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Wissenschaften Hamburg**

Hamburg University of Applied Sciences

Master Thesis

**Risk Communication during the A (H1N1) 2009
Influenza Pandemic in Europe: Avoiding
Communication Problems during future Pandemics**

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September 2013

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1. Abbreviations

IHR- International health regulation

PHEIC- Public health emergency of international concern

WHO- World Health Organization

USA- United States of America

ILI- influenza-like-illnesses

ECDC- European centre for disease control

CDC- Centre for disease control

ARI- Acute respiratory infection

EU- European Union

EEA- European Economic Area

EWRS- Early warning and response system

EMA- European medicines agency

SARS- Severe acute respiratory syndrome

EC- European commission

UK- United Kingdom

CERC- Crisis and emergency risk communication

HBM- Health belief model

PAHO- Pan-American health organization

GPs- General practitioners

HCWs- Health care workers

MOH- Ministry of health

2. Introduction

According to the WHO, the A (H1N1) 2009 Influenza Pandemic (also known as the Swine flu) was the first influenza pandemic in the 21st Century (1). Historically, pandemics have been experienced for over hundreds of years. With an estimated 1-50 million excess deaths during these periods the 1918 Spanish influenza, the 1957 Asian influenza and the 1968 Hong Kong influenza were the best-documented pandemics of the 20th century (2). The International Health Regulations (IHR 2005) that entered into force in 2007 was tested for the 1st time following a Public Health Emergency of International Concern (PHEIC) affecting multiple Countries and regions. The A (H1N1) 2009 influenza pandemic transpired against a background of vigorous Pandemic Preparedness Planning and Responses (including simulations, communications strategies etc.) at Local, State, National and International levels.

As early as March 2009, the government of Mexico had reported cases of Influenza-like-Illnesses (ILI) in different regions of the Country. By the 23rd of March, there were over 854 cases of Pneumonia and 59 deaths from the Capital (3). Cases were also reported in Southern California (USA). The Scientists from the Centre for Disease Control and Prevention (USA) were the first to detect the emergence of the novel influenza virus 2009 (4). On the 25th of April 2009, the Director General of the World Health Organization (WHO) under the advisement of the Emergency Committee called under the rules of the International Health Regulations and declared the ongoing event as a Public Health Emergency of International Concern (5). The ensuing chain of events following this announcement occurred really fast. On the 27th of April, the WHO Director-General raised the level of influenza pandemic alert from level 3 to 4 citing that the likelihood of a pandemic has increased (6). On the 29th of April, the alert phase was further raised to level 5 because of the A (H1N1) influenza virus capacity to spread rapidly in every country of the world (7). And on the 11th of June 2009, following the confirmation of nearly 30 000 cases in over 74 different countries the WHO further raised the pandemic alert level to 6 (8).

The spread of the virus was impressive. By November 2009, more than 206 countries and oversea territories had reported laboratory-confirmed cases plus over 6520 deaths (9). In the United States alone, the CDC estimated that the A (H1N1) 2009 virus caused illness in more than 60 million Americans, 270 000 hospitalizations and nearly 12 500 deaths (4). In Europe so many cases were reported even though it was challenging to say for sure if they were attributable to the H1N1 2009 or to influenza-like-illnesses (ILI). The first confirmed cases in Europe (Spain and the UK) were seen in Travelers returning from Mexico, but the virus did go on to spread to other EU/EEA countries. According to data from the report of the European Centre for Disease Control (ECDC), 925 861 reported cases (27 reporting EU countries) of ILI and 7 202 014 cases of Acute Respiratory Infections (ARI) were reported during the official pandemic period of 68 weeks (10). A total of 2290 deaths were reported in Europe from April 2009 to January 2010 according to the ECDC epidemiological daily update (11).

Following the emergence of a novel influenza virus and the rapid push-up of the pandemic alert level by the WHO to level 6, the pre-planned responses and management systems of many countries was set in motion. During the early phase of

the pandemic most countries implemented the “containment/delaying” management strategy, which included the use of antiviral drugs for early treatment and prophylaxis; isolation of close cases; and quarantining of their contacts. Meanwhile for the peak phase, the measures were changed towards a “mitigation” approach, which meant recommendations of personal protective measures like; frequent hand washing, covering the mouth when coughing and social distancing (12).

The pandemic response within the European Union and the European Economic Areas (EU/EEA) during the 2009 H1N1 influenza pandemic was chiefly the responsibility of individual EU/EEA countries with the European Commission playing the role of coordinating the management efforts within the European Union (13). Since the virus was not widely spread within Europe from the beginning of the pandemic, vital information regarding the “known unknowns” (severity, particular risk groups and antiviral susceptibility) was lacking. So the initial response included but was not restricted to information gathering from the first affected countries in Europe (the UK and Spain), science watch and media monitoring (13). The European Centre for Disease Control (ECDC) also activated its Epidemic Intelligence that covers all activities related to the early detection of health threats, their verification, assessment and investigation as a basis for recommending control measures (14). Other measures undertaken are agreement within the EU/EEA countries upon a uniform case definition; case-reporting system within the European Commission’s Early Warning and Response System (EWRS); the provision of a platform for the surveillance of virology, morbidity and mortality; and supporting the health security council in developing recommendations on schools closure, travel advices and target groups for vaccination (13).

Vaccine production only began during the post pandemic phase and was facilitated by the cooperation and exchange of information between the Mexican authorities and the Centre for disease Control and Prevention (CDC) in the United States (3). The A/California/07/2009 is the name given to the virus that was subsequently isolated by the CDC (15). Diagnostic tests was rapidly developed and disseminated to all European countries and to the rest of the world (13). As of 19th July 2010, 38.6 million people (or 42.6 million if people vaccinated with nationally authorized vaccines are included) had been vaccinated with one of the three centrally authorized vaccines in the EU/EEA countries. Hungary using its domestically produced Fluval P vaccine became the 1st EU country to start vaccination. The first three mock-up vaccines authorized by the European Medicines Agency (EMA) are Celvapan, Focetria and Pandemrix, followed by Arepanrix and Humenza (authorized through the emergency procedure) (16). Other vaccines used within the EU countries include; Panenza in Germany, France, Belgium, Italy, Luxembourg and Spain; PanVaxH1N1 in Germany; and Celtura in Switzerland and Germany (13). The WHO also handled the deployment of the pandemic (H1N1) 2009 vaccines that was donated by countries and vaccine manufacturers (1).

Risk communication plays a vital role in the handling of Pandemics and other crisis situations (natural disasters, outbreaks, chemical and nuclear disasters) in that effective risk communication can mitigate fears and even influence desired behavioral modifications among a population. According to a literature review published by the ECDC, “effective risk communication is essential to limiting morbidity and mortality caused by communicable diseases, in addition to minimizing damages that communicable diseases can cause to national economies and public health

infrastructure” (15). Being a pandemic of the Internet age in which the access and exchange of information is just a click away, the public were faced with the dilemma of multiple sources of information (print media, social media, internet, TV etc.), which would not have been the case a few decades ago. Furthermore, the high rate of movement of people, animals, goods, and the porosity between borders presented huge problems in dealing with the A/H1N1 2009. Thus, Poorly planned risk communication in this context will eventually lead to negative reactions from the public, disorganized response to the pandemic, and unwillingness by the public to implement official recommendations (17). The ECDC report described the activities of risk communication as one that is carried out with the aim of providing the public with meaningful, relevant, accurate and timely information in relation to health risks in order to influence choice (15). In other words, the process of risk communication through every phase of an outbreak/pandemic has to be a dialogue between involved parties regarding the risks involved rather than advocacy coming from the part of the authorities which preys on the fears of the public in order to persuade them to take action (18).

Pandemics are shrouded by uncertainties, whereas risk communication is about communicating these uncertainties (or known unknowns) to the public, healthcare workers and the relevant stakeholders. Thomas Abraham stated in his report that “any measures taken to mitigate future risks, whether a pandemic or natural disasters, have to be based on shared understanding between those who have the technical and scientific knowledge of the risk and those who have to bear the risk, and take actions to mitigate it”. He further mentioned “this can only happen through a two way exchange of information that will contribute to a public understanding of the risk” (17).

