

Chapter 9

The ASSET Research Project as a Tool for Increased Levels of Preparedness and Response to Public Health Emergencies

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Abstract Epidemics and pandemics are natural events recurring over the time: their impact can be appropriately minimised but most countries only rely on emergency response. The European Decision 1082/2013 on serious cross-border threats to health is innovative in recognising risk communication as an essential tool in coping with public health emergencies of international concern (PHEIC). The

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Decision serves as proper context for the EU-funded ASSET (Action plan in Science in Society in Epidemics and Total pandemics) research project that aims to create the blueprint for a better response to PHEIC, through improved forms of dialogue and better cooperation at different levels on Science-in-Society (SiS) issues (governance, engagement, ethics, gender, science education, open access). A Mobilization and Mutual Learning (MML) approach was developed through the ASSET Strategic and Action Plans toward different targets and relevant stakeholders. An integrated participatory approach needs to be recognized into the national plans for preparedness and response.

9.1 Background

Epidemics and even pandemics are natural events that are and will be occurring over the time: they cannot be completely prevented. However, their impact can be strongly minimised by an appropriate response (Morse 2009; IOM (Institute of Medicine) 2009). This is by no means an easy task, bot for intrinsic difficulties and due to the increasingly poor response rate by target population to strategies of mitigation of epidemics and pandemics (Manfredi and d’Onofrio 2012). This is due mostly to the

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generalized lack of trust by Civil Society (CS) in institutions that has been termed as the phenomenon of the “post-trust societies” (Löfstedt 2005; Marmot 2017). Unfortunately, the response capacity of European Member States to health threats is still very heterogeneous and overall inadequate to cope with cross-border international health threats. Indeed, most countries only rely on emergency response that is evidence-proven not to be the most efficacious approach (Murray et al. 2015). Two striking examples of inadequate responses to health threats can be the risk communication during H1N1 flu pandemic in 2009 (Crosier et al. 2014) and, more recently, Ebola alert in 2014 when planned training for professionals revealed to be a strategic component (De Castaneda et al. 2015). Since the World Health Organization (WHO) International Health Regulations (IHR) implementation (World Health Organization) is ongoing but still far from a full application in several countries, the European Parliament and the European Council agreed to approve Decision No 1082/2013 on 22 October 2013 on serious cross-border threats to health and repealing Decision No 2119/98/EC (European Parliament and European Council). After the report submitted by the Commission in 2015, a monitoring on the implementation of this Decision is due to the European Parliament and the Council every three years thereafter (European Commission). A Health Security Committee (HSC), composed by Member States representatives, is hereby established as technical body. A former HSC was already existing and revealed to be instrumental in setting up this decision. Anyway, it stood for an “informal body” while the actual committee took well defined and wide ranged tasks in coordinating and supporting the European Commission (European Commission, DG Health and Food Safety, Public Health, Crisis Preparedness and Response, Risk Management). At the Ebola conference organized by Directorate General (DG) SANTE in October 2015, even HSC communicators network members endorsed the set of recommendations released which reflect all difficulties experienced by the officials in charge of communication during the crisis that has not much evolved since the 2009 pandemic (Crosier et al. 2014). In the Decision 1082/2013, public health (PH) measures in relation to several categories of serious cross-border threats to health are recalled by making clear enough that the application field of the Decision itself does not cover only the area of communicable diseases. Indeed, the broad list encompasses: threats of biological origin (communicable diseases, antimicrobial resistance and healthcare-associated infections related to communicable diseases, biotoxins or other harmful biological agents not related to communicable diseases) as well as those of chemical or environmental or unknown one; events which may constitute Public Health Emergencies of International Concern (PHEIC) under the IHR, provided that they fall under one of the categories of threats set out in points listed above; epidemiological surveillance of communicable diseases and of related special health issues (European Parliament and European Council: Decision No 1082). Another innovative aspect of this Decision is definitively the recognition of risk communication as one essential tool in coping with health threats. Countries are in fact requested to include appropriate risk communication strategies into the mandatory annual health response and preparedness plan (Ibidem, par. 22 of considerations). Moreover, coordination of risk and crisis communication at European level, to be adapted to Member State needs and circumstances, aims at providing consistent and integrated information in the European Union to the public help the healthcare professionals (Ibidem, art. 11 par. b).

