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Final publishable summary report

1.1 Executive Summary

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 Decision has been serving 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 in ASSET through its Strategic and Action Plans toward different targets and relevant stakeholders.

In terms of, respectively, public engagement and mobilization citizen consultations were successfully performed in eight European countries and a series of local initiatives was developed in 12 cities.

Concerning the involvement of relevant stakeholders in the field, authorities were engaged in a High Level Policy Forum (HLPF) discussion as well as scientific community and industry have been involved by two content-specific platforms and an associated web portal.

In ASSET, communication enhanced both the internal Community of Practice (CoP) through a web platform and the external networks, mainly with and promoted by the project website.

According to transparency principles and in order to achieve a participatory dialogue as open as possible, the ASSET website has been developing 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.

The outstanding conclusion after four years of work on ASSET is that an integrated participatory approach needs to be recognized into the national plans for preparedness and response.

1.2 Summary description of project context and objectives

Project context

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 that has been serving as proper context to ASSET (Action plan in Science in Society in Epidemics and Total pandemics).

As a Mobilization and Mutual Learning Action Plan (MMLAP) research project, it aimed 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.



ASSET meant 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 for a Responsible Research and Innovation (RRI). The six SiS key areas considered in ASSET are:

- Governance
- Public engagement
- Ethics
- Gender
- Science education
- Open access

ASSET was 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 definition started from editing the Strategic Plan and a Roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs.

Project objectives

According to the agreed logical framework, ASSET overall objective to contribute to incorporating SiS issues into the RRI system related to pandemic or epidemic preparedness is linked to meeting three specific objectives:

- strong multidisciplinary research partnerships to effectively address identified scientific and societal challenges
- related SiS topics are explored and mapped
- participatory and inclusive strategies are developed to efficiently address these topics.

These specific objectives have been in turn linked to specific tasks of the work programme:

- Effectively addressing identified scientific and societal challenges means that the project work is referenced in strategic documents and actions relating to R&I policy in epidemics/pandemics, which relates to WP2 (identification of topics), the communication actions (WP7), especially science communication (T7.5) and the policy actions (WP6).
- The success in exploring and mapping the identified Science in Society topics is measured by the effectiveness of the MMLAP strategy to create stakeholder mobilisation and participatory approaches (WP3) that, in turn, stimulate the engagement of the targeted stakeholder groups in the actions carried out under WP4 and WP5.
- The identified Science in Society topics are efficiently addressed if the implementation of the ASSET action plan (WP4, WP5 and WP6) leads to visible effects in actual policy making.

The graph included in the Figure 1 below illustrates the relationships between specific objectives and Work Packages as per project protocol.

