and offline sources during the time of the outbreak.

Table 7. Myths around the 2009 (H1N1) pandemic and vaccines

1. Myths about the 2009 (H1N1) Influenza (Swine Flu)

PERSONAL CONCERN

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

GENERAL CONCERN

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

2. Myths about H1N1 vaccines and preventive measures

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

3. Myths about use of alternatives to H1N1 vaccines and preventive measures

- It is enough that someone just eats organic food, takes vitamins, wears a mask, washes hands and drinks plenty of liquids.
- Face masks alone can protect someone from the swine flu.
- Bringing a child to a 'swine flu party' is the better option for building a natural immunity to the virus40.
- There is no treatment for the flu.
- Antibiotics can effectively fight the flu.
- Resting is the best treatment for the flu.

4.2.3 Case examples from the Anti-vaccination campaign

The Internet is the fastest growing source of health information. The anti-vaccination movement has utilized the Internet and its ability to reach consumers seeking information pertaining to vaccine and vaccine safety. The instance of anti-vaccination websites identified in systematic scientific reviews has grown from 51 sites in 1999 to 78 sites in 2004 (Zimmerman et al, 2005). A systematic review performed in 2009 found the following themes on anti-vaccination sites (Kata, 2010):

1. Safety and effectiveness
2. Alternative medicine
3. Civil liberties
4. Conspiracy theories
5. Morality, religion, and ideology
6. Misinformation and falsehoods
7. Emotive appeals
8. Content aspects

[40] The same belief existed during the 17th century when mothers brought their children to 'pox parties'.

When entered as a Google.com search term, "vaccination" reveals the following anti-vaccination organizations appearing in the top ten results:

#4: The Vaccination Conspiracy and Holocaust (www.whale.to/vaccines.html)

#5: National Vaccine Information Center (www.nvic.org)

#6: Vaccination Liberation (www.vaclib.org)

#8: Natural News – Vaccination (www.naturalnews.com/vaccination.html)

For the purposes of this analysis of "opponents to vaccines and their communication networks, contents of their Web sites, and arguments," a selected sample of major international opponents in English were chosen, summarized, and analysed, with additional sites reviewed.

The National Vaccine Information Center[41] (NVIC) is a national, charitable, not-for-profit organization advocating for the institution of vaccine safety and informed consent protections in the public health system. According to its mission, the NVIC is "dedicated to the prevention of vaccine injuries and deaths through public education and to defending the informed consent ethic in medicine." The NVIC maintains that it is an "independent clearinghouse" for information on diseases and vaccines, monitors vaccine research, development, policymaking, and legislation while advocating that scientific studies must be conducted to (1) define various biological mechanisms involved in vaccine injury and death, (2) identify genetic and other biological high risk factors for suffering chronic brain and immune system dysfunction after vaccination, and (3) evaluate short and long-term health outcomes of vaccinated and unvaccinated individuals to determine the health effects of vaccination. The NVIC maintains an extensive Website hosted by Mercola.com (www.nvic.org) and describes its site as "the oldest and most influential consumer-operated vaccine information Website." Translation for the website is available in twelve languages. The Website is organized by the following categories (1) Vaccines, (2) Law and Policy, and (3) News and Events, and includes an assortment of tools. The NVIC endorses "the right to informed consent as an overarching ethical principle in the practice of medicine for which vaccination should be no vaccination" and maintains that "vaccination is a medical intervention performed on a healthy person that has the inherent ability to result in the injury or death of that healthy person. The NVIC provides an overview of each communicable disease and the corresponding vaccination. The NVIC asserts that it is "dedicated to the prevention of vaccine injuries and deaths through public education."

The World Association for Vaccine Education[42] (WAVE) is a "globally focused, non-profit, educational institution advocating reformation of the mass vaccination systems." WAVE "provides an avenue for a public exchange of non-medical vaccine information, ideas, and a continuously updated database of documents that concern vaccine risk and uselessness." WAVE's intent is to provide a balance of information available to the public regarding vaccination, acknowledge vaccine reactions, and advocate and maintain freedom of choice. WAVE is guided by an international board of ten directors with the mission to: "promote independent thinking, personal responsibility, and social evolution" and is "dedicated to the prevention of vaccine injuries and deaths through public education and awareness."

[41] National Vaccine Information Center. http://www.nvic.org/. Accessed July 15, 2012.
[42] World Association for Vaccine Education. http://www.novaccine.com/. Accessed July 15, 2012.

WAVE describes itself as “the most complete vaccine research resource” and encourages the public to “study vaccine data from a non-medical point of view.” WAVE maintains an extensive website (www.novaccine.com) in which states: “vaccines contributed little to the eradication of diseases like smallpox, tetanus, or polio”; “drug companies conduct studies and determine effectiveness by merely measuring antibody response”; “vaccine risk may be a difficult thing to precisely assess, but undeniably each vaccine includes a significant risk worth considering”; “some of the [vaccine] ingredients are extremely toxic and have detrimental effects on human health.”

