



Effective Communication
in Outbreak Management for Europe

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Risk communication during the 2009
A/H1N1 pandemic – European
stakeholders' experiences and their
wishes for the future

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1 Summary

To increase the acceptance of large-scale pandemic response measures such as vaccination, among the general public and at-risk groups it is imperative to understand the intricacies of risk-communication. The aim of the E-com@EU Project is to develop evidence-based risk communication strategies in order to respond effectively to major epidemic outbreaks in Europe. The mixed risk communication experiences of public health experts and other stakeholders involved in the management of the 2009/2010 A/H1N1 pandemic in Europe, is the context in which this research is embedded. The aim of the stakeholder analysis is to gather qualitative information on the problems stakeholders at different levels faced during the risk communication process at the time of the 2009 A/H1N1 pandemic. This includes their perception about the mode, quantity, quality and timeliness of the information received as well as the difficulties faced in passing on this information to others e.g. media, health authorities and the public. In addition the expectations and wishes of the experts as to what should be improved with respect to risk communication in future is to be explored.

A semi-structured interview questionnaire was developed based on published risk-communication literature. Stakeholders involved in the management of the A/H1N1 pandemic (from national health authorities (macro-level), local public health authorities (meso-level), physicians and health care staff (micro-level)) from eight European countries (Germany, The Netherlands, United Kingdom, Sweden, Poland, Romania, Italy, and Spain) were invited for a telephone or personal interview. Europe's political, economic and social diversity was taken into account by selecting interviewees from at least one north, south, east and west European country. 25 interviews were conducted. These were analysed based on the qualitative content analysis technique of Philip Mayring by building inductive categories.

1.1 Key findings from the Stakeholder Interviews

1.1.1 Giving and Receiving information

Macro-level stakeholders stated that participating in the Europe wide audio-meetings organized by DG Sanco was a very good platform for information exchange. Receiving first-hand information in a short time (before it became public) and also being informed about the situation and the response activities planned in other European countries was considered very valuable. National authorities had to occasionally react to media/public queries regarding why response and control measures in their country differed from those of neighbouring countries. Insights gathered during these meetings helped health authorities to anticipate and respond to these questions.

Some perceived the role of the ECDC as technically very sound but the impact and visibility of their messages as low in the European scene, especially in comparison to the CDC in the US or the WHO. According to the expert the situation would have been easier if the European countries could always rely on the information given by the ECDC as the voice at the European level. The stakeholder also suggested to have one spokesperson from the ECDC for media announcements and to clearly phrase messages in terms of what should be done and also what is not recommended, what people should be aware of etc. This would increase trust in supra-regional authorities.

Some meso- and micro-level stakeholders criticized that they did not have opportunities to feed-back their first-hand experiences to the regional level about what was useful and what not, where problems were arising etc. although they were the ones in direct contact with the public and patients and not the macro-level. They criticized that they were asked to engage in time consuming activities for e.g. taking swabs for laboratory testing from each suspected case, when the case load had already become too high (Netherlands) or first asking the authorities for permission to get a suspected case tested (Germany). Not seeing any sense in what they were being asked to do against the background of a heavy work-load was perceived as frustrating.

Optimizing information flows and fostering a two way exchange of information (between macro-, meso- and micro-level) was an issue specially mentioned by meso-level stakeholders. A German expert mentioned that for e.g. public health officials during the early phases were confronted with decisions such as suspending classes or even closing entire schools if a case was reported. Exchanging information with other municipalities on how they are handling the situation would have helped in the decision making process.

One Spanish expert felt that numerous protocols, guidelines and recommendations were given out by different sources in an unstructured manner. He said that a lot of work goes into their preparation, it overloads especially front-line health care workers like GPs and it is not used in the end. Having one trusted and reliable source that summarizes the most important aspects regularly and clearly signposts or highlights the key news or announcements on the website so that these can be picked-out immediately, was suggested as a solution for simplifying the work and avoiding confusion. Another suggestion was a targeted approach for communicating information to specific professional groups (e.g. GPs or midwives or public health nurses etc.), the GPs for e.g. do not need to get information relevant for hospitals. This was practiced in the UK, where a regular bulletin was sent out by email to the GPs informing them about the latest developments of the pandemic and/or the vaccine. Hence, GPs did not necessarily need to look at other sources when they knew that the source is reliable. In addition a robust feed-back loop was installed i.e. GPs had the possibility to feed-back comments or questions to the health authorities.

A Dutch public health nurse mentioned that reading the newspaper before coming to work, helped her to be prepared for the queries the public visiting the health office on that day might have.

A macro-level stakeholder from Sweden mentioned that the question which needs to be asked is 'when does new information merit an information update?' Decisions should be made on threshold levels for when a new update should be sent out. Finding the right balance so as not overwhelm specially front-line health-care professionals with information is

important. In line with this a Dutch meso-level stakeholder suggested that apart from receiving information from the regional/national level when a change of situation or mode of operation warranted this, it would have been helpful to be informed at regular intervals (for e.g. once weekly) confirming that the recommended mode of operation is still in place. He said that they would have liked to be informed about which pandemic phase they were actually in i.e. were they following a strategy of containment or mitigation.

Apart from paying attention to the content of messages and the audience to be addressed it is also important to consider and weigh which media channels/tools are to be used. One expert mentioned that the public may be reluctant to read recommendations and information in textual form. This could mean using new media like twitter to reach a broader spectrum of people or to use video-clips to disseminate information. It would for instance be easily possible for a (local) health authority to not only disseminate information in textual form, but also as short video-clips. This highly visual method helps setting the information in context and linking it with a face thus giving the messages greater credibility. It also offers the possibility to use the voice and gesture to underline the key messages. The clip could be posted on the homepage of the institution and be distributed via multiple channels (Flu App, Facebook, twitter...).

1.1.2 Vaccine issues

Countries with well established seasonal influenza vaccination programs and good coverage rates (e.g. Sweden, Netherlands) in general also reported better pandemic influenza vaccination coverage rates. Hence well-established infrastructure and logistics are likely to enhance the success of such large scale pandemic vaccination programs and also the acceptance in the public on account of them being familiar with the system.

The interviewees mentioned issues like lack of trust in the vaccine's safety, accelerated vaccine authorization, media messages about the dangers of the vaccine and specially the adjuvants and that the disease was probably not as severe, as being some of reasons the for skepticism and negative public attitude. In many instances this led not only to exceptionally

low vaccination rates but also had a negative influence on subsequent seasonal influenza vaccination coverage. According to the experts, a notion that came up among the public was that if the pandemic flu vaccine is so controversial then why should the seasonal influenza vaccine be safe or even useful. A Swedish expert suggested that to enable the public to make informed decisions regarding vaccination, the risks associated with pandemic A/H1N1 infection versus the risk of vaccination need to be more clearly explained.

Experts from a number of European countries including Romania, Italy, Spain and Sweden stated that skepticism and negative perceptions led to a substantial drop of 15 – 25% in seasonal influenza vaccine uptake in the subsequent years and this has still not fully recovered to pre-pandemic levels in all countries. While the high vaccine coverage in Sweden (~60%) may have been the reason for fewer A/H1N1 cases and deaths, the number of cases developing narcolepsy following vaccination was higher in Sweden compared to other countries. This led to massive public criticism. This complication however was not mentioned by experts from the other countries.

Health-care support staff (e.g. midwives, GP assistants) on account of their more direct link to the patients or risk groups (e.g. pregnant women) tends to have a strong influence on health behaviour decisions. One stakeholder reported that midwives in England for e.g. tended to not recommend pregnant women to get vaccinated against A/H1N1, which maybe one explanation for the low vaccine uptake among pregnant women. The low vaccine uptake among health professionals in many European countries highlights that the concerns these professionals may have about recommended control measures need to be identified and taken seriously. Organizing meetings with key-representatives from these groups to inform them in detail about the reason for the decisions, to listen to their concerns and discuss options and even modifications of recommendations could be a way to address this issue pro-actively before they cannot be influenced anymore.

1.1.3 Media and communication

Experts from Sweden and Spain mentioned that prominent individuals especially when they have good communication skills can have a very decisive influence on public behaviour. A

doctor in Sweden who got infected with A/H1N1 and had severe symptoms later publically promoted the vaccine, while a doctor, nun and public health activist in Catalonia, Spain strongly opposed vaccination. The experts felt that this had quite an influence on the public's decision making process.

An example of how messages which are surrounded by a high degree of uncertainty can be communicated to the media appropriately was given by a Spanish expert. He reported how they established positive relations with the reporters of important newspapers and TV-channels in the region. They adopted a pro-active role by inviting the reporters and giving them basic information about the new pathogen and about pandemic management. The fact that the journalists consulted the expert when they picked up new messages about the pandemic, in order to clarify and understand the issue at hand before reporting about it shows that they had built-up a certain degree of mutual trust and a closer working relationship. Even when journalists are informed about the situation of an emerging disease they still tend to cherry-pick the information to release a big headline. However building up a good relationship with the media and giving out clear information and being transparent about what is known and what not and what may happen, was described as the best way to counter this issue.

Experts also said that the first statement or information released about a topic dominates, because other media tend to subsequently repeat this message. It was mentioned that it is much more difficult to correct a wrong statement or rumor than to be the first one to release the information. One expert stressed the need for public health agencies and health authorities to have very competent media persons who are able to phrase correct statements in an appropriate manner. To avert the development of rumors and extensive amount of enquiries, the importance of giving all stakeholders in a region or area, information at the same time was also emphasized.

An expert from Italy said that communication from the health authorities should be clear, timely and serious, the background being that a mouse like puppet which is popular among

children in Italy was used to convey messages about the pandemic and the vaccine. This was perceived as inadequate and non-serious for the situation.

1.1.4 Additional aspects

A macro-level expert from Sweden felt that decision making aids for public health professionals (in consultation with ethicists etc.) on thresholds (for e.g. number of deaths averted etc.) at which an official vaccination strategy should be decided/ initiated, would have been very helpful and should be prepared ahead of time for possible future outbreaks.

Public transparency in the decision making process is important to be prepared for later criticism. A Swedish expert suggested that the decision steps at each stage should be comprehensible, they should be clearly documented and retrievable for e.g. through a website, as a means of justification why certain decisions were taken and others not.

One public health officer criticized the data collection/reporting practices. They were required to report a detailed set of data for each case, which was not feasible since they often had to get the information from the treating physicians; this led to loss of information. It was suggested to instead decide on a minimum dataset that is feasible to obtain and report and other information could be added on if feasible.

1.1.5 Conclusion

The information and insights gained from the present study may help to improve risk communication during and before pandemics at a European level. The stakeholders' experiences lend support to the notion that an urgent need for a more systematic and well-planned implementation of risk-communication strategies and also available guidelines exists within the EU countries. From the findings three basic areas for effective risk communication during pandemics emerge: (i) the first being the existence of a conducive environment in which risk communication can function, (ii) the second being the technical pre-requisites for

functioning risk communication implying that the communication infrastructure ensures that right person receives the right messages at the right time and (iii) the third being the actual content of the risk messages. The stakeholders' views indicate that for effective risk communication, (1) professional stakeholders should be able to access reliable information rapidly through pre-established channels, (2) good relations between public health and media experts must be established and fostered by a regular exchange of information to build up mutual trust, and (3) society's trust in public health authorities must be improved long before a pandemic. In a tightly connected Europe, this cannot function exclusively within national boundaries; a Europe-wide approach is needed.

Table of Contents

1 Summary	1
1.1 Key findings from the Stakeholder Interviews	2
1.1.1 Giving and Receiving information	2
1.1.2 Vaccine issues	4
1.1.3 Media and communication	5
1.1.4 Additional aspects.....	7
1.1.5 Conclusion	7
Table of Contents	9
Abbreviations	12
2 Background	13
2.1 The 2009 A/H1N1 Pandemic	13
2.2 The A/H1N1 Virus	16
.....	17
2.3 The A/H1N1 Pandemic Compared to the Seasonal Influenza	18
2.4 Risk Communication in the Public Health Context	19
2.4.1 Risk	20
2.4.2 Risk Communication	21
2.6 The Risk Perception Model	23
2.7 The E-com@eu-Project and Workpackage 1	25
3 Method	27
3.1 Literature Review	27
3.2 Analysis of Stakeholder Interviews	28
3.2.1 The Sample.....	28
3.2.2 The Questionnaire.....	29
3.2.3 Data Organization	31
3.2.4 Qualitative Content Analysis.....	32
4 Results	34
4.1 Literature Review	34
4.1.1 Vaccine Concerns	34
4.1.2 Trust Issues.....	35
4.1.3 Communication Difficulties.....	35
4.1.4 Organizational Problems.....	36
4.2 Stakeholder Analysis	36
4.2.1 Vaccine	37
4.2.2 Communication.....	42
4.2.3 General Problems.....	49
4.2.4 Future Risk Communication.....	53
5 Discussion	57
5.1 Potential Sources for Bias	57

5.2 The Environment in which Risk Communication is to Function	60
5.3 The Technical Pre-Requisites for Functioning Risk Communication	62
5.4 The Content of Risk Messages	65
6 Conclusion	70
7 References	71
8 Appendix	77
8.1 Questionnaire	77
8.2 Article Abstract: Risk Communication During the 2009 Influenza A/H1N1 Pandemic: Stakeholder Experiences From Eight European Countries	80
8.3 Literature Review – Data Extraction Sheet	82
8.4 Literature Review – References	88



Tables

Table 1: Number of interviewed Experts by Country and Level of Management _____ 29

Table 2: Coding Categories and Sub-Categories used in the Analysis _____ 37

Figures

Figure 1: The evolution of the 2009 A/H1N1 Influenza Virus _____ 17

Abbreviations

A/H1N1	Influenza A virus subtype H1N1
CDC	US Centers for Disease Control and Prevention
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
E-com@eu	Effective Communication in Outbreak Management: development of an evidence-based tool for Europe
EDS	excessive daytime sleepiness
EU	European Union
EWRS	Early Warning and Response System
GP	General Practitioner
HC	Health Canada
HCW	health care workers
HPA	Health Protection Agency
NCCID	National Collaborating Centre for Infectious Diseases
NHS	National Health Service (UK)
OECD	Organisation for Economic Co-operation and Development
PubMed	US National Library of Medicine, Bethesda, MD
RKI	Robert Koch-Institut
WHO	World Health Organization
WP	Work packages

2 Background

This chapter introduces the topic of risk-communication during pandemics by giving a brief description of the 2009 A/H1N1 pandemic, the virus, and the difference between the A/H1N1 pandemic and seasonal influenza. The second part of this chapter summarizes the concept of risk communication, and models explaining their relation. In the end we give an overview of the E-com@eu-project, its tasks and specify how this study contributes to the project.

