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PANDEM

Pandemic Risk and Emergency Management

D5.1 Workshop to identify needs and innovations to strengthen pandemic surveillance, communications and governance

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1 BACKGROUND

Pandemic Risk and Emergency Management, PANDEM, is a Coordination and Support action funded by the Horizon 2020 Secure Societies Programme under the topic: Crisis management: Feasibility study for strengthening capacity-building for health and security protection in case of large-scale pandemics - Phase I Demo.

Pandemics have had a major impact on the health and security of human populations for millennia. Plague killed one third of Europe's population in the Middle Ages and Spanish flu killed 40-50 million people in the early 20th century. In addition to known pandemic prone pathogens such as SARS coronavirus, smallpox, Ebola and novel influenza viruses, new or previously unrecognised pandemic threats may emerge from a number of sources. Pathogens from animal origin will continue to breach the species barrier and may become transmissible from human to human. The world also faces the threat of drug resistant strains of known bacteria or viruses that are becoming increasingly difficult to treat with current medical countermeasures, which could drive future pandemics if not carefully managed.

In addition to these factors, the rapid global expansion of laboratories working on highly dangerous pathogens in bio-safety level (BSL) 3 or 4 facilities has increased the risk of accidental release of a virulent pathogen due to human error. This is particularly so where regulatory, bio-security and bio-safety measures may be sub-optimal.

Finally, radicalisation and greater availability of methods to manipulate pathogens have increased the risk of their deliberate release. In addition to the demands on the health sector, a suspected deliberate release event also raises specific law enforcement and security concerns such as attribution and interdiction.

The convergence of risk factors driving disease emergence, amplification and dissemination of pandemic prone pathogens means that emerging diseases pose a greater threat to mankind now than ever before. The H1N1 influenza pandemic in 2009 spread around the world in weeks affecting all countries with significant health, economic, political, social, cultural and environmental [1]. The recent Ebola crisis highlighted the urgent need for far-reaching improvements in public health capabilities and infrastructure, international preparedness and response, and research and development related to emerging infectious diseases.

In response to this challenge, the European Commission (EC) is funding research on building response capacity in Member States. This research is also investigating ways in which the

European Union (EU) and Member States can be supported to implement EU Decision 1082. This Decision provides new legislation to streamline and strengthen EU capacities to respond effectively to serious cross border threats to health such as pandemics. The EC identified three core areas for which capacity building is required to strengthen pandemic management as *surveillance*, *communications* and *governance*.

The objective of PANDEM is to identify important gaps in technologies, systems and capacity in these areas at Member State, EU and global levels. There is a particular focus on enhancing the capacity of Member States to collaborate on cross border risk assessment, response and recovery.

The project's specific objectives are to:

1. Review current best practice for pandemic management at global, EU and Member State level.
2. Identify major gaps, improvement needs and priority research questions for pandemic management.
3. Identify potential solutions for improved technologies, systems and capacity that would lead to better pandemic management, more efficient use of resources and better cross border risk assessment, response and recovery.
4. Set the foundation for a multi-disciplinary, intersectoral network of experts in the EU to improve pandemic management.
5. Incorporate innovative solutions identified into a roadmap for a larger Phase II demonstration project.

A pandemic has been defined as “an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people” [2]. This definition can be applied to other infections subject to global spread such as cholera or HIV but for the purposes of the PANDEM project, we are focussing on the rapid spread of an infectious agent over a relatively short timeframe. While there is no element of severity in this definition, as the call refers to high impact pandemics, we will look at threats that have the potential to lead to severe pandemics. The research findings of PANDEM will be relevant to pandemics due to natural, accidental and intentional release events.

In addition to the roles of Member States in emergencies that the EU declare under Decision 1082, PANDEM will also address EU Members States' responsibilities under the International Health Regulations (IHR) (2005). The IHR requires state parties to report public health emergencies of international concern (PHEIC) to WHO. A PHEIC is defined under the IHR [3]

as ‘an extraordinary event which is determined to constitute a public health risk to other States through the international spread of disease and potentially requires a coordinated international response’. This definition implies a situation that is serious, unusual or unexpected, carries implications for public health beyond the affected State’s national border and may require immediate international action.

With consortium experts from the health, communications, information technology, security, defence, legal and crisis management fields, the project is investigating how these key sectors in pandemic management can collaborate more effectively in order to prepare for and respond to the next pandemic. The project is also assessing recent developments in information and communication technologies to support and improve intersectoral cooperation for pandemic management.

2 EXPERT WORKSHOP: AIMS AND OBJECTIVES

The first PANDEM *Expert Workshop* was held at the Metropole Hotel in Brussels on February 17-18th 2016. Participants included the PANDEM consortium and 26 invited experts from 11 Member States and the USA with a range of backgrounds including public health, microbiology, information technology, communications, law, defence, security, insurance and crisis management (Annex 1). The composition of the expert group was chosen to ensure representation from a broad range of areas and input from institutions with national, EU and global mandates. Representatives from DG SANTE, DG HOME, DG ECHO and ECDC participated in the workshop. Academic institutions, private sector, public health and security agencies were represented. Topics investigated included pandemic threat analysis, risk assessment, surveillance, crisis management, communications as well as policy issues such as governance and legal frameworks for pandemic management.

Pandemic experts and stakeholders were invited to discuss and critically review current state of the art, good practice, gaps and user needs. In addition they were asked to guide and assist the project in ensuring that the solutions identified by the project adequately target and address the research priorities and innovations required. The need for balance of national interests, resources and capabilities of each Member State and the promotion of synergies for multinational collaboration at the European level was emphasised.

3 WORKING GROUP I: SURVEILLANCE

3.1 Objectives

The Surveillance Working Group convened external experts and PANDEM consortium members to discuss, review and advise on the wide-ranging disciplines, demands and challenges associated with pandemic surveillance. The Working Group objectives were to:

- Identify current good practice, tools and systems for threat analysis, risk assessment and surveillance.
- Identify gaps that can be filled with currently available solutions and research and innovations needed.