The Think Twice Global Vaccine Institute[43] is a clearinghouse for information on vaccine risks with a collection of books and other informational resources on vaccination. The Think Twice Global Vaccine Institute “provide[s] parents and other concerned people with educational resources enabling them to make more informed vaccine decisions,” encouraging “an uncensored exchange of vaccine information and supports every family’s right to accept or reject vaccines.” It is affiliated with the New Atlantean Press, a publisher and distributor of holistic books that includes links to purchase a variety of anti-vaccination books. The organization maintains: “Parents are entitled to a full disclosure of all pertinent data and the freedom to choose whether or not to vaccinate their children.” The Think Twice Global Vaccine Institute is promoted by a Web site (www.thinktwice.com) that provides “uncensored information about vaccines and how they affect our children”, in which it asserts: “It’s the vaccinated children who spread disease. Many of the disease outbreaks that we are warned about today, are caused by, and occur in, recently vaccinated children.” Furthermore, “recently vaccinated children do carry the disease germ and are able to spread it to other children.” The group additionally recommends to “consider homeopathic alternatives or to do nothing and contend with disease if and when it occurs. Breastfeeding and natural foods work for many families.” Furthermore it is stated that “many children (and adults) receive vaccines and shortly thereafter have a serious reaction, often requiring emergency hospitalization. Such reactions include seizures, autism, immunological damage, neurological damage, sudden infant death syndrome, and/or a number of other rare and elaborately named "new" diseases.” It asserts, “Often, the doctor, nurse, or hospital personnel will try to convince you that the reaction is "normal" and nothing to worry about. Other times they will claim your child contracted a simple virus, or is screaming uncontrollably (nonstop for hours!) because she didn't like the needle prick. These are all lies. Doctors almost NEVER admit a correlation between vaccines and serious reactions.”

The European Forum on Vaccine Vigilance[44] is a coalition of groups in Europe that inform the general public, the politicians, and the press about the adverse effects of vaccinations. The European Forum on Vaccine Vigilance is a “forum of European organizations [sic] which are dedicated to the investigation and prevention of such health derangements, under the presidency of ALIS (France) and the LIGA (Spain).” Its goals are as follows: (1) provide information about vaccine adverse effects and their consequences for society in terms of financial, social and psychological cost; (2) promote freedom of choice as to vaccination in all European countries; (3) provide a discussion forum for European groups, and to support the exchange of information; (4) enable common political viewpoints; and (5) prepare common action. The European Forum on Vaccine Vigilance maintains a

[43] Think Twice Global Vaccine Institute. http://www.thinktwice.com/. Accessed July 15, 2012.

[44] European Forum on Vaccine Vigilance. http://www.vaccinatieschade.be/efvvwebsite/e1.html.Accessed July 15, 2012.

Website in multiple languages http://users.telenet.be/vaccine.damage.prevention/englishhomepage?68,10.

A thorough review of the anti-vaccination campaigns brings to light the specific tactics used by such organizations to influence the decision-making of the general population. All these tactics play on human behaviour, psychology, societal pressure, and prevailing cultural belief and they can be recognised in the following description:

- nearly all of the anti-vaccination groups reviewed affirm to promote "informed decision-making": while the anti-vaccination movement promotes "informed" decision-making. However, it is unclear whether the information they are relaying is always accurate or reliable;
- many of the anti-vaccination campaigns cited or used testimonies from "trusted" health professionals;
- it is particularly common in the anti-vaccination campaigns to find out the use of "scientific" data regarding vaccine safety;
- another very commonly used strategy by anti-vaccination organizations is to utilize first-hand stories of harm caused by vaccinations;
- the anti-vaccination movement also maintains that the pharmaceutical companies that develop vaccinations are motivated by profit and greed, and along similar lines, it uses a handful of additional strategies to promote trust from the public. Non-inflammatory and often scientific-sounding titles are used which convey an air of authority and credibility;
- this previous tactic is paired with using celebrities as spokespeople for the movement: many anti-vaccination campaigns are led or endorsed by well-known performers, actors, writers, or others in pop culture. This serves to draw attention to the issue, capture a wide audience, and popularize an issue that may not otherwise enter the public eye;
- the anti-vaccination movement is usual to disseminate information to the public by taking advantage of a wide variety of multimedia strategies, such as the Internet, social media (e.g., Twitter and Facebook), blogs, and other strategies that consumers are comfortable with and use frequently;
- finally, many of the case studies use the argument that they are seeking the truth from the medical establishments, government, and the pharmaceutical industry.

4.2.4 Seeking for information via search engines online and the anti-vaccine movement

For many people that use the internet, Google is the most popular search engine with an estimated 900 million unique visitors each month[45]. Google is a very useful tool in trying to gather a broad range of information from a variety of sources and viewpoints, and can serve as a useful indicator as

[45] eBiz – Top 15 most popular search engines, < http://www.ebizmba.com/articles/search-engines>, viewed 15 June 2012.

to what information people are immediately exposed to when they seek answers or perspective online.