2.1 The 2009 A/H1N1 Pandemic

To understand the situation in which public health experts had to communicate about the risks associated with the transmission of a new influenza virus, the key events and major control measures during the global spread of the influenza-virus sub-type A/H1N1 from March 2009 to August 2010 are summarized. It was the first pandemic of the 21st century and contrary to expectations the world was not prepared for it. Experts were arguing about the right way to deal with it: Some propagated mass-vaccinations for all citizens, others just wanted to vaccinate special risk groups, and some did not want to vaccinate at all. The different stakeholder could not even decide on one name for the pandemic: The WHO was called it „*pandemic H1N1/09 virus*“ to distinguish it from the seasonal H1N1 viruses (Fukuda, 2009). The U.S. Centers for Disease Control and Prevention referred to it as the „*novel influenza A (H1N1)*“. The media used less accurate names and called it „*Swine Flu*“ or „*Pig Flu*“ because of it evolving from a re-assortment of bird and human flu viruses and a Eurasian pig flu virus (Trofonov, 2009). The names used actually had an impact on the public's behaviour: For instance the name swine flu led in some regions to the misleading belief that pigs were responsible for the spread of the pandemic and people should avoid eating pork. The name however took its origin from the observation that until 2009 the virus was transmitted to humans only through the intensive contact with pigs.

In March and early April 2009, more than usual reports of patients with influenza-like illness (ILI) were picked by Mexican health authorities in different parts of the country. On April 12, an ILI outbreak was reported from a small community in the state of Veracruz, Mexico. This

was made public in accordance with the International Health Regulations, which require any ‘public health emergency of international concern’ to be reported to the WHO (CDC, 2009b). The new virus sub-type was first described in April 2009 in California. On April 17, 2009 the US Centers for Disease Control and Prevention (CDC) announced that *„two cases of febrile respiratory illness occurring in children who resided in adjacent counties in southern California were caused by infection with a swine influenza A (H1N1) virus“* (CDC, 2009a). In earlier years the CDC had received reports of approximately one human swine influenza virus infection in the United States every one to two years – however all occurred after direct or close contact to pigs. The two children and their families however reported no contact to pigs or to persons in contact with pigs which raised concern (CDC, 2009a). Laboratory investigations showed that the influenza virus strains of the infected children in California and the Mexican cases were identical. Between March 1 and April 30, 2009 a total of 1,918 suspected cases were reported to Mexican health authorities, including 286 probable and 97 confirmed cases resulting in 84 deaths (CDC, 2009b).

Initial observations showed that the new virus was spreading fast and had a higher lethality than seasonal influenza. *„Our estimates suggest that 23,000 (range 6000 to 32,000) individuals had been infected in Mexico by late April, giving an estimated case fatality ratio (CFR) of 0.4% (range: 0.3 to 1.8%) based on confirmed and suspected deaths reported at that time“* (Fraser et al., 2009). From this scientists judged the clinical severity as being less grave than in the 1918 influenza pandemic, but comparable to the pandemic influenza-virus sub-type A/H1N1 of 1957. Although the 1957 influenza was less severe than the 1918 influenza, it was still responsible for the death of one million people. Yet it was not just the ‘feared’ high lethality, but also the fact that especially young and previously healthy people experienced severe symptoms, that alarmed the WHO (World Health Organization, 2011).

Early estimations on the severity of the virus made the WHO act fast: On April 25, 2009 the Emergency Committee held its first meeting since it was established in 2007. After the meeting WHO Director-General, Dr. Margaret Chan, declared *„The Committee nevertheless agreed that the current situation constitutes a public health emergency of international concern“* under the International Health Regulations (2005) and advised all countries to intensify surveillance for influenza-like illness and respiratory disease (Chan, 2009a). Two

days later the committee met again and raised the pandemic alert level from Phase 3 to Phase 4 (Chan, 2009b). By April 28th seven countries reported confirmed cases (the United Kingdom, Spain, New Zealand, Israel, Canada, the United States of America and Mexico). Four of six WHO regions were affected. On 29 April, WHO raised the level of influenza pandemic alert to phase 5 and advised all countries to activate their pandemic preparedness and response plans (World Health Organization, 2009a; ECDC, 2010). Although only a few countries were affected at this stage, Phase 5 was a signal that a pandemic was coming up and human to human spread of the virus into at least two countries of one WHO region was evident (World Health Organization, 2012). On June 11 the WHO announced the pandemic alert level 6 – the highest possible level which indicates a global pandemic, but says nothing about the severity of the disease. Until September 2009 the virus continued to spread globally and became the predominant circulating influenza virus (WHO, 2009). By the end of September and throughout October most European countries started their vaccination program. In October 2009 the overall number of cases in the world started to decline, but some regions of the world still experienced a rising number of transmissions (Sekkides, 2010). Almost sixteen months later on August 10, 2010 Dr. Margaret Chan declared the end of the pandemic. The decision was based on a recommendation from the Emergency Committee which assessed the „global situation, as well as reports from several countries“ and came to the conclusion that the „new H1N1 virus has largely run its course“ (WHO, 2010). Until August 2010, the official end of the pandemic, about 18500 confirmed A/H1N1 related deaths from more than 200 countries had been reported to the WHO (WHO 2011a). In retrospect WHO states that „*the number of pandemic deaths reported to WHO by its member states during the influenza A(H1N1) pandemic of 2009/10 is based on laboratory confirmation and is widely considered a gross underestimate*“ (WHO, 2011b). They name a number of reasons for this:

- Not all the suspected pandemic influenza-associated deaths were tested and confirmed
- Where access to health care was limited, deaths may have occurred without being recognized
- Some deaths will probably have been misclassified

In general the WHO suspects that the number of deaths in countries with limited or no laboratory testing capacity are severely under represented (WHO, 2011b). A modeling study from Simonsen et al. Published in 2013 claims that the „*respiratory mortality from the 2009 influenza pandemic was about 10-fold higher than laboratory-confirmed mortality*“. In their calculations they estimate that from April 1, 2009 through to December 31, 2009 between 123,000 and 203,000 pandemic influenza deaths occurred.

To understand why the virus was scaring so many experts it is important to understand how it differed from seasonal influenza.

2.2 The A/H1N1 Virus

Molecular genetic analyses done by the CDC revealed that the virus resulted from a process called re-assortment. In this process, genetic material of various virus subtypes admixes and results in a new virus. This biological process occurs when one organism is infected with two different influenza viruses at the same time. Domestic pigs are an ideal species for this process as they are susceptible to infection by both bird and human influenza viruses. The new swine influenza A/H1N1 virus (Figure 1) was most likely derived from the US triple re-assortment swine influenza virus and a Eurasian H1N1 swine influenza lineage (Schaberg & Burger, 2010).

H1N1 viruses were relatively common in North American pigs from the beginning of the 20th century. The first change occurred, when in 1998 a new triple-reassortant H3N2 virus emerged. The new virus contained genetic material from swine (H1N1), North American avian, and human (H3N2) influenza (Schaberg & Burger, 2010). This indicated that a large proportion of people might be non-immune to this new strain of influenza and that the seasonal influenza vaccine might not protect from contracting the virus (CDC, 2010). A high number of deaths could be the consequence. But in April 2009 this was all speculation; no one knew how different or similar the new virus was compared to the seasonal influenza virus– and how severe an infection would be. Now, in retrospective, a comparison between the pandemic and the until then circulating seasonal influenza can be made and shall be done in the next paragraph.

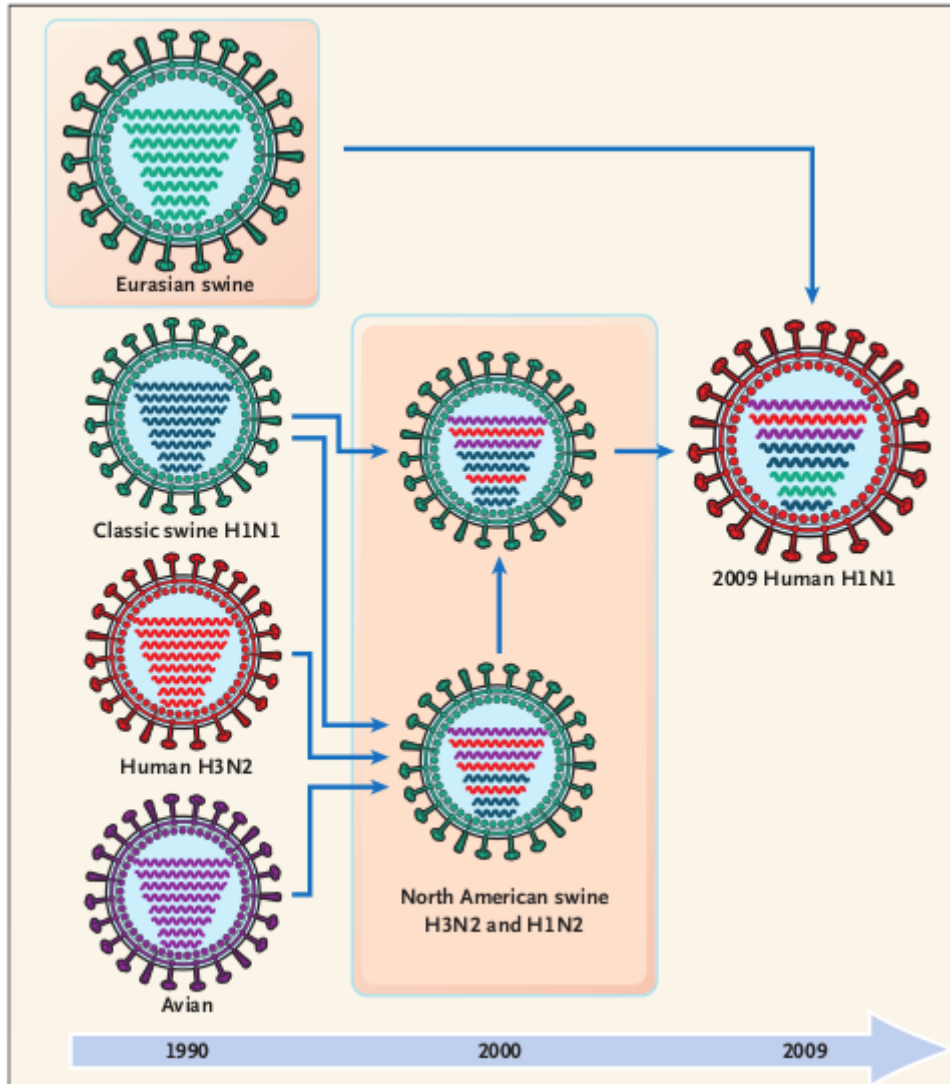


Figure 1: The evolution of the 2009 A/H1N1 Influenza Virus

The eight segments seen within each virus stand for following proteins of the influenza A virus (top to bottom): polymerase PB2, polymerase PB1, polymerase PA, hemagglutinin, nuclear protein, neuraminidase, matrix proteins, and nonstructural proteins (Trifonov/Khiabaniyan/Rabdan, 2009).

2.3 The A/H1N1 Pandemic Compared to the Seasonal Influenza

The common clinical symptoms associated with the A/H1N1 pandemic were: headache, fever, cough, sore throat, vomiting, diarrhea and body aches (RKI, 2009). Except for vomiting and diarrhea the symptoms did not differ from those patients experienced during seasonal influenza. Most A/H1N1 patients experienced a mild infection and symptoms. The majority of patients with severe disease conditions had underlying risk factors, these would have also led to complications with seasonal influenza (Nicoll & Coulombier, 2009).

A visible difference between the A/H1N1 pandemic and seasonal influenza patients was that mostly younger age groups were affected by the first. Also a higher percentage of fatal outcomes occurred in younger age groups (Department of Health, 2009; Schaberg & Burger, 2010). In England, 85% of A/H1N1 related deaths were under 65 years of age with the median age being 43 years (Pebody et al.; 2010). This differs strongly from typical seasonal influenza epidemics in which 80-90% of deaths are estimated to occur in people 65 years of age and older.

To illustrate the strength of this shift, researchers calculated the years of life lost due to the pandemic in 2009. They estimated that three times more years of life were lost than with the same number of deaths from the seasonal influenza (Dawood et al., 2012). The higher susceptibility of younger population groups might have been caused by the fact that many people aged over 65 were immune, due to prior exposure to a similar influenza virus that had been circulating before the 1950s (Donaldson et al., 2009; Hardelid et al., 2010).

The most important reason for the development of severe symptoms and a fatal outcome were underlying risk factors like asthma, hypertension, obesity, pregnancy etc.: 77% of the 308 fatal cases in the UK belonged to this group (Pebody et al.; 2010). The relative risk for a fatal outcome was especially high for those with underlying chronic conditions. In the UK it was observed that persons in one of the risk groups had a nine times higher risk of dying from an infection with pandemic A/H1N1 compared to the general public (Donaldson et al. 2009).

