"Science, H1N1 and society:
Towards a more pandemic-resilient society"

Final Report from the Expert Group on

"Science, H1N1 and Society"

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Executive summary

H1N1 pandemic management stimulated a number of controversies around the world in 2009 and, although world media coverage faded in 2010, the debate is still going on in 2011. Has the pandemic been managed in an optimal way by health authorities at various governance levels, from municipalities to the World Health Organisation (WHO)? Was the scientific advice underpinning the decisions adequate, in particular regarding proper assessment of the pandemic risks and vaccination strategies? These questions seem to have attracted most of the stakeholders' attention. Nevertheless, what may seem to be an issue relating only to scientific advice and decision-making may have much broader ramifications, touching on several aspects of the relationship between science and society, and involving education, communication of science, participation of civil society in research and decision-making, open access to scientific information and research results and gender issues.

The European Commission's Directorate for Science, Economy and Society decided in mid 2010 to set up an Expert Group on Science, H1N1 and Society ('H1N1 Expert Group', or 'HEG') in order to clarify the 'Science in Society' (SiS)-related research questions raised by the H1N1 pandemic and associated crisis management.

The work presented here does not duplicate efforts undertaken by other national or international organisations (such as the WHO, Council of Europe or European Parliament), or more specialised groups led by the European Commission. On the contrary, the HEG work builds on the results of such groups and concentrates on opening up Science in Society issues.

Scientific expertise mobilisation in the A (H1N1) pandemic

The HEG group reviewed various aspects relating to the involvement of scientific expertise in the management of the A (H1N1) pandemic through various documents from the WHO, articles in international health journals, European Union documents and some national reports.

It appeared that:

— following the SARS and avian flu crises, most countries had preparedness plans for influenza, as recommended by the WHO and 'prescribed' in the renewed International Health Regulations;

— in Europe, those national influenza preparedness plans had been the core subject for evaluation exercises between 2005 and 2008, and they were considered to be in place and potentially efficient;

— the world, and Europe in particular, was ready for a severe influenza, but at the time scared and very sensitive to any alert;

— in the first months of 2009, deaths occurred in Mexico, which were classified as influenza deaths, and from April 2009 the disease started to spread, in the USA in particular;

— virologists, epidemiologists and infectious disease specialists were immediately and strongly mobilised, in a close interaction between the Mexican and US authorities, and

especially the Centers for Disease Prevention and Control (CDC) in Atlanta and the WHO office in the Americas (PAHO).

In mid May 2009, the scientific evidence was the already the following:

1. There was unquestionable evidence that H1N1 was spreading all over the world **but at the same time remaining mostly mild**.
2. Scientists were at the same time expressing other scientific concerns, questions and hypotheses. At this stage it was only the usual and legitimate scientific prospective thinking, not based on any new 'scientific evidence': the new strain of H1N1 virus **could** well become more lethal… and **there could be genetic material sharing with H5N1** (avian flu). Thus, in the context of worldwide fear created by the occurrence of a new virus, the H1N1 virus created a greater threat and more concerns than new scientific data or facts on this very precise issue.

In mid May 2009, the WHO, through a process agreed in its governing bodies by all Member States in the previous years for H5N1 influenza preparedness, moved to declare a phase VI pandemic. Therefore, although scientific facts were in favour of a moderate impact, in May 2009 and June 2009, major decisions had already been taken at the international level, partly because the situation almost automatically activated many decisions previously agreed at national levels.

A year later, it appeared that A (H1N1) was really not the killer virus that was feared, although a significant number of people had died from severe influenza syndromes. The new strain spread all over the world, but this was not a sanitary disaster, rather a mild pandemic.
However, this mild pandemic had become a major societal crisis, suggesting failures in its political, technical and scientific management.

Starting in 2010 and up to now, the WHO has been criticised and is still under evaluation; in Europe, the European institutions (Parliament, Council, European Commission) have commissioned expert works and produced various communications on the management of the H1N1 pandemic. Some national inquiries have been carried out regarding the management of H1N1 by governments.

Scientific expertise is often mentioned in those evaluation reports as having failed, sometimes on the basis of possible biased advice that could be linked to financial conflict of interest, but also for failing to give proper estimations of the situation and exaggerating the potential risk of the new virus.

In addition, the communication of the research community and researchers relative to other parts of the society was highlighted by a 'trust crisis', lack of confidence in scientific expertise and competition with other information sources, which were often less 'evidence based'.

What followed after the summer of 2009 on scientific mobilisation? Scientific expertise could no longer influence the major decisions that had already been taken. But was this group still on board for influencing their implementation and understanding their impact? It appeared that, apart from microbiology, epidemiology and medical research, the mobilisation of other scientific knowledge was much less visible and not comprehensively described during the course of the pandemic.

How to utilise better a wide range of scientific knowledge?

The criticisms that were aroused during the pandemic on scientific expertise illustrate that there may be an essential difference between good science and good expertise, although scientific expertise should mix both. But good expertise can also come from non-scientific professionals and citizens.

Science is about questioning, doubting, addressing and testing all alternatives at the same time in order to challenge them, whatever their likelihood. Expertise and decision-making concern putting facts and evidence in order, and ranking the likelihood of various risk scenarios while taking into consideration the contextual information. It is also about providing good cost/benefit comparisons of various decision options.

It is certainly not granted that the best scientists, especially if they are strongly specialised in their field, can provide useful and relevant evidence-based expertise to decision-makers in a direct way. At the very least they should consider always separating facts from scientific hypotheses. This was mentioned by the HEG group as justifying some new mechanisms for interfacing research and decision-making, especially in crisis situations. Clearly, the direct link of a few hyper specialists with decision-makers can create adverse effects if not backed by mediation processes through interacting with other scientific views and societal concerns.

The HEG group identified major weaknesses where additional scientific inputs could have been a source of progress by improving the use of scientific expertise.

1. **A first set of weaknesses** comes from lack of knowledge in the fundamental understanding of the virus at the beginning of the pandemic: its interaction with humans, its capacity to be dangerous, the risk factors for severe individual impact, the efficacy of treatments, vaccines and hygiene measures. The expert group highlighted that although influenza has been a major human threat for decades, it is surprising to discover that some basic questions were not sufficiently scientifically investigated to build some kind of scientific consensus. It was suggested that there was a lack of research independent of industrial interests, but also that not enough research has been focusing on basic influenza mechanisms, in particular targeting questions essential for the protection of the society at large and not only for scientific interest. The expert group felt that research funding programmes are often designed and elaborated with little input from civil society. There could be more mechanisms for bringing questions raised by civil society at large systematically into the research agenda. In addition, the elaboration of worldwide comprehensive lists of central issues that lack scientific answers, prepared in collaboration with all parts of the society, could create a reference guide for designing research programmes in influenza management and similar types of threats.

2. **A second set of weaknesses** comes from the lack of input from a broad variety of concerned scientific disciplines into the decision process. After the initial dominance of scientific expertise coming from microbiology, epidemiology and medicine, when decisions were made on worldwide actions, the scientific input into decisions became much less visible and systematic. Decision about generalised hygiene measures or

> vaccination campaigns were executed without significant and visible input from scientific expertise, in particular from the social sciences. Current knowledge about public perceptions, citizens' preferred sources of information and also the impact of health professionals were not taken into consideration. Closing of schools, mobilisation of hospital and health facilities or contingency plans did not really involve scientific expertise from economics and systems and organisation sciences. Education and communication initiatives for the public were carried out without significant expertise input from the communication sciences, although a lot of knowledge existed on the handling of communication in previous health crises and crises in other domains. The scientific knowledge on social media impact and expansion was not utilised or mobilised in a proper way for communicating on the pandemic, apart from some local or national examples. Researchers on ethics were not explicitly involved as advisors for decisions challenging individual freedom, or the threatening competition between individual and collective values.

Therefore the expert group insisted on the need for, and utilisation of, multidisciplinary scientific expertise in crisis situations, together with a strong advocacy for mechanisms imposing balanced scientific expertise input to decision-making from all scientific disciplines.

How to make the 'right' decision?

The HEG group highlighted a number of considerations and requirements for an 'ethical' decision-making process.

The group did not investigate the decision-making process within national governments or international organisations, i.e. the institutional management of the crisis. Many evaluations have been done or are still ongoing, mostly oriented toward finding individual or institutional responsibilities.

However, the HEG group considered that there is room for more systematic evaluative research on governance issues — and especially ethical issues — in health crisis situations. Proper evaluations should probably be planned and supported immediately after the start of major threats, in order to be able to alert on ethical and other societal issues related to values in real time.

These scientific evaluations should also focus on identifying weaknesses and failures in the way in which scientific expertise and its products (advice, documents, communication, etc.) are involved and interact with society and decision-makers, in particular in crisis situations. In democratic societies, it is expected that those mechanisms enter into some kind of democratic, ethical, transparent and 'traceable' process.

Responses to the H1N1 influenza situation conducted by various countries could also be considered as a reflection of the political influence of different groups and stakeholders. Therefore identifying major stakeholders through political mapping — a form of stakeholder analysis — would help to define groups and individuals as well as their interests, and this information should be taken into account.

Cost-effectiveness evaluations of specific decisions as essential background knowledge were clearly missing.

Perceptions, cultures and trust

Sources of knowledge other than science are producing expertise. These various knowledge sources are mobilised in a sanitary crisis, ranging from civil protection organisations to influential specific groups of populations having 'contradictory stakes', from NGOs involved in diseases and health protection to media professionals, community organisations dealing with information and communication, and industry, etc.

Perceptions of risk are embedded in psychological and social contexts that influence experiences, choices and decisions. The HEG group analysed knowledge about perceived risk, how influencing factors shape the understanding of threats and how the choice of perspective influences evaluations.

The interacting influencing factors chisel out various norms and experiences that create cultural differences, for example between experts and laypersons or societal subgroups. An influenza virus belongs to the health risks domain, and seasonal influenza is a familiar but usually not life-threatening phenomenon. In the current context of the A (H1N1) virus, experts forecasted a possibility of a potentially dangerous pandemic situation on the basis of historic trends and early inconclusive data laden with uncertainties. The situation turned into a widespread pandemic that was not severe, and hindsight judgements sometimes ridiculed precautionary measures planned or effectuated, and found, for example, the level of invested resources to be unacceptable in comparison to the resulting consequences.

The HEG group reviewed information on the diversity of European perceptions on H1N1 and trust in diverse sources of information. The European societies had the feeling that they were well informed on the A (H1N1) pandemic, although with huge variations between countries. The variations between countries are even more important concerning levels of trust and distrust in various sources of information, such as health professionals, national authorities, European authorities, the media, and the Internet. This shows that health professionals remain very highly regarded as relevant sources of information by European societies.

This points to the necessity of pursuing additional research into the social trust area, and of closely following up the influencing factors within countries in more detail. It gives a hint of the underlying complexities that may shed light on information needs and design of information materials.

The variations also ought to be further studied to gain better bases for the improvement of education, type of information sources used and preferences for information materials within various cultural settings.

Risk communication, media and pandemic influenza

The communication between the research community and researchers and other parts of the society was marked by a 'trust crisis', lack of confidence in scientific expertise and competition with other sources of information, some of them very heavily surfing on the crisis for reasons other than the 'public good'.

In the case of an ever-changing pandemic influenza situation, ideal communication is just not possible to achieve. Consequently, managing dynamic communication during a pandemic

crisis without losing public trust is a challenging task for the public health authorities and their communications departments.

In the initial stages of H1N1, reports on an outbreak in Mexico were widely broadcast, accompanied by scary photos of people wearing masks. Also massive estimates of possible deaths were communicated rather uncritically. Thus, in the case of H1N1, the mass media bear some responsibility for the spread of fear.

In the EU countries we witnessed a kind of remorse among members of the press after the relatively mild course of the pandemic. Some also accused epidemiologists and public health authorities of having overstated the threat. However, both types of reactions came after the battle.

The H1N1 pandemic also showed several examples of mediated risk conflicts, where statements or demands from stakeholders led to a change in the recommendations made by public health authorities. For example, the Danish health authorities had to adjust several times their advice and recommendations about who were the vulnerable groups that should have first access to vaccination. Also, recommendations for general practitioners to wear goggles, gloves, masks and protective clothing when examining people with symptoms of influenza were changed during the pandemic.

The Internet has fundamentally changed the conditions for, and complexity of, risk communication. Although the merging of the 'risk society' and the 'network society' still need to be much more closely investigated, three consequences for risk communication emerge, all of them influencing public authorities' ability to communicate on pandemic risk. First, the immediate and uncontrolled spread of all kinds of information worldwide makes traditional information keeping a thing of the past. Second, the Internet provides great opportunities for spreading false information and for rumour-mongering. Finally, the Internet favours the development and fast growth of all kinds of subcultures, some of them held together by common perceptions of risk.