In this context, a small-scale research was conducted, for providing an overall idea of the type of information that a person can be presented with, in an attempt to retrieve some details about an infectious disease outbreak, a virus or a vaccine. This approach was partly based on the methodological framework adopted by Kata (2010). Some keywords were identified, relevant for someone making an internet search in response to the 2009 (H1N1) pandemic. The keywords that were identified as most suitable – based on the commonality of their use in everyday language – are presented below, as these were inserted in Google (in original language, i.e. English, Spanish and Italian respectively):

- Flu + Symptoms
- Swine + Flu + Vaccination
- Flu + Vaccination + Risk
- Swine + Flu + Symptoms + Vaccine
- Flu + Vaccine + Dangerous

The idea was to check on the first 10 results after having inserted the keywords, since it has been demonstrated that people seeking for information on health online, most often examine the first 10 results that appear after a Google search (Eysenbach and Kohler, 2002). To enrich our understanding about the associations made with these words on a cross-cultural level, we performed the same research across four different countries (UK, US, Italy, Spain), using the respective extension domains (i.e. google.com, google.co.uk, google.it, google.es). Note that the US and the UK are two countries with strong presence of the anti-vaccination movement, therefore it was expected that comparatively to Spain and Italy, more results would be linked to urban myths, legends and conspiracy theories around vaccination.

The results from this Google research are presented in Tables 8-11.

United States

Table 8: Search results from the US Google (google.com).

Keywords	Additional research word suggestions by Google	Number of websites on vaccine side-effects or vaccination 'myths and facts'
Flu symptoms	2012 Children	None
Swine flu vaccination	Side effects Programme For babies	3
Flu vaccination risk	Groups Pregnant women With pregnancy	5
Swine flu symptoms vaccine	Side effects Risks After	5
Flu vaccine dangerous	-	9

United Kingdom

Table 9: Search results from the UK Google (google.co.uk).

Keywords	Additional research word suggestions by Google	Number of websites on vaccine side-effects or vaccination 'myths and facts'
Flu symptoms	Children 2011 2009	None
Swine flu vaccination	Side effects Programme Conspiracy	5
Flu vaccination risk	Groups Pregnant women With pregnancy	7
Swine flu symptoms vaccine	Side effects Risks After	7
Flu vaccine dangerous	Ingredients Pregnant women	9

Italy

Table 10: Search results from the Italian Google (google.it)

Keywords	Additional research word suggestions by Google	Number of websites on vaccine side-effects or vaccination 'myths and facts'
Flu symptoms	April 2012 Cure 2010	1
Swine flu vaccination	-	9
Flu vaccination risk	-	7
Swine flu symptoms vaccine	After	7
Flu vaccine dangerous	-	9

Spain

Table 11: Search results from the Spanish Google (google.es)

Keywords	Additional research word suggestions by Google	Number of websites on vaccine side-effects *or* vaccination 'myths and facts'
Flu symptoms	Types Swine	None
Swine flu vaccination	-	5
Flu vaccination risk	-	4
Swine flu symptoms vaccine	-	9
Flu vaccine dangerous	-	8

Such results would suggest that people who might be a bit sceptical about the benefits and overall impact of vaccines, and take the step to retrieve some more information online, are very often exposed to vaccine controversies that certainly offer little in helping to make any final decision about the benefits of immunisation. There is a wide variety of views offered on the effectiveness and

efficacy of vaccines, from websites dedicated to alternative therapies, to scientific blogs and news stories.

It is important to note that in the case where keywords such as ‘flu’, ‘symptoms’ and ‘vaccination’ had been used, the majority of results provided links to official sources, offering guidance about how to better deal with the flu. However, in the case of combination of keywords such as ‘vaccine’, ‘flu’, ‘risk’ and ‘dangerous’, the majority of results for all countries, provided direct links to news reports, sceptic groups and organisations opposing vaccination uptake.

It was observed in the case of the US and the UK that certain suggestions made by Google.com and Google.co.uk after having entered the keyword, such as ‘side-effects’, ‘conspiracy’ or ‘ingredients’, can motivate the user to follow down a path that leads to urban myths and contemporary legends surrounding vaccines. In the case of Spain and Italy, stories and views about the negative effects of getting vaccinated, appeared in the same frequency as in the case of the US and the UK, despite the fact that anti-vaccination movement in those countries is not as powerful in presence.

The tactics used online by the anti-vaccination movement are a powerful agent in shaping public perceptions and behaviour about vaccination, and people in general become very easily exposed to contradictory and misleading messages and information.

5. COMMUNICATION: LESSONS LEARNT AND EXERCISES UNDERTAKEN BY VARIOUS COUNTRIES AND INTERNATIONAL ORGANIZATIONS

"*Conflusion (the aggregation of streaming together of multiple confusing items, as in a confluence of confusion) is what the public is feeling in response to the seemingly endless stream of contradictory news about H1N1 influenza"*
Picard A., *The Globe and Mail*, October 9, 2009

"The fundamental difficulties are that the messages will be more numerous and more complex, and the precise content of the messages is uncertain for now and will depend on the specifics of how the public health situation unfolds"
Executive Office of the President of the United States, 2009

In the case of an infectious diseases outbreaks, appropriate communication and education ensure that the public, health care professionals and stakeholders know how to best protect their health and the health of others. Timely and accurate communication is essential to inform and educate, as well as addressing concerns and reactions to a spreading epidemic or pandemic. Also, effective communication is considered to be essential not only to provide advice, information and reassurance, but also to encourage individuals to take personal preventive actions, to ask support for necessary national responses, and to build and maintain their confidence in the government response during a pandemic.