9.2 Methods

The Decision 1082/2013 serves as proper context for the EU-funded ASSET (Action plan in Science in Society in Epidemics and Total pandemics) research project [[ASSET \(Action plan in Science in Society in Epidemics and Total pandemics\)](#)]. ASSET is a Mobilization and Mutual Learning Action Plan (MMLAP) (Horizon 2020; European Commission Work Program 2013) whose aim is to contribute in tackling the state of uncertainty and confusion which characterised communication in the last influenza pandemic as a major risk factor affecting trust between citizens and health authorities (Expert (HEG) Group on Science, H1N1 and Society: Towards a more pandemic-resilient society 2010). ASSET aims to create a blueprint for a better response to pandemics and PHEIC in general. This can be achieved through improved forms of dialogue and better cooperation at different levels within Science-in-Society (SiS) issues ([European Commission, Research & Innovation](#)) for a Responsible Research and Innovation (RRI). The key areas considered are: governance, public engagement, ethics, gender, science education, open access ([Responsible Research and Innovation](#)).

ASSET is required to develop what actually represents a relevant challenge to all national authorities: scientifically based risk communication strategies and appropriated tested tools for a more effective communication offer. According to a continuity perspective with initial capacity building activities and the thematic study of evidence available in literature, the Action Plan ([ASSET Deliverable 3.3 Action Plan Handbook](#)) definition started from editing the Strategic Plan ([ASSET Deliverable 3.1 Strategic Plan](#)) and a Roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs ([ASSET Deliverable 3.2 Roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs](#)).

9.2.1 *The Strategic and the Roadmap for the Definition of the ASSET Action Plan*

The ASSET Strategic Plan provides the framework for developing MML strategy and, as a consequence, for the actions and activities to be included in the Action Plan. The ASSET Strategic Plan offers a model of change so as to make it easier to acquire the mastery in terms of knowledge, attitudes and behaviours in case of a threat like a pandemic, to build a more resilient society. Consequently, the Strategic Plan has at its core the development of citizens' awareness, empowerment and action on the RRI mainstreams (governance; unsolved scientific questions and open access to scientific outcome; participatory governance and science education; ethics, law and fundamental rights; gender issues; intentionally caused outbreaks), by implementing instruments and tools of the MML approach.

Another pillar of ASSET is the Roadmap indicated above ([ASSET Deliverable 3.2 Roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs](#)) that calls for a rethinking of the research