Trust is regarded as an important element of risk communication. Public trust in institutions is essential to the management of a pandemic, but in societies where trust in the political and medical authorities is on the decline, it becomes a predictor of compliance with officially recommended protective measures and even vaccination behavior (19). Thomas Abraham in his review on lessons learnt from the pandemic reiterated that “if one of the aims of communication is to build a common understanding between the health agencies and the public, then low-vaccine uptake, allegations of collusion between health agencies and the pharmaceutical industries, and allegations of the pandemic being a fake pandemic reflected failures in communications” (20). Lack of trust in authorities as a result of past experiences and dissonance of information between messages passed by the authorities (through the media) which was counteracted by daily personal experiences can also affect the perception and ultimately the behavior of the public as shown by a study among the French adult population (21).

Personally, I think the best thing about the A (H1N1) 2009 influenza pandemic is that it was not the pandemic the world was told to expect. It wasn't as severe as its predecessor from 1918, nor was it as fatal as governments, the media and the public health institutions had promised (worst-care-scenarios). Nevertheless, for the time it lasted (from the pre-pandemic to the post-pandemic phases), it exposed weaknesses in the response systems of various countries, organizations and even the practice of risk communication per se. This dissonance might have weakened the trust between the public and the authorities, raised doubts about the vaccine safety and the true intentions of the big pharmaceutical companies and eventually lead to lack of compliance to recommended protective measures and vaccine uptake.

At this junction, the questions lurking at the back of my mind are, what really is an effective risk communication? At what point during a pandemic/outbreak does risk communication reach its limit? And what becomes of it at this juncture? There is a considerable amount of research and literature reviews regarding risk communication, but will it suffice to say that the theoretical aspect of risk communication is only a shadow of what happens in reality? Were the frontline public health officials overwhelmed by their workload, multiple sources of information, frequent updates and constantly changing guidelines? Did any of the stakeholders (physicians, minority groups, the vulnerable and high risk groups) feel left out in the risk communication processes? And with the memory of the 2003 SARS outbreak still fresh in mind, was that not enough to prepare the world for the A/H1N1 2009 influenza in order to avoid a repetition of previous mistakes in regards to risk communication?

This master thesis will look at the A/H1N1 2009 pandemic in Europe through the eyes of a group of stakeholders (mainly the officials in public health agencies, health care workers, front-line physicians etc.) in order to gather qualitative as well as quantitative information on their perceptions and perspectives in terms of the difficulties they faced during the management of the A/H1N1 pandemic and their wishes with respect to the function and flexibility of what effective risk communication tools should be able to accomplish.

My thesis is part of a Work Package (A/H1N1: Time dependent influences of epidemiology and risk communication on human behavior) in an ongoing project funded by the European Commission (EC) titled “**Effective Communication in Outbreak Management: Development of Evidence-Based Tool for Europe**”. The main goal of this thesis is to develop a Questionnaire directed towards the above-mentioned stakeholders in Europe, whose knowledge and attitude regarding preventive measures (vaccination, antiviral treatments and non-medical interventions) may have an influence on the decision making of the general public. Moreover, they play a vital role in communication during outbreaks because they are usually the first point of contact for members of the public. They are also considered to be role models, a source of relevant information and a potential source of transmission of infections. Data collected through this Questionnaire will be used to inform decisions and policies for better management and response to future major epidemic outbreaks in Europe.

3. Risk Communication (in the Public Health context)

This chapter will shed light on the generalities about risk communication but will be mostly focused on the public health aspect of it. Risk communication has come a long way, before and during the 1970s the public was satisfied in letting the authorities handle emergency or crisis situations. They were not involved in any of the decisions/policies in regards to matters that might have negative health effects on them. But it all took a different turn in the 1980s and that was how risk communication was born (22).

From the public health point of view, communicating risk has been resourceful in motivating people to (1) quit smoking, (2) use their seat-belts while driving, (3) evacuate homes during emergencies, (4) avoid drinking and driving, (5) avoid living under power lines, (6) avoid living near power plants, and (7) become aware of passing on genetic risks (22). As mentioned in the introduction, the idea behind risk communication is pointing out potential health hazards to the public in order to motivate them to take actions. However, the reaction of the public is as important as other aspects of risk communication. According to Covello and Sandman “there are many risks that make people furious even though they cause little harm and others that kill many, but without making anybody mad” (22). An effective good risk communication is judged based on its potential to meet the needs of all the segments of the population especially the vulnerable groups, and its ability to gear the public towards actions.

3.1. Definitions

The ECDC report defined risk communication as “the exchange of information about the health risks caused by the environmental, industrial or agricultural processes, and policies or products among individuals, groups and institutions” (15).

Barbara Reynolds book on Crisis and Emergency Risk Communication (CERC) described risk communication as “a discussion about an adverse outcome and the probability of that outcome occurring”. It further stated “through risk communication the communicator hopes to provide the receiver with information about the expected type (good or bad) and magnitude (weak or strong) of an outcome from a behavior or exposure” (23).

3.2. What are the rationale for risk communication?

In an era of a rapidly industrialized and globalized world, the need for a well-planned and adequate response to any type of health emergency/pandemic/outbreak remains a top priority to the delegated authorities responsible for the management of such events. The rationale behind risk communication includes but is not restricted to:

1. Emergence of new diseases
2. High rate of international travel
3. Aging population

4. Climate change
5. High population density in high-risk areas
6. Increased technological risks
7. Re-emergence of diseases and Antibiotics resistance (23)

3.3. Theoretical models of risk communication

A quick overview of the four theoretical models of risk communication described by Covello et. al in 2001 will be discussed in this section. According to them, risk communication is based on the following four models: mental-noise, negative dominance, trust determination, and risk perception. I will be discuss each of them shortly but will go more in-depth in regards to risk perception by linking it with the health belief theory model.

3.3.1 The mental noise model: this model states, “When people are in a state of high concern because they perceive a significant threat, their ability to process information effectively and efficiently is severely impaired” (24). This inability to effectively and efficiently process information could lead to charged emotions (fear, worry, anger outrage) which in turn makes it impossible to have a rational discussion with the individual as to how to confront the situation. This emotional state is what generates the mental noise described by Covello et. al (24). To this effect, it is important that effective risk communication be timely, accurate and easily comprehensible, contain repetitions, and must reach its intended audiences (15, 25).

3.3.2 The negative dominance model: this model is in line with a central theorem of modern psychology. The model holds that in an emotionally charged situation, people tend to put more value on losses and negative information or outcomes than on gains and positive information or outcomes. According to this model, negative information or outcome (over-dramatization by the media of affected persons during a pandemic, or negative information spread by anti-vaccination groups) tend to last longer in the minds of the public in comparison to positive information or outcome. Covello et. al mentioned “risk communications are most effective when they focus on what is being done rather than what is not done” (24).

3.3.3 The trust determination model: I mentioned earlier in my introduction that public trust in institutions is very important in the management of any pandemic. When the people feel the have been unfairly treated, exposed to threats, and lied to, their natural instinct will be distrust towards the authorities. Trust is achieved over time through actions, listening, and communication skill. But in situations where the trust relationship between the public and the authorities is badly damaged, the involvement of trustworthy third party sources and the use of the four pairs of trust determination factors (caring and empathy; dedication and commitment; competence and expertise; and honesty and openness) should be deployed in order to establish or maintain trust (20, 24).

3.3.4 The risk perception model: based on the cultural, linguistic, ethnic/racial, gender, and geographical differences seen around the world, it should make for easy understanding that the perception of risk will differ from region to region, person to person, and culture to culture respectively. These factors added to the risk perception factors defined by Covello et al. might alter the perception of risk to varying degrees (15, 24). Risks that are perceived to be manmade, permanent, involuntary, unfamiliar, exaggerated, unfairly distributed and out of control of the individual will certainly influence the individual's level of fear, anxiety, worry, distrust, anger, outrage, helplessness and compliance to officially recommended protective measures like frequent hand washing, covering the mouth when coughing, social distancing measures and vaccination uptake (15,23). For these reasons, studies, surveys, and focus groups might be useful at the early phases of a pandemic to gather information based on the perception of the public, and to use this data for effective risk communication (24).