Pandemic influenza communication has been based on a strategic risk communication approach, and consisted of five principles (WHO, 2004, 2005a; 2005b; CDC, 2007): building trust, announcing early, being transparent, respecting public concerns and planning in advance. These goals were to address and meet the communication expectations of the public and the partners, including government officials and medical professionals.

The communication strategy included flexibility and proactive communication in response to the evolving situation, managing uncertainty, and acknowledging what was unknown, as well as what was known. The communication strategy was focused on few objectives: providing information to help health care services, addressing the public to manage the new virus, marketing and advertising tactics for infection prevention behaviours, personal preparedness, and over the time, a call to action for people and HCWs to get vaccinated.

Whilst the guidelines and the objectives appear straightforward, more difficult was to manage a complex situation that requires an understanding of the broader political, social and cultural environment in which communication occurs (Abraham, 2009). H1N1 pandemic management stimulated a number of controversies around the world in 2009 and, although world media coverage faded in 2010, the debate is still going on.

Methods

A systematic search was performed in the: MEDLINE; Cinahl; EMBASE. The search was conducted between June 2012 and July 2012, though initially we did not use a language restriction. On the whole, 81 relevant papers were included.

5.1 Internal communication

Internal communications is a key during crisis situations, and at the same time it is particularly critical; in fact, coordinating communication on both a vertical and horizontal level can be complicated. Within this scenario, the international organizations, such as the WHO and the CDC/ECDC played a valuable role in regularly updating health professionals to address action and concerns on specific questions (EU Conference Report, 2011).

For many countries and agencies the need to improve internal communications has become more and more important (Sweet, 2009; Deirdre Hine, 2010; Tay et al, 2010; WHO Europe, 2010; WHO, 2011; Greco et al, 2011). For example, in Canada planning in advance work with national and international partners formed important links that were useful during the H1N1 response. But, the messages provided across federal, provincial, and territorial jurisdictions weren't always consistent. The reviewers indicate that is necessary to improve coordination among different approaches, communication and marketing tools, tactics and messaging. In particular, the WHO (2010) suggested that the following are needed to improve communication effectiveness within the health care system:

- Development of vertical networks between the ministries of health and health care workers
- New communication tools (e.g. established through the internet) should be considered, as they have proved to be helpful
- Coordination within a hospital benefits from choosing one person to disseminate information, primarily necessary for early identification of cases, but also during other stages of the response

Moreover, the communication strategies for the healthcare sector should take into account the possible differences in expectations, and explain clearly the rationale for the decision as well as customize the messages to different healthcare worker audiences (Tay et al, 2010).

Other critical elements were the information and the communication about vaccine, and the related issues, such as the safety of adjuvants, the vaccination of pregnant women and serious adverse events following pandemic vaccination. A lesson learnt from most countries is that more communication on vaccine safety data was needed at the time the vaccination was implemented (EU Conference Report, 2011; DH/NHS Flu Resilience, 2010). Furthermore, healthcare professionals were considered as the pivotal in disseminating reliable information about vaccines and antivirals. For this reason it is fundamental to explore particular needs and concerns of healthcare professionals, focusing on the design of future communications strategies (European Medicines Agency, 2011).

In the UK, the involvement of professional health bodies appeared of fundamental importance in those discussion aimed at creating sources of direct clinical advice for health professionals during a pandemic. This may be most appropriately hosted by one or more of the professional bodies (Deirdre Hine, 2010). The development of a CDC guidance is an example of this collaborative communication and the sharing of information that took place between CDC, HHS, other federal agencies, and external partners (CDC, 2010). This process is particularly important since there have been several instances in which recommendations have been controversial, particularly those regarding hospital infection control, which have sometimes been based on hypothetical concerns rather than

epidemiological data. Some of these recommendations generated controversy and even outright opposition from caregivers. For example, CDC's recommendation for use of N95 respirators by those caring for hospitalized 2009-H1N1 patients is discordant with the views of several other expert bodies. Such conflicts can generate confusion and anxiety at many levels in the hospital workplace, impairing effective compliance with proper infection control, and undermining physician confidence in health agencies and public confidence in local infection control measures at a time when confidence levels need to be maximized (US President, 2009; Socialstyrelsen and Swedish Civil Contingency Agency, 2011).

5.2 Communication "with" the general public

The institutions must get […] learn to communicate "with" public and not "to" the public
EU, 2010

Tickle the public, make 'em grin, the more you tickle, the more you win;
teach the public, you'll never get rich, you'll live like beggar and die in ditch
Old jingle on the journalism - O'Doherty – The Dublin review of books

The difficulties found in communication during the H1N1 pandemic, urged some agencies to think that in the future science and research would want to focus more on firmly determining a pandemic's virulence before communicating it to the public (Public health agency of Canada and Health Canada, 2010). But it is by now evident that this approach is unsuccessful (WHO, 2005; CDC 2007). It is important to bear in mind that any future pandemic will take place in a multisource environment and therefore a wait-and-see approach may not be the best one to take with the general public.