It has been mentioned that an average global user of the Internet spent over five hours a month on Facebook. The total number of users of social media is difficult to estimate due to multiplicity of social media channels, but some estimates give a figure of 900 million users worldwide. Social media thus present a very attractive mean of mass communication with a very low cost of broadcasting.

In the USA, the CDC has undertaken several initiatives enabling people to spread information on swine flu (for example by signing up for newsletters or adding buttons and badges on their profiles on social networking sites). Such activities could become an important complement of regular activities in Europe as well, but proper scientific evaluation of the impact is still missing.

Also, during the H1N1 pandemic several countries experienced a public reluctance to get vaccinated. The reluctance was manifested not only among the general public, but also among health professionals like doctors and nurses.

The 'University of Google' allows individuals' access to specialised medical scientific information previously accessible only through subscription-based specialist journals. But the

Internet is also a vast galaxy of unverified bits of information, research, speculation, generalisations, anecdotes, conjecture, half-truths, etc.

Although the examples are few, anti-vaccination messages were communicated rapidly through the Internet and caused some confusion in the general public. And it should be kept in mind that well-organised opposition groups with their own agendas and intentions can abuse social media. This may be the case with some anti-vaccination groups that create a growing threat to vaccination programmes.

Research agenda

As a conclusion, the HEG group identified some research topics which would deserve further research. These include:

— reviews, based on historical data and previous experience on influenza, highlighting specific scientific issues to be clarified or to be solved by science;

— elaborating lists of unsolved scientific question regarding influenza and pandemic situations;

— righteous power: democratic versus elitist perspectives on decision-making;

— facilitating the utilisation of scientific knowledge in decision processes;

— decision-making and public participation in a crisis situation;

— evaluative research;

— mapping of experiences in bringing research closer to democratic institutions at all levels (parliaments, regional governments, local authorities).

A. Introduction

1. Background

H1N1 pandemic management has stimulated a number of controversies around the world in 2009 and, although it faded away in world media coverage in 2010, the debate is still going on in 2011. Has the pandemic been managed in an optimal way by health authorities at various governance levels, from municipalities to the World Health Organisation (WHO)? Was the scientific advice underpinning the decisions adequate, in particular regarding proper assessment of the pandemic risks and vaccination strategies? These questions seem to have attracted most of the stakeholder attention. Nevertheless, what may seem to be an issue relating only to scientific advice and decision-making may have much broader ramifications, touching on several aspects of the relationship between science and society, involving education, communication of science, participation of civil society in research and decision-making, open access to scientific information and research results, gender issues, etc.

The European Commission's Directorate for Science, Economy and Society decided in mid 2010 to set up an Expert Group on Science, H1N1 and Society ('H1N1 Expert Group', or 'HEG') in order to clarify what are the 'Science in Society' (SiS)-related research questions raised by the H1N1 pandemic and associated crisis management.

The work of the expert group presented here does not duplicate efforts undertaken by other national or international organisations (such as the WHO, Council of Europe, European Parliament), or more specialised groups led by the European Commission (such as the External Relations DG or the Health and Consumers DG). On the contrary, the HEG work built on the results of such groups and concentrates on opening up Science in Society issues.

2. The pandemic 'prepared' society

Following the SARS and avian flu crises, most countries had preparedness plans for influenza, as recommended by the WHO and 'prescribed' in the renewed International Health Regulations. In Europe, these national influenza preparedness plans had been the core subject for evaluation exercises, jointly conducted by the European Commission, the WHO European office and the European Centre for Disease Prevention and Control (ECDC), in the years 2005–08, and they were considered to be in place and potentially efficient.

The world, and Europe in particular, was ready for a severe influenza. However, as mentioned by the WHO Director-General, Margaret Chan, at the World Health Assembly on 18 May 2009 ([1]): 'For five long years, outbreaks of highly pathogenic H5N1 avian influenza in poultry, and sporadic frequently fatal cases in humans, have conditioned the world to expect an influenza pandemic, and a highly lethal one. **As a result of these long years of conditioning, the world is better prepared, and very scared**.

'As we now know, **a new influenza virus with great pandemic potential, the new influenza A (H1N1) strain, has emerged from another source on another side of the world**. Unlike the avian virus, the new H1N1 virus spreads very easily from person to person, spreads rapidly within a country once it establishes itself, and is spreading rapidly to new countries. We expect this pattern to continue.'

([1]) http://www.who.int/entity/dg/speeches/2009/62nd_assembly_address_20090518/en/index.html

And then WHO Director General follows with another statement:

'Unlike the avian virus, H1N1 presently causes mainly mild illness, with few deaths, outside the outbreak in Mexico. We hope this pattern continues.'

The world was prepared: it expected an H5N1 pandemic, very aggressive and lethal, but it got H1N1, spreading very fast but mild, and it seems that all preparedness plans were lacking such a prospective alternative scenario.

A number of 'controversies' presented through media, social networks and political debates followed, starting as soon as April 2009. This contributed to a situation of institutional crisis, including a high level of distrust in scientific expertise.

Two institutional events outlined below suggest the scope of the main weaknesses of our societies in the case of a pandemic, despite their intense preparedness.

The first was the **launch of the WHO external review** of the WHO's response to the H1N1 influenza pandemic on September 2010. The Director-General highlighted the following issues to be investigated ([2]), recognising weaknesses in the management of the pandemic at worldwide level:

— unused investments made at various levels following international or national recommendations;

— perception of biased advice linked to conflicts of interests;

— irrelevant definitions of pandemic phases, resulting in dramatisation of the situation instead of allowing a reasonable and planned management of it, which was the original goal of the phasing approach;

— unproved clinical value of antiviral therapies;

— difficulties explaining the coherence between acknowledging the mildness of most cases of the disease but taking worldwide measures for a real pandemic in a rather rigid way;

— problems in managing the discrepancies between prospective expectancies and the real situation: is it safe, and how to scale down existing preparedness plans;

— lack of flexibility in vaccine management, linked to finite capacity and long production time, leading some decision-makers to order the maximum of doses, with no way of stepping back;

— electronic scrutiny by the public at large, including through social media, with multiple sources of information, genuine or not, leading to individual and autonomous decisions;

— the public health community being 'prepared' for a pandemic as a technical issue but unprepared for civil society questions and criticisms. The result was major distrust, in particular on decisions over vaccines, often leading to low levels of people being vaccinated.

The second example is taken from the **'**Commission staff working document on lessons learnt from the H1N1 pandemic and on health security in the European Union' ([3]). The main issues that were highlighted are:

([2]) http://www.who.int/dg/speeches/2010/ihr_review_20100928/en/

([3]) Commission staff working document on lessons learnt from the H1N1 pandemic and on health security in the European Union,

— the individual procurement of pandemic influenza vaccines and antivirals by Member States during the influenza H1N1 pandemic having weaknesses in terms of equitable access and purchasing power to obtain favourable contractual conditions on price, liability, confidentiality and flexibility to adjust the quantities ordered to actual needs, etc.;

— poor solidarity between EU Member States;

— weak resilience of the health sector;

— need for increased preparedness and response in other sectors of society and the economy and increased interoperability between sectors to be better able to service the health sector;

— need for increased cooperation and communication between all stakeholders including key international stakeholders.

The solutions and recommendations that are proposed in most evaluations, audits and other reviews seldom consider actions to bring civil society into the picture as a major actor for sharing, understanding the stakes and learning together and as a proactive partner in decisions and communication.

Civil society remains mostly the 'weak part of the picture', or an obstacle to good implementation of measures, 'something' to be 'educated' and 'informed'. Most solutions include improved communicating **to** civil society but no real involvement of its relevant parts in the evaluation and management of the crisis.

Clearly, this presents an unexplored area for the Science in Society perspective, involving the following topics.

1. What scientific knowledge is worth mobilising in a pandemic? It could be argued that not only biology, medical science, health and biotechnologies are of relevance, but also social and political sciences, scientific evaluation research, systems and organisational research, research on ethics, cultures, media and information, etc. which, together, take an epidemiological approach.
2. What processes, pathways or organisational networks could be developed to facilitate interactions with civil society? This matter could concern novel organisational or participatory ways to improve interactions in information and learning processes and in the understanding of key scientific issues, as well as more general communication improvement issues.
3. What could be done to improve civil society's long-term resilience with respect to pandemics? Measures to be considered here could include educational aspects, long-term planning issues, improvements of fast access to trustworthy information and exchange of knowledge, increased knowledge of cultural and group-specific aspects of perceiving and managing threats, exchange of knowledge, and cultural enforcement of values enhancing key aspects of civic resilience.

3. Objectives and scope of the work

European Commission, Brussels, SEC(2010) 1440 final.

The scope of the HEG work is related to the broad Science in Society one, i.e. covering decision processes in the field of science and technology (S & T), but also issues relating to capabilities, understanding, perceptions and engagement of all stakeholders. The scope is therefore multidisciplinary and interdisciplinary by nature.

The Science in Society actions within the European research area have as an overall aim to contribute to an open, effective and democratic European knowledge-based society, by promoting societal sensitivity within the actions and programmes leading to the European research area, and contributing to the Europe 2020 strategy, helping to gear science and technology policies to societal needs and 'grand challenges' and building relevant capacities in the Member States and acceding countries.

From 2010 onwards, a new approach to Science in Society has been outlined, ensuring a stronger SiS dimension in the development of the European research area. It will promote focused and structured actions, with greater EU added value, wider impact and a wider range of key actors/stakeholders, mobilise new stakeholders, and seek to develop a better visibility at EU level, and a better accessibility to the programme, by relevant stakeholders.

The work can cover issues as diverse as expertise, scientific advice, risk governance, participation of citizens and civil society organisations in S & T activities and/or deliberations, communication, access to S & T information and knowledge, education of young people and lifelong learning, the role of women in science, ethics and meta-ethics of S & T, fundamental rights and fundamental freedoms.

Specific aims of the HEG work have included to reflect on the A (H1N1) crisis within the Science in Society framework, and to explore research questions raised by the H1N1 crisis at the interface between Science and Society, to organise the set of questions in a rational research agenda and to help launch the SiS research calls on this agenda.

Of special interest is that we have been asked to scrutinise risk and scientific advice issues, and various assessments of the crisis, as well as risk communication and public perception, understanding and engagement in relation to A (H1N1) within the framework of broader Science in Society issues (citizens' involvement, education, gender, young people, culture, communication, etc.).

HEG took into account other relevant ongoing EU work in the same field (H1N1), as well as policies and activities of international organisations involved in H1N1 pandemic management, primarily the WHO, but also materials from various national settings.

B. The challenges

1. Scientific expertise and the A (H1N1) pandemic

The HEG group first reviewed various aspects of the involvement of scientific expertise in the initial management of the A (H1N1) pandemic. This involved mainly various documents from the World Health Organisation, which was the international expertise body the most strongly involved in the pandemic, but also articles in international health journals, European Union documents and some national documents.

In the first months of 2009, deaths occurred in Mexico, which were classified as influenza deaths, and from April 2009 the disease started to spread to the USA in particular as well as overseas. Virologists, epidemiologists and infectious disease specialists were immediately and strongly mobilised, in a close interaction between the Mexican and US authorities, including the CDC in Atlanta and the WHO office in the Americas, PAHO.

A month later the world was facing a worldwide spread of the new virus. Some scientific knowledge was already available on the virus itself and its clinical impact. The 7 May 2009 issue of the *New England Journal of Medicine* (a worldwide reference journal in medicine) published articles describing the new strain, its origins and past history and some early results on its pathogen capacity. An editorial stated: 'Although it has been just over a month since the first cases were identified, **it seems unlikely that this outbreak will lead to widespread, severe illness and deaths**. However this may be just the first wave, and we will carefully monitor this outbreak.' ([4])

A week later, on 15 May, the Director-General of the WHO, Margaret Chan, told the intergovernmental meeting on pandemic influenza preparedness in Geneva that ([5]): 'Today we know that a virus with great pandemic potential… has emerged. The virus has quickly demonstrated its capacity to spread easily from one person to another, to spread widely within an affected country and to spread rapidly to additional countries. **Outside Mexico, where the outbreak is not yet fully understood, the overwhelming majority of cases have been mild and self-limiting, with no need for treatment**. Cases of severe or fatal infections have been largely, but not exclusively, confined to people with underlying chronic conditions. **We do not know if this partly reassuring picture will be maintained**….'