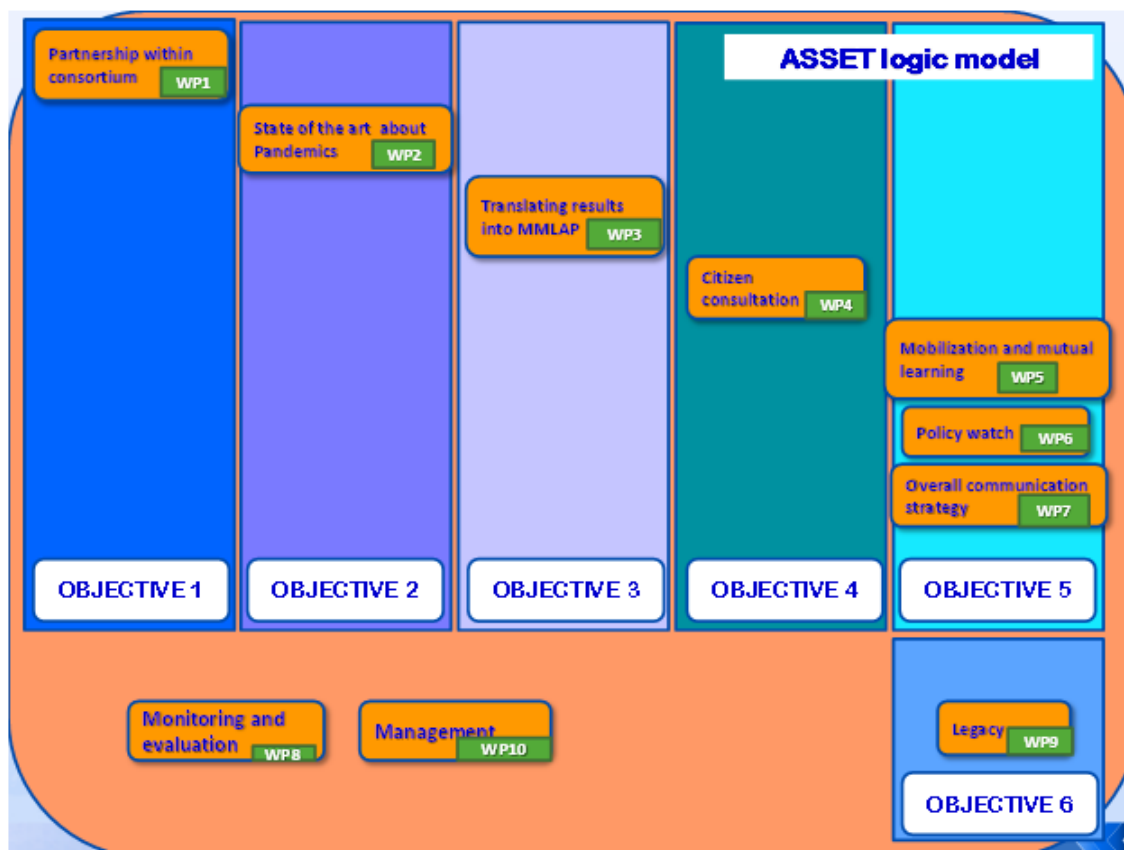


Figure 1.: Relationships between ASSET objectives and its WPs

1.3 Description of the main S&T results/foregrounds

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 Strategic Plan plays a crucial role in defining a clear focus not only for the actions to be carried out by project members but also for relevant Stakeholders in general, to engage societal actors in the research and innovation process, and to create equal conditions for citizen’s engagement, possibly also including specific strategies into pandemic policies in the European member states.

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, by implementing instruments and tools of the MML approach, the Strategic Plan has at its core the development of citizens’ awareness, empowerment and action on the RRI mainstems:

- 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.



Overview on the main results per each thematic area

Governance

During 2009 A(H1N1) pandemic, the World Health Organization, as well as national and other supranational agencies, were harshly criticized for the Governance of the crisis: lack of transparency in potential conflict of interest with pharma industry led to lack of trust in communication coming from authorities. Together with other factors, this caused scarce adherence to vaccination against pandemic flu and a persisting distrust that impaired vaccination coverage against other infectious diseases in most developed countries in following years. In further emergencies (such as Ebola epidemic in Western Africa and Zika epidemic in Latin America), the relevance of a two-ways, participated communication and of including gender and ethical issues in the governance of infectious crises became even more evident. One of the main objectives of ASSET project was bringing Science-in-society issues to the attention of policy-makers, by different means.

A report on governance ASSET experts prepared a report on Governance of Epidemics and Pandemics, which reviews the issue using 2009 A(H1N1) pandemic as a case-history from three interrelated perspectives:

- World Health Organization, which had revised the International Health Regulations (IHR, 2005) and strengthened its position as a central global force with authority and accountability in the field of international health.
- Pharma industry: Conflict of Interests (CoI) with health authorities and its potential impact on the decision making process held by health authorities.
- Media, regarded as the “watching dogs” who should have monitored governance performance during the 2009 H1N1 pandemic, examined analysing through WHO and the Centers for Disease Control and Prevention (CDC) virtual press conferences during the pandemic.

The High Level Policy Forum ASSET gathered 15 members from different countries (Norway, Sweden, Italy, UK, Denmark, France, Israel, Bulgaria, Luxembourg, Romania, Ireland and Greece) in a High Level Policy Forum in which hot topics about pandemic preparedness and response could be discussed. Email exchanges and three personal meetings (2 in Brussels and 1 in Copenhagen) allowed members to tackle with issues such as participatory governance of epidemics and pandemics, vaccination hesitancy and ethical issues in pandemic preparedness planning.

Meeting at the European Parliament On 2017, 26th April, a Policy Workshop at the European Parliament presented ASSET project and the results of citizens' consultations organized within the project to members of Parliament of relevant committees.

ASSET brochure: a tool in case of Infectious Threats By a leaflet addressed to European Public Health Authorities ASSET offered its research, expertise and tools to consider Science-in-Society issues in epidemic and pandemic preparedness plans, as requested by CE Decision 1082/2013/EU.