National health agencies put a great effort in developing a clear, consistent and coordinated communication across the full range of communication channels, tailored to the needs of specific audiences, even if these activities have been implemented with great variability in the various countries. This was considered crucial for maintaining public trust, compliance and support essential to the effective management of a pandemic.

5.3 Communication to the media

Media standards and values differ from those of the scientific and health communities. The major goals of the media are to be first, write stories with impact, win prizes, impress sources, figure out what is really happening, tell stories in a compelling way, and get on the front page. These aims do not properly coincide with the health expert's goal of educating the public and gaining public confidence, understanding, and cooperation (Fineberg, 2008). For this reason it is important to engage a trusting relationship with journalists improve the prospect of a good working relationship during a crisis. Consistent news briefings and the establishment of a collaborative relationship with the media during this time are important elements to maximize communication through traditional media (Tay et al, 2010). The European Union recommended also the constitution of a selected group of available experts to answer questions from journalists, as well as the availability of spokespersons, factors that are both considered essential (EU, 2010).

5.4 Communication on vaccination

A particular challenge in communication about the vaccination programme derived from public uncertainty regarding the safety of H1N1 vaccines. Some myths and rumours circulated widely on the Internet and through viral emails claiming unsubstantiated problems associated with vaccination. Although mainstream media generally discredited such claims, alternative media sources perpetuated myths and often used sensationalism to sustain viewer interest. Public health organizations sought to counter these rumours with frequent updates, including factual information about what was being found through safety monitoring and through disseminating tools and information to healthcare providers and other consumer information sources (Schuchat et al, 2011).

Rapid response strategies are needed to combat negative rumours about the vaccine and coverage, as well as criticisms received in the mass media. Hence, information must be transparent to earn people's trust. Activities and messages should reflect an appropriate understanding of the information needs and communication practices required for each audience (PAHO, 2009). The nationals programming must proactively address safety concerns and adverse events, as well as respond to anti-vaccination messages and concerns (Levine et al, 2010).

Finally, Levine et al (2010) reported that in Israel National priority groups for pandemic vaccine were different than those for seasonal vaccine, thus leading to some confusion. Priority groups and vaccination strategies as well may be different among countries.

During the World Influenza Congress in Singapore, it was highlighted that poor communication may also underlie poor influenza vaccine uptake by healthcare workers despite recommendations that they should be vaccinated to protect the high-risk patients with whom they may have contact (Petrovsky, 2010).

In Sweden, where over sixty percent of the population were vaccinated, the factors that led to a greater probability that a person would decide to uptake the pandemic vaccination were: a higher degree of perceived risk of being infected; a higher degree of anxiety about this form of influenza; and a higher degree of trust in the authorities. Furthermore, those who decided not to be vaccinated thought that the authorities were exaggerating the risks associated with the pandemic. Indeed, one of the most important questions for future preparedness is the need to maintain the public's confidence in the authority (Socialstyrelsen and Swedish Civil Contingency Agency, 2011).

5.5 Effective communication

Language

Some reviewers suggested that some of the terminology used during the pandemic was not widely understood by the public. The scale of the government's planning assumptions did nothing to allay the widespread belief that a 'pandemic' meant a very severe disease, rather than referring, as it does, to the geographical nature of its spread. Also, the use of the terms 'containment' and 'reasonable worst case' should be reconsidered as they can be easily misunderstood (Deirdre Hine, 2010; EU Conference report, 2011). This requires that agencies should review their use of language during pandemics to ensure that it accurately conveys the aims of the response efforts and the levels of risk.

Media channels

During the crisis, authorities should engage the most effective channels to reach the general population and the specific risk groups. Communication strategies have been based on the use of different media and communication channels. Among the traditional ones, the most commonly used were television and radio (including community broadcasts), the printed press, and announcements on public thoroughfares. Furthermore, new online communication technologies (including social networks) and mobile telephones have proved to be effective communication tools. However, their use was mainly limited to urban areas and was selectively directed to upper and middle-class people with a higher education. (PAHO, 2009).

Spokespersons

The countries adopted a 'single authoritative voice' to provide information to the media (Deirdre Hine, 2010), or different types of spokespersons who had credibility with the target population, that could help to transmit pandemic influenza messages (Public health agency of Canada and Health Canada, 2010; PAHO, 2009). Most states used their Chief Health Officers as their main media spokespersons, thus creating a natural link between decision-making and public communication responsibilities (Weeramanthri et al, 2010).

Targeting messages

Reaching a particular group is essential for an effective communication. In Sweden, a public opinion survey conducted during the pandemic found it hard to ensure that the message reached young people/young adults, and people whose mother tongue was not Swedish (Socialstyrelsen and Swedish Civil Contingency Agency, 2011).

Some countries use a *segmented communication* to meet the need of the different population targets or particular groups at risk, such as pregnant women, people with chronic diseases, and harder-to-reach communities or those with specific concerns (Deirdre Hine, 2010; CDC, 2010). The general public was reached through the dissemination of numerous print materials in multiple languages or by their active downloading from institutional or health authorities websites. For the CDC, special audiences were identified for additional print materials including Native Americans, African Americans, Hispanics, young adults, first responders, and healthcare workers (CDC, 2010).