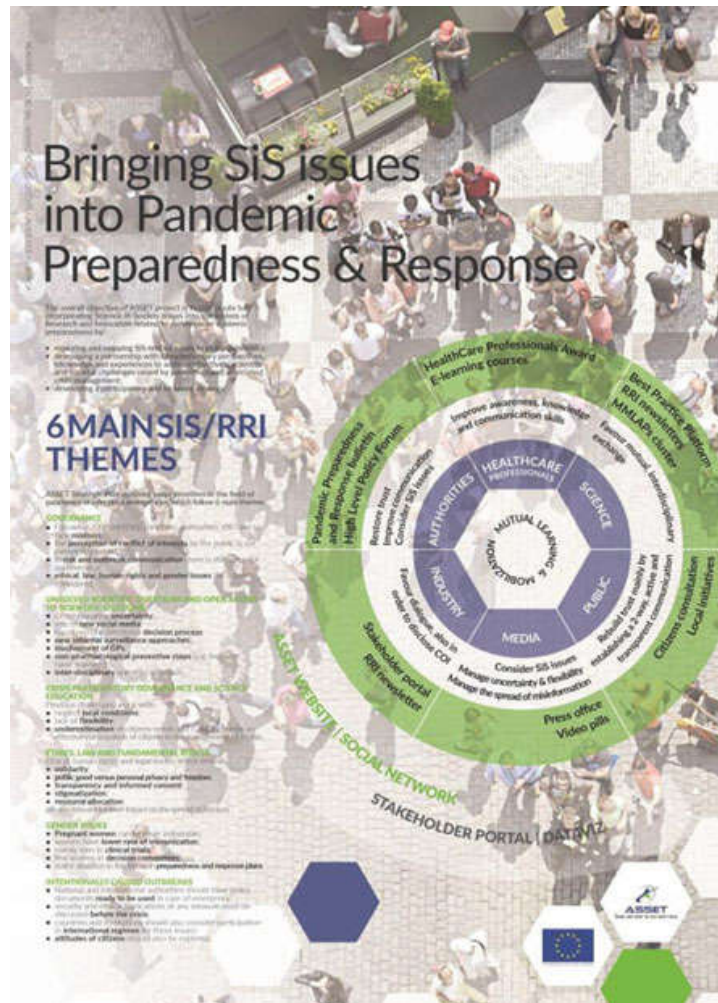
process and pipeline to include “citizen-scientists” as intellectual co-owners of projects; the involvement in research efforts of networks of general practitioners (GP) as they are the interface between Science and the CS; an education to mutual communication between the scientific community on one hand and the lay public on the other hand; the need to start a consistent body of research on how to prevent and minimize the possible risks related to a massive Patient and Public Involvement (PPI) in biomedical research concerning epidemics and pandemics as well as in health research more in general.

Basing on objectives, strategies and actions outlined both in the ASSET Strategic Plan and in its Roadmap, the ASSET Action Plan Handbook is a concise and practical executive manual, which includes detailed description and timetable of MML actions and related responsibilities. Its main purpose is to explain clearly and practically how ASSET project could contribute to bring some SiS themes identified within the Strategic Plan into the public debate on epidemic and pandemic preparedness and response. It can also represent a model of actions for other projects and stakeholders, by highlighting main targets, presenting some relevant contents and describing possible tools of such actions of citizens’ consultation, MML, policy watch and communication ([ASSET Deliverable 3.3 Action Plan Handbook](#)) (Fig. 9.1).

9.3 Results

As recalled in the ASSET Strategic and Action Plans, a participatory governance strategy is developed according to an MML approach. In terms of, respectively, public engagement and mobilization citizen consultations ([ASSET Citizen Consultation](#)) were successfully performed in eight European countries and a series of local initiatives ([ASSET Responsible research and innovation newsletter](#)) is being developed in 12 cities. Concerning the involvement of relevant stakeholders in the field, authorities are engaged in a High-Level Policy Forum (HLPF) ([ASSET High Level Policy Forum in Brussels](#); [ASSET High Level Policy Forum members meet first time](#)) discussion, as well as scientific community and industry, are involved by two content-specific platforms ([ASSET Best and Promising Practice Platform](#); [ASSET Sex & Gender & Vaccination Platform](#)) and an associated web portal. In ASSET, communication enhances both the internal Community of Practice (CoP) (Wenger 2011) and the external networks. According to transparency principles and in order to achieve a participatory dialogue as open as possible, the ASSET website develops many tools that allow both healthcare professionals, media and lay public to discuss, the most outstanding example is represented by the way which social networks are greatly valued ([European Commission Work Program 2013 Capacities Part 5 Science in Society C 2012](#)).