The risk perception factors include:

1. **Voluntariness:** Risks from activities perceived to be involuntary or imposed (e.g., Exposure to chemicals) are less readily accepted than risks perceived to be voluntary (e.g., Not wearing the seatbelt)
2. **Trust:** Risks related to institutions/organizations that are not trusted (e.g., pharmaceutical companies and the vaccines during the A/H1N1 pandemic) are perceived to be greater than with risks related to credible and trustworthy institutions.
3. **Reversibility:** Risks perceived to have irreversible adverse effects are judged to be greater than risks considered to have reversible effects.
4. **Equity:** Risks perceived to be unfairly distributed (e.g., affecting only the poor or vulnerable populations) are less readily accepted than risks that are fairly distributed.
5. **Human vs. natural origin:** Risks that are of human origin are judged to be greater and less readily accepted than risks originating from nature.
6. **Familiarity:** Risks perceived as unfamiliar (e.g., the onset of a new viral pandemic) are deemed to be more serious and less accepted than risks that are familiar (e.g., the seasonal influenza)
7. **Victim identity:** Risks from activities that produce identifiable victims are perceived to be greater than risks from activities that produce statistical victims.
8. **Controllability:** Risks perceived to be under the control of others are less accepted than risks that are under one's control.
9. **Dread:** Risks that evoke fear, terror, worry, and anxiety among the public (e.g., Anthrax, HIV, Ebola virus) are judged to be greater than risks that evoke no such feelings.
10. **Uncertainty:** Risks perceived as relatively unknown are less readily accepted than risks that are already known to science.
11. **Media attention:** Risks that receive a lot of media coverage are perceived to be greater and more serious than risks that receive little or no media coverage.
12. **Ethical/moral nature:** Risks that are perceived to be ethically questionable or morally wrong are less readily accepted and perceived greater than risks that are not perceived as ethically questionable or morally wrong.

13. **Benefits:** Risks that seems to have unclear, questionable, personal or economic benefits are less readily accepted and judged to be greater than risks with clear benefits.
14. **Effects on children:** Risks from activities that affect children are judged to be greater than risks that do not.
15. **Catastrophic potential:** Risks that are perceived to be able to cause significant number of fatalities, injuries, and illness grouped in time and space are less readily accepted and judged to be greater than risks from activities that have random and scattered effects. (22,23,24,25)

Different health behavior models have also been used to shed light on the link between perception and the likelihood to take action, and one such cognitive model is the health belief model (HBM). According to the health belief model, behavior change of an individual in response to a threat is determined by the individual's perception of his/her vulnerability to the condition, the severity of the condition should he/her be affected, and the effectiveness and outcomes/benefits of the particular behavior or actions. These beliefs are also reinforced by stimuli also known as 'cues to action' that motivates the individual to adopt the new behavior or action. The triggering stimuli may be internal (being personally affected during a pandemic) or external (media reporting or affected close contacts). Another additional factor to this model is the individual's confidence in their capacity to take action otherwise known as self-efficacy (26,27).

Other factors known to indirectly influence an individual's perception include: the educational level; social variables; proximity to current outbreaks; and how the authorities handled the situation in previous outbreaks/emergency situation (26,28,29).

3.4. Outrage and Hazard in risk communication

Risk communication usually occurs against a background of high public emotions and questions as to who did what, why it happened, and what is being done to safeguard the public. The terminologies 'Outrage and Hazard' both refer to risk, but it's who uses it that makes the difference in the context of an emergency. Outrage is the public's definition of risk, while hazard is what the experts mean by risk. It suffices to say that outrage is the emotional measure of the risk and it is grouped into high/low outrage, while hazard is the scientific/technical measure of the risk, and it is further grouped into high/low hazard (22,25). In a typical high hazard/low outrage situation, the authorities are alarmed and doing their best to lure the public into action or raise their awareness as to the dangers or potential health effects of the situation, while the public's response is apathetic. The reverse is the case in high outrage/low hazard situations where the public is outraged while the experts are apathetic (30).

Evidently, high outrage also affects the perception of hazard as described by Sandman in the sense that when the public is outraged, then tend to erroneously perceive the hazard to be equally high (31). But irrespective of the situation (high hazard/low outrage or low hazard high outrage), risk communication has to be applied wisely to ensure proper management of the situation because outrage is as important as hazard. An expert might call the public ignorant, unreasonable and overly reactive in a low hazard/high outrage situation because to them a low hazard situation means low fatality, mortality, and morbidity. Nevertheless, in risk communications we must

always bear in mind that the public's definition of risk is far broader than that of the experts. What Covello and Sandman called "outrage factors/components" (also known as risk perception factors) which are very important in the determination of an individual's response to any public health emergency further explains this (22). These outrage factors include: voluntary versus involuntary, familiar versus exotic, fairly vs. unfairly distributed, controlled by the individual vs. controlled by others, reversible vs. permanent, well understood or self explanatory vs. poorly understood risks, human vs. natural origin, affecting children vs. affecting adults, and not memorable vs. memorable (22,23,25). The combination of the outrage factors plus hazard factors (mortality and morbidity statistics) is what makes up a person's assessment of a risk and whether or not he/she can accept it (22).

Efforts have to be made to reduce the measures of outrage (voluntariness, fairness, human origin etc.) as well as that of hazard because they both play significant roles during a pandemic. High hazards/ high outrage situations have to be managed appropriately, even though low hazard/high outrage problem is not considered seriously by the experts, effective risk communication should still be used to calm the fears, worry and anxiety of the public. According to Sandman "if your problem is outrage problem to begin with, outrage management is easier, cheaper and more effective than hazard management" (31).

3.5. Barriers to effective risk communication

Pre-planned risk communication messages are prone to unexpected surprises and difficulties right from the beginning or during different phases of a pandemic. For this reason, risk communication has to be dynamic, flexible, and adaptable in order to maintain public trust and support that is necessary for the management of the pandemic. In Europe for example with 25 official spoken languages, risk communication during the A/ H1N1 influenza 2009 pandemic could not have been without its shortcomings in terms of passing across messages that is suitable to every culture, region and population groups. Barriers to effective risk communication include:

1. Cultural and economic diversity (15)
2. Mixed messages from multiple experts (22,25)
3. Delay in release of information (25)
4. Paternalistic attitude of the experts/authorities (25)
5. Lack of trust in the government and public health system (20,22,32)
6. Uncertainties and incompleteness of data (22)
7. Selective media reporting (22)
8. Not countering rumors/misconceptions in real time (25)
9. Psychological and social factors which include: traditions; past experiences; poor health status; inadequate housing; poverty; overconfidence and unrealistic optimism by individuals; difficulty in understanding probabilistic information; public's desire for certainty; reluctance to change beliefs and practices; and the public's assessment of the risk (22,32)

3.6. Characteristics of an effective risk communication

According to a communication strategy report published by the Pan American Health Organization (PAHO), an effective influenza communication should do the following:

1. Inform and educate the public
2. Enhance knowledge and understanding
3. Establish and maintain trust and credibility
4. Position the organization/agency as the main source of information and expertise
5. Engage the public
6. Encourage collaboration and cooperation
7. Encourage constructive dialogue
8. Gain support for policies and plans
9. Create informed decision making
10. Address rumors and misinformation
11. Encourage appropriate behavior

Source: the PAHO/WHO regional office (33)

3.7. The Seven cardinal rules of risk communication

In 1998, Covello and Allen drafted the seven cardinal rules of risk communication that has become an important reference point in the field of risk communication owing to the fact that it can be used for both the public and private sector respectively. These rules are:

1. **Accept and involve the public as a legitimate partner.** Always bear in mind the people's right of involvement in decisions that might have effects on their health, values, and their communities.
2. **Listen to the public's concerns.** People are often more concerned about issues such as trust, credibility, control, benefits, voluntariness, empathy, caring, and compassion than about mortality statistics and quantitative details.
3. **Plan carefully and evaluate your efforts.** Different goals, audiences, and media will ultimately require different communication strategies. One must avoid the 'one size fits all' approach. An effective risk communication is dependent on careful planning and evaluation.
4. **Be honest, frank, and open.** Trust and credibility are important in any risk communication strategy and must be maintained at all cost.
5. **Coordinate and collaborate with other credible sources.** Collaboration between different sources can be effective in communicating risk, while disagreement between organizations and experts can make risk communication even more difficult.
6. **Meet the needs of the media.** The media are usually the main source of transmission of information during communications and the way they pass on this information can influence different outcomes. So they must be handled delicately.
7. **Speak clearly and with compassion.** Avoid the use of technical terms, jargons, and never forget to acknowledge an illness, injury or death as a tragedy. (34)

4. Methodology

4.1 Search strategy

In order to obtain published academic literature needed for the development of the questionnaire a number of databases and journals were searched, and they include: Pub med; the Cochrane library; Hamburg University of Applied Sciences (faculty of life sciences/Public health research); PLOS ONE; Google Scholar; the Journal of Public Health; British Medical Journal; and Elsevier. The reference list of the retrieved documents was also used to identify additional publications.