Timely communication

One of the main lessons learnt was the importance of the strategies aimed at providing regular information on the latest developments of pandemic along with the public preventive measures. This has helped to prevent public panic and to promote personal protection against infection (Liang et al, 2012). Another important factor for an effective communication was the timely and a transparent provision of updated information in order to ease anxiety, and to successfully engage citizens in measures to curb the spread of the disease (Tay et al, 2010).

5.6 Planning communication

In many countries, a specific plan guided communications and social marketing response during the H1N1 pandemic (Executive office of the President of the US, 2009; Sweet, 2009; CDC, 2010; Public health agency of Canada and Health Canada, 2010; Deirdre Hine, 2010; Van Tam et al, 2010). It

clearly appeared that, without key activities such as media training and the creative development of an advertising campaign, it would have been very difficult to launch any effective campaign.

In general, during the first phase of communication, the strategy intended to promote infection prevention behaviours including: frequent hand washing, coughing into one's arm and not one's hand, staying home if sick. These messages were later complemented with personal preparedness and immunization information.

In some cases, a general plan was prepared including different responses and communication strategies based on different potential scenarios of the pandemic evolution in order to ensure preparedness and to cover a variety of contingencies (Executive office of the President of the US, 2009; Socialstyrelsen and Swedish Civil Contingency Agency, 2011).

On the other hand, in the case of the 2009 H1N1 pandemic, it was observed that the absence of a comprehensive and coherent communication strategy created confusion and lead to a loss of credibility among the stakeholders and public alike (Van Tam et al, 2010).

5.7 Areas for action

The expert reviewers (WHO Europe, 2010) found that the 2009–2010 response in the European Region suffered from some problematic areas and thus required stronger emphasis on the following main issues:

- Risk communication in general, especially regarding vaccination
- Vertical communication within the healthcare system (with greater emphasis on frontline healthcare workers)

During the pandemic the communication strategies were designed on the premise of the 'reasonable worst–case'. This assumption meant that there was an obvious gap between what the government was saying and what was observable on the ground, namely that the disease was mild in most cases and that mortality levels were low. "This gap could have risked damaging the government's credibility and undermining public trust in the response" (Deirdre Hine, 2010).

In Switzerland, in order to raise public awareness, it was decided to adopt a communication strategy based on a worst case scenario. But due to the lack of coordination among the various stakeholders, within a relatively short time, the messages became confused. The delay in the delivery of the vaccine and the extensive academic discussions which took place about "which vaccine for whom?" were at the heart of this confusion. To complicate matters even further, the escalation phase then turned into a de-escalation phase; clear, credible communication became close to impossible (Van Tam et al, 2010).

In Australia, communication became inconsistent partly because different parts of the country went through the pandemic at different times and officials had been faced with the challenge of adjusting the response to cope with an infection that had not been as dangerous as the worst case scenario expectations that underpinned planning (Sweet, 2009).

Internal communication

During a pandemic, a strong effort to coordinate information across different levels is needed. However, there were cases where contradictory or slightly different messages were communicated based on national, regional, and local level, but also among countries and International agencies. These differences led to confusion amongst the population about whose advice to follow during the pandemic. For example, while the advice of the Public Health Agency of Canada was based on the best scientific evidence available at the time, the application of this advice varied across the country due to differences in provincial legislation and policies. Only during the second wave, did the federal and provincial/territorial governments collaborate on positions on masks and gloves and tried to take a collective decision so that all were approaching the issue in the same way (Public health agency of Canada and Health Canada, 2010).

Communicating risk and uncertainty

For a long time, there was considerable uncertainty about the pandemic's development and impact. The government, together with the devolved administrations, was in a challenging position of simultaneously asking the health services to prepare for the worst, while trying to reassure the public and accurately communicate the level of risk.

The problem of communicating uncertainty, risk and shifts in scientific thinking is not limited to the public or other external stakeholders. It is also problematic when communicating findings, evidence and processes to decision makers and decision influencers (such as national agencies at regional or local level) trying to ensure the approval of messages to be communicated to the general public.

In a crisis situation it is important to follow the communication principles which emphasize a focus on transparency and acknowledge uncertainty as well as the commitment to frequent updates if new information emerges. Empathy and openness are key components of message delivery and can even help to sustain the credibility of the investigation and response, even when information is limited and there are more questions than answers available (Schuchat et al, 2011). Furthermore, the best practice in communicating risk underlines the importance not just of openness but also of transparency in the way in which assessments are made and decisions are taken (Deirdre Hine, 2010).

Flexibility of communication

In unpredictable situations, plannned statements should be very quickly revised, and the strategy, messages and materials should be promptly adapted to fit the circumstances (Deirdre Hine 2010).

Proactive and assertive communication

The results of the reviewed papers highlighted that the agencies could have been more proactive in identifying and challenging inaccurate information and in responding to concerns and misunderstandings. A more aggressive communication campaign focused on dispelling concerns that the vaccine was not safe and had been rushed into production without the usual rigorous testing and licensing may have helped uptake rates. Communication with sections of the public that expressing particular concerns may also have been useful, and would have played an important role in tackling rumours and misunderstanding. (Deirdre Hine, 2010).