Fig. 9.1 Six main science in society (SiS) themes for responsible research and innovation (RRI) and six targets for action in the ASSET plan. Source D3.3 ASSET Action Plan Handbook, p. 58



9.3.1 Public Engagement Through Citizen Consultations and MML Initiatives

As we have stressed, restoring trust is one of the main goals within the European policies for PH as far as the relationship with CS are concerned (Löfstedt 2005; Marmot 2017). A fundamental step to reach this objective is the establishing of a two-way, active and transparent communication. Thus, ASSET developed citizens' consultations in eight European countries (Bulgaria, Denmark, France, Ireland, Italy, Norway, Romania, Switzerland). To minimize the influence of external events and possible investigation biases, all consultations were simultaneously held on 24th September 2016. Lay citizens to be involved in the ASSET consultations were selected according to the same set of criteria in all countries, reflecting the demographic distribution of the general population in the own country with regard to age (from 18 and up), gender, geographical zone, educational level, occupation and other criteria of national relevance. Avoiding any claims to statistical representativeness, a number of 50 citizens per country was set out as good enough to give a realistic picture of the quantitative tendencies.

Furthermore, ensuring people are chosen in each country according to the parameters indicated above results in a reliable snapshot of the views in each country population ([ASSET Deliverable 4.1 Citizens Meeting Preparatory Materials](#)). The 425 participating citizens were asked relevant issues related to preparedness and response when epidemics, pandemics or PHEIC in general occur. The main conclusions were focused on principles that affect risk communication and the most attention was paid to vaccination-related issues. First, citizens believe that developing honest, clear and transparent communication can restore and further increase the public trust (no matter how bad the situation is). They think it is their right to know and understand occurrences. Advice materials for vaccination have to be updated, clarified and standardized even considering particular target groups, like pregnant women or elderly. In citizens' opinion, PH authorities should devote more resources to collect inputs in order to inform policies on epidemic preparedness and response even if it is clear to people that in emergency situation, PH interest should infringe upon the individual freedom. In such a scenario, GPs and healthcare workers (HCW) are recognized as crucial figures. As a consequence, they should be trained to adapt to the changing society. Moreover, authorities are urged to be visible and present on the web, since the use of the Internet is increasingly widespread ([ASSET Deliverable 4.3 Policy Report on Pandemic Consultation & Public trans-national synthesis report](#)).

Another strong opportunity to connect local, national and international contexts is constituted by a series of local initiatives that are run beside the diversified range of instruments elaborated to communicate effectively with stakeholders on a limited scale. Twelve ASSET partner cities (Rome, Milan, Paris, Lyon, Dublin, Athens, Brussels, Oslo, Sofia, Bucharest, Geneva, Haifa) are in fact identified to host local initiatives to promote MML at local level and to enhance the transferability of the most effective policies and practices ([ASSET Responsible research and innovation newsletter](#)).

9.3.2 Authorities Involvement Through a HLPF

The matter of trust (Löfstedt 2005; Marmot 2017) applied to an improved communication and to considering SiS issues represents the core activity of the ASSET HLPF ([ASSET Deliverable 6.1 High Level Policy Forum Report 1](#); [ASSET Deliverable 6.2 High Level Policy Forum Report 2](#)) that brings together selected decision makers from 11 different countries (Bulgaria, France, Greece, Ireland, Israel, Italy, Luxembourg, Norway, Romania, Sweden, United Kingdom) in a constantly supported dialogue to promote ongoing reflection on European strategic priorities and challenges recalled for tackling epidemics and pandemics. The ASSET HLPF works basing on a scientific assessment first and a complementary appraisal phase where know-how and opinions of stakeholders are added in the discussion. Such this intricate process necessitates effective interaction among several relevant actors: as this interaction must happen very quickly and under intense public scrutiny, preparedness is essential. The ASSET HLPF is therefore intended to be a place for stakeholders to meet, learn from each other, and

come up with better policy proposals. Beside a virtual discussion run on a dedicated web-based platform, three HLPF physical meetings were developed: in Brussels on 12th March 2015; in Copenhagen on 15th January 2016; in Brussels again on 28th April 2017. HLPF members interrogated on which are the relevant scenarios affecting PH crisis management in Europe and three main settings were selected: participatory governance; ethical issues in pandemic preparedness planning; vaccination hesitancy. The three issues are linked by the public involvement (Colgrove 2016).