The surveillance workshop was divided into four sections:

1. **Identification of threats:** to set the scene for the workshop, each expert was asked to identify the main pandemic threats. The group was encouraged to think not only of pathogens but to widen the concept in order to capture a broad range of possible threats and vulnerabilities.
2. **Good practice:** experts reviewed the tools and systems that were considered to be working well today.
3. **Gaps and needs:** experts identified gaps and improvement needs for pandemic surveillance and risk assessment.
4. **Research and innovations:** research and innovations needed to strengthen capacity for pandemic surveillance and risk assessment were discussed.

The following ‘three phases of needs’ were defined based on the temporal components of a pandemic. Needs during these three phases were addressed at national level (N), European level (EU) and global level (G). The three phases are:

1. **Preparedness phase** (normal circumstances with no signs of a pandemic),
2. **Detection phase** (signals indicate potential pandemic), and
3. **Pandemic phase** (pandemic verified and ongoing).

3.2 Identification of threats

The main pandemic threats identified were:

- Genetic changes in known pathogens leading to an increase in transmissibility and/or virulence thereby triggering a pandemic. This could occur naturally or by genetic manipulation followed by accidental or intentional release.
- Emergence of a new pathogen that, in the worst case scenario is airborne, and for which no treatment and no vaccine is available.
- Zoonoses due to changes in the epidemiology of known pathogens or appearance of a new disease as potential sources of the next pandemic. Vector borne transmission of diseases was identified as a major threat.
- Emergence of a foodborne or waterborne disease that could be transmitted by the person-to-person route would also represent a major threat given that it would also immediately impact food and water security.

It was emphasised that the settings in which a pathogen emerges can be more important than the causative organism. Inherent vulnerabilities and/or failures in risk management and health system resilience can further drive disease transmission. Examples of system failures in local and global contexts include:

- Delays in event or disease detection.
- Delays in risk recognition, risk assessment and information transmission.
- Lack of resources (both human and technological) to obtain/estimate early information about key parameters describing the pandemic, such as infectiousness, severity and mortality.
- Lack of capabilities and/or capacities and resources to mount a rapid and comprehensive initial response.
- Inability to track cases and contacts in real-time and use these data to drive on-going risk assessment and decision making so that interventions can be adapted and refocused based on evolving local needs.

3.3 Preparedness phase

Good practice

Current good practice in the *preparedness phase* were identified as:

- Communication networks – formal and informal expert networks among professionals through which information is shared (N) (EU).
- Good information sharing systems at EU level with use by all Member States – e.g. the Early Warning Response System (EWRS) (EU).
- ECDC's Rapid Risk Assessments were considered very useful (EU).
- Syndromic surveillance systems that provide early warning of unusual events and trigger further investigation, assessment and response.
- Integration of broader epidemic intelligence sources to early warning systems (e.g. internet, media sources, social media, drug purchasing data).
- Transnational surveillance networks that allow data to be pooled for risk assessment (e.g. influenza laboratory networks) (EU) (G).
- Good ICU surveillance systems for influenza set up in a number of countries during the last pandemic to monitor disease severity and impact on risk groups (N).

Gaps and needs

The gaps and needs for strengthening pandemic surveillance and risk assessment identified by the experts were categorized into tools, skills and structures and systems:

Tools

- Establishing comparable data formats for data collection about new threats and tools for sharing between countries (G).
- Improving participation of private laboratories and data quality from this source; this may require legislation (N).

Skills

- Training of senior policy makers including politicians to enhance understanding and familiarity with the terminology and procedures within pandemic management (G) (EU) (N).
- Training and coordination for first responders such as paramedics and intersectoral responders, with increased efforts to harmonize procedures, protocols and methods whenever possible and to develop common intersectoral training (EU).

Structure & Systems

- Improved systems for information sharing between clinicians/other health care workers and public health and management professionals (EU) (N).
- Need for evaluation of interventions during a pandemic in a more systematic way to learn what is working and when (G).
- Systems for the use of “big data” collection from social media for syndromic surveillance/mass gathering surveillance (G) (EU) (N).

Research and innovations needed

In this section of the Working Group’s deliberations, experts identified the following research questions and innovations needed to improve management of pandemic surveillance and risk assessment.

Tools

- IT solutions for electronic reporting and contact tracing that also allow flexibility in data collection to adapt quickly in an event where additional specific data is needed (e.g. pregnancy status, belonging to a specific risk group) (G) (EU) (N).
- Development of tools and systems to make it possible to evaluate and follow the impact of a pandemic (G) (EU) (N).
- Development of rapid diagnostic tests and point of care diagnostics with strong EU validation and European standards and consideration for biosafety issues (N).
- In-depth studies to obtain calibrated baseline data, background level of important denominators from the community. For instance travel patterns in inter-pandemic periods (G).
- Baseline studies on susceptibility in the population, including serosurveillance studies (G) (EU) (N).
- Identify performance indicators on level of disruption of society (N).
- Identify and validate proxy indicators for disease prevalence: identify non-clinical information sources such as over-the-counter (OTC) sales, web queries, etc. (N).

- Improving environmental sampling techniques as this is useful to identify threats (G) (EU) (N).
- Determining when “big data” is useful, not useful, and misleading (G).
- Developing a predictive model for drug susceptibility to a pandemic pathogen based on the combination of past and current genomic and proteomic information and on state of the art regarding the susceptibility monitoring of pathogens with pandemic potential (G). This could be combined with the EU repository of the most promising commercial and experimental drugs.

Skills

- Regular training of health care workers on procedures such as use of personal protective equipment, safe sampling procedures for diagnostics. Development of e-learning platforms/tools to achieve this (EU) (N).
- Research in contact tracing, with the potential added value of using social media data/mobile telephone data (N).