Share and move! Six issues of a Pandemic Preparedness and Response Bulletin addressed to authorities and policy makers have been published, which include both activities and issues emerging from the project and other relevant news coming from other actors in the field.

Unsolved scientific questions and open access to scientific outcome

Following the proposals of the Experts Groups on Science, H1N1 and Society, designed by the European Commission, the ASSET project elaborated a Reference guide of unsolved scientific related research questions raised by the H1N1 pandemic and associated crisis management. It shows “a lack of research independent of industrial interests, but also that not enough research has been focusing on basic influenza mechanisms”.



In a “post-trust society” with low confidence in authorities, the research community is challenged on many weak areas and topics. Some relevant “unsolved questions” in the field of epidemics and pandemics related to society are:

- Communicating science in presence of uncertainties, such as at the beginning of an outbreak
- Involvement of civil society to contrast the actual one-way decision processes with no feedbacks from the civil society
- Absence of compliance to the “epidemic intelligence framework” and low exploitation of data coming from new informal surveillance approaches
- Lack of involvement of GPs in the process of increasing the awareness of pandemics and negative attitudes of healthcare workers towards vaccines, for example
- Underestimation of the role of social networks to understand public perceptions and to disseminate information and increase knowledge and awareness
- Inter-disciplinary scientific approach to public health problems (e.g. scarce interest towards sociology, anthropology, behavioural mathematical models in epidemiology).

Paper series Within ASSET project, a scientific paper series (ISSN 2532-3784) has presented various Science-With-And-For-Society issues in the form of an open access scientific quarterly newsletter. Experts in the ASSET consortium as well as invited authors have discussed them in the form of short communications.

- Issue n. 1 - Science for and with Society aiming to the public health emergencies response and preparedness
- Issue n. 2 - Democracy and human rights under Public Health Emergency (PHE) threat
- Issue n. 3 - National borders and the spreading of diseases
- Issue n. 4 - The Social Networks in Public Health Emergency Preparedness and Response
- Issue n. 5 - Risk communication in time of an epidemic or pandemic
- Issue n. 6- The role of citizens in times of an epidemic or pandemic
- Issue n. 7- Continuous Training for Medical Professionals: The case for health communication and disaster preparedness training.

Good examples A section of ASSET website is dedicated to gather good and best “practices” on Science-in-Society related issues in public health research on epidemics and pandemics. This collection could help to:

- Promote the good practices themselves so that they may become widely adopted
- Transfer knowledge of good practices among researchers, practitioners, institutions and organizations
- Develop best practice guidelines
- Validate best practice guidelines
- Disseminate and encourage adoption of “candidate best practice”.



Participatory governance and science education

Participation is one of the key element of democratic institutions. One of the aim of ASSET is to engage citizens in the debate on pandemic crisis prevention and management. Such a task requires several tools and a proper communication approach, which should flow back and forth between experts and the public.

Citizen consultation ASSET aimed to provide inputs for the development of effective policies on pandemic crisis, and to engage citizens in the debate of public health crisis prevention and management. In order to do that, it was thus important to gather citizens' voice and bring it to authorities, and to establish a two-way participated communication with the public. With these purposes in mind, ASSET experts organised a citizen consultation to allow people living in eight countries to discuss and express themselves on some key topics.

ASSET website A project such as ASSET could not work without a proper online platform. The ASSET website has been designed as a portal that not only gathers relevant resources and information on epidemics and pandemics, but also as a tool to facilitate dissemination and engagement. It is conceived as a hybrid between a magazine – with periodically updated articles that examine in depth some of the project topics – and an institutional website – with easy access to official documents, technical papers and recommendations from health authorities.

Ethics, law and fundamental rights

A person with symptoms of a possible infectious disease who, afraid of being stigmatised, refuses to seek medical care. An institution that hides information or undisclosed conflict of interest, or that provides drugs and vaccines without accurate and justified priorities – thus fuelling distrust in authorities. The choice of restricting people's freedom by quarantine to prevent the spread of an infectious disease. These are just some examples of how ethics is deeply entangled with pandemic and epidemic response. ASSET addressed main stakeholders to consider these issues in the debate on epidemics and pandemics, and to promote ethical best practices in the event of public health emergencies.

