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WP7 COMMUNICATION

D7.14 Research and Innovation Newsletter Report

ASSET Project • Grant Agreement N°612236

ASSET

Action plan on SiS related issues in Epidemics And Total Pandemics

7th RTD framework programme

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Contributing partners: **ISS, IPRI, HU, ZADIG**

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D7.14 Research and Innovation Newsletter Report

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Leader: LYONBIOPOLE – Other contributors: ISS, IPRI, HU, ZADIG

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V1	Draft	17/11/2017	LYONBIOPOLE / Ondine Freté	First draft sent for contributions to the contributing partners
V2	Draft	22/11/2017	ZADIG / Eva Benelli	Input on the section related to the dissemination
V3	Pre-final	28/11/2017	LYONBIOPOLE / Ondine Freté	Integration of changes in the pre-final version
Vf	Final	19/12/2017	LYONBIOPOLE / Ondine Freté	Finalisation of the deliverable



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List of Acronyms

Acronym	Defined as
CMS	Content Management System
IMI	Innovative Medicine Initiative
RRI	Responsible Research and Innovation
WP	Work Package



EXECUTIVE SUMMARY

This deliverable aims to provide a final, comprehensive report on the Responsible Research and Innovation (RRI) Newsletters delivered twice a year during the project's lifetime. In total 6 project's newsletters dedicated to RRI have been published and disseminated to academic and industrial stakeholders since 2014. The elaboration of these newsletters is an important activity of the project's communication strategy and targets both the academic and industrial partners.

In this deliverable, all the aspects related to the partner's activities to deliver the newsletters since the beginning of the task (M18) until its end (M48) will be presented and analysed. In this respect, the deliverable is structured in two main parts:

- **Objectives and content of the Newsletters** presenting the main objectives: to inform on the latest news related to responsible research and innovation, and to provide updates on the project's milestones in line with RRI. This section provides an analysis of what has been published in the six project's newsletters in terms of content.
- **Dissemination of the newsletters explaining** how the main dissemination channels have been used to disseminate the newsletter targeting more than 7000 stakeholders working as science journalists, communicators, health professionals from both public and private sector, employees of national and international institutions through the ASSET mailing list.

The last part of the document provides the annexes gathering all newsletters' issues from June 2015 to December 2017.

The newsletters are also available online:

- ✓ [ASSET Newsletter – 1](#)
- ✓ [ASSET Newsletter – 2](#)
- ✓ [ASSET Newsletter – 3](#)
- ✓ [ASSET Newsletter – 4](#)
- ✓ [ASSET Newsletter – 5](#)
- ✓ [ASSET Newsletter – 6](#)



1. Introduction

The publication of ASSET newsletters related to the responsible research and innovation (RRI) during the project's lifetime is described within the task 7.10 (m12-m48) and is fully part of the communication strategy presented in the deliverable 7.1 produced at the beginning of the project (m6).

As part of the different external communication activities, the RRI newsletter was presented in the D7.1 as “*a biannual Research and Innovation Newsletter devoted to Responsible Research and Innovation (RRI) in the field of antiviral drugs and vaccines. The newsletter will target researchers both in academia and industry. The newsletter will present the progress of the ASSET action and will keep researchers abreast on the most update news about RRI in their research field*”.

In this this respect, six newsletters have been produced during the during the project's lifetime, every six months - from June 2015 to December 2017. As task leader, Lyonbiopole (LYON) was responsible for delivering high-quality newsletters in time, supported by four task contributors: ISS, IPRI, HU and ZADIG.

Being the work package leader (WP7), the role of ZADIG was particularly relevant in order to make sure that the newsletters were coherent with the other external communication documents such as the Pandemic Preparedness and Response Bulletin, the articles “news and features” published on the website, etc.



Before the publication of the first newsletter in June 2015, some very important preliminary work had been done by the partners involved in the task. This included for instance the creation of a template for the newsletters, a mailing list set up, the identification of relevant source of information dedicated to RRI (e.g. blog.rri-tools.eu, Journal of Responsible Innovation and many peer-reviewed medical journals). The collection of information and topic selection for each newsletter was done in a collaborative manner between the partners, as well as the newsletter's review before each publication.



All the ASSET newsletters are available on the project's website:

<http://www.asset-scienceinsociety.eu/outputs/newsletters>

And in the annexes of this deliverable.

Figure 1: Picture of the Newsletter's cover page



2. Objectives and content of the Newsletters

The responsible research and innovation newsletter was based on two main objectives: to inform on the latest news related to responsible research and innovation (2.1) and to provide updates on the project's milestones in line with RRI (2.2). To a lesser extent, the newsletters aimed also to provide brief information on forthcoming events, recently published articles, etc.

All the newsletters were produced with the same format containing four sections: Editorial, Focus, ASSET Progress, Event and News. For example, the index of the newsletter issue 2 was composed of the following topics:

- **EDITORIAL:** Patients' demands – a shift in the traditional science/technology centred approach
- **FOCUS:** Roadmap towards responsible and open citizens-driven research and innovation
- **ASSET PROGRESS:** Implementation of RRI through ASSET tools
- **EVENTS & NEWS**

In total, 18 articles have been provided through the project's newsletters and more than 35 brief news and events.

The selection of content to be published was the result of a collaborative process led by the task leader, Lyonbiopole, involving the task contributors. Following both objectives described above, the following sections (2.1 and 2.2) provide a more detailed overview of what has been published in the project's six newsletters.