9.3.3 Science and Industry Addressed by the Best Practice Platform and Dedicated Portals

In the ASSET Action Plan, science is associated with the specific objective to favour mutual and interdisciplinary exchange and industry is mainly targeted to foster dialogue, also to disclose conflict of interests (COI). A best practice (BP) is defined in the Business Dictionary as “a method that has consistently shown results superior to those achieved by other means, and that is used as a benchmark” (Business Dictionary). Furthermore, a good practice is a method that has shown results or preliminary results superior to those achieved by other means. In this perspective, a BP has to be enforced by a wide consensus. Such a consensus is often not yet reached in the complex and young area of applying SiS to PH, and in particular to the communicable diseases where most frequently good practices can be found. The ASSET Best Practice Platform (BPP) (ASSET Best and Promising Practice Platform) is an ongoing collection of good, promising and best practices on SiS related issues in PH research on epidemics and pandemics. A key element of these practices is in fact the active CS involvement during the inception/design phase, in their implementation or the evaluation step. Mainly addressed to the scientific community, the BPP is further sided by a Stakeholder Portal (SP), to provide a gateway to interested industry representatives or universities and research institutions in discussing both on experiences collected and on issues needed to develop new practices. Finally, starting from practices and feedback gathered, guidelines for the development of best practices would be delivered.

As indicated above, gender is one of the six SiS issues to achieve an RRI. Therefore, the gender pattern is retrievable in ASSET mainly by the Sex & Gender & Vaccination platform. It includes resources, contents and articles written by experts aimed to disseminate and promote gender-sensitive and women-centred research on pandemics (ASSET Sex & Gender & Vaccination Platform).

Communication on the Web and Use of Social Networks to Reach Lay Public and Specific Targets (Media, HCWs) According to the communication plan released at the beginning of the project, in ASSET communication gets different functions: ensures the project’s visibility through traditional and new media tools; documents every major advancement made in the project; allows educational opportunities and knowledge transfer among partners, stakeholders, policy makers and general public. In continuity with values of transparency and participatory dialogue moving an ASSET, its website is an entirely open platform, targeted to

health professionals, media and even lay public [[ASSET \(Action plan in Science in Society in Epidemics and Total pandemics\)](#)].

If healthcare professionals are concerned about the improvement of their awareness, knowledge and communication skills, media are mainly targeted in managing uncertainty, flexibility and the spread of misinformation. The website includes several thematic sections and makes outputs generated available: deliverables, papers, presentations, newsletters, bulletins, a glossary of terms, analytics, press materials (press releases/reviews/kit), articles, videopills and data visualizations ([ASSET Deliverable 7.3 Web Portal Report 1](#)).

As recalled above, social media are recognized not only as relevant channels for dissemination ([ASSET Deliverable 7.5 Media Report 1](#)) but also as places to monitor because of the huge content that is developed there. One specific objective is indeed the exploitation of social media potentiality for citizens and stakeholders mobilization in pandemic emergencies. In order to develop social conversations coverage, a dedicated application has been finalised to identify the most influential Twitter users on specific topics, according to a list of keywords and hashtag ([ASSET Twitter Influencer Analysis](#)).

9.4 Discussion

ASSET has been building up a process as a whole made of public consultation, stakeholder involvement and MML actions that might find application in several PH sectors. The current practice in European PH policies shows in fact that if the communication cycle among authorities, HCWs, the scientific community, population, media and industry is poor, then problems unavoidably arise. A recent example is the 2014/2015 Ebola epidemic in Western Africa (Crosier et al. 2014), although the scenario is similar for the vast majority of other outbreaks. The 2009 flu pandemic has already shown that it is impossible to implement effective control measures without proper understanding by CS ([World Health Organization](#)).