At this stage, it seemed that the scientific and medical knowledge, if we look at facts only, was reassuring and showing a mild impact.

Dr Chan continued by mentioning that: 'Other factors could alter the severity of the current disease patterns, **though in completely unknowable ways**.'

She then described two other factors of fear linked to scientific expertise: 'First, scientists are concerned about **possible changes that could** take place as the virus spreads to the southern hemisphere and encounters currently circulating human viruses, as the normal season in this hemisphere begins. Second, as all of you know, the H5N1 avian influenza virus is endemic in poultry in some parts of the world. It is out there, entrenched? **No one can predict how the H5N1 virus will behave under the pressure of a pandemic**.'

([4]) Baden, Linsey R. et al, 'Editorial', N Engl J Med 2009; 360:2666-2667 .
([5]) http://www.who.int/entity/dg/speeches/2009/pandemic_influenza_preparedness_20090515/en/index.html

In short, the scientific situation in mid May 2009 was the following.

— There was unquestionable evidence on the fact that H1N1 was spreading all over the world but at the same time remaining mild.

— Scientists were, however, at the same time expressing some fear based on much less 'evidence'; they expressed hypotheses for the future, without facts of data to support their views at this stage of the pandemic. Those scientists mentioned by the Director-General of the WHO explained to her that this new strain of H1N1 virus **could** well become more lethal… and they also advised that **there could be genetic material sharing with H5N1**, but again there was no information on the likelihood and no more scientific evidence on the progress of the virus than in the period before the start of the pandemic. Therefore they expressed only a current and legitimate scientific projection on the influenza threat emergence, but in the context of the fear created by the occurrence of a new virus, it provoked more threat and concerns than before although it was not based on 'new' scientific data or facts on this very precise issue.

On 2 July 2009, the Director-General of WHO, in a meeting in Mexico on 'Influenza A (H1N1): Lessons learned and preparedness' ([6]), confirmed that: '**We are still seeing a largely reassuring clinical picture**. The overwhelming majority of patients experience mild symptoms and make a full recovery within a week, often in the absence of any form of medical treatment. Research published last week confirms that this pattern, in which most patients experience mild influenza-like illness, has also been seen in Mexico.'

But she also announced: '**We are in phase VI — that is, we are in the early days of the 2009 influenza pandemic**. As we see today, with well over 100 countries reporting cases, once a fully fit pandemic virus emerges, its further international spread is unstoppable.

'Therefore, although scientific facts were in favour of a moderate impact, in May 2009 and June 2009, major decisions had already been taken at international level, partly because the move to a phase VI pandemic situation almost automatically activated many decisions previously agreed at national levels.

'It must be remember that many countries had preparedness plans for influenza, following the SARS and the avian flu crisis, as agreed in the governing bodies of WHO by its Member States. The WHO Director-General's address **in December 2008** (before the occurrence of A (H1N1)) to the intergovernmental meeting on pandemic influenza preparedness is instructive ([7]). She said: 'This meeting is yet another expression of the continuing concern about the serious consequences of an influenza pandemic. This concern is shared among governments, and among their multiple ministries, all around the world.

'The concern is rightly placed, as is the emphasis on preparedness. I can think of no other health event that is so rapidly global in its sweep, or so potentially devastating in terms of human illness and deaths, and severe economic and social disruption.

'The current financial crisis has taught us how quickly an adverse event can spread throughout the systems that link us all so closely together. Public health has very few cost

([6]) http://www.who.int/entity/dg/speeches/2009/influenza_h1n1_lessons_20090702/en/index.html
([7]) http://www.who.int/entity/dg/speeches/2008/20081208/en/index.html

estimates that can compete with the multi-billion dollar bailouts that make the headlines these days. But we do know, from a recent World Bank estimate, that the global economic costs of the next influenza pandemic could reach USD 3 trillion.

'We all want the May 2007 resolution on pandemic influenza preparedness to be as fully, and fairly, implemented as possible. Preparedness requires shared responsibility and collective action on multiple fronts. Previous sessions of this intergovernmental meeting have assigned some priorities to these actions. I believe that progress has been made….'

In Europe, those national influenza preparedness plans had been widely prepared and subjected to evaluation exercises. The evaluations had been conducted jointly by the European Commission, the WHO European office and the ECDC, starting as early as 2005 ([8]), and they were considered successful although improvements could be made.

Therefore, before summer 2009, most countries in Europe had already engaged in ordering A (H1N1) vaccines, antiviral treatments and individual protection masks, all with different patterns but clearly in competition with each other more than in a collaborative way, as highlighted by many documents from EU institutions, one being a comprehensive overview by the European Parliament in February 2011 ([9]).

In this overview, scientific expertise is challenged on many aspects, including: the definition of a pandemic; the definition of severity of the disease; the public health response and decisions; the definition of priority groups for vaccines; the independence of research from commercial interests; the knowledge of the performance of vaccines and treatments; and the communication with the public on risk issues.

At the national level, as highlighted by an example from France, the management of the pandemic created a political crisis: two parliamentary evaluations and additional audits by auditing national institutions were conducted. In France, 94 millions doses of H1N1 vaccines had been ordered. How was scientific expertise involved in this decision? The scientific experts advising the minister for health, gathered in the 'Haut conseil de la santé publique' (HCSP), an expert body created by the 2004 public health law, made the following statement in their advice on vaccines strategies on 26 June 2009 ([10]):

'Après avis du Comité technique des vaccinations, le Haut conseil de la santé publique estime, compte tenu des nombreuses incertitudes concernant aussi bien la maladie que les vaccins ainsi que des potentiels aléas des études de modélisation, ne pas être à même de proposer à ce jour des recommandations concernant la stratégie d'utilisation des futurs vaccins pandémiques A (H1N1)' (ref 26 juin). In summary, these scientific experts declared that they were not in a position to make recommendations on the vaccine strategy for the whole population, on the basis of available scientific data.

On 7 September 2009, they made the following statement on the pandemic itself ([11]): 'Sur la base des données actuellement disponibles, la létalité de la grippe A (H1N1)2009 apparaît actuellement modérée, proche de celle de la grippe saisonnière. Cependant, à la différence de ce qui est observé durant les épidémies saisonnières, au cours desquelles plus de 90 % des décès surviennent chez des personnes âgées, la plupart des formes graves et des décès liés à la

([8]) http://www.ec.europa.eu/health/ph_threats/com/common.pdf
([9]) http://www.europarl.europa.eu/sides/getDoc.do?type=REPORT&reference=A7-2011-0035&language=EN
([10]) http://www.hcsp.fr/explore.cgi/hcspa20090626_H1N1.pdf
([11]) http://www.hcsp.fr/explore.cgi/hcspa20090907_H1N1.pdf

grippe A (H1N1)2009 sont observés chez des sujets de moins de 60 ans. De plus environ un tiers des décès surviennent chez des sujets sans co-morbidité associée, les femmes enceintes constituant un groupe particulièrement à risque.' Thus, they insisted that data from the first months of the pandemic show a mild pandemic, with low mortality. They expressed some concerns about severe cases in the population without any particular associated diseases and in relation to pregnancies, and then they proposed recommendations for targeting the vaccination to specific groups.

In conclusion, at this stage in June 2009, after a few months of A (H1N1) spreading all over the world, **science was telling the world: it is a mild pandemic**. But decisions were already made on major actions and could probably not be reversed for most of them. It was clearly not in the mandate of the HEG group to comment directly on the relevance of those decisions that were based on other considerations than scientific data.

The problem had moved on, as already highlighted by the Director-General of the WHO at the abovementioned meeting in Mexico city in July 2009 ([12]). After a statement on the mildness of most influenza cases, she declared: 'But there are some exceptions that must be the focus of particular concern. For reasons **that are poorly understood, some deaths are occurring in perfectly healthy young people.** Moreover, some patients experience a very rapid clinical deterioration, leading to severe, life-threatening viral pneumonia that requires mechanical ventilation.
'**In keeping our populations informed, we face a difficult challenge**. **We cannot be alarmist**, as this risks flooding emergency wards with the worried well, creating disruptively high demands for staff, hospitals, and laboratories. I am sure you will agree: health services need to stay fit for genuinely severe cases. **At the same time, if we are overly reassuring, patients in genuine need of treatment**, where rapid emergency care can make a life-and-death difference, **may be lulled into waiting too long**.

'**For a pandemic of moderate severity, this is one of our greatest challenges: helping people to understand when they do not need to worry, and when they do need to seek urgent care**. This is one key way to help save lives.

'Ladies and gentlemen, **between the extremes of panic and complacency lies the solid ground of vigilance**. This meeting is all about vigilance: taking stock of what we have learned, and preparing for whatever surprises this capricious new virus delivers next.
Constant, random mutation is the survival mechanism of the microbial world. Like all influenza viruses, H1N1 has the advantage of surprise on its side.

'**We have the advantages of science, and of rational and rigorous investigation, on our side, supported today by tools for data collection, analysis, and communication that are unprecedented in their power**.'

A year latter and up to now, as we have already mentioned, the WHO has been heavily criticised and is still under evaluation; in Europe, the European Union institutions (Parliament, Council, European Commission) have commissioned expert works and produced various communications on the management of the H1N1 pandemic. Some national inquiries have been made on the management of H1N1 by their governments.

([12]) http://www.who.int/entity/dg/speeches/2009/influenza_h1n1_lessons_20090702/en/index.html

Scientific expertise is often mentioned in these evaluation reports as having failed, sometimes on the basis of possible biased advice that could be linked to financial conflict of interest, but also for failing to give proper estimations of the situation, exaggerating the potential risk of the new virus. In addition, the communication of the research community and researchers with other parts of the society was marked by a 'trust crisis', lack of confidence in scientific expertise and competition with other sources of knowledge, often less 'evidence-based'.

What followed after summer 2009 on scientific mobilisation?

Apart from microbiology, epidemiology and medical research, the mobilisation of other scientific knowledge is much less visible and easily described. It is, however, needed, especially on issues such as: communicating on risk with professionals, with policymakers, and with society; anticipating reactions from civil society as a whole; and evaluating decisions and the governance of the crisis.

At this stage of the pandemic, with major decisions already being in an implementation phase, the question for optimal use of scientific experts should have been: how can scientists help and which scientists can help in insuring the optimal implementation of those decisions which have already been taken? How can they help adapting them to what seems to be a less dramatic situation than announced?

Although the mandate of the expert group mentioned avoiding the duplication of institutional evaluations, **there is a lack of scientific evaluation of the governance of such a crisis by political and administrative institutions. Evaluation should be supported, including the role of scientific expertise in the process.**

2. How to utilise better a wide range of scientific knowledge?

This section deals with the notion that, in addition to the scientific needs of factual knowledge on the core 'causal factors' of a health threat, many issues concern or address other kinds of scientific knowledge that could contribute to decisions. There is no such thing as perfect and simple 'scientific answers' to complex risk management or mitigation coming from 'super experts' in a single scientific field. For example, to tackle a pandemic, there is a need to better understand and design a methodology for involving valid and appropriate science and knowledge in the decision process. We find the following questions to be valuable in reflecting upon these challenges:

— What needs to be known?

— What is available, or known, and what is not available, or unknown?

— Who is in a position to provide the knowledge?

— Who can help with translating the science available into the decision process?

The difficulty with the exercise of management in a pandemic or any health crisis is that there is uncertainty, and often a 'surprise' element as well, and the process cannot be fully prepared in advance. And this applies also to a list of what needs to be known. Therefore the approach to problem solving should be organised in a carefully prepared way. For example, it could include:

1. formal collaboration of researchers from various disciplines, including actors from the non-scientific field (e.g. key civil society organisations, local or national government, other kind of expertise);
2. defining formally what needs to be known;
3. defining what is relevant and to whom;
4. following-up in real time on changes in available knowledge;
5. providing appropriate synthesis of scientific data for optimal interactions between decision-makers and the general public.

Planning, preparations and work conducted under conditions of high uncertainty will certainly require change and adjustments. Nevertheless, such work must be done. An ideal resilient society would, however, be able to anticipate change and need for adjustments to such a degree that vital functions are upheld and key results somehow achieved. The task of how to rationally and efficiently involve key sciences, all necessary knowledge and competencies beyond scientific and research capabilities in a planning and decision-making process stands out.

However, the criticisms that arose during the pandemic relative to scientific expertise illustrate that there may be an essential difference between good science and good expertise, although scientific expertise should mix both.