2.1 Updates on latest news related to responsible research and innovation

Introducing the concept of responsible research and innovation (RRI)

The first newsletter (issue 1) set the scene regarding the concept of RRI with a "focus" article "What is at stake talking about Responsible Research and Innovation". This article was based on two reports published by the European Commission: *Responsible Research and Innovation. Europe's ability to respond to societal challenges* (EC 2012) and *Options for strengthening responsible research and innovation* (EC 2013). This two-page article consisted in an introduction of the concept in a transversal manner. The articles published in the following newsletters were much more focused on the field of antiviral drugs and vaccines.

RRI applied to field of vaccines and infectious outbreaks

For example, in the newsletter issue 2, the responsible ASSET partners decided to focus on the RRI scientific research working on the patient side by publishing an editorial called "Patients' demands: a shift in the traditional science/technology centred approach". The article aimed to demonstrate the relevance of a new approach where patients become active partners in the decision-making process with regards to their health and use of vaccines, therapeutics and medical devices.



Other news related to RRI were drafted in order to spread information on relevant publications on infectious outbreaks, e.g. on Zika (*Zika, the burden of uncertainty*, R. Villa. Clin Ter 2016), on Ebola (*On irresponsibility in times of crisis: learning from the response to the Zika virus outbreak*, Marko Monteiro, Clare Shelley-Egan & Jim Dratwa (2017), Journal of Responsible Innovation).

EU projects delivering on RRI

Furthermore, short articles highlighted the results on other European collaborative projects working in the field of RRI, such as the IMI project EUPATI (Enabling and Educating Patients to Give Meaningful Input into Drug Development) or the H2020 project Sparks engaging European citizens with the concept and practice of RRI through the topic of technology shifts in health and medicine.

Event announcements

Lastly, relevant events organised by external stakeholders or by the consortium partners were announced in the newsletters (the public workshop dedicated to Science and Music at the Verbier Festival, as well as the first, second and third edition of the ASSET Summer School).

2.2 Updates on the project's milestones related to RRI

The second main objective of the newsletter was to provide updates on the project's milestones related to RRI. In this respect, many articles have been drafted following the project's lifetime and results. The first issue of the newsletter provided an overview of the ASSET project's structure (work packages) and ambitions ("Creating a knowledge baseline – ASSET study and analysis").

Three main project's activities have been particularly developed in the newsletters: the RRI tools, the citizen consultation and the local initiatives.

The development of RRI Tools

After having established a study and analysis baseline, the ASSET project entered into an operative phase in which concrete tools were being set up. These tools (Mobilisation and Mutual Learning Action Plan, Action Plan Handbook and toolbox) have been presented in the project's newsletter issue 2. In the following newsletter issue 3, the priorities for the Mobilisation and Mutual Learning Plan of Action were described following six main cross cutting themes indicated by the RRI.

The citizen consultation

The citizen consultation was also a very relevant project's activity in the RRI field. That is the reason why three articles have been dedicated to this topic. A first "editorial" article in the newsletter issue 4 introducing the issue "What is at stake about citizens' consultation on epidemics?", followed by a focus on "The eight citizens' consultations of the ASSET project". In the newsletter issue 5, a third article aimed to describe the policy recommendations identified during the citizen consultation and their presentations at the European



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Parliament in Brussels. It also provided the link to all the detailed results of the consultation on the project's web tool.

The local initiatives

Another important RRI related activity took place during the last project's year: the local initiatives organised in the different partners' countries. Three articles described this project's activity from the elaboration of the local initiatives "Mobilisation and Mutual Learning: ASSET Local Initiatives", through their development "Update on the ASSET Local Initiatives" to their concrete delivery. The last newsletter issue 6 provide a complete overview of the 15 initiatives delivered in the partners' countries.



3. Dissemination of the newsletters

The project's newsletters had the objectives to make the ASSET research results known to academic and industrial stakeholders' groups in a targeted way, to enable them to use the results in their own work.

Two main dissemination channels have been used to disseminate the newsletter, namely the mailing list and the ASSET website.

Mailing list

The newsletter was sent by the ZADIG team via e-mail to a mailing list of 7424 contacts built together with the project's coordinator ISS.

The main targets were science journalists and communicators, health professionals from both public and private sector, national and international institutions.

To dispatch the newsletter a tool implemented within the website CMS has been used at the beginning of the project but it didn't allow the project's partners to keep track on the number of views and clicks on the links. That is the reason why, ZADIG proposed to use another tool and switched to phplist to send the newsletters.

As example, the newsletter issue 4 was visualised by 1685 persons, 1010 of them were unique visitors. The issue 5 was visualised by 1791, 1106 of them were unique visitors.



Figure 2: Tool used to disseminate the newsletter

Website

Once dispatched, all the newsletters, as well as all the bulletins and news alerts, have been uploaded on the dedicated page of the website. Under the section "Outputs", a specific page has been created on the ASSET website in order provide a repository for the RRI newsletters. All the newsletters have been uploaded by ZADIG on this page: <http://www.asset-scienceinsociety.eu/outputs/newsletters>