The ASSET public consultations highlighted very interesting and significant needs and also the citizens' willingness to be more actively engaged in PH actions in general and in relation to emergencies in particular. This issue is perceived as highly urgent by a vast majority of consulted citizens. They, indeed, think that consultations should be considered as routinary: it strongly marks how much citizens want to engage and provide their personal input ([ASSET Deliverable 4.3 Policy Report on Pandemic Consultation & Public trans-national synthesis report](#)). Moreover, this adherence of the population to participate in consultations provides evidence that citizens consider themselves as competent: they are able to be part of the decision-making policy by providing valuable data, concerns, useful information but also by disseminating evidence released by PH authorities (Rufo 2017). Furthermore, such an engagement process is relevant in all promotional activities related to disease prevention, and indeed the health literacy (Batterham et al. 2016) is the ground for enhancing the so-called participatory research (Buyx et al. 2017; World Health Organization 2009; Catford 2010). It is noteworthy that not all PH issues seem to be fine to make citizens be consulted: it is even true where extension

and impact or contribution is inversely proportional to the health literacy degree. If antimicrobial resistance (AMR) is an issue that HCWs, decision makers and, consequently, lay public too, hold a very poor knowledge about and studies analysing attitudes, practices or behaviours could be more suitable tools, inversely, sexually transmitted infections (STI) or PHEIC represent a good example of communicable diseases to ask population about. Such consultations could be relevant also in situations that do not imply the spreading of an infectious agent, like the circulation of a radioactive cloud or the dissemination of a new allergen inducing intense skin reactions. Exercises like those carried out in ASSET prove citizens wanting to be more engaged with all kinds of civic policy and delivery, confirming what is stated by Nabatchi and Leighninger who stress to what extent PPI is relevant in many dimensions: morally by practicing a right, instrumentally by increasing the legitimacy of a process, substantially by providing valuable knowledge (Nabatchi and Leighninger 2015).

On the issue of epidemics and pandemics, the most relevant input is that citizens themselves decide from an educated or a knowledgeable place what are the best measures to protect them and their families from the next pandemic. It presumably differs from country to country, because each European State would have a different expectation of their government, they also have a different level of citizen engagement, dialogue and interaction. One of the most relevant outcomes to be achieved by engaging proactively stakeholders concerns the beneficial improvement to official surveillance data because citizens can provide complementary information that increases the sensitivity of the system. This could be particularly useful when outbreaks start for the detection of emerging epidemics.

PH authorities should devote more resources to collect citizen input to policies on epidemic preparedness and response. This kind of citizenship engagement is relevant in a European context and also related to the different trust outcome (Löfstedt 2005; Marmot 2017). Citizens believe that honesty and transparency can increase the public trust—no matter how bad the situation is- and that it is their right to know and understand the accurate situation, both by general and by tailored communication to specific target groups as pregnant women or minority groups. In matter of trustable sources of information, decision-makers should pay attention to the fact that citizens believe the most people with whom they communicate directly, in particular, their GPs. These last and policymakers should be trained to adapt to the changing society: further investments are then needed from one hand to make GPs better trained and facilitators rather than expert controllers and on the other hand decision makers who also need to be proactive in the constant conversation with the population. This will occur only if supported by adequate investments.

In such scenario, communication plans need to be established and expert staff supporting the decision makers ought to be consulted. Decision makers rarely take into account communication needs: it is the reason why they have to be trained for an optimized communication, and they are likewise asked to carefully consider advice coming from experts. Unfortunately, people believe also in unverified sources, often on the internet. People probably resort to the web because it is the fastest way to get informed: at any time they can find what they want from multiple

worldwide sources. Knowing that people get informed mostly from the internet, correct and updated information should be offered on websites which citizens recognize they can trust. This is an important step for people to rely on international and national health authorities.