Science is about questioning, doubting, addressing and testing all alternatives in order to challenge them, whatever their likelihood. Expertise is about putting facts and evidence in order, and ranking the likelihood of various risk scenarios while taking into consideration the contextual information. It is also about providing good cost/benefit comparisons of various decision options.

It is certainly not granted that the best scientists, especially if they are very specialised within their field, can provide the best interface for providing useful and relevant evidence-based expertise to decision-makers. At the very least, they should always separate facts from hypotheses. **This was mentioned by the group as justifying some new mechanisms for interfacing research and decision-making, especially in crisis situations**. Clearly, the direct link of a few specialists with decision-makers can create adverse effects if not backed by mediation processes through interacting with other scientific views.

Therefore a specific task concerns how to develop and organise structures and competences that incorporate multiple outcome possibilities and manage ‘surprises’ in the process without losing the overall objectives. A third issue relates to how to develop and facilitate collaboration in view of, for example, competition, limited resources and the playing of ‘blame games’ in cases of failure. Science policy is partly carved out within the wider society and successful strategies define the agenda setting. The defining of the ‘right’ science in societal risk situations therefore lays the basis for the questions asked and answered, and that process goes beyond scientific fact finding. Finally there is a need to recognise that a ‘new type of crisis’ often requires ‘thinking outside the box’, which in turn requires reflection on what scientific and social issues could be better developed or managed given a different framework, structure or content composition.

2.1. Formal collaboration of researchers from various disciplines

A key question is which scientific areas can be utilised to help prevent and mitigate events such as influenza pandemics. Regarding H1N1, clearly the immediate need for knowledge relates to the virus itself, its genetic identity, its origins, its circulation in the environment, its transmission to and from species, its potential for human casualties and its resistance or sensitivity to treatments and vaccines, etc. This involves fundamental biology, immunology, infectious diseases specialists, clinical epidemiology and other medical specialists.

Statistical analysts and mathematicians are needed for defining virus dissemination models and estimates of the size, scope and potential impact of the pandemic. Infection spread modelling requires input from, for example, behavioural scientists, and from experts and actors on information, media and opinion development and social movements. Economists are needed to provide models and estimates of the consequences of various scenarios of virus impact and societal disruptions. But models need to be presented to the world as potential 'scenarios' only, helping the thinking, and not as the 'state of the art' of what will happen.

In-depth knowledge of previous pandemics is needed, and not only regarding the virus impact and diffusion. It also ought to cover population reactions and expectations in various sociological and political contexts, and calibrations of the results to appropriate economic contexts. Sociologists and political scientists should work closely with communication specialists in order to provide information on obstacles to good communication processes related to decisions taken, including innovative channels. Such competencies are also needed to provide understanding and knowledge related to dissident views, opponent groups and rumour-mongers.

Good analysis of institutions and management structures is a key aspect in efficient preparedness and management. Public health specialists involved in health systems organisation and financing, risk assessment and management, programmes and policy evaluation and health impact assessment and health economists ought to be involved to provide facts and data on the way health systems can absorb emergency programmes and cope with disruptions in routine functioning.

The list is not exhaustive. However, essential preparations must precede a crisis situation since the urgency to take proper decisions in a crisis does not allow a wide and exhaustive consultation of all kind of scientific input at that time. We have noted a need to identify, gather and make use of essential scientific information from various fields.

Regarding the H1N1 crisis, a central evaluation question is therefore: which scientific fields were mobilised by various international organisations and institutions and in society at large in different countries? If not all fields were mobilised, what were the reasons and effects? And, based on lessons learnt, could the crisis response have been differently organised to cover all relevant knowledge?

In the WHO, it seems as if the Director-General used a very select expert group of people coming mainly from the infectious disease field, working directly with WHO units specialised in the same field, without confronting this highly specialised knowledge in a systematic way with other aspects of the crisis that could have involved other parts of her own organisation and executive team, such as those concerning the health system, health information, essential health technologies, programmes at country level, other infectious diseases management, programme and policy evaluation, health education and prevention programmes. Such a

confrontation of various points of views coming from different fields of health expertise might potentially have produced better results — at least in explaining decisions to WHO stakeholders and the general public.

Similar examples can be found at national levels. For example, in France, as already mentioned, a formal public health expertise mechanism, the HCSP, is routinely in place, as required by law ([13]). More than 100 health specialists in various fields, including social sciences, evaluation, health economics and geographical analyses, are appointed for a four-year mandate to advise health ministry departments and participate in specific commissions and working groups. Their independence from conflicts of interest is scrutinised and made transparent. Regarding the H1N1 pandemic, the minister for health put in place a very limited group, highly specialised in influenza, to give direct advice in addition to the HCSP. It created some 'tension' as this group elaborated recommendations which were only in a second step put forward for 'validation' by the HCSP, instead of doing the reverse.

Therefore the full potential of using the wider expertise group could not be utilised. Had the larger group been actively involved, it might have limited some suspicions, which came later, of undue influence of the pharmaceutical industry linked to the highly specialised experts.

2.2. Defining formally what needs to be known

In 2009, a fair amount of knowledge was already available in various specialisation fields because influenza, apart from surfacing as a new strain, is not new. Viruses are not new risk agents, and the management of preventive care and treatment of patients are not new human activities. In addition, the SARS crisis in 2003 and the H5N1 (avian flu) crisis in 2005 created such a worldwide concern that many research activities focused specifically on enhancing knowledge on influenza and crisis preparedness.

However, no specific 'list of scientific knowns and unknowns' was ever circulated. Nor could such a comprehensive compilation of the scientific state of the art be expected. Not even institutions providing funds for research systematically target specific questions. At most, areas of research are proposed to researchers, and the researchers define what is really at stake from the point of view of their specialisation. The overall outcome of research funding processes always includes many unanswered questions. We note that with respect to the influenza pandemic situation no specified body took on the burden of defining all the specific needs for scientific knowledge.

Clearly, just gathering scientific experts is not enough to provide scientific data that is not yet available. However, it is a starting point in reviewing some central questions, namely:

— What scientific knowledge is currently available?
— Which questions cannot be answered by available scientific knowledge, and why? For example, is knowledge unavailable due to results being inconclusive, or because the research has not been done?
— Which difficulties in managing a pandemic can be helped and supported by science?

It is suggested here that a group with broad expertise would be able to produce a more comprehensive basis for defining what needs to be known than a very specialised group. Multidisciplinary perspectives would certainly add different types of issues and thus an

([13]) http://www.hcsp.fr/explore.cgi/accueil?ae=accueil

increased complexity to the work, but would also better simulate the complexity of the situation in wider society and include reflections and deliberations covering larger areas of research and possible mitigation measures. The innovation potential of such an approach had already been demonstrated when, in 2001 and 2002, the German Federal Ministry for Research and Education initiated the 'future' dialogue process. This interdisciplinary, interinstitutional foresight and dialogue process developed the research agenda for Germany and also involved non-research actors. The outcomes enjoyed broad acceptance — within and beyond the research community — and cast new light on issues and aspects not previously 'on the radar' of the research community. Similarly, ideas generated and proposals developed by citizens in the pan-European 'Meeting of Minds' project (2005–06) and the German 'Wissenschaft debattieren' (2009–10) show that this non-expert perspective can offer highly valuable insights, with direct impacts and implications for research and action.

2.3. Defining what is relevant, and to whom

As a pandemic outbreak is suspected and confirmed, decision-making takes on an increasing sense of urgency. Health authorities have to balance public expectations of action with the basic principle of evidence-based policy. A pandemic situation involves a dynamic, rapidly changing situation with an imperfect flow of information. Information is critical to allow institutions, organisations and individuals to prepare a response. In addition to the common understanding of the need to contain the pandemic, specific data need to be collected and shared.

Some hazards, particularly natural disasters, can be said to be 'known'. Their causes and likely impacts are usually understood and often well defined, although there is considerable uncertainty in estimates regarding their occurrence. Events that have occurred previously can be measured and evaluated, and similar events better managed in the future. Other risks are purely theoretical or even not considered, i.e. 'unknown.' Theoretical risk events and social risks may be well defined, but it is not possible to assign narrow probabilities as to the occurrence of specific events (e.g. a hostile UFO landing in Europe, terrorism, systemic financial instability). An approach to theoretical, non-frequent and social risks is therefore to consider and develop plausible models of how reality might unfold. Risks always require governments or businesses to account for uncertainty in the utilised models — and the uncertainty part is of course larger the less is already known — as well as to build resilience into their systems, through measures such as preparedness and continuity planning, stockpiling, admitting slack in the system and diversification of sources of vital goods or services. Interdisciplinary and international foresight exercises with stakeholders, not just experts, might help to develop shared visions for such possible situations and can be used to help map out possible action pathways for a broad spectrum of actors. Such foresight methods and activities have already been developed and implemented by the Directorate-General for Research and Innovation, for example via the transnational ForSociety ERA-Net project.

Regarding the H1N1 pandemic, we have noted that secondary controversies and societal debates sometimes emerged on the basis of knowledge uncertainties, insufficient information and unanswered scientific questions. Lack of explicit explanations on scientific uncertainties may have played a role in the 'public crisis', especially when expert debates and controversies started to feature prominently in the media. Aspects in need of elaboration include:

— the pathogenic capacity of new strains;

— the natural evolution of serologic status after influenza infection;

— the natural epidemiology of influenza (seasonal), and the lack of solid routine data collections in many countries;

— the range and conditions of efficacy of antiviral treatments;

— the efficacy of influenza vaccines, even in routine conditions (seasonal influenza) and regarding specific populations (e.g. children, people with chronic diseases, pregnant women);

— the risk of adjuvant elements in vaccines;

— the cost-effectiveness of various measures proposed;

— the real impact of individual and collective prophylactic measures such as washing hands, antiseptic solutions, masks, exclusion from work, closing schools and isolation rooms in hospitals;

— mobilising, at best, all professionals.

The lack of clarity about scientific information and the unavailability of answers to some questions on obscurities or unknowns relating to the influenza pandemic highlight the restricted way in which scientists participate or are asked to contribute to solving problems in society. Influenza is not a new disease, and answers to some of the questions could have been made more easily available, and some of the unknowns could probably have been investigated earlier. For example, how can the scientific community justify the lack of solid evidence on the efficacy of antiviral therapies on influenza viruses in general, on masks or washing hands for individual protection, or on school or work exclusion, etc.?

It is widely advocated among scientists that dramatic discoveries come from research activities that are not focusing on anything 'operational' or applied. There are also scientists who consider that this assumption should not be challenged, or replaced with a more commanding structure giving more stringent directions to research. Civil society lacks the tools for asking scientific teams to focus on precise topics and for organising a coherent strategy of scientifically answering specific questions. Thus, the issue of scientific freedom in choosing direction and the specific topic of research is highlighted against priorities of societal and public needs made by other actors or bodies. Actively involving civil society in helping to identify and develop the research agenda, together with researchers, policymakers, funders, industry and other users of research, could help bridge this gap, as was shown in the 'future' project.

2.4. Following up in real time on changes in available knowledge

We note some difficulties in incorporating new data and knowledge regarding the impact of the pandemic into the decision-making process. This became especially noticeable in the situation that required adherence to strategies or stepping back from actions already on the way. As early as May 2009, as described above, the world had the information that the pandemic was probably milder than initially estimated.

However, the decision chain process outlined within the WHO and agreed to by all its Member States led to increased pressure for action. Most expert groups, expert committees, international specialised institutions (e.g. CDC, ECDC) recommended interventions targeting specific populations, for vaccination and for prophylactic actions. Despite their advice, governments sometimes took more far-reaching decisions.

Preparing for a 'worst case' scenario is a precautious choice, and calls on the research society to investigate how to efficiently combine optimal preparedness, swift adjustment to new and valid knowledge, appropriate public information and cost-effectiveness. With this in mind, identifying and developing new and unusual networks for such situations could also prove to be an adaptive and cost-effective method. Involving atypical actors with extensive networks as well as modern social media tools to gather and disseminate information could help address the difficulties experienced.

2.5. Providing appropriate syntheses of scientific data for optimal interactions between decision-makers and the general public

One issue related to the knowledge process, and the availability of scientific evidence as a basis for decision-making, is the fact that decision-makers often have to answer rather immediately to very operational questions. Science, on the other hand, is a slow and sometimes unpredictable endeavour. Therefore, very often the science production process does not match the calendars of decision-makers. In addition, scientists may reflect that decision-makers ask the 'wrong questions', or the former cannot translate their specialised knowledge into interpretable concrete answers.

Furthermore, some scientific knowledge may be 'avoided', or ignored on purpose, at some point of the decision-making process — for example when other concerns must be weighed into the decision.