Targeting messages

Most communication activities targeted the general population with guidance for specific populations coming later in the process. While a broad communication strategy is essential in keeping citizens informed, a more targeted approach may also be necessary to ensure higher risk groups or vulnerable populations to receive the timely and specific information necessary to respond to the pandemic (Public health agency of Canada and Health Canada, 2010; Deirdre Hine, 2010). Agencies must also acknowledge that population segments are different and need to be involved in both the development and management of pandemic response initiatives, appropriate for different communities and sensitive to existing cultural practices (Gray et al, 2012).

Also, public health messages are often subject to differences in interpretation that can vary considerably according to individual perception of the risk and trust in the government as well as according to different abilities to understand and interpret data and information, especially in the context of uncertainty (Van der Weerd, 2011; Kiviniemi, 2011). During the H1N1 pandemic public health agencies faced these kinds of challenges in their efforts to provide clear information and advice to the public while at the same time balancing what was known and not known on the outbreak. Public health officials faced with the task of disseminating infection control messages to the public in the context of sustained media coverage also oftenhad limited knowledge about how the information would reach the population and the population's ability to learn and act upon it. Under these circumstances, public officials in both the U.S. and abroad had no choice but admit the lack of science supporting policyrecommendations and modify such recommendations once more evidence became available (Fogarty, 2011).

New and social media

The 2009 H1N1 was "the first pandemic with a blogosphere and other rapid communication tools that were impossible to ignore" (ECDC, 2010). New and social media were used both to disseminate information and to monitor the issues of concern of the population, with the aim, for example, of identifying the concerns that pregnant women had about vaccination. Their use was different among countries but the CDC provided best practice examples of how social media can be employed during a pandemic. In the UK, Facebook, Twitter and YouTube were primarily used to re-direct people to National Health Service website rather than to engage in discussions (Deirdre Hine, 2010). However, in other countries the use of new media, and social networks in particular, was limited. For the future, the WHO declared that the use of new information technologies, including social networks, should be an essential part of a strategic communication planning, including research, training and guidelines for Member States (WHO, 2011).

Communication with the media

Different National Health Agencies started to consider that journalists need to be engaged in a more proactively way, these could include disseminating transcripts of media briefings, using podcasts and making more use of social networking and digital technology.

5.8 Recommendations from WHO expert reviewers

The expert reviewers (WHO Europe, 2010) evidenced that in the European Region there is a need for an effective communication among healthcare professionals, the public and other stakeholders . The areas that must be further implemented or developed were identified from the following critical points:

- Providing guidance on strategies for effective communication to the public, which include training needs of ministry spokespersons
- Developing indicators to monitor the extent to which the information received by healthcare professionals is appropriate and useful

Regarding risk communication capacity:

- General strengthening of risk communication capacity and capability at the national, regional and local levels is needed
- The communication on the criteria for the transition between the phases (e.g. geographical spread versus the severity of disease) needs to be improved
- Needs for a rapid information flow from national to regional levels, including outbreak investigation findings, surveillance data, etc. to ensure a timely response

A very critical issue was identified to be the communication about pandemic vaccines:

- It is important to communicate to healthcare workers and the public the efficacy and safety of vaccines in countries that have access to the vaccine in a unified and effective way
- Campaigns on vaccine efficacy and safety need to be more aggressive and run in a timely manner, e.g. before vaccine arrival
- Awareness and effective use of new information technologies and media (e.g. social media) is essential through the provision of training, guidelines and research

In this scenario and for the future, the role of International agencies, such as the WHO, but also national agencies like the CDC, was fundamental to improve communication during crisis, in particular:

- To support the development and reinforcement of risk communication networks
- To revise the pandemic guidance with respect to the phases
- To improve flexibility of guidance by providing multiple planning scenarios (e.g. mild/severe situations) and clearer guidance on actions required and dependent upon possible different situations faced at regional level

Furthermore, this expert review suggests that there are common thematic elements that should be considered as essential by individual Member States when revising, re-formulating or updating national pandemic plans (and associated preparedness activities) during the post-pandemic evaluation period. These are:

- **C**ommunication
- **C**oordination
- **C**apacity
- **A**daptability (flexibility)
- **L**eadership
- **M**utual Support

CALM

CONCLUSIONS

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 centres, on-line response capacities, NGO 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 issue 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 news 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) (Eysenbach, 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 uses 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.

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APPENDIX 1

Table 1. Factors associated to protective behaviour among general population.