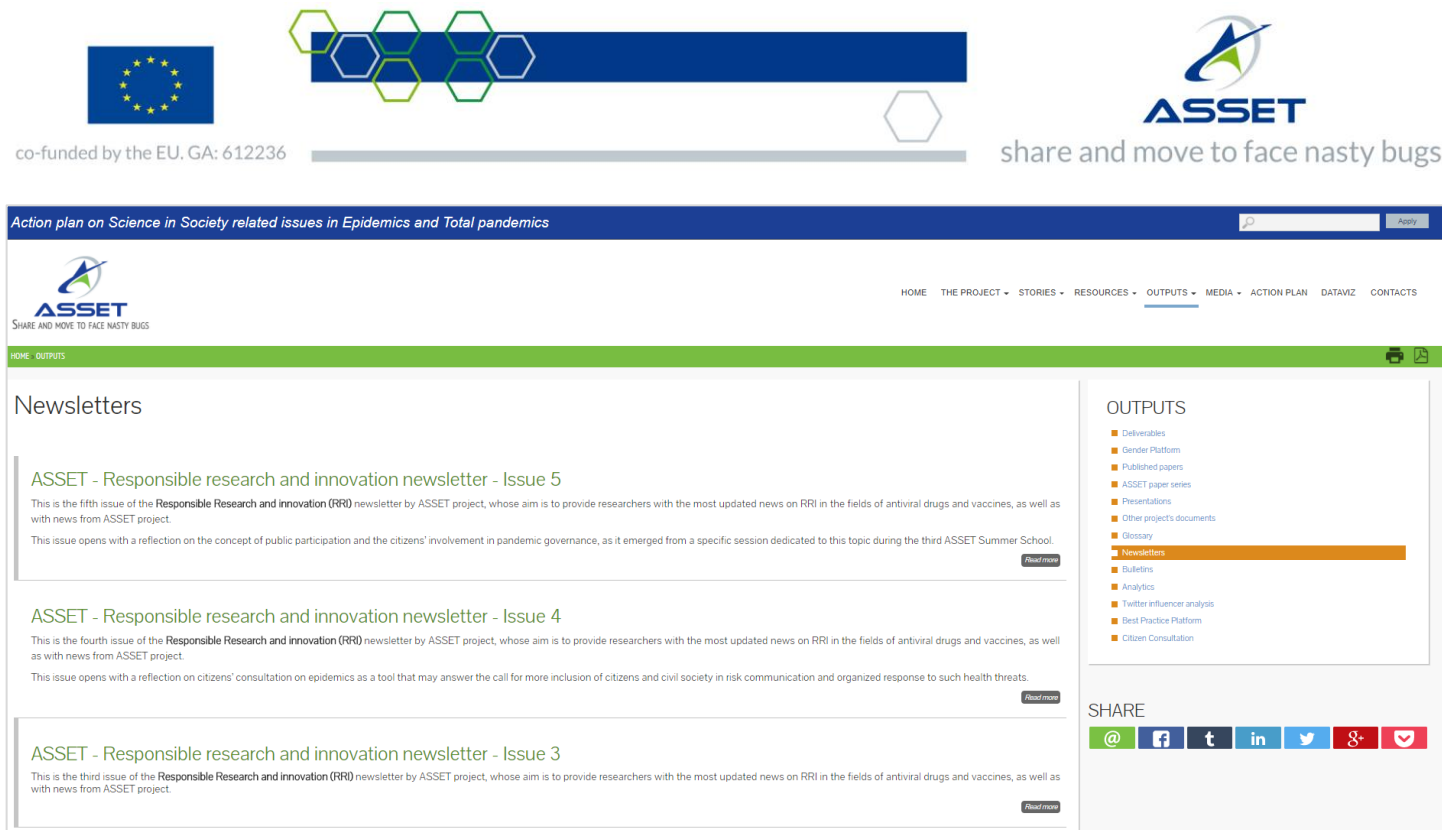


Figure 3: ASSET Web page dedicated to the newsletters

These newsletters will remain available on the project's website after the project's end and will remain a relevant source of information related to the RRI activities developed during four years within the ASSET project.

Beside those two main channels, the newsletters have also been disseminated through other channel, on the social networks and within the partners' networks.



Figure 4 : Twitter as dissemination channel for the newsletter

For example, Lyonbiopole has uploaded the newsletters on its own [website](#) and has spread it out within its own monthly newsletter in French (4359 contacts) and in English (730 contacts).

By doing this, Lyonbiopole has contributed to the targeted dissemination within the academic and industrial stakeholders of its own networks.

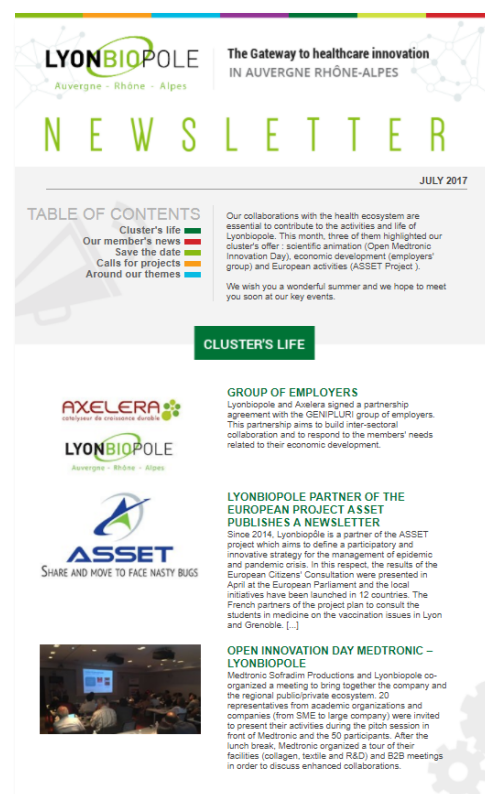


Figure 5: Article in the Lyonbiopole's Newsletter



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The newsletters have also been uploaded to the partners' websites in order to reach their own network:



PARTNERS IN PROLEPSIS

- » Preventive Medicine
- » Medical Research
- » Occupational Health
- » Environmental Health
- » Education
- » Statistics
- » Humanitarian Actions



CORPORATE SOCIAL RESPONSIBILITY PROGRAMS

Calendar

<< November 2017 >>

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19	20	21	22	23	24	25
26	27	28	29	30		

01 FEB Next Events

Newsletter

Μάθετε τις τακτικές δράσεις και τα τελευταία νέα της Prolepsis

Submit

Newsletter History

Institute of Preventive Medicine Environmental and Occupational Health

[Home](#) [The Institute](#) [Programs](#) [Cooperations](#) [Supporters](#) [Publications](#) [News](#) [Contact Us](#)



[Home Page](#) » [News](#) » **ASSET - Responsible research and innovation newsletter - Issue 5**

ASSET - Responsible research and innovation newsletter - Issue 5

July 13, 2017

The fifth issue of ASSET Newsletter is out. Prolepsis participates as a partner in ASSET project. ASSET aims to promote a cooperation with scientific institutions, that offer additional knowledge, perspective and experiences in order to effectively address scientific and social challenges raised during a pandemic and to be trained accordingly in Crisis Management.

This issue opens with a reflection on the concept of public participation and the citizens' involvement in pandemic governance, as it emerged from a specific session dedicated to this topic during the third ASSET Summer School.

Following that, the issue introduces the results of the eight citizens' consultations organized by the ASSET project, which have been presented at the European Parliament.

Finally, the issue presents an update on the local initiatives organised by ASSET project, with the aim of promoting mobilization and mutual learning at local level and to enhance the transferability of the most effective policies and practice.

You can read all the latest news [here](#).



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Relative links
<http://www.asset-scienceinsociety.eu/>

[Back](#)

Figure 6: Article on the Prolepsis website



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ANNEXES

All the ASSET Newsletters are available under this section:

- ✓ **Issue 1 – June 2015**
- ✓ **Issue 2 – December 2015**
- ✓ **Issue 3 – June 2016**
- ✓ **Issue 4 – December 2016**
- ✓ **Issue 5 – June 2017**
- ✓ **Issue 6 – December 2017**



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ENJOY READING THE ASSET NEWSLETTER

Providing you with news on RRI in the field of antiviral drugs and vaccines, in the framework of the ASSET project!

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ASSET PROGRESS: Creating a knowledge baseline – ASSET study and analysis	pg 4

Association Lyonbiopole - ISS - IPRI - University of Haifa - Zadig have collaborated to this first number.



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ASSET Action plan on Science in Society related issues in Epidemics and Total pandemics



EDITORIAL: THE ASSET EUROPEAN PROJECT

EVENTS & NEWS

First Edition of the Summer School on Science in Society related issues in Pandemics, 21st to 24th September, Rome – Italy

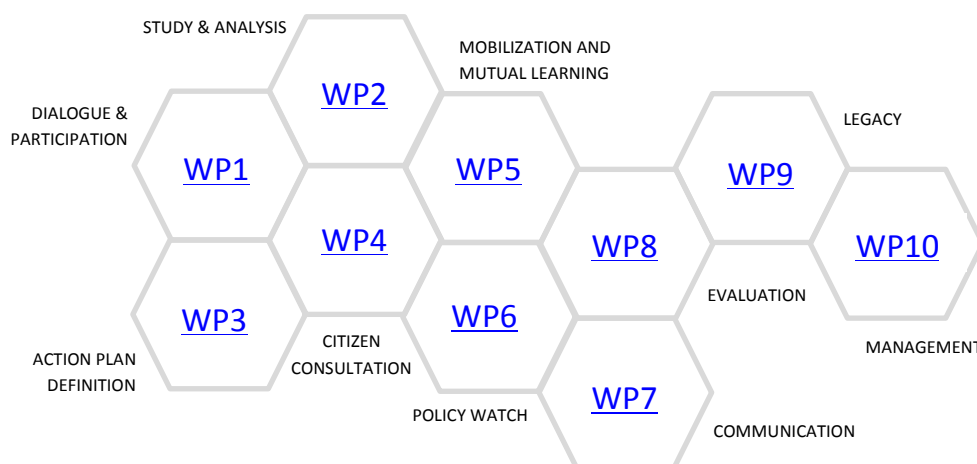
The ASSET Summer School aims at establishing an interactive learning space for researchers and practitioners in the field of Science in Society (SiS) related issues in Pandemics. It focuses on sharing and exchanging issues related to conducting and communicating research in SiS according to a transdisciplinary perspective, ranging from public health to social science and communication. The course will address and critically discuss current discourses on research methodologies and findings as well as on practice-based cases.

Deadline to register: 15th July 2015;
[here](#)

Have a look at the ASSET Pandemic Preparedness and [Response Bulletin "Share and move"](#), an updating tool on policy initiatives concerning pandemics and related crisis management, developed at local, national and international levels. This Bulletin - seven editions to be issued by December 2017 - deals with the latest key health data, information and indicators in matter of Public Health Emergency Preparedness (PHEP), Emergent Communicable Diseases, revisions of national pandemic plans and/or strategies, as well as of relevant statements and recommendations in the field.