Pebody et al. (2010) reported an overall case fatality rate of 0.4 per 1.000 clinical cases. A similar finding had been reported earlier by Donaldson et al. (2009). In addition, he stated

that mortality in this pandemic is lower than observed in previous pandemics, but this applied only to previously healthy people. Patients with underlying chronic conditions had a high relative risk for a fatal outcome – compared to the seasonal influenza. „*The population risk of death for those falling into a vaccination group (...) was nine times that for those not in an at risk group*“ (Donaldson et al. 2009).

The main risk groups did not differ between the pandemic and seasonal influenza: it were people with chronic respiratory disease, chronic heart disease, chronic renal disease, chronic liver disease, chronic neurological disease, immunosuppression, and diabetes mellitus (Department of Health, 2009). Among conditions with the highest risk for a fatal outcome were A/H1N1 patients with chronic neurological disease, chronic respiratory disease, chronic liver disease and immunosuppression, and pregnant women. The latter were for the first time at special risk from an influenza infection. This is why many countries included them in the priority groups for vaccination, which had not been done for the seasonal influenza vaccination campaign (Pebody et al. 2010). In other countries scientists reported similar findings about severe and fatal outcomes and underlying risk factors (Louie et al., 2009; Santa-Olalla Peralta et al., 2010). Experts often face a problem, when they try to warn the general public about a certain risk: Lay people often don't fully understand the terms the experts are using. The problem however may be more complex, as Gigerenzer et al. (2007) point it out that health experts too encounter problems in understanding and appraising certain risks. The next section discusses the terms and some concepts surrounding: risk and risk communication.

2.4 Risk Communication in the Public Health Context

This section will shed light on the generalities about risk communication but will mostly focus 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 with regard to matters that might have negative health effects on them. It took a different turn in the 1980s and that was how the concept of risk communication was born (Sandman, 2001).

From the public health point of view, communicating risk has been resourceful in motivating people to for e.g. (i) quit smoking, (ii) use their seat-belts while driving, (iii) evacuate homes during emergencies, (iv) avoid drinking and driving, (v) avoid living under power lines, (vi) avoid living near power plants, and (vii) become aware of passing on genetic risks (Sandman, 2001). 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” (Sandman, 2001). 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.

2.4.1 Risk

Humans have always been facing hazards. In the stone-age caveman had to deal with dangerous animals, threatening weather conditions, or hostile clans. Traditionally they had four options to act in a situation: They could flee, fight, play dead, or use trial and error. If rain was pouring from the sky, they searched for a cave or a tree for shelter. If an animal attacked them, they could fight, flee, or play dead (Renn, 2005). The most complex situation was the interaction with other humans. With the passage of time, the threats were changing to floods, earthquakes, plagues, famine, or war. They all could threaten a human’s life. With the development of a more complex society the hazards became more complex too. For example during the industrialization a person had to choose: Do I want to live in a bigger city, where I have better opportunities to work and therefore avoid dangers like starvation, but at the same time increase my risk get infected with a dangerous disease? Two important terms emerged: Hazard and risk. The National Research Council (1989) calls a hazard *„an act or phenomenon“* which *„has the potential to produce harm or other undesirable consequences to some person or thing“*. This danger can have a natural cause (e.g. an earthquake) or it can be man-made (e.g. a war). *„The concept of risk further quantifies hazards by attaching the probability of being realized to each level of potential harm“*, they state further. This definition also fits to the risk definition, which is used by insurances: Probability of

occurrence (in a certain time period) and magnitude of an event (Leppin, 1994, 37). It is not possible for an individual to judge the magnitude of every possible hazard nor the probability of its occurrence, and even for hazards which could affect an individual personally, they often have to rely on the judgment of experts: General practitioners (GPs), scientists, or politicians. The experts have to transfer their knowledge about a certain hazard to the individuals – in a way they can understand. They have to communicate about risks.

2.4.2 Risk Communication

The literature provides a variety of definitions for risk communication (Hampel, 2006). The Organisation for Economic Co-operation and Development (OECD, 2002) defines it very broadly: *„risk communication includes all exchanges among interested parties (individuals, social groups, industry and governments) about health and environmental concerns“*. The European Centre for Disease Prevention and Control (ECDC) defined risk communication as *“the exchange of information about the health risks caused by the environmental, industrial, or agricultural processes, policies, or products among individuals, groups and institutions”* (Infanti, Sixsmith, Barry et al., 2013). Wright, Sparks, and O’Hair describe it in their book *Health Communication in the 21st Century* (2013, 334) as *“a discussion about an adverse outcome and the probability of that outcome occurring”*. They further state that *“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 behaviour or exposure”* (ibid). Summed up risk communication is an exchange process between stakeholders in a society, in which risks are identified, judged, and potential coping strategies are evaluated.

The success of risk communication does not mean that the receiver of the messages follows the instructions of the sender. The US based National Research Council (NRC) rather sees it as a process, which should involve the whole society and is not just a specific action or information delivery process (NRC, 1989). A society, which supports a democratic decision-making process and the well-informed action of the individual should aim at giving the receiver the best possible information about the risk. *„Risk communication is successful to the extent that it raises the level of understanding of relevant issues or actions and satisfies*

those involved that they are adequately informed within the limits of available knowledge” (NRC, 1989).

The OECD formulates in its handbook ‘*Guidance Document on Risk Communication for Chemical Risk Management*’ goals for a successful risk communication. Similar to the NRC they don't want the recipient to adopt a certain opinion or start a specific action. They are rather interested in improving the knowledge about a certain risk in a way that the recipient is in the end able to take a decision based on his or her knowledge about the hazard and his or her personal values and preferences. „*The ultimate goal of risk communication is to assist stakeholders in understanding the rationale behind a risk-based decision, so that they may arrive at a balanced judgment, that reflects the factual evidence about the matter at hand, in relation to their own interests and values” (OECD 2002, 13).*

The problem is that in real life situations, experts and the general public often have different perspectives and priorities and are concerned about different issues. Peter Sandman (2001) focuses on this issue and distinguishes between hazard and outrage.

To Sandman hazards are similar to the experts definition of risk: As magnitude of an event multiplied with the probability of its occurrence. On the other hand he defines outrage as “*all the things that people are worried about that the experts ignore” (Sandman, 2001).* Slovic et al. (1987), too, recognized a divergence between the risk perception of experts and lay people. They tried to show this in an experiment: Two groups (league of women voters versus risk-experts) had to rank 30 activities and technologies according to their riskiness. The results showed a huge difference in the judgment:

The participants from the group of women voters ranked (1) Nuclear power, (2) Motor vehicles, (3) Handguns, (4) Smoking and (5) Motorcycles as the top five risks.

The experts considered (1) Motor vehicles, (2) Smoking, (3) Alcoholic beverages, (4) Handguns and (5) Surgery as the top five risks in descending order.

The risk ranked highest by the women voters, nuclear power, did not even make it in the top five ranked risks of the experts. While on the other hand surgery and alcoholic beverages was not perceived as a risk the women voters were highly concerned about. Slovic concludes that experts and lay people principally judge risks in different ways.

In the case of the A/H1N1 pandemic in Europe this was a phenomenon seen after the arrival of the vaccine in September 2009. Shortly before the vaccination campaign was to start in November, the weekly news magazine “DER SPIEGEL” published a story which warned about potential health risks in connection with the A/H1N1 vaccination (SPIEGEL, 2009). The opinion leading magazine which was then selling more than a million copies a week was judging the risks differently than the experts, which decided to run a vaccination campaign, while the magazine advised against the vaccination. The authors of the article were scared about the vaccine – not the virus.

This view should not be seen as the opinion of the general public, but shows how different experts and lay people – even if they are editors of the SPIEGEL – judge risks. They wrote:

„Immun gegen die Impfung – Kinderärzte rebellieren, Frauenärzte warnen: Die Impfkampagne gegen die Schweinegrippe gerät in Verruf. Sind die Deutschen Versuchskaninchen in einem gigantischen Pharmaexperiment?“ (Immune against the vaccination – Pediatricians revolt, Gynecologists warn: The vaccination campaign against swine flu is earning discredit. Are the Germans guinea pigs in a gigantic pharmacy-trial?) (SPIEGEL, 2009). Similar newspaper articles were observed in other countries of the EU, but the vast majority (94 %) stayed neutral on the topic (Duncan, 2009).

How people perceive risks, is a question which the scientist David Covello is researching on since the 1970s. The model he developed will be described in the next paragraph.

2.6 The Risk Perception Model

To understand how the process of risk-perception is working Covello et al. (2001) developed a risk-perception model, with four sub-groups: mental-noise, negative dominance, trust determination, and risk perception.

1. The Mental Noise Model

The mental noise model says *“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”* (Covello et al., 2001). This inability to understand information could lead to charged emotions (fear, worry, anger or outrage) which in turn makes it hard to have a rational discussion with the individual about the situation. This emotional state is what generates the mental noise described by Covello et al. (ibid). To counter this effect, they recommend that communication should be timely, accurate, easily comprehensible, and repetitive. This is also recommended by other authors (Infanti et al., 2013; Reynolds & Seeger, 2007).

2. The Negative Dominance Model

The negative dominance model says 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 (e.g. over-reporting by the media about 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 outcomes. To counter this effect it is sensible to *“focus on what is being done rather than what is not done”* (Covello et al., 2001).

3. The Trust Determination Model

The trust determination model states that public trust in institutions is very important in the management of any pandemic. When the people feel they 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 is important. This could for example be credible research institutions which are highly valued in a certain society. The researchers also mention the use of trust determination factors that they present in pairs:

caring and empathy; dedication and commitment; competence and expertise; and honesty and openness (Abraham, 2011; Covello et al., 2001).

4. The Risk Perception Model

The risk perception model is based on the cultural, linguistic, ethnic/racial, gender, and geographical differences seen around the world. The perception of risk will differ from one region, person, and culture to another (Covello et al. 2001). These factors added to risk perception factors might alter the perception of risk to varying degrees: risks that are perceived to be man-made, permanent, involuntary, unfamiliar, exaggerated, unfairly distributed and out of control of the individual are perceived as more threatening. They increase the individual level of fear, distrust, and outrage to officially recommended protective measures like frequent hand washing, covering the mouth when coughing, social distancing measures and vaccination uptake (Infanti et al., 2013; Reynolds, 2007). This means a potential hazard from a nuclear power plant to the people living close to it (man made, unfairly distributed, out of control of the individual) is perceived higher than the hazard from drinking alcoholic beverages (voluntary, self-inflicted).

This risk perception model existed long before the A/H1N1 pandemic outbreak but as Thomas Abraham states in the BMJ (2010) such models were seldom used by stakeholders during the pandemic: *“The principal failure was this: instead of using the tools and principles of risk communication to create public understanding of the risks posed by a pandemic, experts and policy makers used another form of communication, advocacy, which is intended not so much to create understanding but to persuade the public to take certain actions.”* To understand why this was not done is one aim of the E-com@eu-project, in which this work is included and which shall be introduced in detail in the following paragraph.

2.7 The E-com@eu-Project and Workpackage 1

The overall aim of the E-com@eu-project is to develop evidence-based risk communication strategies in order to respond effectively to major epidemic outbreaks in Europe. The mixed

experiences of the public health experts and other stakeholders during the A/H1N1 pandemic in 2009 /2010 in Europe is the context in which this research is embedded. The project is co-financed by the 7th Framework Program for Research and Technological Development (FP7) of the EU. The Framework Programs are funding programs developed to support research in and about Europe. The E-com@eu-project funded for four years, is subdivided into 10 workpackages and involves nine international partners. The team brings together *„knowledge in epidemiology, media analysis, social marketing, risk perception and discrete choice experiments in order to develop an evidence-based behavioural and communication package that can be applied by health professionals and health agencies throughout Europe in case of major epidemic outbreaks“* (E-com@eu Study Group, 2011).

In order to increase the acceptance of large-scale pandemic response measures among the general public and at-risk groups, the project amongst others aims to understand the risk communication processes during the A/H1N1 pandemic in Europe. It is essential to take into account the perspectives, wishes and needs of those who are actually involved in the process of risk communication to the public that is those who are eventually going to use the communication tools. Hence this study (part of work package 1) will assess the stakeholder (public health officials) perceptions on official and public action and reaction during the A/H1N1 pandemic. It will specifically explore the difficulties stakeholders faced in receiving information and also in communicating complex messages about uncertain and unknown issues to a sceptical public. Semi-structured interviews will be conducted in eight EU countries namely Germany, The Netherlands, United Kingdom, Sweden, Poland, Romania, Italy, and Spain. The views of different stakeholder groups, such as nurses, physicians, or state officials in ministries and public health agencies who constitute an important link at the policy/public interface will be assessed. Their suggestions and wishes with respect to desirable improvements in risk communication will also be explored. The experiences made and difficulties faced by these stakeholder groups during the A/H1N1 pandemic will help inform the development/ improvement of communication tools.

3 Method

The methodological approach used to achieve the objectives of this study included a comprehensive literature review; the development of a semi-structured interview questionnaire; the recruitment of professional interviewees at the national, regional, and local levels in different European countries; and finally a qualitative analysis of the interviews. These are described in detail below.

3.1 Literature Review

To develop a profound understanding of the problems that arose during the 2009 influenza A/H1N1 pandemic risk communication process, a comprehensive literature search was conducted in Medline using PubMed (US National Library of Medicine, Bethesda, MD).

The search terms used in Pub med were as follows: risk communication, communication difficulties, H1N1, pdm09, 2009 influenza pandemic, and influenza pandemic. Two searches were conducted. The first search syntax was “risk communication AND (pdm09, 2009 influenza pandemic, or influenza pandemic).” The second search syntax was “communication difficulties AND (pdm09, 2009 influenza pandemic, or influenza pandemic).” The limits used were: articles published in the years 2000 to 2012 and articles in English and German. Emphasis was placed on studies looking at the European situation; nevertheless, no geographic restriction was placed on the literature search. A data extraction sheet was used to systematically collect information related to the study question from the published articles [see appendix 8.3 and 8.4].