General Internet search (Google) was also used to obtain conference presentations, Country reports, papers, and other types of grey literature. Furthermore, specific website of countries/organizations was also targeted for publications/reviews: European centre for disease control and prevention; centre for disease control and prevention (USA); health Canada; health protection agency (UK); national collaborating centre for infectious disease (Canada), World health organization; and the national health services Scotland. The reference list of these documents was also consulted to further retrieve other publications.

4.2 Search Terminologies

The search terminologies used to obtain the literature included, but were not restricted to the following:

‘Risk communication and the A/H1N1/ pdm09’

‘Risk communication during the 2009 influenza pandemic’

‘Communication difficulties and the influenza pandemic’

‘Risk communication and the 2009 influenza pandemic: reviews, Europe, EU, Asia, Americas’

4.3 Inclusion/ exclusion criteria

The categories was formulated based on studies/reports/reviews published between the year 2000 and 2012, even though a majority of the studies was between 2009 and 2012. The studies had to be in the English language (websites like the ECDC and the WHO have their contents in English despite serving many non-English speaking countries in Europe). Emphasis was placed of studies looking at the European situation; nevertheless, no geographic restriction was placed on the literature search.

4.4 Categories and Questionnaire development

Following the selection of studies that meet the above-mentioned criteria, a table of categories was developed in order to give a clear view of the communication difficulties encountered by different stakeholders during the A/H1N1 2009 pandemic.

This tabulated categories was further used to develop a questionnaire that will enable the collection of qualitative as well as quantitative data from the target stakeholders (mainly in the health sector) regarding difficulties they faced with risk communication during the 2009 pandemic period.

5. Results

In total 25 studies from different countries/regions were used for the development of the categories (see Table 1).

Table 1. Number of Studies selected from each given Country or Region.

Country/ Region	Number of studies
Turkey	1
Netherlands	2
Italy	3
USA	2
Germany	4
Australia	1
Hong Kong	1
Japan	1
Asia	1
Greece	2
France	2
Worldwide (mostly developing countries)	1
Canada	1
EU 27	1
Germany/France/USA/Canada/Mexico	1
Australia/Canada/USA/Mexico/UK	1

Based on the information extracted from these studies, five distinct sets of categories were developed to summarize the difficulties/shortcomings of effective risk communication during the A/H1N1 2009 pandemic (see Annex for table with categories).

The following are the categories:

1. Vaccine Concerns

This category is based on the concerns and worries about the safety and efficacy of the vaccines as reported in the studies in regards to the vaccines and the vaccination campaign respectively, during the A/H1N1 2009 pandemic. Out of the 25 studies chosen, 17 of them reported various concerns that includes;

1. Fear of potential side effects from the use of the vaccines
2. Accelerated authorization procedure of the vaccines
3. Concerns regarding the safety and efficacy of the vaccines
4. The vaccines was inadequately tested before being pushed into the market
5. Skepticism regarding the necessity of vaccination since the A/H1N1 pandemic was not considered to be of a serious threat
6. Contents of the vaccines like Adjuvant and thiomersals (vaccine preservatives)
7. Distrust in vaccines
8. The apathetic attitude of the authorities in addressing the concerns of the public and health professionals regarding the vaccines

9. Disagreement with the recommendation of vaccination for non-traditional groups (e.g. Pregnant women)
10. Discrepancies between vaccine content for different groups

2. Trust Issues

This category covers issues relating to the level of openness, honesty and trust towards the government, public health experts, health authorities, pharmaceutical companies, and the media. The Trust issues were mentioned in 14 of the 25 studies. Their major trust issues reported in the studies include but are not limited to:

1. Distrust in the government
2. Trust in the ministry of health and institutional responses to the outbreak
3. Lack of trust in medical science and pharmaceutical companies
4. Questionable credibility of the sources of information as a result of multiple sources of information and contradictory messages
5. Unreliable scientific data
6. Distrust towards the media as a result of perceived overestimation/overhyping of the seriousness of the threat posed by the pandemic
7. Lack of transparency by the government
8. Lack of confidence in the vaccines by the health professionals
9. Distrust towards public health officials to provide correct information regarding the safety of the vaccines
10. Lack of openness and honesty by the government about issues related to vaccination

3. Communication difficulties

The communication difficulties category looked at risk communication in terms of timeliness, clarity, frequency and volume of information dissemination during the A/H1N1 2009 pandemic. These difficulties were mentioned in 23 studies. The following are the results on communication difficulties:

1. Messages/information/updates received lacked clarity
2. Multiple and contradictory sources of information.
3. Insufficient information on the benefits and possible side effects of vaccines
4. Overwhelming volumes of emails, daily updates, and guidelines
5. Information dissemination process was slow and lacked timeliness
6. Great difficulty identifying new information from the daily frequent updates
7. Poor communication strategies and vaccination awareness campaigns lead to low vaccination coverage
8. The authorities didn't do enough to counter the myths and misconceptions regarding the H1N1 2009 influenza modes of transmission and potential effective protective measures.
9. Poor co-ordination and communication between different stakeholders
10. Insufficient scientific data
11. Certain groups were inadequately targeted for vaccination
12. Difficulty in applying some of the centrally developed guidelines at the clinical/field level

4. Roles and Responsibilities

Mentioned in 15 out of the 25 studies used, this category is based on the roles and responsibilities of different stakeholders (the government, public health experts, frontline physicians, health workers etc.) in the management of the pandemic. It looks mainly at what was done or what should've been done. The results are as follows:

1. No clarity in the definition of roles and responsibilities of different stakeholders involved in the pandemic management
2. Paternalistic attitude of the government/health authorities/experts in handling the pandemic
3. Some stakeholders like the health care workers and frontline physicians did not feel engaged in the decision making processes
4. The knowledge and attitude of the HCWs posed a barrier to vaccination coverage because they were not rightly targeted in the vaccination campaign
5. Physicians and HCWs failed to act appropriately as role models to the public as a result of insufficient information/doubts regarding the safety and benefits of the vaccines
6. Unhappiness with the top-down management approach of the pandemic
7. Some HCWs were not aware of their potential roles in transmission of the virus and the impacts they might have through absenteeism

5. Resource Issues

Last but not the least this category was reported in only 9 of the 25 selected studies. It covered problems encountered during the pandemic period in terms of availability of vaccines, diagnostic tests and tool kits, human and financial resources. The reported issues include:

1. Logistic and storage difficulties
2. Not enough or in some cases no patient educational materials
3. Lack of a proactive reminder systems for the vaccination campaigns
4. Unavailability of specific diagnostic tests and tool kits in certain regions
5. Vaccine and antiviral shortages
6. Poor data management
7. Significant care burden on emergency rooms in health facilities
8. Lack of flexibility in responding to the needs of specific regions
9. Overwhelming workload in relation to pandemic activities

6. Discussion

The ultimate goal of my thesis is to develop a questionnaire which will be used to gather data from stakeholders in the health sector regarding problems they faced in regards to risk communication during the A/H1N1 2009 pandemic influenza and what they wish for during future pandemics. This data will be used to make informed decisions for the management of future pandemic. But in order to realize this, I had to first analyze relevant studies published during the A/H1N1 2009 pandemic influenza period, extracted what were the trending risk communication difficulties, and organized them into different categories. This was presented in my results section.

6.1. Vaccines and infectious disease outbreaks

Vaccines are considered the gold standard therapy for managing infectious disease outbreaks. The announcement of the isolation and subsequent development of a vaccine against a virus during an outbreak gives governments and health authorities across countries and regions a glimmer of hope that help is finally on the way. But this supposedly good news is usually met with mixed feelings from different stakeholders.

My results on vaccine concerns outlined the fear of potential side effects; the accelerated authorization procedure; concerns regarding the safety and efficacy of the vaccines; worries that the vaccines was inadequately tested before being introduced to the market; skepticism regarding the need for vaccination since the pandemic was relatively mild; contents of the vaccines (adjuvant and thiomersals); distrust for vaccines; the attitude of the government and health authorities in addressing the concerns about the vaccines; disagreement with the recommendation of vaccination for non-traditional groups; and discrepancies in the content of vaccines for different groups as the major difficulties that plagued the vaccines and vaccination respectively during the A/H1N1 2009 pandemic influenza (35,36,37,41,42,43,44,50).

Vaccines are important to any health authority for the management of an outbreak, but the development of vaccines and or having vaccination policies is no guarantee that all the stakeholders will equally accept it, or that a high vaccination rate will be achieved. Countries might have similar vaccination policies but their vaccination coverage is never similar (58).