ASSET (Action plan on Science in Society related issues in Epidemics and Total pandemics) is a four-year Mobilisation and Mutual Learning Action Plan, co-funded by the European Commission, started in January 2014 aimed at forging a partnership with complementary perspectives, knowledge and experiences. Scientific and societal challenges raised by pandemics and associated crisis management will be addressed, with the aim of exploring and mapping Science in Society (SiS) related issues in global pandemics. The final goal is to define and test participatory and inclusive strategies, in order to identify the necessary resources to make the action sustainable after the project completion

The ASSET newsletter will provide Researchers with the most update news on the Responsible Research and Innovation in the fields of antiviral drugs and vaccines as well as with the ASSET project news.





FOCUS: What is at stake talking about Responsible Research and Innovation

A report prepared for the European Commission emphasized that early consideration of an RRI approach in a field of innovation can help to ensure that research funding is not wasted and to identify developing fruitful markets that meet social needs.

European Commission (2013) [*Options for strengthening responsible research and innovation*](#).

The European Commission is determined to bridge the gap between the scientific community and society at large.

In 2001, the «Science and Society» Action Plan was launched with the main objective to foster public engagement and a sustained two-way dialogue between science and civil society and to build a framework for Responsible Research and Innovation (RRI). The grand societal challenges that we are facing will have a far better chance of being tackled if all societal players are fully engaged in the co-construction of innovative solutions, products and services.

Responsible Research and Innovation means that societal actors 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 the European society. RRI is an ambitious challenge for the creation of a Research and Innovation policy driven by the needs of society and engaging all societal players via inclusive participatory approaches.

The RRI framework consists of 6 key elements:

- **Engagement.** One of the ideas encouraged by the concept RRI, even if it can seem utopian and overoptimistic, is the mutual learning to develop joint solutions to societal problems.
- **Gender Equity.** Developed countries seem to have overcome gender differences; nevertheless research institutions need to keep a modern structure, particularly regarding their human resources management.
- **Science education.** To make change happen, education for future researchers is necessary; this might be achieved by launching creativity and encouraging children and youth towards maths, science and technology and, of course, creativity.
- **Open Access.** In order to be responsible, research and innovation must be both transparent and accessible for everybody. Nowadays scientific results are becoming underdeveloped due to the difficulty to access many publications and data due to their non-free online access.
- **Ethics.** Society is based on shared values, and that's why research and innovation must respect fundamental rights and legal aspects and display the highest ethical standards. However we all should try to discover if these standards suppose an advance or, if instead of that, they draw out high quality results.
- **Governance.** Policy makers have the responsibility to prevent harmful or unethical developments in research and innovation.

Source: European Commission. “Responsible Research and Innovation. Europe’s ability to respond to societal challenges”. 2012.





EUPATI - Enabling and Educating Patients to Give Meaningful Input Into Drug Development.

It is a collaborative public-private partnership project of 30 organizations that is funded by the Innovative Medicines Initiatives (IMI). It was formed to increase the number and capabilities of patients and related organizations to advise on drug development. The first “class” of 50 patients will “graduate” in November 2015. The EUPATI project will also develop an internet-based toolbox for patient advocates and a public Internet library covering all aspects of preclinical development, clinical trials, regulatory affairs, pharmacovigilance, benefit-risk assessment. (Source: [European Patients' Academy on Therapeutic Innovation](#)).

[Read more](#)

RRI and Patients' engagement in the development of medicines – issue and example

Stakeholders involved in the development of medicines insist on the necessity to refer to patients to better identify their needs and priorities. Inefficient drug development is partly due to the fragmentary or inconsistent patients' engagement. Consequently, unmet medical needs leads to a lack of required therapeutic options and high costs to society and involved partners.

On the contrary, what makes drug development innovative, more efficient and faster is the patients' involvement, delivering more relevant answers to patient's needs and allowing to earlier and better prioritization of research, improved resource allocation and improved trial protocol.

This also implies that the market success of medicines depends on their capacity to respond to patients' health needs that can be identified efficiently through direct and constructive interactions with them.

The patient's involvement is increasingly at the centre of drugs development process and many initiatives engaging patients exist.

RRI in ASSET: A Roadmap towards responsible and open citizen-driven, research and innovation on vaccines and antiviral drugs.

ASSET focuses on epidemics and pandemics and will link these subjects to users' involvement to elaborate a roadmap. The objective is to identify and establish best practices on how and when to involve users in the health-related Research and Innovation process and in the drug development. Based on this, the project will transpose relevant practices from other medical fields to the field of pandemics and epidemics.

Soon a virtual community to facilitate exchange of experience between partners of projects similar to ours and promote best practices will be created. It will be a good way to challenge the ASSET activities and learn from other initiatives with which ASSET partners may not interact on a regular basis.



ASSET PROGRESS: Creating a knowledge baseline – ASSET study and analysis

An updated Ebola vaccine: immunogenic, but will it protect?

The largest outbreak of Ebola virus ever recorded has been ongoing for about 16 months in West Africa. In the past week, Liberia, which had nearly reached the halfway point to being declared Ebola free, has reported a new case, and new Ebola infections continue to be confirmed in Sierra Leone and Guinea.¹ With more than 24 000 cases and almost 10 000 fatalities, this outbreak is one of the biggest public health crises so far this century. When the outbreak was first confirmed in March, 2014, none of the experimental vaccine platforms with promising results in non-human primate studies had advanced beyond assessment in phase 1 clinical trials in human beings, let alone been approved for human use.

[Read more](#)

Along with the roadmap, in its “study and analysis” workpackage (WP2), ASSET is establishing the state of art of research and existing studies on pandemics, and their wider societal implications, research and innovation in this area and the operational and regulatory environment.