A report on ethical issues The first step in this direction is represented by the Ethics, law and fundamental right report, a document produced by ASSET experts to provide an overview on these topics and to discuss them in the light of public health emergencies, such as epidemics and pandemics. The first part of the report presents the international policy landscape on what constitutes fundamental human rights, both at European and world level. However, sometimes priorities and needs in a state of emergency may come into tension with ethical principles and societal norms. This is the reason why another section of this report is dedicated to those key values that should always be considered when addressing similar issues.

- Restriction of personal freedom
- Duty to provide care in pandemics
- Priority setting and resource allocation
- International cooperation and global governance.

The final section of the report deals with two other issues with serious implications for pandemic preparedness and response. One is the risk of having individuals or entire communities that become the target of stigmatisation for a number of reasons, such as the perceived connection with the geographic origin of the outbreak in question, or their actual connection to perceived animal origins of an outbreak, and finally due to the fact that those individuals have actually become infected themselves. The other is the existence of vulnerable groups – such as pregnant women, children, people with disabilities, elderly people, the ill and the wounded – that should have priority access to first aid and any emergency evacuations.



The analysis of national pandemic plans How are European countries dealing with ethical issues in health emergency plans? This is the question that led ASSET experts to analyse national preparedness and response plans. Their aim was to assess how often ethical principles and their application were mentioned in national pandemic and epidemic plans. And their investigation revealed little concern for ethical aspects and a lack of discussion on ethical issues in most of the plans developed by European countries. Only four of them – Switzerland, United Kingdom, Czech Republic and France – have a dedicated section to this topic, while others, like Spain or Italy, just mentioned them without any further discussion. ASSET analysis (also presented with a [datavisualization](#), accessible from the website) may represent a useful tool to guide future drafters of pandemic plans, since it aims at encouraging debate on the necessity to update all national pandemic plans including ethical issues.

Gender issues

Sex and gender have a significant impact on how people prepare or react to epidemics and pandemics, since they may lead to differences in risk perception, vulnerability, health behaviours or even clinical trials efficacy. For instance, females and males differ in their immunological responses to seasonal influenza virus vaccines, with the former having higher antibody responses to influenza vaccinations. This is particularly relevant, since both vaccines and drugs are mainly tested on men, so that we cannot be sure that in women they have the same safety and efficacy. Another example is that of pregnant women, who are especially at risk during an epidemic, due to unique factors connected to their conditions.

ASSET project faced this issue in two ways: by collecting evidence about the impact of gender and age inequalities with respect to infectious outbreaks; by disseminating and promoting gender-specific and women-centered research on pandemics.

A report on gender issues What awareness exists of gender differences in vaccination? What communication strategies have been employed for vaccination take-up from a gender perspective? What kind of information policies do exist for groups with particular needs in terms of gender, such as pregnant women or older women?

These are some of the questions that drove a research performed by ASSET experts, described in the [Report on gender issues](#). They analysed the available literature and conducted interviews with stakeholders from various areas concerned with pandemics, epidemics, and vaccinations. They found that there is an evident need for a more gendered approach to influenza epidemics and vaccination, and produced a series of recommendations to address these issues.

A platform for dissemination [Sex & Gender & Vaccination](#) is a platform that gathers contents and articles from ASSET experts, aimed to disseminate and promote gender-sensitive and women-centred research on pandemics. In particular, it aims to spread information on flu pandemics related risks, notably for pregnant women and infants, preventive measures, antiviral drugs, vaccines and vaccination, and make information available to women to enable them to make informed and responsible decisions.

Sex and gender in clinical trials It is often said that sex and gender differences are perceived as overlooked in research design and in clinical trials, even those on vaccines. According to the World Health Organization (WHO), many reports of influenza vaccination rates as well as the safety, efficacy and effectiveness of vaccines around the world do not disaggregate data by sex. Some ASSET experts performed a study to compare participation rates of males and females in clinical vaccine trials, finding no significant differences. However, the fact that only a minority of the trials disaggregated data by sex and gender is a highly relevant finding, for it indicates that such a distinction was not perceived as important.

An [interactive graph](#) was also realised, to encourage viewers to estimate the percentage of women involved in clinical trials and then comparing their guess with the real result.



Intentionally caused outbreaks

Biosecurity While terrorism is becoming a serious threat all over the world, there is a growing concern about the possible misuse of biological agents to cause outbreaks.

To understand and tackle the main governance problems posed by this risk, ASSET carried out an analysis of the history, state of the art and policy documents concerning intentional biological attacks in a report on Intentionally Caused Outbreaks in democratic societies. The main challenges are about:

- The tension between secrecy and transparency
- The freedom of research and security
- Citizen involvement.