In addition, the Cochrane Library (John Wiley & Sons, Chichester, United Kingdom) and; Google Scholar (Google Inc, Mountain View, CA) were searched. The reference list of the retrieved documents was also used to identify additional publications. General Internet searches using the search engine Google (Google Inc, Mountain View, CA) was also done to obtain conference presentations, country reports, papers, and other types of grey literature. Furthermore, Web sites of international health organizations and national ministries were searched for publications. These included the European Centre for Disease Prevention and

Control (ECDC), the Centers for Disease Control and Prevention (CDC), Health Canada (HC), the Health Protection Agency (HPA), the National Collaborating Centre for Infectious Diseases (NCCID), and the WHO.

The information collected served as an important source for the development of the questionnaire guideline to interview professional stakeholders.

3.2 Analysis of Stakeholder Interviews

The aim of the stakeholder analysis is to specifically gather qualitative information on professional stakeholders perceptions and perspectives in terms of the difficulties they faced during the risk communication process at the time of the 2009 A/H1N1 pandemic. It also aims to explore their wishes with respect to the function and flexibility of what risk communication tools should be able to accomplish. The questionnaire guideline was used to interview stakeholders (state officials in public health agencies, physicians, health care staff etc.) in different European countries.

3.2.1 The Sample

From December 2013 to April 2014, requests were sent to 63 experts, 32 of whom replied. Finally 25 experts agreed to give us an interview. 25 semi-structured interviews were conducted with experts from 8 European countries (Table 1). To be included as an interviewee, the experts needed to be involved in the management of the 2009 A/H1N1 pandemic in a European country.

A snowball sampling method using the network of the researchers was used to establish contact with the professional stakeholders involved in the management of the influenza A/H1N1 pandemic in their respective countries. According to their job description they could be classified into one of the following levels: micro-level (for example general practitioners or nurses) – those with direct contact to potential patients, meso-level (persons working in a regional public health office) – those who may have contact to the public e.g for vaccination but also with local press etc., and macro-level (epidemiologists and public health experts

working at the national level) – those who interact with European and international pandemic management organizations and have contact to the press. The countries were chosen with the aim of including at least one county each from eastern, western, southern, and northern Europe and to thereby include countries with different health care systems and infrastructures as well as well as different political backgrounds and also financial resources. The interviews were conducted via telephone (n=21), face to face (n=3), and in written format (n=1). The language was either English or German. The interviewees were assured confidentiality; information gathered during the interviews will not be brought in connection with their name or designation, only with their country and their management level (macro, meso, micro). Hence neither the names nor the designations of the 25 interviews will be disclosed. The interviews were digitally recorded and ranged between 8 and 55 minutes. After the interview process they were transcribed and the language was transformed to a written format. Incomplete sentences or wrong grammar was corrected without changing the meaning.

Table 1: Number of interviewed Experts by Country and Level of Management

Country	Micro-Level	Meso-Level	Macro-Level
Sweden	1	1	1
Poland	0	1	1
Romania	1	0	1
Italy	1	0	1
Spain	1	3	0
United Kingdom	0	3	1
Germany	2	1	0
The Netherlands	2	2	1
Sum	9	10	6

3.2.2 The Questionnaire

The sociologist Cornelia Helfferich describes in her book *‘Die Qualität qualitativer Daten – Manual für die Durchführung qualitativer Interviews’* (The quality of qualitative data – a

manual for the conduction of qualitative interviews) (2011) some important aspects that should be taken into account while developing a qualitative interview questionnaire.

According to Helfferich the first step is to decide on a precise research topic. In this work the research topic is predetermined by the proposal of the E-com@eu-project, which has been presented above. In the following the researcher has to choose a target group, which in this case are the professional stakeholders, that have been involved in the management of the 2009 influenza pandemic. Other decisions which have to be made prior to the interview process, according to Helfferich, are selection of the interview-style and the strategies for data analysis. Based on the research topic and the information collected from the literature search, the questions were formulated, care was taken to formulate open semi-structured questions so that the interviewees have the possibility to express their views and share their experiences. The content of the main questions were based on the research questions and included the following main categories: The stakeholders tasks during the pandemic; their experiences with the communication about risks during the swine flu pandemic; their perception of important factors influencing this communication process; and their wishes with regard to a tool, or other forms of support or materials that would help them with future risk communication. The semi-structured nature of the questions allowed for the incorporation of important topics of interest that come up and may not be directly related to the questions (Helfferich 2011, 168ff.).

For the development of the questionnaire Helfferich recommends to formulate the leading-questions *“so offen und flexibel mit der Generierung monologischer Passagen wie möglich, so strukturiert wie aufgrund des Forschungsinteresses notwendig”* (As open and flexible as possible, to facilitate the generation of monologues passages (by the interviewees), as structured as needed, based on the research interest) (ibid., 181).

The construction of the interview guide follows the so called *“SPSS-Prinzip”*. SPSS stands for *Sammeln, Prüfen, Sortieren und Subsumieren* (collect, check, organize, and subsume).

According to Helfferich the researchers should start with a brainstorming and collect all their questions about a certain topic. Those should afterwards be checked for their openness and usability, sorted according to topics, and then subsumed/categorized according to some main-aspects (ibid., 182ff.). At this step in the process one needs to check, if the questions

would encourage the interviewees to talk, to achieve this the questions should be formulated as open as possible (ibid., 185).

Qualitative research aims to detect the special. According to Helfferich, qualitative research should aim to detect from a single case what holds true for the general. She emphasizes that it is crucial in the analysis process to compare the findings with other research on the topic (ibid., 185).

It is important and considered good practice not to overload the questionnaire, to enable openness in the interview process, while maintaining a clear structure. The interview guideline should follow the natural flow of arguments and should avoid leaps or interruptions. The interviewer should allow the interviewees to talk freely, expand on topics they are interested in, and may ask subsuming questions in the end (ibid., 180). We took care to follow all the above mentioned recommendations while developing the questionnaire for this research. The technique of reflective listening was used by occasionally repeating the essence of what the interviewee said both in-order to signal that the interviewer is attentive and interested but also to provoke further elaboration on the topic or occasionally a correction of the interviewers interpretation specially when the interviewees were not very proficient in English. The questionnaire was pre-tested and adapted only in minor aspects, which is why we also included this interview in our analysis. The final questionnaire can be found in the appendix 8.1.

3.2.3 Data Organization

All interviews were transcribed with the help of the audio transcription software F4 (audiotranskription.de, Marburg, Germany). The transcribed interviews were edited, that is, incomplete sentences or incorrect grammar was corrected without changing the meaning. Breaks or special intonations were not highlighted. The software MAXQDA version 11 (VERBI GmbH, Berlin, Germany) was used to structure and analyse the interview content. All (25) interviews were transferred into MAXQDA.

3.2.4 Qualitative Content Analysis

The interpretation of the interview data followed the qualitative content analysis method of the educational theorist and psychologist Philipp Mayring (Mayring, 2010, 54). The inductive category development approach based on Mayring's process model was chosen (ibid., 75).

The development of inductive categories is a reductive process which implies that the content of the material (interview statements) is reduced to the most important aspects which are based on the study question. Initially selection criteria for the inclusion or exclusion of the material, based on the research questions are defined. In addition the degree of abstraction i.e. how wide or narrow the margin of inclusion for material should be set needs to be determined. This influences whether more or less material is included in the final analysis and will determine whether a few categories with a broader content spectrum are built or more categories with more precise and specific contents.

Following this the material is scanned sentence by sentence to see whether the selection criteria, within the defined degree of abstraction are fulfilled. If so a category is opened and assigned a title which best describes the content in that category for e.g. trust or media or behaviour etc. and the corresponding material assigned to that category. This process is continued and the materials (statements/sentences) selected are either assigned to existing categories if adequate, a process called subsumption. If the material found does fulfil the selection criteria but does not fit into any existing category a new category is opened and named. After scanning 10 – 50% of the material (in this study approx.. 20%)the developed categories are rechecked to see if the selection criteria and degree of abstraction defined initially are adequate for answering the research question.

For our study each interview was scanned sentence by sentence to retrieve information contributing to the research questions. During this process inductive categories were developed and information/quotes/sentences from the interviews shifted into the respective categories. As new information came up that did not fit into any category, new categories were developed. If the content of a statement was relevant for more than one category they were assigned to both categories. In the next step all statements belonging to a category

were reviewed and subsequently summarized to extract the essence, following Mayring's recommendations for a structured content analysis (ibid., 54).. This was carried out for all categories. This approach helps to organize the gathered information and to highlight the aspects important to the experts. It also helps to detect overlaps i.e. which aspects are considered important by many experts and which maybe specific to the situation or experiences of an individual expert. The analysis units varied from single statements to whole passages of the transcription if they made sense in the context.

Since our main focus is to explore the difficulties stakeholders at different levels faced both in giving and receiving information and to identify factors which hindered this process, the interviews were scanned for information on these topics and the categories developed accordingly. In addition information on the suggestions and wishes of how this process could be improved in future was specifically filtered out. The extracted information is analysed per category and presented in detail in the results section.

4 Results

This chapter briefly describes the findings of the literature review on which the questionnaire was based and then focuses in detail on the information gathered from the stakeholder interviews.

4.1 Literature Review

A total of 25 relevant studies from 11 countries or regions were identified and used for the development of the semi-structured interview guideline (see appendix 8.1, 8.3 and 8.4). On the basis of the information extracted from these studies, 4 sets of categories emerged, under which the main risk communication problems during the 2009 A/H1N1 pandemic were summarized. The categories were vaccine concerns, trust issues, communication difficulties, and organizational problems.

4.1.1 Vaccine Concerns

This category summarized the concerns and worries about the safety and efficacy of the A/H1N1 vaccines used during the pandemic of 2009 and 2010 as reported in the studies. Of the 25 studies, 17 reported vaccine concerns. For example:

- Fear of potential side effects from the use of the vaccines
- Mistrust due to the accelerated authorization procedure
- Skepticism regarding the need for vaccination when the A/H1N1 turned out to be a relatively mild infection
- The vaccines were inadequately tested before being pushed on the market
- Lack of trust in vaccine adjuvants and Thiomersals (vaccine preservatives)
- Disagreement with the recommendation to vaccinate non-traditional groups like pregnant women

4.1.2 Trust Issues

This category covered issues related to the level of trust towards the government, public health experts, health authorities, pharmaceutical companies, and the media. Of the 25 studies, 14 mentioned trust issues. For example:

- General distrust in the government
- Lack of trust in medical science and pharmaceutical companies
- Multiple sources of information with contradictory messages
- Unreliable scientific data
- The impression, that the media is overestimating the seriousness of the pandemic
- A lack of transparent decision making by governments, leading to distrust also about vaccination
- Lack of confidence of health professionals in the vaccines
- Distrust towards public health officials to provide correct information regarding the safety of the vaccines

4.1.3 Communication Difficulties

This category summarized problems concerned with the timeliness, clarity, frequency, and volume of information during the A/H1N1 pandemic. Of the 25 studies, 23 mentioned communication difficulties. For example:

- Information received lacked clarity
- Insufficient information on the benefits and potential side-effects of the vaccines
- Overwhelming volume of emails, daily updates, and guidelines
- Wrong timing of updates, so that experts had difficulties identifying new information from the frequent daily updates
- No clear communication strategies
- Myths and misconception around the influenza have not been tackled adequately
- Poor communication between different stakeholders
- Crucial groups such as HCW have not been addressed adequately
- The apathetic attitude of the authorities in addressing the concerns of the public and health professionals regarding the vaccines

4.1.4 Organizational Problems

This category summed up the organizational problems during the pandemic. Of the 25 studies, 15 mentioned organizational problems. For example:

- Unclear definitions of roles and responsibilities of different stakeholders in the pandemic management.
- Some stakeholders like front-line physicians did not feel engaged in the decision making process and criticized this.
- Physicians and other HCW had problems with the top-down management approach during the pandemic.
- Some physicians and HCW ignored their potential roles in transmission of the virus and the impacts they might have through absenteeism.
- Logistic and storage difficulties.
- Not enough patient educational materials.
- A lack of proactive reminder systems for the vaccination campaigns.
- Antiviral and vaccine shortages.
- Poor data management.

A detailed description of the studies and the extracted data is given in the appendix 8.3 and 8.4.

4.2 Stakeholder Analysis

Based on the questionnaire and the interviews four major themes emerged from the interviews: (1) vaccine, (2) communication, (3) general problems, and (4) future risk communication, which are described in detail below. All topics have further sub-topics (Table 2).

Table 2: Coding Categories and Sub-Categories used in the Analysis

Code categories	Sub-categories
Vaccine	Vaccine Concerns
	Long Shadow of the Influenza A/H1N1 Pandemic
Communication	Receiving Information
	Giving Information
	Media
General Problems	Stakeholders Perception of the Pandemic
	Trust
	Public Information Seeking
	Transparent Communication
	Globalization of Information
	Timing of Crucial Events
Future Risk Communication	

4.2.1 Vaccine

As reasons for the low vaccination coverage rates in their country the stakeholders mention the late arrival of the vaccines, the moderate character of the pandemic, vaccine safety concerns, and skepticism regarding the need for vaccination among a large part of the HCW. Generally they found it problematic to predict how severe the pandemic would be.