ASSET and RRI: A two way dialogue between science and civil society

A guide on “Unsolved scientific questions related to pandemics and epidemics” aims at outlining the main unsolved scientific questions regarding pandemics, with particular focus on influenza and by taking as particular case study the H1N1 2009 pandemic. The global aim was to identify key points for an optimal preparedness in case of a possible future pandemic taking into account scientific expertise, citizen’s risk assessment and new governance models.

Several recommendations have been issued, among which: the World Health Organisation (WHO) should revise the pandemic guidance concerning phases in order to include other epidemiological indicators like severity; a key issue is the timeliness of availability of pandemic vaccines, and donation issues from the WHO stockpile; the regulation of vaccine distribution has to be needs-oriented more than market-oriented, equity of access during possible future pandemics is a priority; across hospitals coordination of resources is now mandatory; the potentially of managing large temporary influxes (triggered by pandemics) to hospitals and other health-care structures is one of the most important issues.

The analysis of Risk Communication during H1N1 showed that specific pandemic has been a turning point on Risk Communication during general pandemics. A number of issues were raised, here are some of the key challenges: transition to a two-way strategies of risk communication, i.e. with feedback from lower hierarchical scales and public to the top deciders; knowledge and exploitation of risk perception among the public; carefully adopt a transparent and coherent policy of communication of uncertainty; manage the scientific complexity of communication of risk during epidemics; full exploitation of Internet 2.0 through social media and smartphone-based apps; develop a paradigm to take care of cultural differences.

“Gender issues in pandemics and epidemics”: a societal perspective connecting with a scientific approach.

ASSET looked at gender differences that effect exposures to infectious diseases as well as access to, information on, and use of, vaccinations in pandemics and epidemics. By using a targeted gender approach, as well as including different population groups for example by age, socioeconomic status, minority status, and gender, a societal perspective is presented that connects with a scientific approach. This also helps highlight existing inequalities in health, as well as focus on prevention and viewing issues across the lifespan and not in isolation.



Some of the conclusions we can draw are first that special attention should be given to vulnerable and marginalised groups providing specific communication campaigns targeting hard to reach groups. Information campaigns could be more effective if the target groups are involved in the design and distribution of the information and to ensure that discrimination is recorded, and measures taken to counter the effects of equity. Research that targets women's attitudes to influenza and vaccinations is recommended. Promoting increased awareness among health professionals of specific problems faced by women of all ages in relation to vaccination is important. The standardisation of data collection methods in a sex/gender-disaggregated should be prioritized.

Epidemics and pandemics: the operational and regulatory environment

ASSET partners reviewed through the report "[Governance of pandemics](#)", the issue of governance of pandemics and epidemics from three interrelated perspectives: the World Health Organization, the pharmaceutical industry and the role of the media. Each perspective, involving a different stakeholder, participates in the process of risk communication, and perform its own role.

We examined past experiences of participatory governance, bringing research about pandemics closer to democratic institutions at all levels: the report "[Crisis participatory governance](#)" starts with effective risk communication that is entirely contingent on successfully identifying the cultural dimensions and priorities of the targeted groups. In doing so, it is critical that the identification is a result of an upstream and downstream, two-way communication process.

A very important aspect of pandemics crisis has been studied through a report named "[Ethics, laws and fundamental rights](#)"; the principal focus of this report is to provide an overview and discuss relevant ethical, legal and fundamental rights considerations in situations of public health emergencies, such as epidemics and pandemics.

The risk of intentionally caused outbreaks has been explored through the "[Report on intentionally caused outbreaks](#)". The objectives of this report are to collect and analyse relevant policy documents and create taxonomy of the main governance problems posed by the risk of intentionally caused outbreaks in democratic societies.

RRI in action through ASSET

Based on the ASSET "[Study and analysis](#)" WP, a **public consultation** will be carried out to make a concrete and policy-relevant example on EU level coordinated public consultation; to give input to policy-making about policies on pandemic crisis in terms of expression of informed ideas and opinion from near-representative samples of citizens and to engage citizens in the debate of pandemic crisis prevention and management.



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EDITORIAL: Patients' demands: a shift in the traditional science/technology centered approach

FOCUS: Roadmap towards responsible and open citizens-driven research and innovation

ASSET PROGRESS: Implementation of RRI through ASSET tools

EVENTS & NEWS



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EVENTS & NEWS

2nd Edition of the ASSET Summer School 15th-17th June 2016 Roma, Italy

The aim is to establish an interactive learning space for professionals involved in Science in Society (SiS) related issues in Pandemics; share and exchange issues related to conducting and communicating research in SiS according to a transdisciplinary perspective, ranging from public health to social science and communication; address and critically discuss current discourses on research methodologies and findings as well as on practice-based cases.

Professionals with a background education and a working experience in the several fields: medicine, public health, philosophy, social science, communication, health care, health economics, administration (max 20). Fields of education and working experience can be different. Additionally, PhD students undertaking courses of study in these areas are allowed to apply, too.

Look at the course [program](#) of the 2015 edition

ASSET High Level Policy Forum - brings together selected European policy-makers at regional, national and EU levels, key decision makers in health agencies, the pharmaceutical industry, and civil society organisations, in a unique and interactive dialogue to promote on-going reflection on EU strategic priorities about pandemics.

The second meeting will be organized in Copenhagen 15th January 2016. Here is the detailed [agenda](#)

Minutes from the first meeting is [here](#)

Have a look at the ASSET Pandemic Preparedness and [Response Bulletin](#) “Share and move” an updating tool on policy initiatives concerning pandemics and related crisis management, developed at local, national and international levels.