The scientific community faces the issue of investigating how scientific evidence is utilised in the decision-making process — for example what is taken into account, how is it weighed into a final decision, and what reasons cause the possible omission or disregard of scientific facts. The task is especially relevant in evaluations and in suggestions of process improvements.

Could valid sources of synthesised information be enforced or created, to function as information 'flagships' and gain official promotion and support from governments and public institutions in times of ordinary life as well as crises? We recognise a need for increased trustworthiness for institutions that provide scientifically based knowledge and socially valid information, to counterbalance unintentional and intentional attempts to increase uncertainty and fear, to dispute information from uninformed sources and to decrease the spread of false or dangerous health information in various media. We also recognise the usefulness of paying attention to the issue of which organisation, present or future, could play such a role in Europe.

3. How to take the 'right' decision?

The following section suggests a number of considerations and requirements for an 'ethical' decision-making process. In a pandemic context, researchers from, for example, social sciences, evaluation of public policies, risk communication and public health should be invited to contribute to the design and follow-up of major decisions. More general but pertinent proposals for the governance of research can be found in the report 'Governance of the European research area: The role of civil society' ([14]), which remains an important and central source of proposals etc. for the issue of governance of science.

([14]) Banthien, H., M. Jaspers, and A. Renner, 'Governance of the European research area: The role of civil society', European Commission, Bensheim/Berlin/Brussels, 2003.

3.1. Democratic approach in a situation of crisis

'A serious pandemic is an exceptional situation which requires the setting of priorities and selective access to health resources. It requires an effort of solidarity from all levels of society, an engagement from those whose mission implies a direct contact with ill people. A consensus on shared ethical values is necessary to preserve the cohesion of society.' (French national plan for the prevention and reaction to influenza pandemic, 20 February 2009 ([15]))

Is the democratic system designed to work only in peace time and times of normality, or is it also intended to uphold democratic principles, including the decision-making power of elected decision-making bodies, in times of disruptions? In the European view, the democratic system, and its way of functioning and executing power, is the preferred system. What happens with its efficiency under pressure? What causes uncertainty in a crisis situation? Are there reasons for a change of decision-making structures, or decision-makers, in a crisis? Are weaknesses built into the democratic system or is the system just especially vulnerable to certain events? If deficiencies are built into a system, such a system seems less resilient and should be subjected to a serious review. However, if systems are basically sound, but vulnerable to certain trends and developments, then the focus of study should be to identify the threats and remedy the weaknesses. Developments during the H1N1 threat seem to have shown that (a) democratic 'rules and routines' were bypassed, and (b) together with insufficient preplanning and concrete precautionary actions, the stress, and low transparency of democratic rules and routines, made civic society vulnerable to several types of attacks.

As already described, uncertainties associated with the H1N1 pandemic led to a strong focus by the WHO, ECDC and EU Member States on early assessments, analysis of primary data and virology samples. Such assessments did not need to be undertaken in every country, and were done by the earliest-affected European countries, particularly those with stronger surveillance routines. This was more efficient than requiring countries to forward primary data for central analysis. However, it sometimes proved difficult to get even those analyses from European countries, and information from the southern hemisphere countries and North America proved equally valuable. This state of affairs is not satisfactory for decision-making, neither is it favourable for the communication necessary for the appropriation of decisions.

There is also a need for mechanisms to include public debates in decision-making in situations of a major health crisis, especially if the crisis becomes particularly characterised by uncertainty and strong feelings of emergency. The availability of complex data from multiple disciplines and sources, as well as conflicting information, creates uncertainty. However, when the severity of health risks is uncertain, as during the influenza pandemic, people need authoritative information about what are facts and knowledge and what is uncertain or not yet known. Thus, people need valid supportive guidance to formulate personal decisions to help protect their own health as well as the health of others. Several central issues related to decision-making and public participation, priorities and agenda setting, and individual human rights issues are suggested for future work in the research agenda. Identifying or setting this research agenda should also be done with the inclusion of all relevant branches of society, as well as interdisciplinary research groups.

We also recognise the need to highlight taking into account existing international responsibilities. For example, populations in countries without efficient public health systems should benefit from specific attention within the planning of specific global responses. In

([15]) http://www.pandemie-grippale.gouv.fr/IMG/pdf/plan_PG_2009_en.pdf

particular, wealthier countries should respect their prior international commitments for international aid resources, and sharing of treatments and other health resources to tackle problems.

3.2. Political mapping: stakeholder analysis and impact on all sectors

Responses to the H1N1 influenza situation presented by various countries could also be considered as a reflection of the political influences of different groups and stakeholders. An analysis of decisions made by public health authorities needs to include the political and social background.

In modern public health work such an analysis is considered a key instrument for understanding changes in healthcare systems ([16]). One available method is political mapping — a form of stakeholder analysis aimed at identifying the main players involved in the political and social processes that influence the implementation of a particular political programme. Political mapping helps to define groups and individuals as well as their interests, information that should be taken into account when conducting a political project. It may also be used as a clue in modifying factors mentioned above in order to increase the political feasibility of a particular project ([17]). The method was first used by Lindenberg and Crosby in 1981 ([18]) and by Austin in 1990 ([19]). A tool supporting political mapping is the PolicyMaker computer software created by Reich and Cooper ([20]).

One of the conclusions of the July 2010 EU Presidency conference on 'Lessons learned from the influenza pandemic H1N1 20092' ([21]) was that the pandemic boosted the awareness and update of business continuation plans (BCP) which needed to be put in place across all sectors — public, private and voluntary. The method also identified as a key added value for the EU to fill in the knowledge gaps and create common understanding of vulnerabilities and interdependencies of different sectors. The importance of having a BCP that covers a pandemic was highlighted by a survey of global business leaders in 2008, just a few years after the H5N1 avian flu and SARS outbreaks. The disruption to businesses from viruses was considered to be just a moderate risk for which there were high levels of preparedness in place.

3.3. Establishing decision criteria and priorities

Measures that are introducing constraints and can possibly determine vital decisions, in particular situations where access to health structures and treatment is limited, should be established based on the principle of fairness, and include both acceptable and feasible aspects. They should respect dignity and justice principles, and include kindness. It is necessary to put in place procedures of control on the processes. The creation of pertinent specific authorities can help decision-making. It is also necessary to establish hierarchies for

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([16]) Krajewski-Siuda, K., 'Health politics: the illegitimate child of health policy', *Lancet*, 369(9 559), 2007, pp. 368–369.

([17]) Reich, M. R., and D. M. Cooper, 'PolicyMaker: Computer-assisted political analysis — Software and manual', PoliMap, Brookline, 1998.
Reich, M. R., 'Applied political analysis for health policy reform', *Current Issues in Public Health*, No 2, 1996, pp.186–191.
Krajewski Siuda, K., and P. Romaniuk, 'Mapowanie polityczne jako metoda badawcza w obszarze polityki zdrowotnej', *Zdrowie Publiczne*, 3, 2004, pp. 446–450 (in Polish).
Krajewski Siuda, K., and P. Romaniuk, 'Ocena szans realizacji koncepcji Narodowego Funduszu Zdrowia przy uzyciu mapowania politycznego jako narzedzia analizy politycznej', *Zdrowie Publiczne i Zarzadzanie* , 2(II), 2004, pp. 76–85 (in Polish).

([18]) Lindenberg, M. and B. Crosby, *Managing development: the political dimension*, Kumarian Press, West Hartford, 1981.

([19]) Austin, J. E., *Managing in developing countries: strategic analysis and operating techniques*, Free Press, New York, 1990.

([20]) Reich, M. R., and D. M. Cooper, 'PolicyMaker: Computer-assisted political analysis — Software and manual', PoliMap, Brookline, 1998.

([21]) http://www.eutrio.be/pressrelease/conference-lessons-learned-influenza-pandemic-ah1n12009

priorities and procedures for access to various facilities: preventive or prophylaxis services (in case of shortage, who should get a vaccine?), and access to healthcare, treatments and hospitalisation. Furthermore, decisions taken in intensive care should be subject to particular attention in order not to penalise other patients (with diseases other than influenza) by lack of attention.

Some people and communities are more vulnerable than others during health crises (people with other diseases, dependent people, old persons, prisoners, people living in social institutions, homeless people). It is essential to define which people and groups are exposed as well as to identify and analyse specific vulnerability factors. Safeguard measures should be put in place and these too should be as robust as possible through being linked into established, non-research and non-health-system networks to help enable rapid mobilisation in case of need.

In crisis situations, reliance on competent professional help is essential. But specific constraints can affect deontological rules and best practices. Some questions for human resources management include the following:

— What about mandatory work for essential professionals? Do they have a right to withdraw or the right to compensation in cases of contamination or death, etc.?

— What about the corporate responsibility to go on producing, and which production is considered essential?

— What continuity of public service activities, such as public health and social services, should be advocated in a context where rules and regulations are less easily implemented by state institutions?

— Can there be such a thing as a code of good professional practice in crisis situations?

3.4. Restricting individual liberties.

There is an increased tension between individual freedom and collective protection in a crisis situation. Health crisis management can justify limitations to individual freedom, such as free circulation of persons and gatherings. For example, some constraints may be implemented, like isolation, quarantine, mandatory prophylaxis and treatment, where an individual's immediate rights are endangered. We recognise the need for more precise definitions, and more detailed descriptions of available control mechanisms, to be utilised in such decisions, which should always be based on the best available evidence from prior experiences. In addition, proper specific follow-up and planned evaluation of the impact and efficiency of such measures should be implemented, as well as technically and financially guaranteed.

4. Perceptions, cultures and trust

Perceptions of risk are embedded in psychological and social contexts which influence experiences, choices and decisions. We review below the study of perceived risk, how influencing factors shape the understanding of threats and how the choice of perspective influences evaluations. The interacting influencing factors chisel out various norms and experiences that create cultural differences, in groups of experts and laypersons or societal subgroups. Rationality is discussed in relation to the concept of framing, and an example of

cultural variation of perceived information effectiveness, trust and distrust is presented based on *Eurobarometer* [22] data related to the influenza H1N1 situation as in November 2009.

4.1. Risk perception and cultural aspects

The study of perception of risk as an interdisciplinary research field developed in the mid 1960s. Much of its impetus originated from debate and social conflicts related to what could be considered 'acceptable' risk (e.g. Sowby, 1965 ([23]); Starr, 1969 ([24]). On the basis of a 'revealed preference' approach, Starr pointed to voluntariness and magnitude of consequences as important dimensions in risk acceptance.

Some hazards, in particular those connected with nuclear energy and synthetic chemicals, had for decades resulted in public concern judged as disproportionate to the appraisals made by risk analysts and scientists. The discrepancy led to intense research efforts in order to understand what factors influence the perception of risk (e.g. Slovic, Fischhoff and Lichtenstein, 1979 ([25])), especially with regard to low-probability, high-consequence (LPHC) types of hazards. The psychometric model (Fischhoff et al., 1978 ([26])) pointed out the central influencing dimensions of catastrophic potential, novelty or new risk, and dread.

It soon became evident that perception of risk involved a number of interrelated social and psychological factors that contributed to the experience, such as personal control, trust, reversibility of effects, scientific uncertainty and degree of controversy, and type of consequence. Other factors including distribution of justice, how risks and benefits are distributed, the media attention, the availability and emotional content of information, involvement of children and the identity of victims were found to be influencing factors (e.g. Drottz-Sjöberg, 1995a,b ([27])). Certainly a number of background factors were investigated and found to play a role in predictions, including gender, age, knowledge and skill, psychological sensitivity and previous experience.

In addition, perceptions of nature and what is experienced as natural seem to be of relevance. In his model development Sjöberg (2000) ([28]) showed the variable 'tampering with nature' to be the foremost driving factor of 'perceived risk', as well as an additional explanatory factor to the traditional psychometric dimensions of 'dreaded risk' and 'new risk'. The concept of 'tampering with nature' seems related to what is experienced as ethical, or morally right, in a risk evaluation context.

It should also be noted that situations characterised by frequent, familiar, consistent and emotionally neutral information that is not subjected to controversy do not normally elicit reactions of concern or perceived risk. For research on perceptions of vaccination see Bostrom (1997 ([29]) and Ball, Evans and Bostrom (1998) ([30]).

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[22] Eurobarometer (2010) Influenza H1N1. Analytic Report. Flash EB Series#287. Directorate General for Health and Consumers.

([23]) Sowby, F. D., 'Radiation and other risks', *Health Physics*, 11, 1965, pp. 879–887.