Structure and Systems

- Research on what the health sector can learn on threat analysis, risk assessment and surveillance from other sectors such as the security, defence and insurance sectors (G) (EU) (N).
- Evaluation of the usefulness of a network of intersectoral stakeholders for informal information sharing (N).
- Establish an international team of modellers and epidemiologists on stand-by in the event of a pandemic to jointly develop scenarios and forecasts based on early findings (G).
- Establish protocols for the evaluation of interventions (stress indicators, performance, intervention indicators, decision for allocation of limited resources...) (G).
- Establish/increase awareness of the existence of a legal framework that would cover the analysis of “big data” (confidentiality, data accessibility, data sharing...) (G) (EU) (N).

3.4 Detection phase

Good practice

Good practice that experts considered would work well during the detection phase were:

- “Hundred first cases” rigorous data collection of the first 100 cases of a new disease, including contact tracing, serology, etc. was considered a useful approach to avoid over collection of data (N).

Gaps and needs

Tools

- Further develop existing platforms for communication between EWRS and IHR (EU).
- Need for better molecular surveillance. This needs to be quick (real-time or near real-time), comparative (need for common tools at the global level) and extensive (rapid monitoring of genetic shift in virulence and/or drug or vaccine resistance and of factors affecting airborne survival and transmission) (G) (EU) (N).

Structure and Systems

- Harmonization of data, in terms of format, nomenclature and data protection for easier comparison and sharing during the early stages of a pandemic (G).
- Harmonization of diagnostic standards and laboratory protocols so results can be comparable (G).
- Improvement of mechanism for cross border transport and transfer of laboratory samples (N) (EU) (G).
- More transparency in early global rapid risk assessments from international organizations (G).

Research and innovation needed

Tools

- Develop a platform for crowdsourcing data for early warning and collection of early information on core parameters (software, protocols, tools) (G) (EU) (N).
- Develop a common decision support tool enabling comparison of possible interventions (EU).
- Validate rapid diagnostic tests and Point Of Care Testing (POCT) and using common EU-standardized standards (N).
- Develop ready to use protocols and legislation to quickly develop studies of susceptibility and serosurveillance in early stages (also possible need of freezing samples during preparedness phase for quick testing in the early phase of the pandemic) (EU) (N).

Structure and Systems

- Rapid research on critical parameters for risk assessment in early stages (G) (EU) (N).
- Need for regulations to avoid delay in data sharing because of publishing purposes both in identification phase and during the pandemic (G).

3.5 Pandemic phase

Good practice

Current good practice that experts considered would work well during a pandemic were:

- Routine surveillance systems running effectively during the preparedness phase, continued to work well during the H1N1 pandemic (N).
- WHO monitoring of key performance indicators in the response (G).
- Communication among Member States (EU).
- Coordination of response by the European Commission (EU).

Gaps and needs

Tools

- Procedures to continuously update data/core parameters from the detection phase for updated risk reassessment during later stages of the pandemic (G) (EU) (N).
- Mechanisms to better monitor the evolution of resistance and virulence of a new pathogen. This implies molecular surveillance providing results in real-time or near real-time, on a comparative format (need for common tools at the global level) and with an extensive information (rapid monitoring of genetic shift in virulence and/or drug or vaccine resistance and of factors affecting airborne survival and transmission) (G) (EU) (N).
- IT solutions for timely epidemiological geographic mapping and visualization of cases and contacts with real-time updating of data (N).

Structures and Systems

- Development of the information sharing and communication capacity of the EWRS system to ensure good oversight of a situation during a pandemic. This would ensure EWRS functions as a useful decision support tool for Member States on implementation of control measures (N) (EU).
- Improvement of monitoring methods for surveillance (N).

Research and innovation needed

Tools

- Tools to improve reporting data from remote areas (G).
- Platform for communication with professionals and public in a more structured, efficient and understandable, eg using infographics (EU).
- Identification of indicators to know when containment measures are no longer useful (N).

Structure and Systems

- Define functional requirements for a communication platform as cornerstone of the EU's pandemic crisis management. Platform would collate information from Member States, from the various EPIS platform, providing access to the TESSy and other relevant databases. The output should be a secure platform for HSC members, with additional platforms with broader access where information could be made available for different audiences, e.g. a restricted access one for the ECDC AF and ECDC competent bodies, one for the network of communicator, and ultimately, one for the public (N) (EU).
- Simplify the possibility for rapid implementation of research studies during the pandemic, for instance ready protocols and legislation (G)
- Rapid research on critical parameters during the pandemic to be refined over time the risk assessment done on early stages (G) (EU) (N).

3.6 Next steps

The issues related to surveillance and risk assessment presented above will be addressed and further developed in the upcoming deliverables of the PANDEM project.

It is clear that routine surveillance systems that operate in periods between pandemics also need to work well during a pandemic. This includes expert networks of professionals within formal/informal communication networks. The need for research and innovation to stress test and making these structures more resilient was emphasised.

A number of areas of research will be further explored in PANDEM. Ensuring relevant and timely information on the threat in the early stages of a potential pandemic is critical. At the animal human interface, rapid detection of early signals of outbreaks in animals and assessment of transmission probabilities of these zoonoses is essential. Improved tools for baseline studies on susceptibility and serosurveillance in humans are required. Further development of next generation genomics and bioinformatics will help to assess a population's susceptibility to a new pathogen. This information can be used to identify at-risk groups in a population and conduct an accurate rapid assessment of risk posed by an emerging pandemic disease. For diagnostic capacity, next generation "lab on a chip"

technologies that can be widely distributed to support rapid diagnostics and point of care testing have the potential to enhance testing capacity across Member States.

Standards for data, the collection of data as well as systems for collecting data are urgently needed. There is a need for harmonization of data and indicators to allow comparability. Development of IT solutions for electronic reporting are needed which should include identification of innovative ways to collect data that will not need extra resources. IT solutions for electronic reporting and contact tracing are required – tools and data will be further required during the pandemic to evaluate progress and effects of interventions. Decision support systems are needed for risk assessment, data analysis and visualisation to provide public health agencies with real-time information to guide pandemic response.