EDITORIAL – Patients’ demands: a shift in the traditional science/technology centered approach

The availability of information from several sources has shifted the traditional science/technology centered approach to a new one where the demands of patients and their relatives are central and they become active partners in the decision-making process with regard to their health. As a consequence, the success of new therapies and public health interventions is increasingly dependent on how the needs of users are taken into the account. The main health users are patients and their relatives and they ought to have the possibility to provide adequate information that would allow a better understanding of all medical process. Moreover, patients ought to be central in individuating the difficulties they encountered when using therapeutics, vaccines, and medical devices.

Until recently, input from patients was listened but not always taken into account. A more active participation of patients and structured interaction between main health users and health care professionals in charge of research and development (R&D) could certainly render R&D more efficient and effective.

However, the public collaboration in research until now has been accidental (de Wit et al, 2015) whereas it should be systematic.

As stated by Jenner et al (2015), lay members of biomedical research projects bring new views on practical aspects of the research that could help researcher to set up studies with realistic timescales and understand how the research can affect both patient and caregivers. Furthermore, experiential knowledge of patients is an added value that can complement scientific knowledge and also lead to better acceptance of research by patients [Elberse 2011]. The impact of Patient and public involvement (PPI) has been investigated in a literature review that concluded that public involvement has a positive impact on design, conduct and inclusion rate of clinical trials and is of particular value in qualitative research.

Source: http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf



FOCUS: Roadmap towards responsible and open citizens-driven research and innovation

Despite increased number of research programs involving patients, robust evidence on the outcome of Patient and Public Involvement (PPI- patients, care givers, health researchers and patients' organizations) is yet desirable. PPI could impact a research study at different levels, ranging from shaping research question to the choice of control arm, ethical issues and communication of the results.

One of the objective the ASSET project is to design a **“Roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs”**. It is supposed to answer the question to what extent, and according to which conditions, user innovation is possible in the field of research and innovation on epidemic infectious diseases prevention and response.

Summarizing the various and inter-related topics we illustrated in this report, we may sketch a tentative roadmap towards best practices for the PPI in biomedical research concerning pandemics:

- **BUILDING THE PPI: Rethinking of the research process and pipeline.**

The public collaboration in research should be systematic and it should start in the very beginning of the research process and throughout all the research process, with variable degree of involvement. Thus appropriate actions have to be implemented, by sensitizing stakeholders of public and private health research.

Users involved in a research project should not feel themselves as guests in the project but as intellectual co-owners without being influenced by professionals.

In the implementation phase of projects, civil society representative ought to be involved in the extraction of key points that follow in general data collection, as well as in the interpretation of research results, especially those that have more impact on their everyday life

it is important to establish a universal terminology that clearly defines the level and the extent of patient's participation in a health-related research. The creation of a consensus terminology will be very helpful for the evaluation of the impact of patient's involvement in health-related research.

- **KEY PLAYERS**

In order to implement a real PPI it is of utmost importance to involve a range of associations. First, general practitioners (GPs) can provide a unique expertise in some domain and that can also perform as an interface between professional researchers and civil society representatives. In the field of pandemic prevention it is highly appropriate to encourage/form new research network of GPs as integral part of projects in this area.

Other important key players are European and national associations of consumers. It is mandatory to sensitize them concerning the risks of possible future influenza pandemics and the relevance of their direct involvement in the related scientific and technological health research.



The example of HIV/AIDS

infection is perhaps among the most relevant areas where civil society organizations are involved in nearly all aspects of prevention and control efforts and drug development.

The European AIDS Treatment Group (EATG) is a voluntary membership-based patient organization that has been at the forefront of the development of the civil society response to the HIV/AIDS epidemic in Europe since its foundation in 1991.

EATG, together with the European Community Advisory Board (ECAB), addresses critical scientific questions around HIV drug-development and related co-infections. EATG holds also several trainings per year to help developing up-to-date treatment knowledge for people living with HIV/AIDS and their care providers.

<http://www.eatg.org/>

In France, HIV infected patients were actively involved for the preparation of the National campaign on **“Positive Prevention”**.

• COMMUNICATION AND EDUCATION

The mutual understanding between research and public health professional and civil society representative is fundamental for PPI.

Preliminary to all PPI projects it is crucial that all participants follow a training course in this field.

As far as the main communication tool is concerned, the Internet, one should encourage the set-up of validated and official internet sites. We need to educate citizens to refer preferentially to these sites. Actions should be enacted to foster the internet-based dialogue between biomedical scientists and patients as well as general public, thus making internet and its social networks both the first stage of the PPI and a tool to develop it.

• IMPLEMENTATION

Development of collaborative structures should start with a research effort (of course in collaboration with civil society) on how to implement bidirectionality in public health decisions.

Another pillar of implementation of PPI is that civil society has the burden of making aware scientists of a wide range of problems to be investigated and that are “orphans” until now.

It has to be supported the introduction of patients-reviewers for project design, scientific articles, grant applications. Moreover, PPI projects should be evaluated in order to assess the value and impact of such partnerships. This implies that specific measurement tools that could evaluate what work, and in which circumstances, have to be developed and validated.

On the contrary information on this kind of projects would be essential to enrich methodological research on PPI.

ASSET PROGRESS: Implementation of RRI through ASSET tools

BEYOND THE ASSET PROJECT

The monographic issue of **Vaccine**, published in August 2015 under the title “[WHO Recommendations Regarding Vaccine Hesitancy](#)”, is a collection of materials produced by a group specifically dedicated to the topic in 2012, under the combined leadership of the WHO and UNICEF.