	Behaviour				
	Hand washing	Avoiding crowded places	Wearing mask	Quarantine	Vaccination
Variable	n/N	n/N	n/N	n/N	n/N
Older people	9/10	4/4	5/6	no association	9/13
Women	13/14	1/2	8/12	1/1	Na 7/9
High educational level	5/7	3/3	8/10	2/2	controversial
Unemployed people	2/2	2/2	..Ns	Ns	Ns
Perceived susceptibility	12/15	4/4	7/7	2/2	10/12
Perceived severity	3/5	3/3	1/2	Ns	9/12
High level of anxiety	5/6	2/2	2/2	Ns	Ns
Perceived efficacy of behaviour	4/4	2/2	1/1	1/1	Ns
Perceived self-efficacy	3/3	Ns	2/2	Ns	Ns

	Behaviour				
	Hand washing	**Avoiding crowded places**	**Wearing mask**	**Quarantine**	**Vaccination**
Variable	**n/N**	**n/N**	**n/N**	**n/N**	**n/N**
Trust	4/4	Ns	Ns	Ns	5/5
Knowledge	5/5	Ns	Ns	1/1	2/3
Uptake seasonal influenza vaccine	Ns	Ns	Ns	Ns	13/13
Primary care physician as source of information or advice from	Ns	Ns	Ns	Ns	6/6

N= number of studies where the effect of the variable on the behaviour was investigated; n= numbers of studies where a positive association between the variable and the behaviour was observed.
Na=where n/N refers to a negative association; Ns=where the association between the variable and the behaviour was not investigated.

Table 2: Summary of factors associated with the compliance with influenza vaccination by target group

Target group	Compliance characteristic	Positive factors associated with compliance	Negatively factors associated with compliance
Health care workers	• Compliance varied from very low (less than 10%) to around 40-50% • Compliance varied widely between and within countries • Compliance varies widely by professional category	• Self-protection • Desire to avoid infecting patients • Desire to protect family members • Perceived safety of the vaccine • Perceived efficacy of the vaccine • Perceived seriousness of disease • Perceived risk of the disease • Perceived seriousness of complications from disease • Access to vaccine • Cost of vaccine	• Fear that vaccine could cause disease
Elderly	• A trend towards increasing compliance rates among those over 65 years of age	• Number of visits to a physician during the year	• Disbelief in the efficacy and safety of the vaccine • Fear of side-effects or influenza resulting from the vaccine
Chronically ill	• Compliance is greater than for healthy people • Compliance is increasing over the years • Compliance in Europe is relatively low • A wide difference in compliance of people with different diseases	• Number of physician visits and acceptance of their advice	• Fear of side effects • Disbelief in vaccine efficacy

Target group	Compliance characteristic	Positive factors associated with compliance	Negatively factors associated with compliance
Pregnant women	• Compliance tends to be better with seasonal influenza vaccines than with pandemic vaccine • Compliance with seasonal influenza vaccination in the U.S. is increasing yearly	• Health care provider recommendation	• Lack of knowledge of the importance of vaccine and where to get it • Concerns for the effects of vaccine on foetal and maternal health
Paediatric population	• A big difference in compliance between different countries and over the years • Compliance of chronically ill children is greater than that for healthy children • Relatively high percentage of children getting only one dose of the vaccine	• Child's influenza vaccination in previous year • Child's receipt of all recommended immunizations • Child's uninterrupted health insurance coverage • Mother's marital	• Using a family doctor rather than a paediatrician • Parents belief that the vaccine was unneeded or that the child was getting too many shots • Parents having a hard time obtaining the vaccine

Table 3: Factors associated with the type of communication

Negatively Influencing Factors	Positively Influencing Factors	Outcome Variables	Type of Communication or Population
Mass Communication	Construction of Influenza in Mass Media Patients behaviour in result of coverage in mass media Vaccination Compliance Risk perception of viewers Uses and Gratifications of health media use Trust	Positive framing of influenza pandemic Using active communication channels High Media Skills Strong relations between journalists and societal roles Consuming variety of communication channels	Negative framing of Influenza Pandemic Low media skills Communication Uncertainty
New Media	Self and Collective efficacy Patients' behaviour Risk Perception Attitudes Vaccination Compliance	High Internet Use Good adaption of Web 2.0 Technologies Active Communication channels Healthy Behaviour Strong ties between sender and receiver - High Interactivity	Bad adaption of Web 2.0 Technologies Unhealthy behaviour Low Interactivity
Personal Communication	Vaccination Compliance	Reminders Written Policies	Fear of side effects
Social Marketing	Trust Affect Barriers Fear Arousal & Appeal Vaccine Compliance Perceptions towards vaccines	Opinion Leaders in the community Healthcare workers recommendations Behavioural-inhibition system PSA's Personal Tailored Message Empathy	Lack of physician recommendations Mistaken assumptions Lack of adequate information Public Anxiety & Panic

Negatively Influencing Factors	Positively Influencing Factors	Outcome Variables	Type of Communication or Population
Risk Communication	Behaviours Risk Perception Knowledge Fear Arousal Vaccine Compliance Attitudes towards influenza vaccination	Targeted communication messages Education	Attitude towards the government Mistrust Ethnic Minorities
Public Participation	Healthcare workers compliance Risk Perception Vaccination Compliance	Opinion Leaders Community Engagement Healthy Behaviour	Emergency Situations Unhealthy Behaviour
Health Experts Participation	Vaccination Compliance Behavioural Responses Barriers Risk Perception Attitudes	Incentives & Sanctions High Self Efficacy Good Public Image High Peer-Review Feedback Organizational informative nature	Low Self Efficacy Bad Public Image Low Peer-Review Feedback
Communication Experts Participation	Risk Perception Information Management	Strong ties between sender and receiver – High Interactivity	Low Interactivity