In the context of training, the use of novel immersive gaming technologies for training of first responders, general practitioners, hospital staff to ensure flexible capacity to cope with a surge in demand for services have the potential to build capacity. In logistics, the use of security and business supply chain processes which could be rapidly adapted to support pandemic scenarios would enhance pandemic management. Examples could include: allocation of stadiums for vaccine administration, use of logistics companies as partners in delivering pandemic products such as PPE and vaccines, use of military resources to support pandemic response.

In addition, establishing platforms for better communication between key groups in pandemic management (intersectoral stakeholders, health workers, national, EU and global level stakeholders) is an important innovation and the development of a new platform for the EWRS was given particular emphasis.

4 WORKING GROUP II: COMMUNICATIONS

4.1 Objectives

The Communications Working Group gathered external experts and PANDEM consortium members to discuss current good practice, gaps, user needs, research and innovation needed in a broad range of aspects of communications between pandemic stakeholders. The experts looked at communication between governing bodies and professionals, and communication with the public. The Working Group also addressed communication and information sharing in both preparedness and response phases.

4.2 Good practice

Deliberation of the definition of “what works” in communications prompted conversations around evaluation and the target outcomes of each intervention. *Communications for reputation management* (e.g. maintaining trust in government or other authorities) and *for behaviour change* (e.g. preventive measures to stop disease spread, or communications to promote vaccination) were identified, with the understanding that building trust and a strong reputation is an asset when communicating for behaviour change.

Examples of “what works” included:

- Promotion of hand hygiene in UK hospitals,
- Communication on the 2009 H1N1 pandemic by the European Centre for Disease Prevention and Control (ECDC),
- Communication during the E.coli outbreak in France,
- Analysis from Japan of “bigmouth” social media users and their role in communications linked to the Fukushima nuclear disaster.

The WHO risk/outbreak communications principles [4] were recapped, recognising that communicating early, being honest and sharing dilemmas are excellent principles, but are often difficult to apply in practice.

4.3 Gaps and needs

The identified gaps and user needs included the following, which spanned both user and policy levels:

Policy level

- Insufficient knowledge about all the research results from various actors. The mapping and linking of all the results and aspects would help to generate the desired knowledge of “what works” in the pandemics field. Expert networks are missing (e.g. expert networks to facilitate mutual understanding between policy makers and first responders).
- Technical issues of information sharing were discussed. There is a lack of harmonisation in the type and format of data to be shared and reported between different stakeholders. This lack of harmonisation causes the problem of too much

data that nobody knows how to deal with, or even the problem of ignoring or non-acceptance of field data sent “in a wrong format”.

- The right level of warning messaging is essential – governments and authorities should avoid being seen to “cry wolf”. One suggestion tabled was that one could adopt levels of warning similar to those used in earthquakes and natural disasters.

User level

- Shortage of skills and knowledge in how to apply the principles and evidence of behavioural science and risk communications; this topic recurred numerous times in the discussion.
- Lack of preparation and lack of flexibility with existing pandemic plans, which hinge on the importance of feedback mechanisms and how to adapt plans in practice.
- Difficulty in getting real time data on how communications is working; there are few examples of how this has been done, partly because of the rapid change in communications and communications technologies.
- How to build trust with highly resistant communities, such as those who are reluctant to vaccinate their children - what is known as “vaccine hesitancy”.
- Importance of developing the skills and techniques to communicate uncertainty – learning from disciplines of science communication and agnotology (the study of ignorance and uncertainty) was highlighted as an ongoing challenge.
- Challenges of updating a plan and messaging in a situation where the facts are changing and maintaining trust of populations as you do this, despite an apparent lack of consistency.
- Responding rapidly via new channels (e.g. social media) and how to determine the level of resources to assign to these channels.
- Challenge of keeping channels of social communications open, and using a “tell us what you’re worried about” approach.
- Difficulties presented by cultural variations in terms of messages and approaches; what works will vary between Member States and communities. A related challenge is how to access relevant data on this from private sector partners, or getting it in advance – e.g. advertisers and marketing companies that test messages and collect data on responses all the time.
- Targeting and personalisation of messaging – the need to target messages and communications, ensuring that they have the best chance of prompting action.

- Identifying audiences and segmenting appropriately is difficult, given that separate communities at very local levels can react very differently.
- Role of health workers in communications – how to help them say the most effective things, even “the mavericks”. The same applies to scientists – they can have vested/other interests in threat rating and communications.
- Role of journalists and the media in spreading fear and misinformation for the sake of making profit – how to get them on side?

4.4 Research and innovations needed

A wide-ranging discussion continued about where priorities for research lie, which was initially dominated by considering the possibilities of new tools. All areas of the “capacity pyramid” [5] were included in the analysis:

Tools

- ICT tools (crisis management, data management, knowledge engineering, decision support tools) are necessary to manage a high volume of data, to manage data-sharing between actors and to interface with the public. There are plenty of ICT tools available on the market, but the tools specifically dedicated for the pandemic field were thought to be lacking. Any new tools have to be developed with proper consideration of health data sharing with the ethical and privacy considerations for data protection integrated “by design”.
- Crowdsourcing for data on symptoms to bridge the gap between communications and surveillance.
- Guidance about how to communicate during a pandemic or epidemic, with built-in variables and flexibility to allow for unknown pathogens and national/sub-national differences.
- A conceptual map of how communications, surveillance and governance all overlap for pandemic preparedness and response, to acknowledge how they all work together.

Skills

- The competencies to actively incorporate new knowledge and theory about communications into planning and action, from areas such as marketing, behavioural science and other aspects of the social sciences.