„The problem is, had we not vaccinated, then the people would not have seen the side-effects [some cases of post-vaccination narcolepsy were seen]. We would be sitting there with vaccine for one Billion crowns. And it would not have been used, people would die, we would have lots of severe cases. If we would not have used the vaccine people would say: You are

crazy. You are not using this vaccine. To say it was wrong or it was right, is very difficult“ Sweden, macro-level stakeholder

“It [the vaccination coverage] was reasonably high in at-risk-groups with the major exception of pregnant woman.[...] Bearing in mind, that the vaccination program was well after the peak of the pandemic.” United Kingdom, macro-level stakeholder

4.2.1.1 Vaccine Concerns

Stakeholders from countries which did not meet their vaccination goals report about safety and efficacy issues concerning the vaccine, both in the general public and among HCW.

“Yeah, because they [the general public] are scared. They refuse vaccination, because they are scared from information on the Internet and media. They thought it was dangerous. Even many health care workers were really not convinced that the vaccination was needed. And then some reports came even in the literature saying that the pandemic was not really so bad and it was a rather mild virus.” Italy, micro-level stakeholder

„At this time we had big anti-vaccination movements here in Spain. Some of them are even health professionals, that say, the vaccine is not safe, it has not been tested. Others said, that the pandemic is a fake“ Spain, meso-level stakeholder

In countries with relatively high vaccination coverage (Sweden and the Netherlands), the stakeholders reported differently.

“I did not notice large fears among the Dutch population concerning the vaccine.”
Netherlands, meso-level stakeholder

„If the government and the local authorities say, you should vaccinate, then a lot of people actually do it without really thinking about it.“ Sweden, micro-level stakeholder

Health-care support staff seemed to have a strong influence on the vaccination behaviour of some segments of the public. For example, midwives in England tended to not recommend pregnant women to get vaccinated against the A/H1N1 influenza, which may partially explain the low vaccine uptake of 15% among pregnant women in the United Kingdom (Mereckiene et.al., 2012).

“There was a strong reaction - for whatever reason - in the midwifery group. And midwives were actually advising pregnant woman not to get vaccinated. And I am sure we lost lives on account of the non-evidence based advice.” United Kingdom, macro-level stakeholder

Yet not only specific groups seemed to have a strong influence on the vaccination behaviour of the public; stakeholders from some countries also reported about prominent individuals who had a considerable influence on the public perception of the pandemic.

“She is a doctor, but she is also a nun. She goes on TV with a nun dress and she seems, that she talks every morning with God. That gives here a strong credibility. And she started to talk on TV about the classic anti-vaccine topics: vaccines are contaminated, are not safe, you can get a lot of very bad diseases, when you get vaccinated, the virus is not a new virus, so we don't need a vaccine and things like that. She had become very popular at that time. That is a very good example of single people with a big influence.” Spain, meso-level stakeholder

“What happened then was that shortly before we got the vaccine a person became severely ill in a hospital in Sweden. A very influential doctor, who has been against vaccination became ill. Became very severely ill in a few hours. And he then said very publicly: “ I have never seen anything like that. This is very scary. This is very dangerous.” A big, strong, Swedish man. And I think this affected people more than many other things.” Sweden, macro-level stakeholder

4.2.1.2 Long Shadow of the Influenza A/H1N1 Pandemic

The annual seasonal influenza vaccination coverage in a country seemed to have an important influence on the uptake and acceptance of the pandemic influenza vaccine among

the public. Hence, it might be possible to prepare for an influenza pandemic by strengthening the seasonal influenza vaccination programs within a country.

“The Netherlands has traditional a high coverage in the risk groups [for the seasonal influenza vaccination]. So when the vaccine was introduced these risk-groups where very likely to be vaccinated again. And they even went for a second round of vaccination. So we really had a wonderful coverage.” Netherlands, macro-level stakeholder

“Every year with our flu vaccine we have no good response, so if we get 20 percent coverage in doctors and nurses, who have contact with high risk persons, we are happy. It is a very difficult task.” Italy, macro-level stakeholder

“I think the number one reason [for the high vaccination rate during the pandemic] is that we have a very high vaccination coverage in our vaccination programs . For all childhood vaccinations we have a very high coverage. And the target-groups now where children and young adults. And it is in the children and up to fifteen that we have the absolutely highest coverage.” Sweden, macro-level stakeholder

“It [the seasonal influenza vaccine] is still only recommended and it can be given on decision of the physician in individual cases. Mostly it is recommended but it is not obligatory. In previous years we had about three percent. Which is really low.” Poland, meso-level stakeholder

“Well we have a lot experience in mass-vaccination campaigns. Because we also do it for our regular, national vaccine program. Once or twice a year we have a big campaign when children that missed vaccinations can come.” Netherlands, micro-level stakeholder

“The priority group where relatively small and the UK has a strong national immunization program. So we have a lot of experience in delivering national immunization and we kind of piggy-bagged on that.” United Kingdom, micro-level stakeholder

Vice versa, issues surrounding the pandemic vaccine, such as, public distrust, rumors or misconceptions, and inadequate official communication about the vaccine or its safety, may jeopardize public trust towards future vaccination campaigns. Hence, not only is the uptake of the pandemic vaccine at stake but further harm maybe caused as the result of a lowered vaccination rate for other diseases like seasonal influenza. Thus, during a pandemic, stakeholders need to bear in mind that their actions will influence the vaccination behaviour for other diseases in the future.

“The seasonal influenza uptake has also gone down since the pandemic. I guess the reason is a miss-trust in vaccination. Miss-trust on the safety. So it is hard for people to understand, what is new, what is seasonal. But during the pandemic they got a lot of information, telling them about dangers of an vaccine and they started to think: Why should the seasonal be save?” Romania, macro-level stakeholder

“No, they did not trust. And we also experienced damage from that also for other vaccines. For example the HPV vaccination campaign and also on the measles vaccination campaign. And from 2009 the anti vaccination movement has raised their level of communication. They say: You see even the health authorities do not know how to deal with a pandemic. They probably also deal bad with diseases like measles or HPV. [...] At the national levels before the pandemic campaign we had more or less 65 percent coverage which was not bad. In the last year it was around fifty. We had a decrease of 15 percent in the last years. This was also from the bad management of the pandemic flu.” Italy, macro-level stakeholder

“But our main problem was actually not choosing the pandemic, since we reached a vaccination coverage of about sixty percent which is the highest in the world. We managed very well in our risk communication but what we got instead was the narcoleptic. As a consequence of vaccination, which has been the real severe thing, because if we get a new and more severe pandemic, we will have much, much more difficulties in convincing people to vaccinate. [...] a situation that has become very problematic for our influenza vaccination coverage. Because people don't dare to take the vaccine after this incident. [...] It went down

from almost 65 percent in the elderly which nearly got narcoleptic till around forty percent after the pandemic. It was probably that the people also where tired on influenza after all the fuzz around the pandemic. But main reason the low vaccination for the low coverage is that the people don't believe that the vaccine is save.” Sweden, macro-level stakeholder

“We dropped on our level of seasonal influenza vaccination. I think most of the countries have done that too.” Sweden, meso-level stakeholder

4.2.2 Communication

This chapter contains the stakeholders views on the communication process itself. Answering the questions, how the experts accessed new information on the pandemic and how they forwarded them to others. The experts judged the role of the media in this process as highly important, which is why their communication with the media is coded in an own group.

4.2.2.1 Receiving Information

Experts at the macro-level and meso-level used multiple sources of information to get updated on the pandemic and its management: conferences, e-mails, Web sites, phone-calls. It seemed important for them to have a broad range of information sources.

“We had a regular telephone meetings and what was then the health protection agency in England [...] I was in several committees and then I had my regular weekly meetings with health protection agency, which was a kind of bilateral meeting. And then I had my operational calls with basically government representatives.” United Kingdom, macro-level stakeholder

“We got the news first from the public media and then we started reading all the trusted webs and then the government started to release more and more on the topic.” Spain, meso-level stakeholder

“From a variety of sources. It was sort of own epidemiological data and information about how the situation was involving outside the UK. That came from the WHO. So from directly accessing the websites. We also had information that was provided by our internal UK organization, the Health Protection Agency, so that gave us information on the UK-situation, some access came out through publications in journals, reports. That sort of thing. Keeping an eye on media reports. To look on more detail for information. And then from a response and policy point of view there was information coming from the department of health.” United Kingdom, meso-level stakeholder

While they want to use many sources, people at the decision-making level have limited time and therefore needed to be informed quickly.

“Yeah, one of the problems we had was not that we lacked information, we had too much information. And in my job as being the coordinator for the local public health department big part of my job in many ways was to keep track of all the guidance and information we had and we had lots of it. And that was a big job of itself. I spend 10-20 hours a week just keeping track of all the information.” United Kingdom, micro-level stakeholder

“It is necessary to be built and communicate key-messages to physicians but also patients, short, clear, to the point, with quick training on the subject.” Romania, micro-level stakeholder

“I have about an hour a day to get new information. If I would personally attend a meeting, then I would need to walk to the tram, ride it for 20 minutes, walk to the meeting, there we would chitchat. Then we would talk for one and a half hours and afterwards I have to do the way back. That is too much. Especially because you have to inform your staff and fulfill your other tasks. But if you do it on the phone, it would be possible to do it in one hour.” [Also ne Stunde kann ich schon aufbringen. Aber wenn man natürlich bedenkt: man muss rechtzeitig zur Bahn gehen; man muss dann zwanzig Minuten mit der Bahn fahren; dann zu Fuß hingehen; dann sammeln sich alle; dann sitzt man anderthalb Stunden zusammen; dann fährt

man zurück und muss ja auch noch seine Leute informieren. Aber ne Stunde, wenn man das übers Telefon macht, das geht dann.] Germany, meso-level stakeholder

„We had an overload of protocols, guidelines and so on. And they would take very much time. But not much people would use them. I think we have done a lot of work, that was not very useful. So I believe we must be much shorter, much simpler. And get things very clear, very short to all the GPs, all the nurses, because the front-line practitioners are overloaded with tons of protocols.“ Spain, meso-level stakeholder

People at the micro-level had different tasks and preferences: while they also wanted to be informed quickly, they preferred one trusted source, preferably in the form of a senior who they can ask if they were in doubt. This would relieve the micro-level stakeholders from some of their responsibility.

“Yes, I received new information daily. From meetings, e-mails, from my superior from everywhere. But this way of getting information from many sources is not good for me. [...] We need to have limited and clear information from a a credited source, not from everywhere and everyone. I would trust my superior.” Italy, micro-level stakeholder

“If I didn't know, what to answer, I asked my superior. He was sitting in the next room. I would say that I call them back.” [Wenn ich es nicht wusste, dann habe ich eben meinen Chef gefragt. Der saß nebenan. Ich habe dann gesagt, ich rufe zurück.] Germany, micro-level stakeholder

“I received information from the RIVM [Rijksinstituut voor Volksgezondheid en Milieu (National Institute for Public Health and the Environment)] That is our plan to work. I don't think I searched for other information. The only problem with that is that they always have been a little bit to late. We had to talk intern about how we are going to act, what are we going to do. So the people on the phone have been waiting for the people talking about the plan.” Netherlands, micro-level stakeholder

Participating in Europe-wide Early Warning and Response System (EWRS) meetings was mentioned as extremely helpful for receiving first-hand information in a short time (before it became public) and also for being informed about the situation and the response planned in other EU (including neighboring) countries. The EWRS is a web-based system linking the European Commission (EC), the public health authorities in Member States responsible for measures to control communicable diseases and the European Centre for Diseases Prevention and Control.

“These EWRS meetings also helped us to decide with the ECDC on some standards. And this was very helpful.” Romania, macro-level stakeholder.

“We had conferences every day and sometimes two times a day. And also in the weekends just to discuss the measures and the appropriateness of measures that countries would take. To inform each other. In these meetings the ECDC would bring in their risk assessments and would discuss the new developments. And the WHO representatives would also bring in the new developments from the WHO perspective. And later the European Medicine Authority was there, the EMA. So, those meetings were wonderful: in a short while you got all the information you needed.” Netherlands, macro-level stakeholder.

4.2.2.2 Giving Information

Many stakeholders found it very difficult to inform others about the risks of the A/H1N1 influenza pandemic. This seems to be partly triggered by the fact that although the influenza A/H1N1 infection often took a mild course, it did sometimes lead to severe symptoms or even death.

„We were quite convinced that we would have quite a mild epidemic, but severe enough to vaccinate. And that message was of course a bit tricky. I think to avoid misunderstandings. It was a mild pandemic which still could have some severe consequences for some people and this could be very scary. So the correct respect for the virus was the main problem. We needed to motivate the people to get vaccinated, without scaring them too much at the same time,

saying that the consequences are severe enough to recommend vaccination. And that was a very difficult issue.” Sweden, macro-level stakeholder

“You should go there and should take samples, wearing a mask, washing your hand using alcohol. And I did that a few times. It was quite scary when you knocked on a door and you put on your mask and your special coat. That sort of was a scary situation. On the other hand I did this with a patient, which was proven to have swine flu. And he said that is not possible. I have to work. I have to go to Amsterdam today. That was just not fitting: me going around with my special mask and a patient, who could not care less.” Netherlands, meso-level stakeholder

Technically, the stakeholders were using diverse channels to give their information to others: oral advice (personal or via telephone), e-mails, conferences, press briefings, and Web sites. Electronic communication dominated on the macro-level and meso-level and more personal contacts dominated on the micro-level. The interviews did not reveal any remarkable differences between the countries.