Other noteworthy findings regarding vaccine concerns that could eventually affect the acceptance of vaccination are:

(1) **The nature of the vaccination campaigns** (41,42,43,44,46,49). This is where the integrity of the government and health authorities comes into question. Vaccination campaigns are not just for the announcement of the availability of vaccines and the priority groups among the population that should be vaccinated. But it should also be effective in mitigating the worries and concerns of the general public regarding the vaccines. This can only be achieved through robust awareness campaigns that can provide frequent updated information and scientific data about the safety, necessity and potential side effects of the vaccines (59).

Targeting frontline healthcare workers and physicians is also another measure that should be deployed in order to mitigate vaccine concerns from the part of the public and ultimately boost vaccination coverage. This is in line with the result of a study in France, which mentioned that the use of vaccination centers instead of the general practitioners might have caused a decrease in vaccine uptake (21). Another study from Australia also pointed out that one of the reason for a low vaccine uptake was because the general practitioners did not offer it (60). Physicians are role models and a credible source of information to the general public, so campaigns that focus on them could prove beneficial in the management of any outbreak. This is also in line with other studies that prove that advice from a GP is linked with a higher uptake of vaccination and reduces the worries, concerns and fear regarding the vaccines (39,44,21,61,62,63).

(2) The perception of the risk of A/H1N1 influenza pandemic. My findings suggest that risk perception of different stakeholders regarding the pandemic might have affected their attitude towards the vaccines and their intention to get vaccinated (37,42,44). Among the concerns mentioned are that the pandemic posed no serious threat and therefore didn't warrant the need for vaccination (50,51,53,54,43); another issue is that some members of the public didn't feel they were part of any risk groups and so didn't think they were at risk of being infected with the A/H1N1 virus (56). This perhaps might be explained by the excessive misconceptions about the vaccines and the seriousness of the pandemic in general (45), and also the extensive media coverage and debates in the media between experts and politicians alike about the pandemic and the vaccines might have also played a part (43,44,64,65). My findings correlates with other studies carried out during the 2009 pandemic influenza period confirming that there is a strong correlation between the risk perception of the A/H1N1 influenza pandemic and the acceptability of vaccination among the population (51,66,67). Furthermore, efforts have to be undertaken to ensure that attention-seeking politicians/groups and the media do not hijack the pandemic for their personal agendas.

Vaccine concerns can pose a barrier to vaccination. Thus in future pandemics the goal of the government and the public health authorities should be the reassurance of the public and health professionals about the safety of the pandemic vaccines through robust educational campaigns, provision of reliable scientific data, counter misconceptions about the vaccines in real time, and the inclusion of front line physicians and healthcare workers in their campaigns and decision processes. Surveys should also be done from the onset of every outbreak/pandemic in order to gather data from the public based on their perception of risks and to what extent these factors affects them in order to ensure effective communication.

6.2. Trust and the public response to a pandemic

Building and maintaining trust and credibility is one of the baseline characteristics of effective risk communication in the event of an outbreak/pandemic (33,34). The trust of the public cannot simply be demanded; rather it can only be achieved over time through actions, listening and good communication skills (20,24).

My results mentioned the following as the most relevant trust issues during the A/H1N1 2009 influenza pandemic: distrust in the government; trust in the ministry of health and institutional responses to the outbreak; lack of trust in medical sciences and

pharmaceutical companies; questionable credibility of the sources of information; unreliable scientific data; distrust towards the media; lack of transparency by the government; lack of confidence in the vaccine; distrust towards health officials to provide correct information regarding the safety of the vaccines; and lack of openness and honesty by the government (36-40,43,44,48-50,53-55).

These findings suggest that the trust of the public during emergency situations like the A/H1N1 pandemic plays a vital role in respect to the outcome of the pandemic management. In emergency situations where the trust of the public is on the low, there is the risk that compliance with recommended protective measures and even the uptake of vaccination will be severely affected. This is in line with the result of a study among the Swiss public showing trust as a predictor of vaccination behavior (19). In the light of other published articles, it has been shown that the public's trust in the government and public health authorities correlates with a high perception of self-efficacy (28,29) and low perception of risk (45).

There were many reasons for the lack of trust during the A/H1N1 2009. These could be partly explained by: the disagreement in the media among experts and the public's perception that the media is either overhyping or downplaying the pandemic (43,51,64,65); insensitivity of risk management authorities to the need for listening, dialogue, and public participation; unwillingness to acknowledge risks; Accusations of affiliations between public health experts and pharmaceutical companies; unwillingness to coordinate, disclose or share information; and irresponsibility or negligence in fulfilling risk management responsibilities (20,24,69). Other studies have also shown that past experiences of the public with the government could either build or weaken trust (19,21,28,29). Thomas Abraham described two situations that could lead to lack of trust; (1) a situation in which lack of trust is based on the perception that the authorities have knowledge and competence but are not fair; and (2) a situation in which the authorities are perceived to be fair and honest but lack openness (20).

My most important observation is that the majority of the literature published on building and maintaining trust during a pandemic applied only a holistic approach in tackling the issues of trust. In other words, it looked at the population in its entirety, while there are only a few studies looking at how to win the trust of specific subgroups within the general population (17). Am very convinced that a "One size fits all" approach cannot be effective in reaching out to these traditionally hard to reach groups as a result of their beliefs, cultures, practices, previous experiences with the authorities, and perhaps the perception of being socially marginalized. Governments and public health authorities need to have a flexible and inclusive campaign in order to win their trust. More research is needed to gather data on the determinants of trust within these groups. Information of this sort can have added benefits in the fine-tuning of pandemic preparedness and responses.

Although trust is an important component of any pandemic management (68), recent controversies over the management of the A/H1N1 pandemic may have done more damage to the credibility of governments and medical organizations, and this might have dire consequences for future pandemics. The question now remains, how does one function in a society where there is no trust? Covello et. al described third party endorsement of trustworthy sources and the use of four trust determination factors (caring and empathy; dedication and commitment; competence and expertise; and honesty and openness) as means to build or maintain the trust of the public (24).

Nevertheless, newer researches need to look at how trust affects the public's response and how this information can be applied during future pandemics to ensure effective communication.

6.3. Communicating effectively during a crisis

The ability to communicate effectively with the public during a pandemic can be very tasking as pandemics are emotionally charged and shrouded with uncertainties. Nevertheless, an effective risk communication can mitigate the outrage of the stakeholders even in high hazard situations.

My results on communication difficulties pointed out loopholes in communication during the A/H1N1 2009 influenza pandemic which should be addressed for future outbreak management. Lack of clarity in messages and updates received; multiple and contradictory sources of information; insufficient information on the benefits and potential side effects of the vaccines; overwhelming volumes of emails, daily updates, and guidelines; slow and untimely dissemination of information; difficulty identifying new information from daily updates; poor communication strategies and vaccination awareness campaigns; lack of effort by the authorities to counter misconceptions regarding the modes of transmission and effect protective measures; poor coordination between stakeholders; poor campaigns aimed at certain groups to take up vaccination; and difficulty applying some of the centrally developed guidelines at the clinical/field level were the main difficulties encountered in communication during the pandemic (35-50,52,53,55-58).

Noticeably, we live in an information age and the possibility of being well informed in the face of a health crisis is arguably the greatest wish of any individual. Because when the public is adequately informed about events with potential health effects, they are able to take timely measures and make decisions to protect themselves (22). But on the other hand, having too many sources of information can often be confusing, times consuming, overwhelming and ultimately detrimental to the management of a pandemic as shown by my results (17,40,46,55).

Evidently, the need for clear and well-tailored messages is particularly pressing when communicating with frontline physicians and other healthcare workers, as studies have shown their knowledge and attitude to influence the public in carrying out recommended behaviors and even vaccination uptake (21,39,44,63). Lack of clarity in messages received, timeliness in the dissemination of information, overwhelming updates and guidelines, and difficulty identifying new information from daily updates received was repeatedly mentioned in the literature looking at the health care professionals during the 2009 influenza pandemic (17,40,55). In accordance with other published literature, effective communication with frontline physicians and HCWs can be achieved by merging the multiple information sources into a single credible source (70,71). Moreover, I think that their active participation in the decision processes will be of added value to the management of any health crisis.