- The skills to evaluate communications interventions and build a more solid evidence base, as well as differentiating exactly why and how interventions work.
- The skills to interpret technical (e.g. scientific or medical) risk assessment and to appropriately communicate it to the general public, despite uncertainties or expert disagreements.
- Training the right people, including spokespeople, in the use of social media and how to deliver effective messages, including communicating uncertainty when appropriate.
- Number of staff allocated to communications before and during a pandemic or epidemic – it was highlighted that there is a disparity among EU countries in that some have very limited staff capacity for communications even during a pandemic, let alone in the preparedness phase.

Structures & Systems

- Research is needed on how to provide the right information to the right users at the right moment. Right actors shall be targeted. Policy-makers, first responders, all other actors – they all have different information needs that have to be taken into account and the delivered information shall be tuned for a particular actor to become efficient.
- Contribution to the CoU (Community of Users on Disaster Risk and Crisis Management) in the security field, initiated by DG HOME is important to facilitate communication between various actors, to map all the relevant actors and research, to be sure that the right tools are developed.
- A platform on which Member States and other relevant parties could share knowledge about preparedness and response, including their plans (which are currently confidential) or simplified versions of the plans, with the aim of developing common approaches to communication where relevant.
- A similar system through which research, evaluations and risk assessments could be shared between Member States and other relevant bodies, enabling universal access across countries to information and reporting about communications before and during a pandemic or epidemic. This could help to alleviate skills and resource differences between nations.

4.5 Next steps

After presenting an overview of findings and discussions, the plenary group session with all consortium members and experts raised a series of questions and issues:

- How to involve the private sector in communications response (e.g. telecommunications companies, marketing companies and others).
- The importance of a “bottom-up” approach and the population’s capacity to communicate among themselves and “self-organise” during a crisis.
- The importance of considering the future of communications and the possible role of the “internet of things”.
- The potential impact of the EU’s data protection reform on the Working Group’s ideas.

With the workshop completed, the project will be following up with experts to gain access to case study materials discussed. In addition to the experts invited to this workshop, the PANDEM project will be reaching out to other informants to gain greater insight into the case studies of choice. Current plans for these include Italy, UK, Sweden, and Canada. As part of the ongoing dissemination efforts, a new PANDEM LinkedIn group will be established where discussion can continue for the rest of the project’s lifespan.

5 WORKING GROUP III: GOVERNANCE

5.1 Objectives

The Governance Working Group gathered external experts and PANDEM consortium members to discuss the current good practice, gaps, user needs, research and innovation needed in a broad range of aspects of pandemic governance.

Given the potentially overwhelmingly broad scope of “governance”, research will focus on four thematic areas which have been identified as important by public health experts, namely Communication; Surveillance; Isolation, quarantine, border control and social distancing measures; Equity and prioritisation of healthcare. The first two themes were also selected to be directly relevant to the other two PANDEM work packages. The experts were invited to consider these four themes in the context of (1) knowledge gaps and research questions, and (2) proposed governance/legal solutions/innovations.

The scope of the discussion was agreed and the EU perspective was taken as national, regional and global actor in the sense of protection of EU Member States and of the EU in general. It was recognised that European interests are interlinked with global interests, particularly those of low and middle income countries; an all infectious disease hazards approach was considered necessary; actors beyond national governments have to be considered, encompassing general public, health professionals and all other stakeholders.

With regard to the themes of “Communication” and “Surveillance”, common agreement was reached on definitions, governance principles and potential gaps and research questions. However, there was insufficient time to discuss the remaining identified themes: Isolation, quarantine, border controls and social distancing measures; and Equity and prioritisation of healthcare. These two themes will therefore be reviewed separately with experts following the workshop.

The term “communication” was defined as:

- Communication between governing bodies and with the public;
- Communication and information sharing in preparation for outbreaks and during outbreaks.

The term “surveillance” was regarded as potentially very broad, as it may include reporting, epidemiological research, virus sharing and genetic sequencing, watch lists, monitoring of social media and a range of other activities.

5.2 Good practice

All workshop participants agreed on the importance of good governance to ensure that in the event of a public health emergency, effective and ethical legal and policy measures are in place to respond in a way that respects rights but also protects the population. However, it is a challenge to evaluate and test “principles of public good” and to make governance arrangements enhance public health responses.

Governance principles were agreed for the themes of Communication and Surveillance which could form a framework within which to identify gaps and research questions. These may be considered examples of “good practice” with the caveat that in many cases we do not currently have the means to test the efficiency or effectiveness of governance

arrangements. These governance principles apply across global, regional and national levels.

Governance Principles: Communication

1. Decisions should follow principles of honesty, stewardship and be science-based;
2. Decisions should follow principles of transparency and openness;
3. Decisions should incorporate engagement with civil society;
4. Aim for collaboration and coordination at national and EU levels;
5. Communication should be as local as possible, and use effective and appropriate channels and voices;
6. Trust is critically important. Who is the voice? Are they trusted?
7. Timeliness, accuracy, uncertainty are all challenging for authorities to deal with;
8. Social media means messages move faster than authorities can sometimes cope with and they are often forced into being reactive.

Governance Principles: Surveillance

1. Accountability is key: both along formal and informal lines;
2. Surveillance needs to inform actions: only collect what you are likely to act upon and avoid collecting data for data's sake or be sure what the purpose of data collection is, to inform action;
3. Privacy is key and needs to be particularly re-examined in light of different forms of data that are increasingly becoming available, or should be;
4. Surveillance data needs to be coherent, needs to allow comparisons to be made (and not undermined by lack of coherence, solidarity) across countries (and regions?);
5. Participation of communities, and other stakeholders in surveillance actions should be considered (including incentives to report);
6. Surveillance needs to move far beyond the traditional reporting systems to take account of, for example, big data that informs emerging patterns of epidemic origin, health services response capacity/capability, inform lessons learnt during and after events.