National and international authorities need policy documents well known among relevant actors and ready to be used in case of emergency, after having discussed the security and ethical implications of any measure before the crisis.

Attitudes of citizens in the area are also in need of exploration, for example considering the risk of the dual use of research results and what information they want to have about intentionally caused outbreaks.

Specific output presentation relating to different target groups considered

It has been reported that another relevant ASSET pillar is the Roadmap indicated above. It showed that its aims require a number of frame-changing steps, among which:

- 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.

As expected, “the Action Plan is composed of action steps and includes a specific plan on competence development aimed at enhancing awareness, knowledge, commitment and capacity necessary to incorporate gender perspectives, ethical considerations, science communication, citizens participation, in flu pandemic preparedness strategies and actions”.

The ASSET Action Plan coordinates the scheduled activities of citizens’ consultation, MML, policy watch and communication, in order to improve their efficacy and effectiveness in light of assessment, with some proposals for a legacy in the future.



The Action Plan Handbook reports specific tools and actions targeted to different stakeholders, as anticipated by the ASSET Strategic Plan (Figure 2).

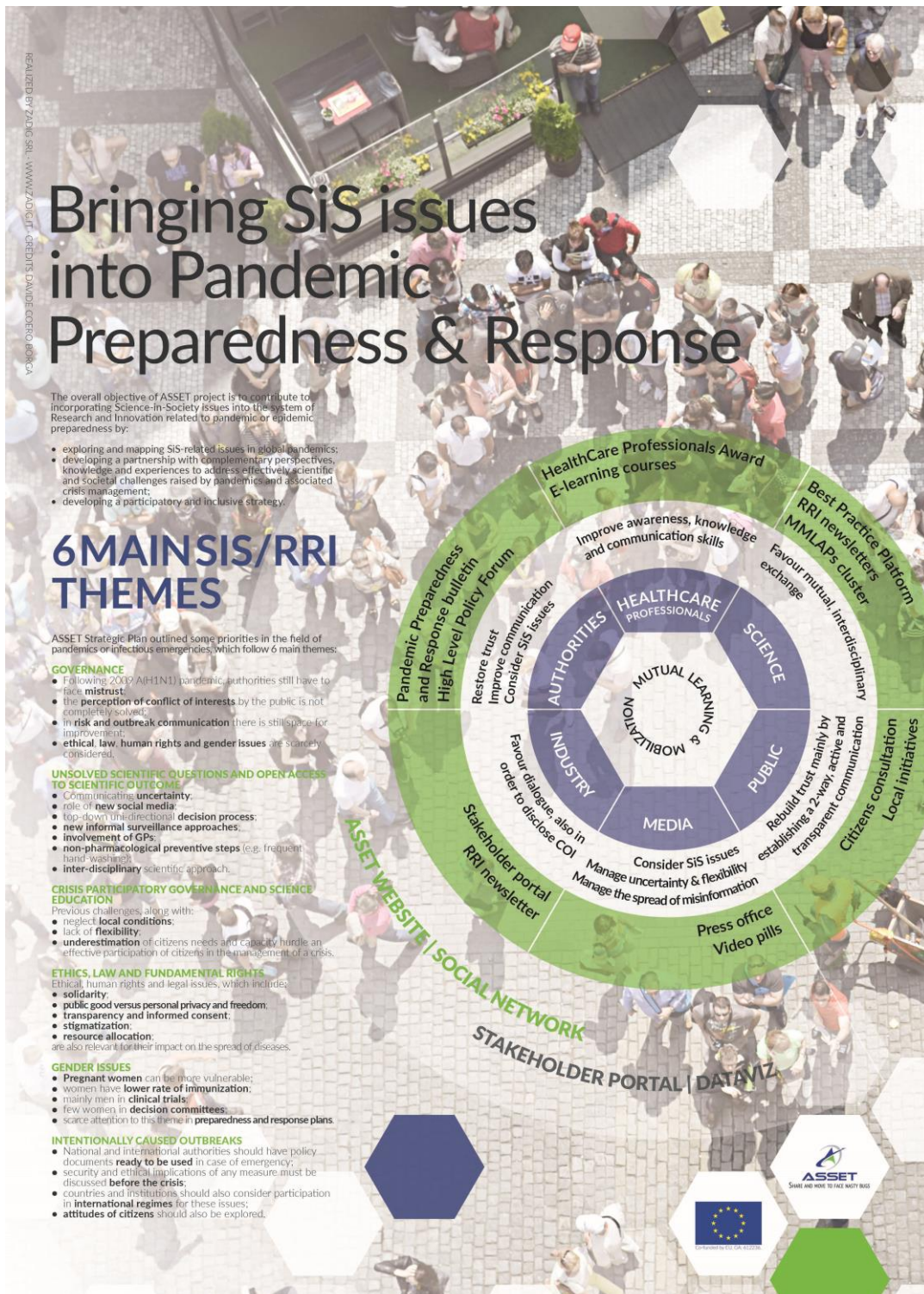


Figure 2.: Six Main Science in Society (SiS) Themes for Responsible Research and Innovation (RRI) and Six Targets for Action in the ASSET Plan (Source: D3.3 ASSET Action Plan Handbook, p. 58)



Public Engagement through Citizen Consultations and MML Initiatives

Within the broad action of contributing to restore trust of public in institutions by a two-way, active and transparent communication, ASSET developed [citizens' consultations](#) in eight European countries (Bulgaria, Denmark, France, Ireland, Italy, Norway, Romania, Switzerland). To minimize 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 snap shot of the views in each country population.

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 has 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 polices 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 health care 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 Internet is increasingly widespread.

Another strong opportunity to connect local, national and international contexts is constituted by a series of local initiatives run beside the diversified range of instruments elaborated to communicate effectively with stakeholders on a limited scale. Eleven ASSET partner cities (Rome, Milan, Lyon, Dublin, Athens, Brussels, Oslo, Sofia, Bucharest, Geneva, Haifa) were 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. Fed by the results of the citizen consultations described above, these local initiatives were intended to capture the "spirit of the place" about large crisis emergency, the specific way(s) in which people living in a city or region perceive, and react to the pandemic threat. More in detail, they are thought to share valid and relevant information, by combining advocacy with scientific inquiry and innovation processes. In each city, relevant stakeholders have to be selected, contacted and involved, such as health professionals, police/army/law enforcement officers, media, and pharmaceutical industry.

Authorities Involvement through a High Level Policy Forum (HLPF)