The occurrence of the pandemic (H1N1) 2009 in the era of the Internet was particularly challenging to conventional public health communication as many public health authorities were poorly equipped to deal with the numerous channels of communication that the internet and social media platforms offered (72,73). Therefore,

channels of communication during an outbreak are very important, and this is where the role of the media comes in. Even though not so many studies have been done so far to analyze the media influence on the A/H1N1 2009 influenza pandemic. Available evidence suggests that well-informed media can have a positive influence on disease perception and willingness to be vaccinated (64,74), only if their messages emphasize the effectiveness of vaccines and other recommended protective measures in protecting against the disease. On the contrary, our studies from Greece (46), Germany (43), and others have shown that excessive media coverage of the pandemic might have been a reason for a low perception of risk and vaccination coverage (44,65,72). Governments and public health authorities need to involve the media in their pandemic preparedness and responses; this can be achieved through media education, inclusion, and timely dissemination of information (22,23,25,34). Furthermore, the potentials of other sources of information (like social networking platforms, etc.) should be studied for use during future pandemics as existing guidelines on risk communication provides no clarification on the use of the Internet during pandemics.

Equally, diversification of the communication strategies, the use of bi-directional communication channels, encouraging collaboration and cooperation, and messages adapted to the social and cultural realities of diverse population should be the “modus operandi” when communicating with the general public, specific risk groups and minorities in the event of a pandemic (33,34). Only then can the public feel empowered and engaged.

Speculatively, I think that addressing the communication difficulties will inevitably have a positive effect on the other categories I have mentioned so far, namely; vaccines concerns and trust issues. Because when there is effective communication with all the stakeholders during a pandemic (assuming all the above mentioned concerns are addressed), the public will trust their governments, public health authorities, and we can be sure of an excellently managed outbreak. But are we ever going to arrive at such a place? It remains to be seen.

6.4. Roles and responsibilities

My results on the roles and responsibilities of those involved in the management of the pandemic showed that clarity in definition of roles and responsibilities; paternalistic attitude of the government, experts, and health authorities; the feeling of not being engaged in the planning processes; failure of frontline health professionals to act as role models; and unhappiness with the top-down management approach were the major concerns of the stakeholders during the influenza A/H1N1 2009 pandemic (17,35,37,40-44,46,48,53-55,57,58).

To be entrusted with a certain role(s) in the management of a pandemic can be very demanding. For this reason, authorities must ensure that the most qualified persons occupy these roles. In line with other published articles, the management of a pandemic must involve a diverse group of experts from different fields, collaboration with frontline health professionals, and public health components to ensure evidence-based decision-making and interventions (21,63,71).

I would say that clearly defined roles and responsibilities could facilitate decision-making, make for easy coordination, cooperation and exchange of information between stakeholders and ease the assessment of the management process.

The roles of physicians, frontline healthcare professional, and the attitude of the government/experts towards the pandemic have already been discussed in my discussions on vaccines and infectious disease outbreaks; trust and the public response to a pandemic; and communicating effectively during a crisis respectively.

6.4. Resource management during a pandemic

From my results on resource issues during the A/H1N1 2009 pandemic, the following were the major concerns; logistic and storage difficulties; lack of availability of patient educational materials; lack of a proactive reminder system for the vaccination campaigns; unavailability of specific diagnostic tests and tool kits in certain regions; vaccine and antiviral shortages; significant care burden on emergency rooms; lack of flexibility in responding to the needs of specific regions; and overwhelming workload in relation to pandemic activities (35,40,44,47,48,52,54,54,58).

Vaccines and antiviral medications are widely used during outbreaks of infectious diseases to control the spread of a virus either as a prophylactic measure, or as a cure for those affected. Thus their absence or limited availability during a public health emergency conveys the fact that affected persons stand little or no chance of survival, and this can have serious consequences for countries or regions affected.

Timely access to vaccines and antiviral medications during the latest influenza pandemic was a challenge and will remain so during future pandemics if appropriate measures are not taken (1,47). But it would be false for one to believe that the above-mentioned statement applies equally to all countries. Reports have shown that while many developing countries and impoverished regions had difficulties accessing the A/H1N1 2009 vaccines and other antivirals, developed countries had stockpiles of them (72,75). Germany and France ordered 50 and 94 millions doses of the vaccines respectively, yet in Germany only 7 million of them were used. A similar scenario was observed in northern Europe, where countries realized only after they had ordered excessive amount of vaccine that only a single dose was needed for protection against the A/H1N1 virus (72). Nevertheless, the stockpiles of vaccine didn't translate into higher vaccination rate among these countries (20,21,43,44).

Evidently, the economics of vaccine procurement is really unfair in these cases, as production and supply of vaccines doesn't match the demand. Vaccine choices of different countries are based on advance purchase agreements, country of origin of the manufacturer (Hungary used the Fluval P because it was locally manufactured), convenience, logistics, licensing and bureaucratic barriers, and vaccine contents (13,58,72). And this might have been the plight of developing countries in procuring vaccines and antivirals, as many of them lack the capacity, infrastructure and perhaps the funds to procure the amount of vaccines and antivirals they needed. This should be addressed if such problems are to be avoided in the future.

Personally, the overburdened emergency rooms, workload related stress (for health professionals), and poor access to diagnostic tools can be solved by; putting in place

effective referral systems to decongest overcrowded emergency rooms; the use of financial incentives in order to discourage absenteeism of staff; proper distribution of personnel according to where they are most needed; provision of psychological and mental health support for the healthcare workers; and finally, the decentralization of laboratory testing from central to local regions to ensure faster test results and reduction of workload in certain regions.

Finally, based on the literature search on risk communication difficulties experienced during the 2009 influenza pandemic and the subsequent arrangement of these communication difficulties into different categories, I developed a questionnaire which will be used to collect data from stakeholders in Europe as to what difficulties they faced during this period in regards to risk communication, what they wished for, and what could be done to ensure effective risk communication during a future pandemic (see annex for questionnaire).

6.4. Limitations

My thesis has some limitations that need to be acknowledged. Firstly, all the studies used in the development of the categories are strictly in English, as a result of that there might have been a selection bias. But I must mention that some of the selected studies that I used were originally published both in English and in the native language from its country of origin. The same applies to data collected from the websites of organizations like ECDC, which also serves many non English-speaking countries in Europe. Secondly, non-coverage bias is another limitation of this thesis, as one might say that my sample size is not representative of all countries in order to get a clear picture of risk communication difficulties. But in order to control for that, I made sure to include as many relevant studies from different countries and regions (see table 1). Thirdly, the main goal of this thesis is to develop a questionnaire that will be used to gather data from stakeholders in the health sector, but unfortunately there isn't a vast literature that evaluated risk communication difficulties faced by these stakeholders in regards to the A (H1N1) 2009 pandemic. So to make up for that, I included studies that looked at the perceptions, knowledge and attitude of the public in connection to the A/H1N1 2009 pandemic.

7. Conclusion

In conclusion, concerns about the vaccines; lack of trust in the government, medical organizations and public health authorities; communication difficulties, failure of those entrusted with certain roles and responsibilities; and resource issues suggests that risk communication during the A (H1N1) 2009 influenza pandemic were not successful despite major investments in pandemic preparedness and responses.

The level of attention accorded to the 2009 pandemic suggests that it was not just a health crisis but also a social, economic and a political event. The public's outcry of foul play and distrust towards the government can be justified in some ways; perhaps because it was not the full-blown deadly pandemic they were promised by the experts and the media. But on the other hand, the only positive thing about the A (H1N1) 2009 pandemic is that it was a mild pandemic (37,42,48). This is supported by a study which mentioned a few possible worst case scenarios: the virus could have been more pathogenic and with multiple strains; total population susceptibility; different modes of transmission; emergence in a developing country and the ability to spread faster than we experienced; no antivirals available; and frequent and severe vaccine associated adverse events (72).

In the future, will the risk communication guidelines developed for outbreak management be suitable for pandemics that could last even longer than what we have experienced so far? In developing future pandemic preparedness response plans, I recommend that decisions be made based on the best evidence available; physicians and other frontline health professionals must be included in the decision making processes; governments and health authorities should widen their infectious disease surveillance systems to include other influenza virus strains, emerging and re-emerging pathogens; risk communication with the public must be diversified; surveys must be made from the onset of any public health emergency to gather information that could be used for evidence based decisions and interventions; more research should be invested in the area of vaccine development to avoid future public and professional claims of inadequate testing and development time. Finally, the usefulness of the Internet and social media should be evaluated and included in future risk communication guidelines.

Conflicts of interest

The author of this thesis declares no conflicts of interest.