([24]) Starr, C., 'Social benefit versus technological risk', *Science*, 165, 1969, pp. 1 232–1 238.

([25]) Slovic, P., B. Fischhoff and S. Lichtenstein, 'Rating the risks: the structure of expert and lay perceptions', *Environment*, 21, 1979, pp. 14–20.

([26]) Fischhoff, B., P. Slovic, S. Lichtenstein, S. Read and B. Combs, 'How safe is safe enough? A psychometric study of attitudes towards technological risks and benefits', *Policy Sciences*, 9, 1978, pp. 127–152.

([27]) Drottz-Sjöberg, B.-M. (1995a), 'Important factors in risk perception' in: O. Walmod-Larsen (ed.), *Intervention principles and levels in the event of a nuclear accident*, TemaNord 507, Nordic Council of Ministers, Copenhagen, 1995, pp. 55–60.
Drottz-Sjöberg, B.-M. (1995b), 'Risk perception and risk communication' in: O. Walmod-Larsen (ed.), Intervention principles and levels in the event of a nuclear accident, TemaNord 507, Nordic Council of Ministers, Copenhagen, 1995, pp. 111–131.

([28]) Sjöberg, L., 'Perceived risk and tampering with nature', *Journal of Risk Research*, 3, 2000, pp. 353–367.
Sjöberg, L., 'Consequences matter, "risk" is marginal', *Journal of Risk Research*, 3, 2000, pp. 287–295.

([29]) Bostrom, A., 'Vaccine risk communication: Lessons from risk perception, decision-making, and environmental risk communication research', *Risk: Health, Safety and Environment*, 8(3), 1997, pp. 177–200.

A matter of concern for experts and professionals, however, are situations that do involve risks but are not really taken to heart by those exposed to the risks. These situations often involve risks to health and life due to long-time exposure or voluntary behaviour, for example radon in the home, addictions or non-healthy and sensation-seeking lifestyles.

Health professionals may warn about such exposures with low success rates of compliance. The voluntary and perceived control factors are important contributors to the explanation of non-compliance, but so is also the psychological mechanism of unrealistic optimism with respect to oneself, in contrast to the perceived vulnerability of others (Weinstein, 1984, 1987) ([31])). In a conference paper Sjöberg (1998) ([32]) asked: 'Why do people demand risk reduction?' and presented empirical data showing that demands for risk reduction correlated strongly with perceived consequences of a risk, but not with its probability (see also Sjöberg, 2000) ([33])). Thus, it can be argued that to actually achieve compliance with well-established health recommendations, an individual must perceive the consequences of the risks as personally threatening.

An influenza virus belongs to the health risks domain, and seasonal influenza is a familiar but usually not a life-threatening phenomenon. In the current context of the H1N1 virus, experts forecasted a possibility of a potentially dangerous pandemic situation on the basis of historic trends and early inconclusive data laden with uncertainties. The situation turned into a widespread pandemic that was not severe, and hindsight judgements sometimes ridiculed precautionary measures planned or effectuated, and found, for example, the level of invested resources to be unacceptable in comparison to the resulting consequences.

Were the decisions resulting in precautionary measures rational or irrational? One approach to such an evaluation is to consider the influence of the 'framing' effect on decisions. Framing represents a concept based on coding the same outcome as either a gain or a loss. In their work on decisions under risk and the development of 'prospect theory', Kahneman and Tversky (1979, 1984) ([34]) demonstrated framing by asking respondents in an experiment to imagine that the USA was preparing for the outbreak of an unusual disease that was expected to kill 600 persons. The respondents then had to choose one of two programmes designed to manage the outbreak. In programme A 200 persons would be saved (chosen by 72 % of the respondents). In programme B there would be a one third probability that 600 persons were saved and a two thirds probability that no person would be saved (chosen by 28 %).

The preference for programme A was interpreted as a more attractive riskless choice than the unattractive gamble of programme B. However, Kahneman and Tversky then presented the exact same situations to other experiment participants but framed the two choice options in terms of number of lives lost. They found that programme C, where 400 lives would be lost, was chosen by 22 % of the respondents. Programme D, which involved a one third probability that nobody would die and a two third probability that 600 persons would lose their lives, was

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([30]) Ball, L. K., G. Evans and A. Bostrom, 'Risky business: Challenges in vaccine risk communication', *Pediatrics*, 101, 1998, pp. 453–458.

([31]) Weinstein, N. D., 'Unrealistic optimism about illness susceptibility: Conclusions from a community-wide sample', *Journal of Behavioral Medicine*, 10, 1987, pp. 481–500.
Weinstein, N. D., 'Why it won't happen to me: Perceptions of risk factors and susceptibility', *Health Psychology*, 3, 1984, pp. 431–457.

([32]) Sjöberg, L., 'Why do people demand risk reduction?' in: S. Lydersen, G. K. Hansen and H. A. Sandtorv (eds), *ESREL-98: Safety and reliability*, A. A. Balkema, Trondheim, 1998, pp. 751–758.

([33]) Sjöberg, L., 'Consequences matter, "risk" is marginal', *Journal of Risk Research*, 3, 2000, pp. 287–295.

([34]) Kahneman, D. and A. Tversky, 'Prospect theory: An analysis of decision-making under risk', *Econometrica*, 47, 1979, pp. 263–291.
Kahneman, D. and A. Tversky, ' Choices, values, and frames', *American Psychologist*, 39, 1984, pp. 341–350.

chosen by 78 % of the participants. Thus programme D, the risky option, was favoured before the riskless option when the researchers used the negative framing. The experiment showed that positive and negative framing resulted in different choices.

Another approach to study rationality and irrationality is to consider risk experiences as products of different 'cultures'. Differences between individuals, and between groups of individuals, based on the ethical and value-related views embedded in social situations, have turned out to be of importance in understanding risk perceptions, choices and decisions. In the early 1990s social and behavioural research on risk focused to a great extent on issues such as cultural bias, rationality, social amplification of risk and trust, in more far-reaching attempts to enhance the understanding of external factors influencing the experience of risk (e.g. Douglas and Wildavsky, 1982 ([35]); Kasperson et al., 1988 ([36]); Inglehart, 1990 ([37]); Sjöberg, 1996 ([38]); Hansson, 1999 ([39])). It has been argued that an approach taking norms and ethical values into account contributes to a better understanding of perceived risk in specific settings. One such setting is existing knowledge or degree of expertise, and many studies have looked at differences between experts' and layperson's appraisals of risk. The groups can be characterised as subcultures using different types of rationality.

A 'culture' provides a standard or frame of reference relative to which information and experiences are tested for validity and reliability. Plough and Krimsky (1987) ([40]) illustrated the differences between technical and cultural rationality of risk and suggested that the former includes trust in scientific methods, explanations and evidence whereas the latter involves trust in political culture and democratic process. The boundaries of technical rationality are narrow and reductionist whereas the boundaries in cultural rationality are broad and include the use of analogy and historical precedent. In the former perspective risks are depersonalised, and there is an emphasis on statistical variation and probability, whereas in the latter perspective risks are personalised, and the emphasis is on impacts of risk on the family and community. Also, technological rationality appeals to authority and expertise, whereas the cultural rationality appeals to folk wisdom, peer groups' views and traditions.

The following results of findings about public opinion on the H1N1 pandemic provide ample examples of both major trends in Europe and opinion heterogeneity across countries. It is suggested here that it would be worthwhile in future research to find explanations for the variation of provided public information, as well as trust/distrust levels, across European countries, and that some attention should be given to characterise influential subgroups within each country. Such knowledge would increase the understanding of very different reactions to the threat of the H1N1 pandemic.

([35]) Douglas, M. and A. Wildavsky, *Risk and culture*, University of California Press, Berkeley, CA, 1982.
([36]) Kasperson, R. E., O. Renn, P. Slovic, H. S. Brown, J. Emel, R. Goble, J. X. Kasperson, and S. Ratick, 'The social amplification of risk: A conceptual framework', *Risk Analysis*, 8, 1988, pp. 177–187.
([37]) Inglehart, R., *Culture shift in advanced industrial society*, Princeton University Press, Princeton, NJ, 1990.
([38]) Sjöberg, L., 'A discussion of the limitations of the psychometric and cultural theory approaches to risk perception', *Radiation Protection Dosimetry*, 68, 1996, pp. 219–225.
([39]) Hansson, S. O., 'A philosophical perspective on risk', *Ambio*, 28, 1999, pp. 539–542.

([40]) Plough, A. and S. Krimsky, 'The emergence of risk communication studies: Social and political context', *Science, Technology and Human Values*, 12, 1987, pp. 4–10.

4.2. European public opinion on the H1N1 pandemic

Statistics from the special issue of the *Eurobarometer* (No 287, data collected in November 2009[41]) on influenza H1N1 show that most respondents in a large majority of the participating countries believed they were well informed about the pandemic influenza. This belief covaried with educational level and urbanisation, and significant differences were not reported regarding age or gender groups. However, the variation across countries should be noted. Table 1 (in Annex 1) shows results from each country for the question 'How well informed do you feel about the pandemic H1N1 flu?' summarised here in two categories, i.e. those well or very well informed and those less or not at all informed. Note that seven countries present data where one third or more of the population felt little or not at all informed (i.e. Greece, the Czech Republic, Romania, Poland, Estonia, Latvia and Lithuania).

The table also includes summarised statistics of trust/distrust in five types of information sources regarding the pandemic H1N1. The question was 'How much do you trust each of the following sources to inform you about the pandemic (H1N1) flu?' The information sources were: health professionals; national authorities; European authorities; the media; and the Internet. Overall results showed most trust in health professionals, such as doctors and pharmacists, with respect to information about the influenza. Note, however, the large variation of distrust across countries. For example, 3.5 % of the Icelandic population indicated little or no trust in the health professionals whereas in Hungary almost a third of the respondents reported little or no trust (29 %). Results regarding trust in other information sources showed that Europeans overall had the least trust in the Internet and the media. The table, which displays only the 'distrust' figures in relation to information sources, reveals that the percentages of people who had little or no trust in the Internet ranged between 21 and 59 %, and that 39 to 74 % distrusted the media (e.g. TV, radio, newspapers).

Overall results related to trust in information from national and European authorities ranked between health professionals and the media/Internet scores. National authorities showed the lowest 'distrust' score in the Nordic countries (i.e. from about 6 % in Iceland to about 15 % in Sweden), and the highest values in France (48 %), Poland (52 %) and Latvia (56 %). Corresponding data for European authorities showed the lowest 'distrust' scores in Malta (about 15 %) and Portugal (about 17 %), and the highest 'distrust' scores in France and Latvia (both about 48 %) and in Germany and Poland (both around 45 %).

The huge variation in the scores across countries, especially distrust in information sources, points at the necessity of pursuing additional research into the social trust area, and of following up the influencing factors within countries in more detail. Average scores for the European Union, or for specific countries, give just a hint of the underlying complexities that may shed light on information needs and design of information materials. The variations ought to be further studied also to gain better bases for the improvement of factors such as education, type of information sources used and preferences for information materials within various cultural settings.

[41] Eurobarometer (2010) Influenza H1N1. Analytic Report. Flash EB Series#287. Directorate General for Health and Consummers.

5. Risk communication, media and pandemic influenza

5.1. Importance of risk communication

In general, effective risk communication is considered to be essential not only to provide advice, information and reassurance, but also to encourage individuals to take personal preventative actions and to encourage support for necessary national responses and contingency measures. Authorities stress the need for communication before, during and after a pandemic ([42]).

The information provided should be technically correct and succinct without seeming patronising. It should minimise speculation and avoid overinterpretation of data and overly confident assessments of investigations and control measures.

Normally, consistency of information is viewed as essential as people become confused and concerned when exposed to different and sometimes conflicting risk messages. That is why authorities are very often inclined to withhold information until they are absolutely sure that the message is true — and to reconcile the message within the authorities before communicating to the public.

However, in the case of an ever-changing pandemic influenza situation, this ideal is just not possible to achieve. Consequently, public authorities have to choose between two options. They can either wait to communicate until they have all the facts at hand or, alternatively, they can communicate successively what they know — and do not know — being fully aware that later on the message will be adjusted or completely changed. Managing this dynamic communication during a pandemic crisis situation without losing public trust is a challenging task for the public health authorities and their communications departments.

On the one hand, the challenge is to warn people of the risk and prepare them psychologically as well as physically for the possibility of a human pandemic influenza and also to encourage them to take appropriate precautions. On the other hand, these warnings must at the same time be modulated so as not to create social disruption and a sense of futility or despair. In other words, public health officials must raise awareness and concern without inducing irrational behaviour ([43]).