The matter of trust applied to an improved communication and to considering SiS issues represents the core activity of the ASSET HLPF that brought 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 worked basing on a scientific assessment first and a complementary appraisal phase where know-how and opinions of stakeholders were added in the discussion. Such this intricate process needed effective interaction among several relevant actors: as this interaction must happen very quickly and under intense public scrutiny, preparedness is essential. The network of stakeholders can only be prepared well through building trust and good working relationships prior to emergencies occur. In addition, identifying and discussing important policy issues and examining how they can be improved,



can only be done comprehensively through the consideration of all viewpoints by the main stakeholders involved.

The ASSET HLPF was therefore intended to provide such this opportunity at the decision levels in Europe: it represented 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.

The ASSET HLPF devoted the most attention to significant challenges in PH emergency preparedness and response, including communication and several SiS related aspects. 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.

These three issues can be seen also altogether, public participation definitively represents an important complement to the foundation laid by plans and laws which are also recalled within the dilemma to mandate vaccination or not, and related hesitancy.

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

In the ASSET Action Plan, science is associated to 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 with other means, and that is used as a benchmark”.

Furthermore, a good practice is defined as a method that has shown results or preliminary results superior to those achieved with other means. In this perspective, a BP had 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) 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. Projects that incorporate themes of SiS but where CS is included with a merely passive role (such as analysis of social media posts or leaflet dissemination) and without impact on policies or communication strategies are not to be considered as practices of interest for the ASSET platform. 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 issue to achieve a 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.

In particular, it is intended to disseminate information on flu pandemics related risks, notably for pregnant women and infants, preventive measures, antiviral drugs, vaccines and vaccination, and make information available to women to enable them to make informed and responsible decisions.



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 ASSET, its [website](#) is an entirely open platform, targeted to health professionals, media and even lay public.

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 looks like a comprehensive folder including 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.

As recalled above, social media are recognized not only as relevant channels for dissemination but also as places to monitor because of the huge contents 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.

Being based on mentions and retweets, such an approach is also effective to find out influential users in the short period. The app was running a daily extrapolation of the most popular accounts by retrieving the keywords indicated. And, accordingly a daily analysis of the top accounts allowed the identification of some main categories, such as institutions, media, private industry, researchers, university, organizations, and charities.