5.3 Gaps and research questions

The governance principles were used as the basis for identification of knowledge gaps and research questions. Questions and discussion related to issues of gaining public trust, managing panic and the major structural governance problems and challenges within the UN system. These outputs came within the general brief of how can governance arrangements enhance public health responses? A number of general governance gaps and research questions were identified:

1. How can we ensure better coordination and collaboration between:
 - Agencies of the EU,
 - The EU and Member States, and
 - EU Member States?
2. How can we evaluate and “stress-test” pandemic preparation and response measures?
3. How can we evaluate and respond to questions of public trust and panic?

Specific knowledge gaps and research questions in relation to the themes of Communication and Surveillance were:

Communication

1. How do we ensure effective and efficient communications across organisations?
2. What is causing the unravelling of public trust? We need to better understand public reactions and whether there any actionable interventions that could ensue from this knowledge.
3. How can the EU tap into new communications innovations?

Surveillance

1. How can surveillance data be better shared across organisations and between Member States?
 - Community objections and sensitivities to data sharing.
 - Do we need better ethical framework questions?
 - Do we need agreements for reciprocity?

2. Assuming digital data is valid, how could that information be used? How can it be linked to response capacity and to what extent can it be used within formal surveillance?
3. What does the public consider an acceptable level of surveillance in terms of balancing security with privacy? Is health surveillance to be governed (or regarded by the public) by the same criteria as military and police surveillance data?

5.4 Next steps

The Working Group recognised that, while extremely important, governance is different to other areas of pandemic preparedness and response as it can be difficult to test the effectiveness of governance measures or formulate them as research questions. Nevertheless, the group were able to agree on scope and, in relation to communication and surveillance, definitions, governance principles, gaps and research questions. Further analysis is needed, as well as review of the remaining two themes, but priorities identified so far relate to:

- Governance measures to improve coordination between and within organisations and government agencies at a national, regional and global level;
- Governance measures to enhance public trust and respond to, or manage, panic among the public.

Building on the inputs gained from the expert participants, the following steps will be taken to further PANDEM research in Work package 4:

- The discussion transcript will be analysed in detail and a document “Working Groups 3 Outputs” will be prepared, circulated and agreed with the workshop participants;
- Individual phone-based interviews will be conducted with further 10-12 experts in health governance during March and April. These interviews will include review of the remaining two themes of Isolation, quarantine, border control and social distancing measures and Equity and prioritisation of healthcare. The workshop outputs will be used to contribute to the interview questionnaire.
- Research projects discussed in the workshop discussions will be investigated further for insights and to avoid duplication of efforts;
- All of the above will contribute to the Work Package 4 reports due for submission in June and September 2016.

6 CONCLUSIONS

PANDEM is reviewing the lessons derived from previous pandemic/epidemic responses and looking at transforming this knowledge to improve tools, systems and intersectoral cooperation. The project is focussing on learning from the emergency management, defence, security and insurance sectors, exploring what new information and communication technologies can contribute, defining the gaps between public health policy and legal frameworks, and addressing cultural and ethical issues.

The workshop represented an important opportunity for the consortium members to engage with a wide range of experts and EU officials to further explore and identify good practice, gaps and needs in the field of pandemic management.

The workshop identified a number of key gaps, improvement needs and potential solutions in the areas of pandemic surveillance, communications and governance. Across these three key pillars of pandemic management, workshop discussions identified specific research and innovations that are needed.

In general the recommendations for research focused on innovative solutions that will increase the capability, capacity, credibility and level of integration/inter-operability of surveillance, communications and governance systems by:

- Accessing and utilising non-traditional data sources such as big data for both surveillance and communications.
- Improving risk assessment and communications through increased sharing and pooling of high value and relevant risk data utilising state of the art information sharing platforms.
- Improving intra-pandemic surveillance through the development of better tools for real time disease mapping, contact tracing and modelling.
- Implementing system-wide exercises that will stress test our systems in advance of a pandemic.
- Focusing on broadening innovations for the complex challenges such as the political processes related to governance, surveillance, information sharing, effective risk communication and improved coordination while recognising that the existing emphasis that has been placed on research into medical products such as vaccines, drugs, personal protective equipment remains valid and justified.

PANDEM will now actively pursue further inputs and consultation with experts to further refine the recommendations emerging from the meeting.

Using this process of iterative consultation and communication with a broad range of experts, we will be able to better define the specific solutions that will be presented within a Roadmap for a Phase II demonstration project.

7 REFERENCES

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5. Potter, C. and R. Brough, *Systemic capacity building: a hierarchy of needs*. Health Policy and Planning 2004. **19**(5): p. 336-345.
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Annex 1 List of Participating Organisations

Consortium members

IGS Strategic Communications, UK

Communicable Diseases Policy Research Group, London School of Hygiene & Tropical Medicine, UK

School of Medicine, Department of Information Technology and Insight Centre for Data Analytics, National University of Ireland Galway, Ireland

Department of Monitoring and Evaluation and Unit for Epidemiology and Health Economy, Public Health Agency of Sweden (FoHM), Sweden

Swedish Defence Research Agency (FOI), Sweden

Centre for Applied Molecular Technologies, Université catholique de Louvain, Belgium

Influenza & Other Respiratory Pathogens programme, World Health Organisation (WHO), Regional Office for Europe

Invited Experts

Centre de Sociologie des Organisations (CNRS - SCIENCES PO), France

Centre for Global Health Security, Chatham House, UK

Directorate General for Health and Food Safety (DG SANTE), European Commission, Luxembourg

Directorate General Humanitarian Aid and Civil Protection (DG ECHO), European Commission, Belgium

Directorate General Migration and Home Affairs (DG HOME), European Commission, Belgium

Public Health Capacity and Communication and Surveillance and Response Support,

European Centre for Disease Prevention and Control (ECDC), EU, Sweden

Federal Public Service of Health, Belgium

Milken Institute School of Public Health, George Washington University, USA

O'Neill Institute for National & Global Health Law, Georgetown University, USA

Health Emergency Response, Health Surveillance Protection Centre, Ireland

Infectious Disease Epidemiology, Karolinska Institute, Sweden

Dept of Global Health and Development, London School of Hygiene & Tropical Medicine, UK