Macro-Level and Meso-Level:

„We have an electronic service system sending electronic guidance. Whenever we want that. To all health authorities and also specialists relevant for infectious disease. They receive via mail a - it is not a newsletter - it is a warning signal. In which we explain the problem, the situation and the measures that should be taken.” Netherlands, meso-level stakeholder

„We immediately send out information via our focal point: From here you will get updates. And we also set up a 24 hour hot-line for professionals, but even also for lay people concerning the pandemic. Later this was changed to normal working hours.” Poland, macro-level stakeholder

„Our campaign was aiming at the general public. By advertisement, probably by a commercials over the television - but I don't remember that. But we had the website, we had advertises in public transports, the pharmacies send out materials to the GPs.“ Sweden, micro-level stakeholder

„So what we did from the beginning we started to collect information and send it around via e-mail. At the beginning we would send one several times a week. And then it went down to weekly. And these bulletins gave the general information that was needed.“ United Kingdom, macro-level stakeholder

„We have email-lists and we send different parts of information trough this channels, where we have one responsible officer in each county.“ Sweden, meso-level stakeholder

Micro-Level:

„I then tried to explain to the people, what the dangers and the advantages were. Because here in Italy the people come to the office, they don't use the email or something like that.“ Italy, micro-level stakeholder

„So all the scared people would call us. So we had a lot of phone call with people asking: I am coughing, I want to travel, what should I do? But also people starting to complain about the vaccination: I don't want it. The things you are doing are all because of the pharmaceutical industry. Not many, but some. I was explaining on the phone: look this is what we know now. If you are healthy you will probably just get a big flu, but if you are in a risk group it might be more severe.“ Netherlands, micro-level stakeholder

4.2.2.3 Media

Most stakeholders thought that the media play a very important role during a pandemic. They accredit the media with a large influence on the publics behaviour. But often they are unhappy with the media's performance. For example, one stakeholder had the impression

that the media were just hunting for the latest, most sensational headline. The stakeholders often felt misinterpreted and that the pandemic in general was misjudged.

“Well, I am never very happy with the press. I mean, when I give an interview and they send it in the television I am happy. But often they try to scare the public very much in the start and in the end they said, we did too much. They are not moderate in their reactions. They are never happy.” Sweden, micro-level stakeholder

“I think that the predictions of the media caused a lot of the miss-conceptions.” Spain, meso-level stakeholder

„So I don't vaccinate against the normal influenza and I was asked about that and I that: No, because I don't belong to the risk group. And that was miss-interpreted, that I did not get the pandemic vaccination. And there was quite a lot of fuzz. Especially in social media. And this was in a radio interview which reached many, many people and that was quite difficult, but that illustrates how important the trust is. I was a very central person and if I did not vaccinate it is a very severe issue.” Sweden, macro-level stakeholder

“Media always plays a big role and they always exaggerate. The media is always interested in a scaring story.” United Kingdom, micro-level stakeholder

“Especially the media was very hard. They reported that it all was very dangerous and all of a sudden it was not dangerous any more.” Sweden, meso-level stakeholder

“I see my influence a lot smaller than the one of the media.” [Ich sehe da meinen Einfluss deutlich geringer als den Einfluss der Medien.] Germany, micro-level stakeholder

While many stakeholders were very unhappy with the press and how they reported, only a few actively tried to build a stable partnership with persons working in the media. Those who did try to build partnerships were much more satisfied with the media echo.

„At the beginning of the pandemic, we decided to go to the main media in Catalonia and to give them a brief introduction about what a virus is, what could be the next steps, what might happen. Just to inform them, not giving a press conference. To make sure that the journalists and the TV anchorman knows a little bit about the disease. [...] We now have a good understanding with the journalists. As soon as they get any news on a spreading disease, they forward it to us and then we search for the quality of that information on more trusted sources. Then when we are more prepared, we agree to answer their questions. That actually has been a good thing, because we have build some sort of mutual confidence.“ Spain, meso-level stakeholder

4.2.3 General Problems

While the existing literature on the risk communication about the 2009 A/H1N1 pandemic is focusing on the vaccine and on the direct communication processes (e.g. receiving information and giving information), there is a huge variety of potentially influencing factors, that are not easily summed up in one group. Some are linked, some aren't. This factors are collected under this chapter which is called general problems.

4.2.3.1 Stakeholders Perception of the Pandemic

Some stakeholders complained about an communication from higher authorities which was not clear about the actual phase of the pandemic. For example if they were in the containment or already the mitigation phase. Other stakeholders wished for an pandemic response plan, which could be adjusted to the actual situation.

„I missed some point where my boss, the government or the RIVM said: 'We change our way of acting!' Because now it is an outbreak. It's not a testing in individual cases any more, but it is an outbreak. We went on for a very long time testing people. And that gave a lot stress. We had the information but we kept on testing.“ Netherlands, micro-level stakeholder

„It is more you do all the work and you are not seeing any sense. And even if you say we need the information for research purposes, we can say: Yes we need the information for research

purposes. Then we can say okay, we need to install the department that it is possible.“ Netherlands, micro-level stakeholder

4.2.3.2 Trust

While poor risk communication damaged the trust in vaccines during the pandemic, as discussed in the section “Long Shadow of the A/H1N1 Pandemic Influenza”, general trust in the government also seems to play an important role during a pandemic. For example, stakeholders from Sweden reported a generally high public trust in government institutions, their recommendations, and actions.

„Swedish health professionals think that the national authorities have a high reliability. A high level of trust. So when all the Swedish authorities supported the vaccination, that had a big impact. And also in the population there is a high level of trust in authorities.“ Sweden, meso-level stakeholder

“If the government and the local authorities say, you should vaccinate, then a lot of people actually do it without really thinking about it.” Sweden, micro-level stakeholder

4.2.3.3 Public Information Seeking

The public information seeking process has changed dramatically in the last years. People tend to search for themselves for information rather than wait to get informed. The Internet plays the main role in this process. This also increases the speed of rumors, spreading virally over social networks. This was also experienced by some stakeholders.

„Yeah, because people will find the news anyway and they will share their own news. And also the people who are critical against vaccination, they use Internet a lot. So you should be part of that. In the 50s 60s the government said something and the people would follow and now they say: 'Well I will look it up on the Internet'.” Netherlands, micro-level stakeholder

„The people have been scared. They did not get information from me but also from the Internet. They mainly have been scared because the media mainly gave information only about the dangers of the vaccine.“ Italy, micro-level stakeholder

4.2.3.4 Transparent Communication

With the conflicting messages some stakeholders mentioned the importance of transparent communication to avoid later criticism. The idea is that decision steps should be comprehensible, well documented and easily retrievable..

“I think before the next pandemic we must have a much more concrete plan for evaluation. For example at what risk-level to vaccinate or why you made certain recommendations. This must be a very public written evaluation at different stages. So you can see, how have been things evaluated and why do we make recommendations, because that is missing now.”

Sweden, macro-level stakeholder

“But I think with respects to transparency when measures are taken like Oseltamivir or advice is given or vaccination is provided I think all information should be there on the website. We did that but I think people were not familiar with where to find it.” Netherlands, macro-level stakeholder

4.2.3.5 Globalization of Information

Due to the technical developments in the recent years, information is moving much faster from one country to another. Therefore health authorities had to react not only to media reports from their own country, but also from neighboring countries. Hence people would ask, why an activity was undertaken in a certain country, but not in their own.

„There were discussions about how other countries have prioritized. Denmark for example vaccinated a much smaller group of people. So there was discussion about this right from the start.“ Sweden, micro-level stakeholder

„Well, countries where of course taking action based on their own political advises. But countries took sometimes measures that was not in line with that what in the Netherlands happened. So that was a problem. So every time we had to explain, why we are doing less than for instance the UK. [...] they had a huge outbreak by that time. So they were already distributing Oseltamivir at every corner of the street. We had had very many inquiries and interviews and they asked me: Why don't you do that in the Netherlands?“ Netherlands, macro-level stakeholder

4.2.3.6 Timing of Crucial Events

The stakeholders mentioned the importance of right or wrong timing to announce events or initiate measures. Although most events cannot be forced or prevented, it is important to consider this aspect when announcing sensitive messages.

“And then we started getting quite a number of very severe cases. Enough severe cases that people got convinced again that this influenza was important. And then people started to get vaccinated.” Sweden, macro-level stakeholder

„An old colleague of mine who is retired right know, but he still works part-time in different clinics. He was very much opposed to the vaccination campaign and then he watched a young man getting very severe influenza. I don't remember if the guy died. But still it was enough for him to go out and write an article in the press of that he switched his opinion.“ Sweden, micro-level stakeholder

„And then something happened: A famous actor died during the pandemic. This has put us in the very strange situation, that the population became mad. Everybody wanted to be vaccinated and we were forced to establish vaccination centers very quickly on different points. There were very long lines for being vaccinated. So this increased the uptake very quickly.“ Romania, macro-level stakeholder

„I mean to be fair. I really think, ever since the vaccinations became available people were, you know fed up to the back-teeth of flu and the pandemic and there was the strong feeling that the danger has passed. [...] So I think it's no surprise, that the vaccine rates were relatively low.“ United Kingdom, macro-level stakeholder

4.2.4 Future Risk Communication

This second part of the research deals with the stakeholders opinions on future pandemics, the future risk communication and their wishes with respect to the function and flexibility of a potential communication tools..

Partly this is dominated by the technical development of the recent years. Generally in form of the rise of the Internet and specially in the increased use of social media platforms such as Facebook or Twitter. The stakeholders were seeing in them a tool to directly contact and inform the public. They also mentioned to use social media as a tool for surveillance.

“It [social media] is specified in our new pandemic plan and it is specified in our general surveillance methods. Especially from our vaccine department. To collect attitudes and of course it will be used in a pandemic as well.“ Sweden, macro-level stakeholder

“I would use a lot more social media now than what was available back then.“ United Kingdom, meso-level stakeholder

“I would definitely use social media. I would use Twitter and what I would be doing is tweeting a message with a link. And what we would do. I don't know if we would use the e-mail-system again. We would probably encourage the people to follow us on Twitter. So they could see latest news. Just sending them the link. Almost certainly we would tweet with links to the website.“ United Kingdom, macro-level stakeholder

“I think in the future you will make more use of social media, than it was done during that time. You would be faster with your information.“ Netherlands, meso-level stakeholder

"We have done monitoring of social media development." Netherlands, macro-level stakeholder

"If I would have something to say and I would do risk communication, I would not use too much text. I would rather post a video on Youtube. (...) To speak in front of a camera is not that easy, but you can say: Please do that, please keep this in mind. Therewith you bring in a lot more calmness and people are fully informed and they don't have to read through the FAQ." [Wenn ich was zu sagen hätte und ich würde so Risikokommunikation machen, dann würde ich das auch garnicht mit soviel Text machen, sondern ich würde eine Rede in Youtube stellen.(...)Vor einer Kamera sprechen ist ja auch nicht so einfach, aber das man dann sagt: Machen sie bitte das, berücksichtigen sie bitte das. Man bringt dann die Ruhe rein und jemand ist voll informiert und jemand muss sich nicht mit lesen und FAQ und so beschäftigen.] Germany, meso-level stakeholder

But not all experts were seeing the sense in using social media. Some of them were not using it in their private life and therefore did not know about the possibilities for a professional use. Others had experiences with it, but did not think that it would be a suitable tool to inform the public during a pandemic.

"I am not a person, which uses Facebook. I think with Facebook you are just able to reach a small group, who otherwise would read the FAQ" [Ich bin kein Typ der Facebook bedient. Ich glaube, über Facebook wird nur eine kleine Gruppe von Leuten erreicht, die sich auch sonst mit FAQ auseinandersetzen würden.] Germany, meso-level stakeholder

"I don't know exactly, whether new media could be used. You are now talking to a person of 57 years. That is a problem. I don't use them myself, so I neither know the possibilities nor the things you could do with it." Netherlands, meso-level stakeholder

“We have used social media during that time, but we don't know, what kind of an effect that had. We are still not sure, if we should use social media. If we should use resources for that or if we should use the traditional media.” Sweden, meso-level stakeholder

“I don't know. I still need to be convinced of them [social media] for that sort of situation. The only time I have used them recently was during a fire in a recycling plant. There were lots of smoke, potentially toxic, and it was drifting to hospitals and I used twitter and looked at the posts coming from the fire brigade and the police. Just to monitor that situation. But that was very immediate, instant, informative reactive. I think it has just a benefit in a very quick, fast-burn situation. I see less benefit in a slow-burn situation.” United Kingdom, meso-level stakeholder

Generally to better manage a future pandemic, experts wished for clear rules to help their decision making process.

“It is good to have the concepts clear, when to initiate treatment, when to isolate, when to give information and to whom.” Spain, micro-level stakeholder

“We really need to have really strict criteria or protocols. To make decisions the next time and they should be open to everyone and they need to be open to people afterwards. So people can go back afterwards and see. That is the judgment that was done.” Sweden, macro-level stakeholder

Contrary to this one expert supported a more flexible approach. He explained, why, in his view, strict rules were contra productive.

„I think what we need is that we need to become more flexible. It is important that a decision taken, can be changed when the situation evolves. Because what was seen in Mexico and in the United States was not seen everywhere else in the world.” Sweden, micro-level stakeholder

Other experts mentioned the importance to reduce the number of official information sources.

“Centralized information given to the media, this is important. And trying to avoid persons that can destroy this positive message.” Spain, meso-level stakeholder

How this would correspond with the freedom of speech was not stated by the expert. But he was not the only one thought that it was necessary to reduce the number of information sources.

“We were constantly confronted with what the CDC says, the WHO says and the ECDC says. Sometimes it is a mess. Perhaps it would be easier if we could say: Well that's very interesting, but we follow the advice of the ECDC. That is quite simple. So in a future pandemic I wish for a 30 second bulletin: The ECDC said...” Spain, meso-level stakeholder

One expert from the UK reported about her recent findings from a project to improve the risk communication of the National Health Service (NHS).