5.2. Communicating uncertainty

The spread of a pandemic influenza has been described as a situation where decisions are being made, while the evidence needed to support them remains silent or absent. Such silence of evidence creates a situation requiring the managing of the 'known unknowns'.

Of course, there are still many well-known factors in terms of a pandemic, such as the general knowledge about the origin and nature of the influenza virus and the historical experience of its spread. But despite this fundamental base of knowledge lots of specific key questions cannot be satisfactorily answered during the spread of the pandemic.

([42]) Gensch, P. 'Social media intelligence — crisis management in the health sector', EU Presidency Conference on lessons learned from the influenza pandemic A (H1N1), Business Intelligence Group, YEAR IN

([43]) 'Challenging futures of Science in Society: Emerging trends and cutting-edge issues', Report of the MASIS Expert Group set up by the European Commission, 2009.

The uncertainties very often lead to the delay of answers or vague statements, such as 'based on present knowledge we consider the virus to be relatively mild', or 'the risk of further spreading seems to be weak'. In fact, these are deliberate statements based on the present state of knowledge. However, the media do not always welcome these 'we really don't know' responses. Instead, they often call for straighter answers to questions like 'How dangerous is the pandemic?', 'Who is actually at risk'? and 'What kind of effects are anticipated from the spread of the pandemic'?

These are, nevertheless, questions that public authorities are expected to answer in order to give advice to politicians, particularly vulnerable groups and the general public about what to do and how to behave during a pandemic. To rely on the best available knowledge, planned continuous updates and transparency with respect to information sources as well as bases for decisions and recommendations help in relaying messages to the public under conditions of high uncertainty.

5.3. Pandemic influenza — a risk communication challenge

Pandemic influenza poses serious potential threats to societies, but precise data and estimates are seldom available. For example, based on historic experiences, the US Centers for Disease Prevention and Control (CDC) has placed the possible casualty rate from a modern pandemic flu at between 200 000 and 2 million in a worst-case scenario. However, in the end, the consequences depend on the properties of the influenza and the management of the situation.

Generally, at the initial stages of disease outbreak, very little is known about the severity of the specific virus strain. The lack of valid information related to this fundamental prerequisite for impact estimation represents a dilemma for the risk communication practiced by the public health authorities. Thus, on the one hand, the health authorities face public demands for openness and transparency, which means that all relevant information should be communicated to the public without undue delay. On the other hand, due to the progression of knowledge, it may soon be necessary to revise the information.

In addition, and in the H1N1 pandemic situation, social media were a critical aspect of the media coverage; information passed quickly to the traditional media, setting the agenda of news stories. Analysis of the genesis and development of news stories about H1N1 showed that in Europe three individual bloggers were extremely influential in terms of media coverage of the pandemic (two medical doctors in France and an astronomer in Germany), all of whom raised questions about the role and impact of vaccinations.

The health authorities handling the H1N1 crisis focused on limited essential functions of surveillance, both in the area of epidemiological surveillance on the number of people afflicted and deaths, etc., and in the area of virological surveillance on the genetic characteristics of the virus. These included mutations and resistance but also serological surveillance to be able to determine whether many cases were asymptomatic. The H1N1 pandemic highlighted the urgent need for greater investment in health communication capacity and infrastructures.

Communicating risks of H1N1 and other pandemic influenza situations presents dilemmas for public health authorities. Under conditions of incomplete knowledge and uncertainty it is difficult to maintain the ideal of correct and consistent information. The difficulties do not, however, prevent or exempt authorities and decision-makers from planning and executing information policies that attempt to approach the high standards that are set. The challenge is

further magnified by the current swift flow of information, internationally and through many different types of information channels, underlining the necessity of collaboration across organisations as well as countries.

5.4. The mediated pandemic risk

The tension between media demand and expert ability to comment is an important point in the risk communication of pandemic influenza. In the initial stages of H1N1, reports of an outbreak in Mexico were widely broadcast, accompanied by scary photos of people wearing masks. Also massive figures of possible deaths were communicated rather uncritically. This fear-causing role of the media was far from an isolated event during the crisis. Thus, in the case of H1N1, the mass media bear some responsibility for the spread of fear. In EU countries we witnessed a kind of remorse among members of the press after the relatively mild course of the pandemic. Some commentators even accused epidemiologists and public health authorities of having overstated the threat. However, both types of reactions came after the battle, because H1N1 turned out to be a rather mild pandemic.

The H1N1 pandemic also showed several examples of mediated risk conflicts, where statements or demands from stakeholders led to a change in the recommendations made by public health authorities. For example, during 2009 the Danish health authorities had to adjust several times their advices and recommendations concerning who were the vulnerable groups that should have first access to vaccination. Also, recommendations that general practitioners wear goggles, gloves, masks and protective clothing when examining people with symptoms of influenza were changed during the pandemic. This happened after the media reported several protests illustrated by photos of GPs in astronaut-like clothing.

In Denmark, a third kind of mediated negotiation arose when reporters discovered that authorities in other Scandinavian countries had very different assessments of which groups were most vulnerable. This gave rise to a heated debate, where the authorities had to go out in public and defend their recommendations.

5.5. Internet and social media

The Internet has fundamentally changed the conditions for, and complexity of, risk communication. Although the merging of the 'risk society' and the 'network society' still needs to be much more thoroughly investigated, three consequences for risk communication emerge, all of them influencing public authorities' ability to communicate pandemic risk.

First, the immediate and uncontrolled spread of all kinds of information worldwide makes traditional information-keeping a thing of the past. Second, the Internet provides great opportunities for spreading false information and rumour-mongering. Finally, it favours all kinds of subcultures, some of them held together by common perceptions of risk. Anti-vaccination groups, discussed below, are an example.

At the beginning of the 21st century, social media became an important phenomenon, changing the paradigm of global communication as compared to the previous century. In social media, people are both a broadcaster and a receiver of messages. Social media enable interactions between Internet users through technologies such as blogs, forums, discussion groups, wiki tools, podcasts, e-mails, communicators and VoIP [44]

[44] Pacha D. Social media, lekcja 1. http://socialmedia.pl/social-media-lekcja-1/

Some benefits of social media are: [45]

— democratisation of media;

— creativity and a re-mix culture;

— community, sharing and connecting;

— increased transparency in government and organisations.

Some results regarding the importance of social media in modern societies are worth considering. According to an analysis presented by The Nielsen Company in 2009, an average global user spent over five hours a month on Facebook.[46] The total number of users is difficult to estimate due to the multiplicity of social media channels, but some estimates give a figure of 900 million users worldwide. With this great number of users, social media present a very attractive mean of mass communication with a very low cost of broadcasting. The mechanism is already used by business companies. For example, 80 % of respondents (marketers) participating in research conducted by the American Marketing Association suggested that their company will increase interest in social media. On the other hand traditional mass media are considered to be losing their attractiveness for marketing activities[47].

In the USA, the CDC has already exploited some of these new possibilities. But this institutional use for non-commercial goals, including H1N1 prevention and information, remains a real challenge. Aside from its traditional activities, the CDC has undertaken several initiatives enabling people to spread information on swine flu, for example by signing up for newsletters or adding buttons and badges on their profiles on social networking sites. Such activities could become an important complement of regular activities in Europe as well, but proper scientific evaluation of the impact is still missing.

The spread of information via the Internet transcends time and space, thus decoupling the risk message from its original socio-cultural context. For example, the first reports of H1N1 came from Mexico where the healthcare system is not at the same level as in more developed societies. The reports of the impact from Mexico were therefore much worse than those available when the influenza hit the USA, where mortality was found to be at the levels of the ordinary seasonal flu.

Also, during the H1N1 pandemic several countries experienced a public reluctance to get vaccinated. The reluctance was manifested not only among the general public, but also among health professionals like doctors and nurses. Although the examples are few, anti-vaccination messages were communicated rapidly through the Internet and caused some confusion among the general public.

Having said this, these new communications tools also offer great potential for established or 'official' information sources and actors to communicate their messages. Social media could and should be utilised by the research and policy communities as part of their broader, non-crisis communications strategies so that these media can also be utilised in situations of urgent need.

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[45] Advantages and Disadvantages of Social Media and Web 2.0 http://compassioninpolitics.wordpress.com/2008/02/01/advantages-and-disadvantages-of-social-media/

[46] Global Time Spent on Social Media Sites up 82% Year over Year http://blog.nielsen.com/nielsenwire/global/led-by-facebook-twitter-global-time-spent-on-social-media-sites-up-82-year-over-year/

[47] 2010 Trends in Marketing: Salaries, Strategies, and Beyond http://www.marketingpower.com/ResourceLibrary/Documents/research/aquent_salary_2010.pdf

Thus, from a public authority point of view, the Internet represents on the one hand a threat because it challenges the authority's exclusive right to choose when and how to inform about risk. On the other hand it provides new opportunities, for example to reach out to people with risk information in places and situations where they really need it.

Mass communication as well as the spread of rumours can cause dramatic changes in the behaviour of a population. However, the spread of an epidemic can also be slowed down if local health authorities work with newspapers and other media to publish the correct data on infection risk and prevention as early as possible.

5.6 Internet and anti-vaccination groups

The Internet is a vast galaxy of unverified bits of information, research, speculation, generalisations, anecdotes, conjecture, half-truths and hearsay. The 'University of Google' allows individuals' access to specialised medical scientific information previously available only to health professionals. In the USA in 2006, up to 80 % of adults with Internet access used the Internet to seek health-related information[4849]).

Following Edward Jenner's cowpox experiments, in which he showed that by infecting a boy with lymph from a cowpox blister, he could protect him from smallpox, widespread smallpox vaccinations began in the early 1800s. Jenner's revolutionary ideas were immediately met with public criticism and objections of a scientific, health, political and religious nature. The modern anti-vaccination campaigns started in the 1970s, when controversy erupted about the safety of the diphtheria, tetanus, and pertussis (DTP) vaccine. In 1998, Dr Andrew Wakefield ignited public fear about a (now refuted) link between the measles, mumps, rubella (MMR) vaccine and inflammatory bowel disease and autism. And in 2009 and 2010, the anti-vaccination movements spread doubts about the safety and effectiveness of pandemic influenza vaccines, without scientific data to support this. The consistency in the attitudes and emotions of the anti-vaccination movements in the 19th, 20th and 21st century is remarkable.

Well-organised opposition groups with their own agendas and intentions can abuse social media. This may be the case with some anti-vaccination groups that create a growing threat to vaccination programmes.

Anti-vaccination groups manage to occupy a disproportionate amount of Internet prime property to spread their messages[50]. When the word 'vaccination' was typed into the Google search engine (on 9 October 2010), eight of the first 20 hits linked to anti-vaccination sites. When the same word was typed into YouTube, the most popular Internet video portal, 18 of the first 20 videos had anti-vaccination messages. It is clear that anti-vaccination activists have quickly learned how to dominate the scene from the earliest days of the Internet, and have rapidly adopted novel ways such as YouTube viral videos, podcasts and blogs to get their message across.

In relation to a crisis situation, anticipating and close monitoring of activities from 'rumour' sites and sites spreading false messages would allow reactivity and preventive measures from official institutions and authorities. The development of an increased preparedness to manage

[48] Goldman RD, Macpherson A. Internet health information use and e-mail access by parents attending a paediatric emergency department. Emergency Medical Journal, 2006;23:345-348

[49] Wolfe RM, Sharp LK, Lipsky MS. Content and Design Attributes of Antivaccination Web Sites. Journal of the American Medical Association, 2002;287:3245-3248.

[50] Davies P. Antivaccination web sites. Journal of the American Medical Association, 2002b;288:1717

this type of misinformation or risk could be a task in future research, including the development of specific surveillance activity, such as observatories.

The difficulty for Internet users without any scientific background is to correctly distinguish what could be considered as genuine health information, based on proper evidence, from systematic ways of discouraging vaccinations and other 'official measures' of healthcare. However, some accreditation activities, such as the certification of 'good evidence-based sites', are beginning to be put in place, recognised and promoted. We suggest that the future research agenda includes possibilities to develop broadly based projects that look into how to enhance availability, usability and trust in scientifically based health information sites on the Internet.

5.7. Dialogue-based communication

According to the Europe 2020 vision for the European research area and the programme 'Science in society: towards reinforcing the societal dimension of the European research area', the Research and Innovation DG is committed to the view that 'science communication is not simply the education of citizens but also the construction of meaning and design of techno-scientific futures, the citizens, scientists and science communicators actively have to face new forms of responsibilities'.