ASSET highlights how much public asks for transparency: concerning epidemics, it is not only about explaining how the disease spreads, what measures should be taken in order to prevent it and some other aspects like this, but it also implies the truth about how serious the disease is, what are the resources of the country at that point in fighting against it and what should be expected. Another important aspect is the way information is transmitted, which ought to be done in an accessible manner and to make sure that the message is correctly and completely acknowledged. More transparent communication allows decision makers to get a better response from the citizens because they would understand the consequences and could even help in stopping the spreading of some diseases. The transparency that citizens want is related to the trust that they have in the institutions responsible for action in case of PHEIC or whenever in offering the elementary PH services.

A key point is to centralize the process overall because the way people respond is influenced mainly by how their needs of information and security are addressed. This is why it is important to know what people want and think regarding different PH subjects, as authorities need to invest in reaching out and engaging citizens. Not just when there is a pandemic event on the horizon but continually in pre-event phases. To date, building a transparent and clear risk communication to restore citizens' trust (Löfstedt 2005; Marmot 2017) is something clear on a theoretical level but hard to be put in practice. In order to achieve this task authorities supported by politicians must develop a strategic communication and marketing plan. A strategic long-term approach is required to reach citizen centric social policy delivery. This implies authorities having different structures and more expertise in market research and citizen engagement expertise. The long term plan in nature requires to invest in brand building, in developing citizen insight and understanding, and targeted segmented communications to the many different audiences that exist in relation to epidemic and pandemic events.

Conversely, PH is a very difficult area where financing are cut on a regular basis. As said, an investment in transparent and honest communication is fundamental to restore trust, however there is also a need for consistency and active listening and response to citizens' concerns and worries. More investment should also be put into encouraging citizen to help with both the implementation of programs and evaluating their effectiveness, efficiency and acceptability. There is definitively a need for agencies to be more proactive and invest further in reaching out to informing and engaging citizens as well as for more financial investment in this area. Although CS wants to contribute and be engaged, however experience shows also that it is difficult to implement that starts with the level of contributors: who should represent the citizen? Research questions on how to better engage with the public without unwanted interferences are still open.

9.5 Conclusions and Future Perspectives

As the wide range of ASSET activities shows, to cope effectively with PHEIC not only medical or healthcare interventions are needed due to potential unwanted side effects on the population: an integrated participatory approach is crucial and should be embedded into the national preparedness plans. Countries are thus required to set out risk communication appropriately in their own response and preparedness strategies. Basing on ASSET outcomes, relevant key perspectives to be addressed in the future according to the recalled SiS-RRI ([European Commission, Research & Innovation, ‘Science with and for Society’ \(SWAFS\); Responsible Research and Innovation](#)) categories can be listed as follows:

Governance (within the law reference frame of the EU Decision 1082/2013) [Define chain of command, Set up a permanent ‘listening’ system to collect citizens voice, Plan and coordinate an integrated health risk communication strategy, Deliver a continuous professional training and update on health risks, Develop periodical preparedness simulation exercises];

Open Access to Data and Information [Provide regular information scientifically/evidence-based, Address people hesitancy on prevention actions, as vaccinations, prophylaxis, isolations/quarantine];

Ethical Issues [Tackle stigma and frailty groups at-risk in health emergencies, Outline rules and limits of potential conflicts between response measures in emergencies and people freedom and privacy, Address procedures on international health risks and migrants];

Gender Pattern [Provide gender-tailored health emergencies responses, Prioritize the female resource potential on health management, Sensitize women both in abiding by non-pharmacological interventions and to vaccination compliance];

Communication for Public Engagement [Prepare integrated preparedness communication plans according to a multistakeholder approach, Be constantly present and proactive on social media, Control and react to inappropriate information by delivering a rapid and appropriate response, Monitoring both evidence in literature and practices/experiences on risk communication];

Science Education [Devote part of the continuous education program for Health Care Workers to health preparedness and response, scientific evidence, health communication, Include health preparedness and communication into the basic HCW curricula, Offer upgrade training to media/communication operators on health preparedness, scientific evidence and health literacy, Empower the pathway toward a responsible open science].

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