“We will probably use already existing routes. Also using telephone conferences. Having control-rooms and sort of cascade information up and down. We would also make sure that we have links to the department of health policy and to the HPA which is now Public Health England. Both on a national and a more regional bases. The contact to health authorities in other countries that would be through the department of health. So the information would go up, across to another country and then down.” United Kingdom, meso-level stakeholder

5 Discussion

This study assessed the perception of professional stakeholders about the significance and power of risk communication in its efforts to reduce the spread of the influenza A/H1N1 virus during the pandemic of 2009 – 2010 in Europe. It aimed to gain insights and suggestions that can be used to improve future risk-communication strategies in Europe and elsewhere.

The research focused on the experiences of European health professionals who were engaged in the management of the A/H1N1 pandemic in their respective countries. It identifies and describes the problems they shared and others that were only mentioned by experts from single countries or certain areas. The findings of the present study need to be interpreted with caution, since it is based on perceptions and opinions of 25 experts. However since all interviewees were experts involved in A/H1N1 related risk-communication either directly (micro level) or at the regional (meso level) or national level (macro) the results of this study do give a good overview. In addition since experts were recruited from eight EU countries (one northern, two eastern, two southern, and three western), the diversity in Europe was taken into consideration. The lack of detailed qualitative information on the risk-communication difficulties faced by expert stakeholders during the A/H1N1 pandemic, is the research gap this study aims to close. The qualitative character of this research explains the relatively small sample size of 25 interviewed experts. Huberman and Miles (1994) argue that „sample sizes that are too large do not permit the deep, naturalistic, and inductive analysis that defines qualitative inquiry“. The number of 25 experts seemed large enough to fill the developed categories with evidence but was still small enough to allow in depth analysis of the interviews. So for the purpose of this research the sample size should not limit the findings of this work.

5.1 Potential Sources for Bias

Another issue to address is the fact that the study relies on self-reported data of the experts. This means that the data collected cannot be independently verified and the researchers have to rely on the reports of the experts. This contains several potential sources for bias:

- Selection-Bias: The experts will probably only remember selected events, which means that some of the experiences they made won't be remembered and will hence not be included in the analysis. We tried to avoid this bias by successively asking for information on topics, mentioned by other stakeholders during the interviews.
- Telescoping-Bias: This implies that experts might remember an event or experience occurring at a time when it actually did not happen. The official time-lines of the ECDC and CDC were compared with the statements of the experts to avoid telescoping bias.
- The Attribution-Bias: The experts might attribute positive events to their own actions and negative ones to those of others. Since the focus lay on identifying the problems the experts faced in their perception, negative or positive actions were not seen as critically important and a threat to the outcome of the study.
- Exaggeration-Bias: The experts may exaggerate the influence of certain actions without real evidence. However since the actual magnitude of a problem faced was only secondary to the fact that it was perceived as a problem by the experts, this did not influence the study outcome.
- Fluency-in-Language-Bias: Due to limitations of the researchers the interviews were only conducted in English and German. For many experts these were not their first languages (most interviews were conducted in English), hence language barriers might have prevented them from mentioning certain aspects. But since most of the macro- and meso-level experts are in positions which require regular use of English, the influence of this bias is to be judged as rather small. At the micro-level the influence of language barrier was a bit higher. To counter this problem it was considered eligible for experts not fluent in English to answer in written format, which was done once, or have a translator (also once).

- Recall-Bias: This bias is probably the strongest bias, because the pandemic had officially ended 3 years before the experts were interviewed. Many mentioned difficulty in remembering some details. Nevertheless, because a comparable study has not been undertaken in Europe so far, this was the best available source and method of obtaining information.

There are not only biases of the interviewees to be mentioned, but also of the researchers.

- Since a snowball sampling method was applied, referrals **may have only been** done within a **selected** group of experts. Those with contradictory views to the referring expert might not have been included. This would result in the effect that the majority of experts involved in the study share views with the researcher, a phenomenon called community-bias. The snowball sampling approach was seen as a pragmatic and feasible approach, to **establish** contact **to relevant** experts who are often short of time and have requests from many sides. The reference from a mutually known person was seen as helpful for establishing a first contact. Since the research question was rather technical (How did you communicate during the pandemic?) and not opinion based (e.g. Do you think the pandemic was over-hyped?), the influence of community-bias if at all was probably minimal.

The information and insights gained from the present study may help to improve risk communication during and before pandemics at a European level. From the findings three basic areas for effective risk communication during the pandemics emerge: (i) The first being the existence of a conducive environment in which risk communication can function. (ii) The second being the technical pre-requisites for functioning risk communication implying that the right person receives the right messages at the right time. (iii) The third being the actual content of the risk messages.

5.2 The Environment in which Risk Communication is to Function

The environment in which risk-communication is to function lays the foundation for effective risk-communication. It is probably the hardest to grasp, to modify or to change but also the most important for a functioning risk communication.

If one looks closely at the difference between the two countries with relatively high vaccination coverage (the Netherlands – 30% and Sweden – 59%) (Mereckiene J, 2012) and the other European countries, two major differences become apparent: the first notable difference mentioned by both Swedish and Dutch experts, are the well-established seasonal vaccination campaigns in both countries. Most stakeholders from these countries were happy with the seasonal influenza vaccination programs and claimed that these had a very positive impact on the population's acceptance of the pandemic vaccination campaigns. This is understandable since well-established routes to contact persons at risk exist; there is a pre-existing relationship of trust to the vaccinating HCW; and potential side-effects were perceived as less scary also based on the positive experiences in the past. This was very different in the other countries: The experts reported that many people had a rather skeptical attitude towards seasonal influenza vaccination, which also reflects in the fact that the percentage of the population at risk, that got vaccinated was quite low. The population did not trust the seasonal influenza vaccine and they did not trust the pandemic vaccine either. This miss-trust leads to the second important point which forms the foundation of well-functioning risk-communication: the general trust in the government.

Asked why their fellow citizens followed the advice to get vaccinated in a situation of uncertainty, stakeholders from Sweden mention the high trust in the government and the health authorities of their country. In the low-vaccination countries the stakeholders rather had the feeling of a strong distrust of the population towards the government and authorities. This paramount importance of trust has also been reported by many other studies (Covello et al., 2001; Slovic, 1999; Peters/Covello/McCallum, 1997).

In Sweden this trust is now at stake on account of cases of post-vaccination narcolepsy which are being attributed to the pandemic influenza vaccine. There is the danger of this compromising not only the successful seasonal influenza vaccination programs, but it might

also cause enormous problems in a future pandemic which might not be as mild. Narcolepsy is a disabling sleep disorder, with symptoms like excessive daytime sleepiness (EDS), cataplexy, sleep paralysis, and hypnagogic hallucinations. In August 2010 Sweden and Finland reported cases of it occurring in children and adolescents following vaccination with Pandemrix (ECDC, 2012). The report came to the conclusion that a *„significant (6 – 7 fold) increase in the diagnosis of narcolepsy in the 5 – 19 year age group in Finland and Sweden following the start of influenza A(H1N1)pdm09 vaccination campaigns were observed“*(ECDC, 2012). As one expert from Sweden pointed out, a major complicating issue with these cases was that the symptoms started late (9-12 month after the vaccination). At this point the vaccination campaign had already been completed. The damage was done, not only to the children suffering from a life-long disease, but also to the populations trust in the government and its vaccination campaigns, or as the Swedish expert said *„if we get a new and more severe pandemic, we will have much more difficulties in convincing people to vaccinate“*. But she also points out the dilemma any country is in, when a new pandemic emerges *„had we not vaccinated, then the people would not have seen the side-effects. We would be sitting there with vaccine for one billion crowns. And it would not have been used, people would die, we would have lots of severe cases. If we would not have used the vaccine people would say: 'You are crazy! Why are you not using this vaccine?' To say it was wrong or it was right, is very difficult“*. While this dilemma can't be solved the experts emphasized the importance of recording the arguments and reasons for why certain decisions were made and others not in the interest of transparency and later evaluation. In addition these arguments and evaluations should be openly accessible in order to create and maintain the trust in the government, especially after difficult decisions are made in a situation of uncertainty.

One other fundamental aspect contributing to effective risk communication was mentioned by another Swedish expert, as being the educational level of the audience. He claimed that it was extremely helpful that *„most Swedes are connected to the web, have Internet and are quite well educated. So I think they understood that there was a threat for quite severe influenza“*. While there is not a remarkably huge difference in the educational levels within

Europe the factor of a populations education for effective risk communication should not be underestimated. As Smith writes in the book *The Social Benefits of Education* „the level of education enhances the effectiveness of information and risk communication programs by increasing people's ability to learn. No separate complementary effect of education has been detected for precautionary activities with either environmental or health issues“ (Smith, 1997, 209).

Another factor which may affect the success of risk communication is the influence and visibility of anti-vaccination movements. Their potential influence was mentioned by many stakeholders – but these groups are relatively small in most European countries and no good data supporting this claim exists. This is an area which is being explored in Workpackage 6 of the E-com project.

Closely linked to this point is the influence of prominent individuals. The example of a medical doctor and nun Teresa Forcadis, who was publically opposing the vaccination campaign in Spain was given and was perceived to have a serious influence on the public. Just as with anti-vaccine groups this influence is hard to measure and no literature about this exists so far.

All these factors which build the background for risk communication have in common that the stakeholders perceive them as very important, but they are hard to influence. Especially education and trust in the government needs to be nurtured and improved over decades. And even if they improve and with it the risk communication this should rather be seen as one positive side effect, since the investment in a countries education is a big investment, which pays off in many ways.

5.3 The Technical Pre-Requisites for Functioning Risk Communication

The second major area for effective risk communication focuses on the technical aspects of risk communication. Overall this does not seem to differ much between the different European countries under study. A difference can however be observed between the micro-, meso- and macro-level experts. Experts at the macro- and meso-level reported that

conferencing with other authorities and stakeholders was a very important source of information for them. Yet many complained that it is also very time consuming. Having regular telephone conferences interspersed with occasional personal meetings, was a solution recommended by some meso-level experts.

Unlike mentioned in a number of studies (Staes et. al. 2011; Nhan et. al. 2012; Lan & Mc Geer 2011; Shobayashi 2011) the high volume of e-mails and updates on A/H1N1 related issues, did not seem to be a big problem for the experts, or at least not a problem they remembered. This could be a subject for future studies.

A problem the experts did remember and which was shared by many countries under study was the poor relationship with the media and a deep unhappiness with their reporting. To sum-up most experts mistrusted the media. In their perception they did not communicate their complex messages adequately. They rather had the impression that they were misquoted and that journalists searched for sensational and dramatic stories with high news value and always had something to criticize.

An example of how such fragile messages which are surrounded by a high degree of uncertainty can be communicated to the media appropriately, was given by a Spanish expert: he reported how they built up a positive and conducive co-operation with the reporters of important newspapers and TV-channels in the region. They adopted a pro-active role by giving the reporters basic information about the new pathogen and about pandemic management. The fact that the journalists consulted the expert when they picked up new messages about the pandemic, in order to clarify and understand the issue at hand before reporting about it shows that they had built-up a certain degree of mutual trust and a closer working relationship. Whether it has improved the quality of the reports, still needs to be researched.

In this context the question arises why recommendations from existing literature like for e.g. the publically accessible WHO handbook *Effective Media Communication during Public Health Emergencies* (2005) were not used. A lot of problems mentioned by the experts could have

been avoided by using the existing guidelines. For example the positive Spanish experience of establishing lasting relationships with the media was explicitly recommended in the handbook mentioned above, written by the risk communication expert David Covello. It is to conclude that for future planning it is important to raise the expert's awareness about the existence of such guidelines, prior to the next pandemic. Recommendations for a better co-operation with the media already exist and even if this has to be developed or improved, the costs for and feasibility of such measures stand in stark contrast to other attempts to increase public compliance. While attempts to increase seasonal influenza vaccination rates, or trust in national authorities, or the general education level are uncontested these require a long time. Nevertheless despite relatively high vaccination rates even the experts from Sweden and the Netherlands complained about the media and their reporting practice. So the influence of the media, even though considered as high, might not have been as strong as the experts believe - or the experts from Sweden and the Netherlands were misjudging the influence media had in their own country as too negative. This assumption is supported by a study of Sandell, Sebar, and Harris (2013) which conducted a qualitative content analysis comparing 81 articles (45 from Australia and 36 from Sweden) in the Australian and Swedish print media during the 2009 A/H1N1 pandemic. They concluded that risk communication in the Swedish media was motivating the public to take responsibility for their own health. They also tried to raise a feeling of responsibility among the community to protect the public's health, and were clear about the uncertainties regarding the pandemic.

Summed up, this second group of factors influencing risk communication are easier and faster to change than the first, but the statements from the experts did not match as well with the findings of other studies as was the case in the first group of influencing factors. Further research is needed to understand the influence of media messages on the vaccination behaviour. While a strong and decisive influence is suspected by many experts, the magnitude of this effect has not been quantified.

5.4 The Content of Risk Messages

The third category is about the content of the risk communication messages. The Flash Eurobarometer survey conducted in 30 European countries to assess the public's opinion about influenza and pandemic influenza A/H1N1 showed that health professionals were considered as the most trusted source of information (European Commission, 2010). The experts mentioned that health care support staff seemingly had a strong influence on health behaviour decisions of the public. However their vaccine uptake was quite poor: vaccine uptake was lower among the GP support staff (34.7%) compared to GPs (50.1%) in the UK (Sethi & Pebody, 2010). Poor A/H1N1 vaccination rates among health care workers were observed in most European countries (Mereckiene J, 2012). The general vaccination uptake of HCW in Germany was only 16%. Midwives in England tended to not recommend pregnant women to get vaccinated against A/H1N1, which may be one explanation for the low vaccine uptake of 15% among pregnant women.

More attention should be paid to informing (non-physician) HCWs who often have a more direct link and therefore might have a strong influence on patients. Messages should be tailored directly to those groups, especially if the feeling arises, that they disturb the risk communication process. An option could also be to organize meetings with key-persons in those groups and inform them in detail about the decisions made and the reasons for these and to listen to their concerns and discuss them.