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9. Annex

9.1. Table of Categories

Study Characteristics			Categories				
Author, year of study, & Ref. nr.	Study design & month of data collection	Country	Vaccine concerns	Trust issues	Communication difficulties	Roles and responsibilities	Resource issues
Hidiroglu et. al. 2010 (35)	Qualitative study (focus group), November 2009	Turkey	Accelerated authorization procedure; Vaccine contents (adjuvant & thiomersal); minor benefits; Not necessary (mild pandemic); fear about safety and efficacy and adverse effects.	Distrust in the government	Information received lacked clarity; the HCWs concerns about the vaccine lead to ineffective counseling of the public.	Healthcare workers (HCWs) didn't realize they could play a role in the transmission of infection to their patients or have an impact through potential absenteeism if they get sick; low level of awareness related to the importance of H1N1 Vaccination	Lack of specific diagnostics tests and tool kits; diagnosis was based solely on clinical diagnosis.
Bults et. al. 2011 (36)	Cross-sectional questionnaire & interview survey, June-July 2010	Netherlands	Vaccines wasn't thoroughly tested; lack of trust in the vaccine effectiveness; and fear of side effects.	Distrust in the government	Lack of clear information on vaccination benefits and possible side effects of the vaccines; Conflicting/contradictory information sources.	Not given	Not given
Van der Weerd et. al. 2011 (37)	Cross-sectional telephone survey, April-November 2009	Netherlands	The H1N1 pandemic was considered to be a mild pandemic and does not call for vaccination; Distrust in the vaccine	Distrust in government	Unclear and contradictory messages; non-risk groups feel included in the communication messages; the public felt they needed more information	Paternalistic attitude of the authorities; the public did not feel engaged/involved in the decisions made by the authorities	Not given
Ferrante et. al. 2011 (38)	Cross-sectional telephone survey, Nov 2009-February 2010	Italy	Not given	Not given	Information received was inadequate regarding preventive measures against influenza, and also lacked timeliness; the desire for a trusted source of information	Not given	Not given
Prati et. al. 2011 (39)	Cross-sectional telephone survey, February 2010	Italy	Not given	Trust in the MOH; trust in the institutional response to the outbreak; & trust in medical science	Providing the public with public with clear and consistent information that reports the risks and focuses on practical things that can be done to mitigate the risks	Not given	Not given
Staes et. al. 2011 (40)	Cross-sectional survey, May-July 2009	USA	Not given	Credibility about the sources of information	Frequently changing clinical guidelines; overwhelming email volume; difficulty identifying new information from updates; multiple sources of information/messages (hard to keep up)	Clarity in definition of roles & responsibilities of different stakeholders; the needs of frontline physicians and HCWs were not put into consideration in the decision processes	No patient educational materials; population based data about the epidemiology of the H1N1 pandemic was lacking
Brandt et. al. 2011 (41)	Cross-sectional questionnaire survey	Germany	Vaccines were untested and rushed into the market; fear of side effects; fear of vaccine contents; concerns regarding safety and effectiveness	Not given	Insufficient information about the vaccine	HCWs couldn't act as a role model to the public because they were not properly educated on the vaccine's safety and benefits (some GPs advised against it)	Not given
Seale et. al. 2010 (42)	Cross-sectional interview survey, Sept.-Oct. 2009	Australia	H1N1 was not severe to warrant vaccination; vaccines wasn't properly tested; vaccine safety; could cause influenza in people; long-term studies was needed to ensure its safety	Not given	More information about the vaccine's safety and benefits was needed; inability to differentiate between H1N1 influenza vaccine and seasonal influenza vaccine	GPs didn't recommend the H1N1 influenza vaccine	Not given
D. Walter et. al. 2011 (43)	Cross-sectional telephone survey, Nov. 2009-April 2010	Germany	Concerns regarding the use of adjuvant in the vaccines	Not given	Poor communication strategies; reduced public awareness which lead to low vaccination coverage	The HCWs were not adequately targeted for vaccination, hence their knowledge and attitude posed a barrier to vaccination coverage	Not given
Blank et. al. 2012 (44)	Cross-sectional telephone survey, Dec. 2009-Jan 2010	Germany, France, USA, China, Mexico	Feeling that vaccination wasn't necessary; distrust in vaccines; fear of side effects; vaccine safety	Distrust towards the media as a result of their overestimation of the seriousness of the threat	Poor public awareness of H1N1 influenza and the vaccine; lack of accurate communication regarding influenza-related health information	GPs didn't consider the threat of H1N1 influenza to be serious and so didn't recommend the H1N1 influenza vaccine	Lack of proactive reminder systems

Study Characteristics			Categories				
Author, year of study, & Ref. nr.	Study design & month of data collection	Country	Vaccine concerns	Trust issues	Communication difficulties	Roles and responsibilities	Resource issues
J. T. F. Lau et. al. 2009 (45)	Cross-sectional telephone survey May 7-9, 2009	Hong Kong	Not given	Not given	Misconception regarding the virus, modes of transmission, and how to protect oneself; the government didn't do enough to counter the myths surrounding the H1N1 influenza virus	Not given	Not given
G. Rachiotis et. al. 2010 (46)	Cross-sectional questionnaire survey, Nov. 2009	Greece	Fear about vaccine safety & side effects; development of anaphylactic reaction	Not given	Insufficient information on the vaccine's safety; multiple controversial sources of information had an impact on the attitude towards vaccination	Authorities didn't do enough to address the concerns of the HCWs regarding vaccine safety	Not given
WHO 2011 (47)	Draft donor report, 2011	Worldwide	Authorities didn't do enough to address the concerns of the HCWs regarding vaccine safety	Not given	Difficulties in communicating about vaccine safety to the public	Not given	Logistic problems, vaccine coverage & availability; short shelf-life of some vaccine
Fisher et. al. 2011 (48)	Review report, 2011	Asia	Not given	Lack of transparency from the government	Lack of co-ordination between different authorities and institutions; public misconceptions; lack of clear communication & undated scientific information; timeliness of information; centrally created guideline often had poor application at the clinical/field level	Paternalistic attitude of the government; health practitioners were not involved in the policy making process regarding the antiviral	Overwhelmed health facilities; underutilization of available resources; shortage of antivirals; poor data management; demand of personal protective equipments exceeded supply
Raude et. al. 2010 (49)	Cross-sectional telephone survey, Nov-Dec 2009	France	Fear of adverse effects; H1N1 was mild & didn't require vaccination; belief that the vaccine was ineffective	Distrust in the media, pharmaceutical companies, and public authorities	Ineffective public health campaign to convince people of the benefit & safety of the vaccines	Not given	Not given
O'Flanagan et. al. 2011 (50)	Report	EU	Skepticism regarding the need for vaccination; disagreement with the recommendation of vaccination for non-traditional groups; vaccine contents; doubt about vaccine safety; and the accelerated licensing process	Lack of confidence of professional in the vaccine	Multiple information sources; conflicting and contradictory information; risk communication wasn't clear; and not enough information about the vaccination program	Not given	Not given
Sypsa et. al. 2009 (51)	Cross-sectional telephone survey, Aug.- Oct. 2009	Greece	Vaccine safety; didn't think the vaccine might be effective; vaccination wasn't necessary	Not given	Not given	Not given	Not given
Trivellin et. al. 2011 (52)	Cross-sectional study, Oct.- Nov. 2009	Italy	Not given	The general public and HCWs didn't trust the media	Overrated severity of the novel influenza virus; risks were over-hyped by the media; ambiguous and untruthful information	Not given	Significant care burden on the emergency rooms
D'alessandro et. al. 2012 (53)	Cross-sectional semi-structured interviews, June 2010	France	H1N1 pandemic wasn't serious to require vaccination; lack of confidence in the vaccine; potential side effects; hastily developed	Unreliable scientific data; damaged bond of trust between the public & the healthcare professionals	Poor dissemination of clear and effective messages about vaccine safety & benefits; health crisis was hijacked by the politicians and the media; insufficient scientific safety data	The healthcare professionals were biased/refused to counsel their patients regarding the decision of whether to be vaccinated or not	Not given
Steelfischer et. al. 2010 (54)	Review	USA	Vaccine safety & fear of side effects; vaccination wasn't needed; doubt about vaccine effectiveness	Distrust towards the public health officials to provide correct information regarding the vaccine safety	Not given	Irregularities among health care professionals regarding recommending the vaccine to patients	Vaccine shortages

Table of categories Contd.