Means for 'innovative science communication at the centre of society' are therefore needed. New concepts and methods will have to be developed to enable better two-way communication between science and society that promotes mutual understanding and learning, exchange of information and experience and a better use of scientific knowledge as well as improved implementation and application of science-based policy. Excellent examples of how this can be done do indeed already exist — be it involving stakeholders in setting the research agenda (the 'future' project), developing new forms and tools for science communication (the 'Wissenschaft debattieren' project) or involving citizens directly in deliberating scientific issues (the pan-European 'Meeting of Minds' project on the future of brain science). These need to be institutionalised and disseminated within the academic and research communities as well as at European level and in the European institutions. In this way, this established body of experience and best practice can be made more widely available for implementation.

Modern communication and engagement strategies on research-related issues require various forms and channels of exchange between experts from different stakeholder groups, the media and muliplicators, as well as the general public.

Research should be engaged in a dialogue with all relevant stakeholder groups that channels and translates information and experience in order to ensure transparent and trustful cooperation and to promote a fast response and learning on all affected levels of research, policy and implementation.

Participatory processes need to fit the needs of the stakeholder groups and the political and cultural framework conditions, and have to be tailored to the specific demands to ensure an informed and issue-focused interaction.

The recent debate around pandemic preparedness demonstrates the urgent need for innovative and dialogue-based approaches in science communication. The European Commission

emphasises that 'the adage that science is too important to be left to scientists captures the normative challenge of integrating science in society, allowing for societal participation, but in such a way that its creative power is not subsumed by immediate interests'. Funding and programme support should be made available — also for organisations not from the scientific or research fields and including the private sector — to help implement this aim. A new era of science communication could include designing improved pandemic preparedness with new ways of communicating within and across countries.

The system of European pandemic preparedness can be significantly enhanced. Science communication on pandemics is risk communication that needs to gain and ensure a high level of trust and transparency among all stakeholder groups.

All information needs to be easily accessible and understandable. Two-way communication needs to be strategically planned and accessible as well as tailored towards different publics with different knowledge backgrounds. This approach needs to be applied to both classical and new media, and must include content-related forms of communication and interaction at an early stage. Telling people what to do in a crisis is too little too late when interacting with them beforehand can effect far greater and more sustainable changes.

Cooperation and exchange between all relevant stakeholder groups needs to be institutionalised and transparent. Methods for learning and knowledge management need to be integrated into the communication and engagement strategy. Initiating a project to collate such learning and to begin the process of institutionalisation and dissemination would be an important first step in this process. Such an undertaking by the Research and Innovation DG and involving key actors would be very welcome.

Thus, research and public policies for pandemic preparedness need to be transparent and processes and information accessible to muliplicators and the public. The communication and engagement strategy needs to be dialogue-oriented and results from modern issue-focused dialogue processes need to be reflected in pandemic preparedness policies and research. This could be achieved through a project initiative as mentioned above.

5.8. How to balance cost and benefits?

It seems that very few cost-effectiveness analysis or economic modelling attempts entered into the H1N1 decision-making process. There were, however, memories of economic disruption during the SARS episode. No systematic review of various alternative scenarios was proposed in the early stages as a support for the decision-making process. Costs were only subject to retrospective criticisms.

The H1N1 threat generated different responses among EU Member States representing different levels of cost-effectiveness. An overview of some of those strategies has been presented in the report prepared for Council of Europe. By comparing steps undertaken by authorities in France, Poland and the United Kingdom, the report describes extremely different strategies.

The figures for the United Kingdom and France show how the pandemic was overstated. In the first and worst scenario, the UK Department of Health expected 65 000 deaths. By January 2010, fewer than 5 000 persons had been registered as having caught the disease and 360 deaths had been noted. In case of France, 312 people died of influenza (up to April 2010),

whilst 1 334 cases of serious infection were registered since the beginning of the pandemic, according to the national institute for the monitoring of health issues, Institut national de veille sanitaire. The actual scale of the pandemic forced the French government to cancel orders for 50 million doses of vaccine (out of a total of 94 million initially ordered). By March 2010, only 5.7 million people were vaccinated. The final French public health bill for vaccines amounted to EUR 365 million and a stock of 25 million doses of vaccine whose shelf life expired at the end of 2010.

Poland is one of the few countries in Europe that did not purchase large quantities of vaccines. This was due to safety fears and distrust of the pharmaceutical companies producing them. As mentioned in the report, in Poland the decision-making process was based on the close collaboration with the European Centre for Disease Control and Prevention (ECDC) and national centres. According to estimations made by the Polish flu pandemic committee, the high-risk group most concerned with vaccination contained 2 million persons. Resources to buy appropriate numbers of vaccines were secured in the budget. However, the minister for health considered that the conditions proposed by the pharmaceutical companies for the purchase of vaccines were unacceptable. Vaccines were to be purchased only by the government (not marketed to private individuals), and the government was asked to take full responsibility for all undesirable side effects (the threat of which seemed real according to the EudraVigilance system). Furthermore, the vaccines were offered at up to 2 to 3 times the price of vaccines used against seasonal influenza.

Further study of national and international strategies appears to be of great importance for national governments and international organisations. Since European governments are being forced to make budgetary cuts, analysis of the cost-effectiveness of different approaches would be an essential tool if properly designed.

C. Research agenda

This part of the report summarises the research needs at the intersection of scientific expertise, citizens' risk assessment and new governance models related to A (H1N1) and other cases of pandemics. The HEG work group has chosen to highlight some potentially fruitful research areas on the basis of reviews of materials and discussions. For each area, the research topics of potential interest and a short explanation are given below.

Reviews, based on historical data and previous experience, highlighting specific scientific issues to be clarified or to be solved by science. In this research area applicants could be invited to review, on the basis of now available data from 2009–10, the lessons learnt across a selection of countries. Projects could be more or less multidisciplinary but should include at least five countries for comparison. The topics could focus on specific fields, such as specialisations in medicine, health crisis organisation or public use of social media, or bridge several specific fields to capture information such as use of available expertise and information materials, collaboration or cross influences. Suggested topics include:

— primary and secondary threats in a pandemic;

— knowledge of viruses, and an overview of yet unknown aspects;

— actors influencing vaccination success and failure;

— rationality, values and emotions.

Righteous power: democratic versus elitist perspectives on decision-making. This research area is rather theoretical and focuses on principles of power and their potential or actual outcomes. Various governance systems could be reviewed and commented on, but among the most interesting aspects to explore are those explaining the construction of the interface between science and politics, i.e. how scientific facts and knowledge are used in civic organisational and political decision-making. Proponents of democratic rule may view science as a tool, whereas proponents of solid scientific knowledge may find their input unjustly weighed in decision-making. Furthermore, 'righteous power' issues involve individual and collective rights, social justice, solidarity and priority setting. One example is the issue of scientific freedom in choosing direction and specific topic of research versus strong political regulations or incentives to steer scientific teams to focus on precise topics. Suggested research topics could be:

— scientific free thinking and choice versus strategic steering of science and political mandates;

— individual rights and the collective good;

— legal frameworks facilitating or hindering European solidarity actions regarding sharing of knowledge and other resources;

— principles for decision-making;

— ethics, justice and availability of healthcare in a multicultural Europe.

Facilitating the utilisation of scientific knowledge in decision processes. This area of research would focus on how decision-makers in ordinary democratic decision-making bodies utilise scientific knowledge. Examples include what facts or types of materials are taken into account, how they are weighed into a decision, what reasons cause the omission of scientific

facts, and what are the overall influencing factors forming a decision. The task is especially relevant in combination with evaluations of the H1N1 pandemic, and in connection with suggestions of decision process improvements. Specific topics could involve:

— decision-making on health threats and societal resilience;

— balancing of benefits and risks under scientific and social uncertainty;

— agenda setting and decision-making in multidisciplinary research contexts;

— risks and benefits of scientific endeavour.

Decision-making and public participation in a crisis situation. There is a need for mechanisms to include public debates into decision-making, particularly in a situation of a major health crisis. This is especially true if the crisis becomes particularly characterised by uncertainty and strong feelings of emergency. Topics related to power of agenda setting, information needs and human rights could be investigated in such a research area, including:

— raising public awareness and creating appropriate conditions for a debate involving members of the general public as well;

— modalities for consulting the whole society;

— models for integrating all kinds of expertise in the decisional process;

— clarification and coordination or integration of all stakeholders within the decision process (representative authorities, associative networks, townships, etc.);

— distribution of responsibilities in situation of crisis;

— preventing distrust in the public and addressing controversies as 'normal elements' and not crisis triggers;

— keeping alive democratic criteria and societal values in major health crises, as well as ways to preserve, as much as possible, the principles of the universal declaration of human rights, in particular as regarding respect for people's dignity and rights.

Evaluative research. Apart from institutional reviews and audits, there is room for systematic evaluation of the governance of pandemics and other crises. This means evaluations with knowledge goals, looking for the understanding of strengths and weaknesses and not looking only at failures in responsibilities for blaming purposes. It is essential to investigate the role of scientific expertise in the knowledge and decision process. Evaluations with research purposes should be planned and budgeted in parallel with any crisis management process.

Elaborating lists of unsolved scientific question regarding influenza and pandemic situations. A research project could be designed in order to bring into the research agenda in a systematic and comprehensive manner a set of questions issued by all kind of researchers, health professionals and civil society at large. It would create a 'reference guide', a framework for designing 'à la carte' research programs in influenza and similar threats.

Mapping of experiences in bringing research closer to democratic institutions at all levels (parliaments, regional governments, local authorities). There are experiences of bringing science and scientists closer to decision-makers and a research project could bring a comprehensive analysis of successes and failures.

Annex 1

Table 1: **Percentages of perceived information level across European countries, and percentages of distrust responses in five information categories (Data adapted from *Eurobarometer* No 287)**

Country	% Informed ([1])		% Distrust in information sources ([2])				
	'Well'	'Not well'	Health professionals	National health authorities	European authorities	Media (TV, radio, newspapers)	Internet
Slovenia	91	8	26.7	35.0	39.6	56.3	39.6
Norway	87	12	10.7	13.2	17.4	69.6	44.8
Switzerland	87	13	13.3	24.9	36.6	69.1	51.9
Finland	87	13	7.4	14.2	24.8	39.6	43.6
Portugal	84	15	10.1	19.8	16.9	46.2	33.2
Malta	85	15	6.0	14.9	14.6	41.2	33.3
Luxembourg	84	15	14.0	31.0	37.3	68.4	56.1
United Kingdom	83	16	8.1	18.3	36.4	65.1	44.5
Iceland	83	16	3.5	6.6	20.4	54.2	43.3
HU: Hungary	83	17	29.0	43.4	33.7	70.7	40.2
IE: Ireland	83	17	7.1	22.1	21.2	49.6	43.5
Belgium	82	17	7.7	21.4	24.3	64.4	55.8
Sweden	82	17	11.0	14.9	23.2	72.8	47.7
Denmark	81	19	7.8	10.6	17.1	56.3	38.3
Netherlands	80	20	8.7	16.0	22.4	64.3	48.9
France	77	22	19.5	48.1	48.0	73.7	59.0
Austria	77	22	15.5	29.7	42.9	66.6	48.6
Germany	75	25	17.2	36.1	45.8	65.8	47.8
Italy	75	25	23.1	42.9	40.5	66.7	48.9
Cyprus	72	29	19.7	24.6	24.0	49.7	33.4
Slovakia	71	28	18.6	24.3	26.8	44.2	36.4
Bulgaria	70	29	21.1	35.6	25.5	39.8	21.2
Spain	69	30	12.8	41.7	38.7	62.3	48.9
Greece	67	33	26.5	43.1	36.8	74.1	35.4
Czech Rep.	66	34	15.3	25.8	32.3	42.4	37.9
Romania	66	34	15.0	34.9	29.4	44.5	31.0
Poland	66	35	23.6	52.0	44.3	57.5	44.5
Estonia	57	42	16.2	24.7	24.4	45.0	34.9
Latvia	51	48	27.4	56.4	48.5	53.8	42.3
Lithuania	43	54	25.4	36.5	25.0	39.3	27.4
EU-27	**75**	**24**	**16.6**	**35.5**	**38.2**	**62.8**	**46.3**

([1]) Question: 'How well informed do you feel about the pandemic H1N1 flu?' Response categories here: 'Well' includes 'very well informed' and 'well informed'; 'Not well' includes 'not very well informed' and 'not at all informed'.

([2]) Question: 'How much do you trust each of the following sources to inform you about the pandemic (H1N1) flu?' Response categories shown here: Sum percentage of the responses 'Trust not much' and 'Do not trust at all'.