Another point regarding the content of the risk communication is that many experts across Europe mentioned the dilemma they faced in raising awareness for the need to get vaccinated without causing a panic. The experts mentioned the panic many people in their area felt, when the pandemic began in late spring of 2009; the many questions of worried persons, which HCWs at the micro level had to answer; and they mentioned the problems they had to convince people to get vaccinated, when the vaccine was available in the autumn of the same year.

Somewhere between April and September the mood in the population changed, with a reason. The first reports about the disease from Mexico were **alarming and scary, following which** a high lethality was suspected, but then – luckily – it turned out to be less deadly as

expected. Many people did not feel threatened anymore. For example, one expert from the United Kingdom said „*I really think, ever since the vaccinations became available people were, you know fed up to the back-teeth of flu and the pandemic and there was the strong feeling that the danger has passed.*”

Studying this problem of a pandemic apparently losing its threat and dread over the course of time and adjusting the risk communication process and messages to this, is crucial for the effective management of a future pandemic. For example one GP from the Netherlands reported visiting a patient wearing his full protective gear including a mask and a plastic overall – just to meet a patient, who was not feeling sick at all and was running around in his house, eager to go to work. Other experts shared similar experiences about such precautions being perceived as unnecessary and over exaggerated. This behaviour of the public does not surprise and is described by Covello et al. (2001). They state that people worry most about hazards which have a high potential for a permanently negative outcome – how likely this outcome is, plays a less important role. In case of the A/H1N1 influenza, getting infected was not unlikely, however having severe symptoms, permanent damage or dying was very unlikely.

An example for the other extreme is the 2014 Ebola-scare in the United States and Europe: An infection was highly unlikely, but carried the high probability of a lethal outcome. The US company Gallup, which conducts public opinion polls, released a study on October 4, 2014 about the worry level of US citizens, that they might infect themselves with Ebola. 22% of respondents answered yes, they were worried. Gallup compared these answers with a similar survey they had conducted on May 3, 2009 about the worry concerning infection with the A/H1N1 pandemic virus. Shortly after the start of the swine flu pandemic 19% of the US citizens were worried about an infection with the virus. During that time between 14 to 34 million US citizens were believed to have been infected with the virus – compared to a total of six US citizens who had contracted Ebola until October 4, 2014 (Gallup, 2014). As mentioned earlier in the background Covello et.al. state that irreversible or permanent outcomes, in this case the high lethality arouse intense concern (Covello, 2001). This element of irrational public risk perception needs to be considered when designing risk communication strategies in future.

The invention and wide distribution of the Internet; the use of mobile phones; social networks such as Twitter, Facebook or WhatsApp; and in recent years the omnipresent smartphones; all this has changed how people communicate. For experts who have to communicate risks this development entails both problems and opportunities.

Most experts had the impression, that social media can be used to communicate directly with their audience, reducing the need for cooperation and complete reliance on the classic media, with whom many experts have been unhappy. Considering this unsatisfactory relationship, this could be an additional channel the experts could use for communication. Nevertheless most experts are uncertain about, how they would specifically use social media. Some were open enough to say, that they think social media might be important, but they do not know exactly how. One concrete plan was mentioned by a macro-level expert from the United Kingdom: *“I would definitely use social media. I would use Twitter and what I would be doing is tweeting a message with a link. And what we would do. I don't know if we would use the e-mail-system again. We would probably encourage the people to follow us on Twitter. So they could see latest news. Just sending them the link. Almost certainly we would tweet with links to the website.”*

A meso-level expert also from the United Kingdom was not convinced about using social media in the manner mentioned above. He did not think, that social media is useful in the case of a pandemic, but thought it might be useful in other risk communication situations: *“I don't know. I still need to be convinced of social media for that sort of situation. The only time I have used them recently was during a fire in a recycling plant. There was lots of smoke, potentially toxic, and it was drifting to hospitals and I used twitter and looked at the posts coming from the fire brigade and the police. Just to monitor that situation. But that was very immediate, instant, informative reactive. I think it has just a benefit in a very quick, fast-burn situation. I see less benefit in a slow-burn situation.”* The uncertainty about the benefit of social media was also mentioned by a Swedish expert, who pointed out, that they used social media, but did not know whether it had any effect at all.

There is research which might indicate that the use of social media can influence vaccination uptake. Marsh, Malik, Shapiro et al. (2014) conducted 21 semi-structured interviews with African American women and asked them about their attitudes, opinions, and concerns

regarding influenza vaccination during pregnancy. One result was that *“messages transmitted via interpersonal networks and social media strongly influence motivation to obtain vaccination during pregnancy.”* The channels for effectively reaching different target populations differ, further comparable investigation which measure the magnitude of such influence, would be an important field of future research.

Considering the seemingly bad cooperation between the stakeholders and the media, there were surprisingly little comments on how to improve the situation. One expert from Spain suggested, that only centralized information should be given to the media. This idea seems rather impractical in pluralistic societies, where the freedom of the press is often protected by the constitution. As is for example stated in article five of the Constitution of the Federal Republic of Germany, *“Freedom of the press and freedom of reporting by means of broadcasts and films shall be guaranteed”*. This gives the media the right to publish, what they think is right. Not to mention, that this would be the paternalistic attitude in communication, which was practiced by some stakeholders during the 2009 A/H1N1 pandemic and heavily criticized by the communication expert Thomas Abraham (2010) . Many experts were surprised by the changing attitude of the population towards the disease and the vaccine. When they worried in spring about the influenza and were eager to get vaccinated, they were worrying about the vaccine in autumn. The experts had the impression, that this huge divergence was not included in pandemic risk communication plans. For the future this would mean developing guidelines for a worst case scenario, but also for a best case scenario and a most likely case scenario. Because seemingly all have their own difficulties. In a best case scenario, for example, questions about the sense of the vaccine purchase of the government might come up. As it has happened after the A/H1N1 pandemic. This should be countered by a tailored communication strategy. Certain risk groups might need special explanations and messages directly addressed at them, why they still need a special treatment. As it was the case with pregnant women during the 2009 A/H1N1 pandemic.

In case of an mild pandemic these are messages which might not save lives during this pandemic, but they might save some in the future. And this is the point where all three bases



for good risk communication are connected. If rumors of corruption, waste of money, or seemingly senseless measures take are not countered after a mild pandemic, they will influence the trust of the population in their government and organizations for the future. And this will affect the risk communication during the next pandemic. Which might not be as mild.

6 Conclusion

The stakeholders' experiences lend support to the notion that an urgent need exists for a more systematic and well-planned implementation of risk-communication strategies within the EU countries. Planning risk-communication for different scenarios best case, worst case and probable case, and also for changing public risk perception as in the case of the A/H1N1 pandemic where the perceived threat reduced with the passage of time but also for situations where the fear might increase, is a lesson learned from this study. Tailoring information to different target populations (different at risk-groups and different health care professional groups e.g. GPs, nurses, midwives, hospital managers etc.) would help to reduce the amount of information to that relevant for the particular group and also address the concerns of that special group.

The stakeholders' views indicate that for effective risk communication all three elements must be improved/strengthened i.e. (i) the existence of a conducive environment in which risk communication can function, (ii) the technical pre-requisites for functioning risk communication and (iii) the actual content of the risk messages. This means (1) professional stakeholders should be able to access reliable information rapidly through pre-established channels, (2) good relations between public health and media experts must be established and fostered by a regular exchange of information to build up mutual trust, and (3) society's trust in public health authorities must be improved long before a pandemic. In a tightly connected Europe, this cannot function exclusively within national boundaries; a Europe-wide approach is needed.

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8 Appendix

8.1 Questionnaire

(minor changes were made based on the stakeholders level of management)

Main questions	Additional questions	Clarifying questions
To begin: What were your tasks / responsibilities during the swine flu pandemic?		
What were your experiences with the communication of risk and information during the swine flu pandemic?	<ul style="list-style-type: none"> • Which main problems did you face during the management of the swine flu pandemic in ...(country)? • How did you receive new/updated <u>information on the pandemic/ vaccination</u>? • How did you perceive the received information in terms of amount and quality? • Did you trust the information? Why?/Why not? • How confident did you feel giving advice to other health professionals/patients during the pandemic? • How did you disseminate new/updated <u>information on the pandemic/vaccination</u>? • How was the pandemic influenza vaccination coverage in your country? (High/Medium/Low) Why? 	<ul style="list-style-type: none"> • Can you expand a little on this • Can you tell me anything else? • Can you give me some examples? • Which information source would you trust?

	<ul style="list-style-type: none"> • How good was the exchange of information with other health authorities during the outbreak? • What do you think worked well during the swine flu pandemic? 	
<p>What could/should be improved during a future pandemic in terms of risk-communication? Which type of information and support would you wish for during a future pandemic?</p>	<ul style="list-style-type: none"> • How would you like to exchange information with other health authorities during an pandemic? • Which way of communication would you prefer? (personal, electronic) • How would you like the health authorities to support you during a pandemic? • How would you like to receive information in case of a new pandemic? 	<ul style="list-style-type: none"> • Can you expand a little on this • Can you tell me anything else? • Can you give me some examples?
	Did you feel that you received updates on the A/H1N1 pandemic in a timely manner?	
	Did you feel well informed about the vaccine to do your job effectively?	
	Have emails been useful to keep you updated?	
	Did you use any official website to keep yourself updated?	
	Was there a hotline you could contact for further information?	
	Did you receive guidelines/recommendations for the management and treatment of patients suspected to be infected with A/H1N1? If yes, were they helpful?	
	Have you been vaccinated against A/H1N1?	



End	Could you suggest/recommend any other expert, whom we should talk to, who could give us information on the topic?	
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8.2 Article Abstract: Risk Communication During the 2009 Influenza A/H1N1 Pandemic: Stakeholder Experiences From Eight European Countries

The paper has been accepted for publication in the Journal 'Disaster Medicine and Public Health Preparedness'

Risk Communication During the 2009 Influenza A/H1N1 Pandemic: Stakeholder Experiences From Eight European Countries

Rasmus Cloes, Amena Ahmad and Ralf Reintjes

Abstract

Objectives: Assess professional stakeholders' (public health officials/health care staff) perceptions in terms of the risk-communication difficulties faced during the different phases of the A/H1N1 pandemic in Europe.

Methods: Semi-structured interviews were conducted with health professionals involved in the management of the 2009/2010 swine flu pandemic, from different European countries. The interviews were recorded, transcribed, and coded with the software MAXQDA.

Results: A total of 25 experts from 8 European countries were interviewed: 9 from the micro-level (nurses and general practitioners), 10 from the meso-level (regional public health experts), and 6 from the macro-level (national public health experts). Analysis of the interviews revealed three main themes: vaccine issues; communication issues; and general problems. As reasons for the low vaccination coverage stakeholders mentioned the late arrival of the vaccines, the moderate character of the pandemic, vaccine safety concerns, and a general skepticism towards vaccination. Communication needs generally did not vary between the European countries, but between the different levels of management: Macro- and meso-level stakeholders preferred fast information but from multiple sources; the micro-level stakeholders preferred one credible source. Throughout Europe collaboration with the media was perceived as poor and professionals felt misunderstood and misinterpreted.

Conclusions: Risk-communication is highly multi-disciplinary; effective risk-communication requires taking into account the needs of those involved in the process of giving and receiving information. Professional stakeholders should be enabled to access reliable information rapidly through pre-established channels; emphasis should be laid on establishing sustainable co-operations between experts and the media, and measures to improve societies trust in



the health authorities, like the transparent communication of uncertainties need to be encouraged.

Keywords: Risk communication; 2009 A/H1N1 pandemic; swine flu pandemic; qualitative research; stakeholder analysis

8.3 Literature Review – Data Extraction Sheet

Study Characteristics			Categories				
Author, year of study, & Ref. nr.	Study design & month of data collection	Country	Vaccine concerns	Trust issues	Communication difficulties	Organizational problems	Comments
Hidiroglu et. al. 2010 (1)	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	
Bults et. al. 2011 (2)	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	
Van der Weerd et. al. 2011 (3)	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	
Ferrante et. al. 2011 (4)	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	
Prati et. al. 2011 (5)	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	

Staes et. al. 2011 (6)	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	
Brandt et. al. 2011 (7)	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)	
Seale et. al. 2010 (8)	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	
D. Walter et. al. 2011 (9)	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	
Blank et. al. 2012 (10)	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	

Study Characteristics			Categories				
Author, year of study, & Ref. nr.	Study design & month of data collection	Country	Vaccine concerns	Trust issues	Communication difficulties	Organizational problems	Comments
J. T. F. Lau et. al. 2009 (11)	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	
G. Rachiotis et. al. 2010 (12)	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	
WHO 2011 (13)	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	Logistic problems, vaccine coverage & availability; short shelf-life of some vaccine	
Fisher et. al. 2011 (14)	Review report, 2011	Asia	Not given	Lack of transparency from the government	Lack of coordination 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	
Raude et. al. 2010 (15)	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	

O'Flanagan et. al. 2011 (16)	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	
Sypsa et. al. 2009 (17)	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	
Trivellin et. al. 2011 (18)	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	Significant care burden on the emergency rooms	
D'alessandro et. al. 2012 (19)	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	
Steelfischer et. al. 2010 (20)	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	

Study Characteristics			Categories				
Author, year of study, & Ref. nr.	Study design & month of data collection	Country	Vaccine concerns	Trust issues	Communication difficulties	Organizational Problems	Comments
Nhan et. al. 2012 (21)	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	
Lan & Mc Geer 2011 (22)	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	
Walter et. al. 2012 (23)	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	

Böhmer et. al. 2012 (24)	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	
Shobayashi 2011 (25)	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	

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