Study Characteristics			Categories				
Author, year of study, & Ref. nr.	Study design & month of data collection	Country	Vaccine concerns	Trust issues	Communication difficulties	Roles and responsibilities	Resource issues
Nhan et. al. 2012 (55)	Cross-sectional questionnaire survey, April-May 2010	Canada	Discrepancies between vaccine content for different groups	Lack of openness; distrust for information sources due to multiple contradictory messages	Slow process; lacking clarity; overwhelming number of information sources; overwhelming number of divergent messages; inconsistencies in the guidelines; lack of communication between frontline physicians & the expert advisory committee	Unhappiness with the top-down management approach; lack of autonomy (physicians); didn't feel engaged; unclear roles of different actors in the pandemic	Increased workload related to pandemic activities; inadequate financial compensation to match the workload; lack of flexibility in responding to the needs of specific regions; limited availability to diagnostic materials; overwhelmed emergency rooms
Lan & Mc Geer 2011 (17)	Literature review	Australia, Canada, USA, Mexico, UK	Not given	Not given	Timely dissemination of information to the frontline HCWs; overwhelming number of updates; some information awareness campaign was of no effect; exaggerated risks; insufficient knowledge about the vaccine, unclear & conflicting messages from the authorities; certain groups were poorly targeted for vaccination	Didn't feel engaged with the pandemic planning process	Not given
Walter et. al. 2012 (56)	Cross-sectional telephone survey, Nov. 2009- April 2010	Germany	Fear of adverse effects; vaccines was not sufficiently evaluated; vaccination wasn't necessary;	Lack of openness & honest by the government about issues related to vaccination; lack of trust in media reporting	Exaggerated reporting about the risks of H1N1 pandemic; insufficient information regarding vaccine safety & benefits	The authorities failed to address misconceptions surrounding the vaccine	Not given
Böhmer et. al. 2012 (57)	Cross-sectional telephone survey, Sept. 2009- July 2010, April- July 2011	Germany	Fear of side effects; vaccination was not needed; didn't feel they were in the risk group	Not given	HCWs were not adequately targeted for vaccination; lack of information; so many controversial discussions about the vaccine	Not given	Not given
Shobayashi 2011 (58)	Report	Japan	Not given	Not given	Overly frequent notifications; updates contained jargons; attention was not paid to the difficulties faced by frontline HCWs	Paternalistic attitude of the government; clear definition of the responsibilities for the public relations officers	Limited availability of vaccines

Table of categories contd.

HCWs- Health care workers

GPs- General practitioners

9.2. Questionnaire

Risk Communication during the A (H1N1) 2009 Influenza Pandemic in Europe: Avoiding Communication Problems during future Pandemics

Country:

Occupation of respondent:

Contact email:

Contact phone number:

Questionnaire completion date:

**Person responsible for validating the transmission of data to the European
Commission:**

Contact email:

Contact phone number:

Questionnaire validation date:

Thank you for accepting to participate in this survey. The aim of this survey is to look at the A/H1N1 2009 influenza pandemic in Europe through the eyes of a group of stakeholders (officials in public health settings, health care workers, public health experts, front-line physicians etc.) in order to gather qualitative as well as quantitative information on their perceptions and perspectives in terms of the difficulties they faced in regards to the management of the A/H1N1 pandemic and their wishes with respect to the function and flexibility of what the communication tools should be able to accomplish. Your participation in this survey is very important because the data collected through this Questionnaire will be used to inform decisions and policies for better management and response during future major epidemic outbreaks in Europe.

This survey is part of a project (**Effective Communication in Outbreak Management: Development of Evidence-Based Tool for Europe**) funded by the European commission.

This questionnaire is committed to the principles of data protection with a view of ensuring your right to confidentiality. All data will be used in a form that will make it impossible to determine the identity of the individual responses. That is, the survey responses will not be integrated, analyzed, or reported in any way in which the confidentiality of the survey responses is not absolutely guaranteed.

VACCINE CONCERNS

Q.1. Were you vaccinated against the A/H1N1 influenza pandemic?

- Yes I was
- No I was not vaccinated

If No, please explain why

Q.2. Did you feel well informed about the vaccine to do your job effectively?

- Adequate
- Inadequate
- Too much
- Too little
- Not applicable to my situation

Q.3. What were the major concerns you faced regarding the vaccines?

Please choose options that apply.

- Skepticism regarding the need for vaccination
- Vaccine safety
- Vaccine efficacy
- Fear of adverse effects
- Vaccine contents (Adjuvant and Thiomersals)
- Accelerated authorization procedure
- The recommendation of vaccination for non-traditional groups (pregnant women)
- Inadequate testing

Q.4. To your knowledge, was anything done to address your concerns regarding the vaccines?

Yes

No

If yes, please specify what was done

Q.5. Were you able to communicate effectively with the public about the safety of the pandemic influenza vaccine?

Yes

No

Not applicable to my situation

Q.6. What would you wish for regarding vaccines and vaccination during future pandemic events?

.....

COMMUNICATION DIFFICULTIES

Q.1. Did you feel you received updates in a timely manner?

Yes, always

Yes, mostly

Sometimes

Never

Q.2. Were you able to identify the new information from the daily updates you received during the pandemic influenza period?

Always

Often

Sometimes

Never

Q.3. How would you describe the types of messages you received during this period?

Please choose options that apply.

- Adequate
- Confusing
- Diverse
- Exaggerated
- Overwhelming
- Insufficient
- Contradictory
- Not implementable

Q.4. Which was your main sources of information?

Please rank in order of importance

- The media
- Internet (Google, social networking sites etc.)
- ECDC website
- Local institutions
- Daily updates
- WHO website
- Public health experts
- Emails
- Ministry of health
- Medical journals
- Teleconferencing
- Others

Please specify others

.....

Q.5. Did you perceive having multiple sources of information as a challenge?

- Yes, contradictory and confusing
- Yes, I did not know which source to rely on
- No, I had no problems with it.

Q.6. Which institutional recommendation did you follow?

- WHO guidelines
- ECDC guidelines
- Your Institution
- Others

If others, please specify

Q.7. Was there clarity in the guidelines you received?

- Yes, always
- Yes, sometimes
- No, received no guidelines
- Not applicable to my situation

Q.8. Was the guidelines you received useful in your local setting?

- Yes
- No

If no, why was it not useful? Please specify

.....

.....

Q.9. Were you able to manage the frequency of updates as the pandemic progressed?

- Yes, adequately
- No, too many updates

Q.10. In the event of a future pandemic what would be your preferred source of receiving information?

.....

TRUST ISSUES

Q.1. How would you rate the openness/transparency of the government/public health authorities during the A/H1N1 2009 pandemic influenza?

1= very open/transparent

5= not at all open/transparent

 1 2 3 4 5

Q.2. Were you confident in the public health experts to provide correct information regarding the vaccines

- Very confident
 Fairly confident
 Not very confident
 Not at all confident

Q.3. What was your most trusted source of information?

Please rank in order of importance.

- The media
 Internet (Google, social networking sites etc.)
 ECDC website
 Your institution
 Daily updates
 WHO website
 Public health experts
 Ministry of health

Medical journals

Others

Please specify others

.....

ROLES AND RESPONSIBILITIES

Q.1. Did you feel your roles and responsibilities in regards to the pandemic management was clearly defined as the pandemic progressed?

Always

Rarely

Sometimes

Often

Never

Q.2. To your knowledge, how would you rate the management of the pandemic influenza?

1= excellent

5= very poor

1 2 3 4 5

Q.3. Did you encounter any difficulties carrying out your assigned role during the pandemic?

Yes

No

If yes, please specify

.....

Q.4. Did you feel included in the pandemic preparedness planning and response processes?

- Yes, I felt included
- Yes, to some extent
- No, I did not feel included

RESOURCE ISSUES

Q.1. How was the pandemic preparedness response capacity in terms of human resources in your region?

- Well prepared
- Fairly well prepared
- Not very well prepared
- Not at all prepared

Q.2. Did you experience resource shortages during the pandemic activities?

Please choose options that apply

- Staff
- Vaccines
- Antivirals
- Diagnostic tools
- Epidemiological data
- Personal protective equipments
- Patient educational materials
- Others

Please specify others

.....

Q.3. How would you describe your workload during the pandemic period?

- Normal
- A lot
- A little
- Moderate
- Overwhelming

Q.4. To what extent did the A/H1N1 2009 pandemic activities in your region impact your workload?

- No noticeable impact
- Minimal impact
- Moderate impact
- Overwhelming impact

Q.5. Do you think your financial compensation matched your workload during the pandemic period?

- Yes
- No

Q.6. Did you feel overwhelmed with the demand of information from the public?

- Yes
- No
- Not applicable to my situation

Q.7. Was there any professional support available on how to deal with the situation?

- Yes
- No
- I did not know

Q.8. For a future influenza pandemic, what would you wish for in terms of resources?

.....
.....
.....
.....

THANKS FOR YOUR PARTICIPATION.