1.4 Potential impact and the main dissemination activities and exploitation of results

General conclusions

In four years of work (2014-2017), ASSET has verified overall what a great challenge is to develop a common language among actors with different scientific and professional background.

The exchange among partners and other stakeholders met during the project has shown how fruitful this multidisciplinary dialogue can be and that it would deserve further efforts in order to better tackle with old and new emerging diseases.

Social psychology and risk communication, as well as computational, social network and big data analysis, can add important information to virology, microbiology, immunology and vaccinology so that preparedness and response can be improved in the future.

Despite the great effort needed to enhance a dialogue among different EU-funded projects, ten of them present and cooperate at the ASSET Brokerage event, on 30th - 31st October 2017 in Rome (and the MMLAP virtual cluster collects 39 different projects).

The experience of ASSET citizen consultations has confirmed the willingness of general public to be involved in pandemic preparedness and response, and the importance of providing it with transparent and complete information before asking its opinion.

ASSET analyses have shown that lessons learnt from previous epidemics and pandemic about the relevant role of engaging society, considering ethical and gender issues and developing an inclusive risk



communication are hardly put into practice even by most national pandemic preparedness and response plans.

Steps forward will hopefully be taken following the European Decision 1082/2013 on serious cross-border threats to health, which requires every three years all Member States to provide the Commission with an update on the latest situation with regard to their preparedness and response planning at national level.

Horizon 2020 with its Science-with-and-for-society program acknowledges that there is still a lot of work to do. It is needed to allow “all societal actors (researchers, citizens, policy makers, business, third sector organizations etc.) to work together during the whole research and innovation process in order to better align both the process and its outcomes with the values, needs and expectations of European society”.

A good job has been done by ASSET and other EU-funded project, but there is still a long way to run before getting to a more prepared, resilient and fair society, also in front of infectious crises.

Analytical conclusions

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, scientific community, population, media and industry is poor, then problems unavoidably arise. A recent example is the 2014/2015 Ebola epidemic in Western Africa, 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.

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 routinely: it strongly marks how much citizens want to engage and provide their personal input. 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.

Furthermore, such an engagement process is relevant in all promotional activities related to disease prevention, and indeed the health literacy is the ground for enhancing the so-called participatory research. 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.

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 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 polices on epidemic preparedness and response. This kind of citizenship engagement is relevant in a European context and also related to the different trust outcome.

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 policy makers 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 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 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 are 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 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 is 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 citizens to help with both the implementation of programs and evaluating their effectiveness, efficiency and acceptability.

There is definitely 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 public without unwanted interferences are still open.

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 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 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.

1.5 Project public website and contact

The ASSET website provides the following information:

- 1) Information about ASSET project and partners;
- 2) Outputs of the project (deliverable, papers, presentations, other documents, Responsible Research and Innovation Newsletters and Pandemic Preparedness and Response Bulletins, and the D2.1 Glossary produced at the beginning of the project);
- 3) News and features on issues related to the project, both about infectious threats and the wider ideas of Science-in-Society, by the website editorial staff, other partners or relevant stakeholders;
- 4) Data visualizations;
- 5) Videos by ASSET and other related projects;
- 6) Links to other MMLAP or related projects;
- 7) A Gender platform, which gathers contents and articles from ASSET experts aimed to disseminate and promote gender-sensitive and women-centred research on pandemics;
- 8) A Best Practices platform, with a collection of good and best “practices” on Science-In-Society related issues in public health research on epidemics and pandemics;
- 9) A Citizens’ Consultation area containing Public Consultation Information Booklet and videos for thematic introductions to the meetings and the main results of the Public Consultation;
- 10) ASSET Analytics area with updated statistics on ASSET website and social media;
- 11) Events related to ASSET fields of interest, both in a list and in a calendar;
- 12) Links to the project social networks (Facebook, Twitter, YouTube Channel, LinkedIn...).
- 13) A library of resources related to ASSET issues (laws and rules, outputs of other related projects, papers and documents by international health authorities and scientific literature);
- 14) A media area containing ASSET press releases, a press review and a press kit.
- 15) The links to the Stakeholder portal.



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share and move to face nasty bugs

Website address: <http://www.asset-scienceinsociety.eu/>

Contact: Eva Benelli, ZADIG, Italy, benelli@zadig.it

The website is also connected to the project activity on social media (Facebook, Twitter and YouTube), main tools of web 2.0.

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