Ministry of Health, Bulgaria

Ministry of Health, Luxembourg

National Institute of Public Health, Romania

National Institute of Public Health, Czech Republic

Security Europe, Belgium

Swedish Civil Contingencies Agency, Sweden

The Warning Project, Belgium

School of Public Health and Population Sciences, University College Dublin, Ireland

Centre for Behaviour Change, University College London, UK

Department of Social Sciences, Wageningen University, Netherlands

Annex 2 Workshop Agenda

Identifying needs and innovations to strengthen pandemic surveillance, communications and governance

PANDEM Expert Workshop, 17-18 February, 2016

Hotel Metropole, Brussels

FINAL AGENDA

Day 1: February 17, 2016

13.00 – 13.15	<i>Registration and welcome coffee</i>
13.15 – 14.30	<p>PLENARY SESSION</p> <p>Welcome of participants: Jean-Luc Gala, Université catholique de Louvain</p> <p>Purpose and structure of workshop: Brooks Tigner, Security Europe - Moderator</p> <p>Current context and PANDEM project: Máire Connolly, National University of Ireland Galway</p> <p>Pandemic preparedness and response – where are we now?</p> <ul style="list-style-type: none">- EU context and serious cross-border threats to health - Decision 1082: Germain Thinus, DG SANTE- Surveillance: Anders Tegnell, Public Health Agency of Sweden- Communications: Iain Simpson, IGS Strategic Communications- Governance: Richard Coker, London School of Hygiene & Tropical Medicine <p>Plenary discussion</p>
14.30 – 15.45	<p>WORKING GROUP SESSION I – Current best practice/state of the art</p> <p>WG 1: Threat analysis, Risk assessment and Surveillance Moderator: Anders Tegnell, Public Health Agency of Sweden</p> <p>WG 2: Communications Moderator: Iain Simpson, IGS Strategic Communications</p> <p>WG 3: Governance and Legal frameworks Moderator: Elizabeth Speakman, London School of Hygiene & Tropical Medicine</p>
15.45 – 16.00	<i>Coffee break</i>

16.00 – 17.30	WORKING GROUP SESSION II - Gaps and user needs WG 1 Threat analysis, Risk assessment and Surveillance Moderator: Darina O’Flanagan, Health Protection Surveillance Centre WG 2 Communications Moderator: Cecile Wendling, Centre de Sociologie des Organisations WG 3 Governance and Legal frameworks Moderator: Elizabeth Speakman, London School of Hygiene & Tropical Medicine
20.00 – 22.00	<i>Dinner</i>

Day 2: February 18, 2016

9.00 – 10.45	WORKING GROUP SESSION III – Research and innovations needed WG 1 Threat analysis, Risk assessment and Surveillance Moderator: Johan Giesecke, Karolinska Institute WG 2 Communications Moderator: Ben Duncan, The Warning Project WG 3 Governance and Legal Frameworks Moderator: Lawrence Gostin, Georgetown University
10.45 -11.00	<i>Coffee break</i>
11.00 -12.45	PLENARY SESSION II - Moderator: Brooks Tigner, Security Europe Presentation by each WG on gaps/needs/research/innovations Plenary discussion including cross-cutting issues
12.45 -13.00	Summary of meeting, next steps – Máire Connolly, National University of Ireland Galway
13.00-14.00	<i>Lunch</i>

Annex 3 PANDEM Data protection and privacy guidelines

The PANDEM Consortium places high value on the protection of the data and privacy of all project participants. Therefore it commits to the following Privacy Policy:

- Personal data (names, email addresses, phone numbers) gathered by PANDEM through its events or website are stored in a separate database.
- Personal data of PANDEM participants are not disseminated, and can be accessed only by the staff of the Consortium Partners on a need-to-know basis. They are not passed on to third parties without prior consent of the events attendees or interviewees.
- Attendees registering at a PANDEM event receive all public information on the PANDEM project and related objectives. Through their registration and participation, it is assumed that attendees agree to have their name included in the list of participants. Should this not be the case, restriction will be immediately notified to the PANDEM event organiser.
- According to the Chatham House Rule, as specified in the PANDEM Research Ethics application, comments are anonymized and there is no quotation in PANDEM reports, except otherwise stated by the events attendees or interviewees. Reports however include the list of organisations registered to the event.
- If recordings are planned to serve specific purposes of a PANDEM event, they will be made only with the prior written consent of attendees, and their use strictly restricted to the terms of the agreement.
- The events might be audio recorded for the sole purpose of improving the report to be written afterwards. In no case should the audio recordings produced be made available to third parties or be otherwise published.
- Recipients of the PANDEM information, newsletters and other dissemination material are put in bcc (blind carbon copy) to prevent personal email addresses to be disseminated to multiple recipients.
- Regarding data gathered before the project, each Consortium Partner comply with EU data protection rules by means of its internal organisational procedures usually applied to such data.

Annex 4. Decision 1082/2013/EU

The principles, roles and specificities of Decision 1082/2013/EU which forms the legal framework for collaboration between EU stakeholders was presented by DG SANTE at the workshop. Decision 1082/2013/EU [6] describes the legal mechanism at EU level for coordination and cooperation in preparedness, and coordination of the management of serious cross-border threats to health, in order to coordinate and complement national policies. It aims to support cooperation and coordination (also clarifying the methods) between the Member States and various actors at the EU level in order to improve the prevention and control of the spread of severe human diseases as well as other hazards across the borders of the Member States, to achieve a high level of public health protection in the European Union.

Decision 1082/2013/EU aims at:

- Strengthening EU Health Security Framework,
- Fostering integrated, coordinated and comprehensive approach for preparedness, risk assessment and crisis response,
- Decision-taking on board the good provisions of Decision 2119/1998/EC for communicable diseases (including antimicrobial resistance and Healthcare associated infections) and covering also bio-toxins, chemical and environmental threats.

The most significant features covered by Decision 1082/2013/EU include:

- Implementation of the IHR core capacities,
- Preparedness and response planning,
- Joint procurement of medical countermeasures (establishment of a mechanism for joint procurement of medical countermeasures. It improves preparedness for all cross-border threats to health as any medical countermeasure for the mitigation of any cross-border threat to health could be procured in common.),
- Epidemic surveillance for communicable diseases,
- Ad-hoc monitoring for bio-toxins chemicals and environmental threats,
- Early Warning and Response Systems,
- Clarification of responsibility for risk assessments,
- Strengthened coordination of preparedness and measures by a strong Health Security Committee,
- Risk and crisis communication as part of the response,
- Recognition of emergency situation.

Preparedness and response planning is recognised as an essential element for effective monitoring, early warning of, and combating serious cross-border threats to health. Decision 1082/2013/EU describes that such planning should include in particular adequate preparedness of critical sectors of society, such as energy, transport, communication or civil protection, which rely, in a crisis situation, on well-prepared public health systems that are also in turn dependent on the functioning of those sectors and on maintenance of essential services at an adequate level. In the event of a serious cross-border threat to health originating from a zoonotic infection, it is important to ensure the interoperability between health and veterinary sectors for preparedness and response planning.

In order to ensure that the assessment of risks to public health at the EU level from serious cross-border threats to health is consistent as well as comprehensive from a public health perspective, the available scientific expertise should be mobilised in a coordinated manner, through appropriate channels or structures depending on the type of threat concerned. That assessment of risks to public health should be developed by means of a fully transparent process and should be based on principles of excellence, independence, impartiality and transparency. That assessment should be provided by the agencies of the Union in accordance with their missions or by the Commission if the risk assessment required is totally or partially outside the mandates of the agencies of the Union. [6, 7]

The role of Health Security Committee (HSC) was specified as:

1. Supporting the exchange of information between the Member States and the Commission on the experience acquired with regard to the implementation of this Decision;
2. Coordination in liaison with the Commission of the preparedness and response planning of the Member States;
3. Coordination in liaison with the Commission of the risk and crisis communication and responses of the Member States to serious cross-border threats to health. [6]

Interrelation of other relevant agencies and scientific committees in the EU was presented at the Workshop by DG SANTE (Figure 1).

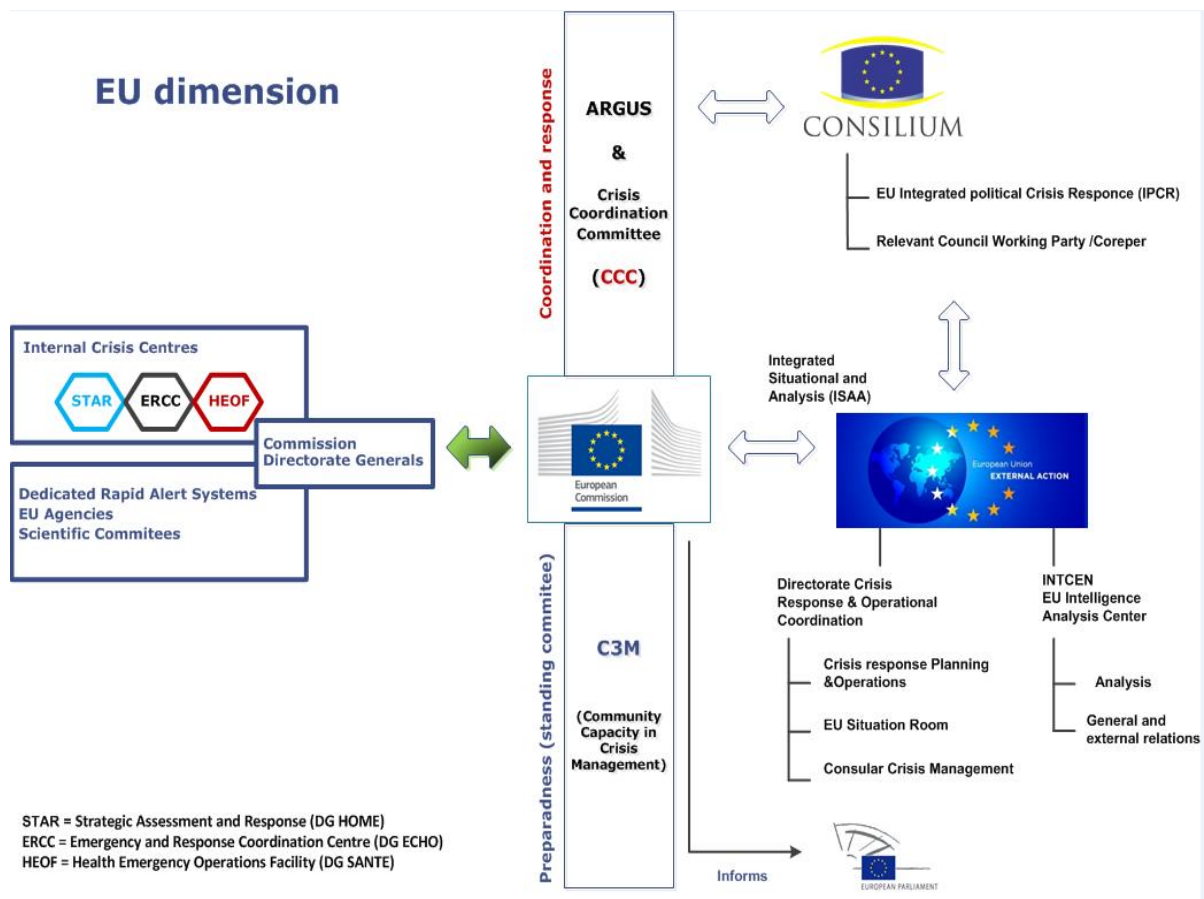


Figure 1. Interrelation of the EU agencies and scientific committees (source: DG SANTE)