[Learn more](#)

Science vs. fear: the Ebola quarantine debate as a case study that reveals how the public perceives risk

This study focuses on newspaper coverage of the Hickox quarantine incident, using it as a case study to examine how the media characterized the spread of disease in an ongoing crisis situation characterized by uncertainty. The study builds on Slovic et al.’s research, who argue that risk perception is comprised of both emotional and analytical aspects.

[Learn more](#)

After having established a study and analysis baseline, the ASSET project has entered into an operative phase in which concrete instruments are being set up.

The above presented Roadmap is part of the workpackage 3 “Action plan definition”. The following tools will compose this plan:

- **The Mobilisation and Mutual Learning Action Plan** aims to provide a framework for MML strategy and, consequently, for concrete actions and activities of the general ASSET strategy. This Action Plan plays the crucial role of indicating a clear focus not only for the actions to be carried out by ASSET members but also for relevant stakeholders’, to engage societal actors in research and innovation process and to create equal conditions for citizens’ engagement, possibly including also specific strategies into pandemics policies in the European member states.
- **The Action Plan Handbook** will provide a detailed description and timetable of Mobilisation and Mutual Learning actions. It will be composed of actions steps and include 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 Toolbox** will develop a set of relevant tools, including standard operating procedures, check-lists, templates, training materials etc. detailing the processes described in the Action Plan Handbook.

You will find soon those documents on the ASSET website.

Based on the ASSET [“Study and analysis” WP](#), a **public consultation** will be carried out to make a concrete and policy-relevant example on EU level coordinated public consultation; to give input to policy-making about policies on pandemic crisis in terms of expression of informed ideas and opinion from near-representative samples of citizens and to engage citizens in the debate of pandemic crisis prevention and management.



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EDITORIAL: Bring some “SiS” Themes into the public debate on epidemic preparedness and response

FOCUS: Industry in the process of epidemic preparedness and response

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ASSET Action plan on Science in Society related issues in Epidemics and Total pandemics



EVENTS & NEWS

2nd Edition of the ASSET Summer School 15th-17th June 2016 Roma, Italy

The aim of our annual Summer Schools is to establish an interactive learning space for professionals involved in Science in Society (SiS) related issues in Pandemics; share and exchange issues related to conducting and communicating research in SiS according to a transdisciplinary perspective, ranging from public health to social science and communication; address and critically discuss current discourses on research methodologies and findings as well as on practice-based cases.

Look at the 1st course [report](#) of the 2015 edition

The [Verbier Festival](#), the most famous classical music international event in **Switzerland**, will host an ASSET event on **July 30th 2016**, a public workshop dedicated to Science and Music. Moreover, a "Conference&concert" open to the general public will be organized alternating talks about epidemics/infectious diseases and a piano concert by an international artist.

ASSET High Level Policy Forum - brings together selected European policy-makers at regional, national and EU levels, key decision makers in health agencies, the pharmaceutical industry, and civil society organisations, in a unique and interactive dialogue to promote on-going reflection on EU strategic priorities about pandemics.

The second meeting was organized in Copenhagen 15th January 2016. Here is the detailed [agenda](#)

Minutes from the second meeting coming soon !

Have a look at the ASSET Pandemic Preparedness and [Response Bulletin](#) "[Share and move](#)" an updating tool on policy initiatives concerning pandemics and related crisis management, developed at local, national and international levels.

EDITORIAL – Bring some “Science in society” themes into the public debate on epidemic preparedness and

To build a more resilient society able to tackle epidemics and pandemics, it is of paramount importance to create conditions of co-operation between stakeholders, decision makers, health professionals, scientists and the citizens. For that purpose, during the last few years, the European Commission has promoted a “Science **with** and **for** Society” approach.

Consequently, a particular project approach called the Mobilization and Mutual Learning Action Plan (MMLAP) was promoted by the European Commission to create potentially useful co-operation conditions between the scientific community, policymakers, citizens and their stakeholders.

ASSET Action Plan Handbook is a concise and practical executive manual, which includes detailed description and timetable of Mobilisation and Mutual Learning actions. Its main objective is to explain clearly and practically how ASSET project could contribute to bring some “Science in Society themes” (i.e. Crisis Participatory Governance, ethical and gender issues, transparency, and so on) into the public debate on pandemic and epidemic preparedness and response.

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.

Action plan handbook is based on the objectives, strategies and actions outlined by the “**ASSET Strategic Plan**” and by the “**Roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs**”. All of these three tasks take advantage of the capacity building activities of “Dialogue and participation” (WP1) and are based on the results of “Study and Analysis” (WP2). Tools mentioned in this plan will be further described in the “**ASSET toolbox**”.

The Action plan coordinates the scheduled activities of citizens’ consultation (WP4), mobilization and mutual learning (WP5), policy watch (WP6) and communication (WP7), in order to improve their efficacy and effectiveness under the monitoring of internal and external evaluation (WP8), with some proposals for a legacy of ASSET project (WP9).



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The example of “A catalogue of good practice standards in RRI” – RRI Tools European project (FP7)

This catalogue constitutes one of the tools for the toolkit that RRI Tools is developing. The goal of the catalogue is to instruct stakeholders in research and innovation (R&I) provided us with part of the rationale for including practices in this catalogue. That is to say, it could be argued, when looked at from the conceptualization of RRI developed in the RRI Tools project that many of the practices in this catalogue could still be improved upon. Nevertheless, they all deserve their place in this catalogue insofar as they provide inspiration to others who work in research and innovation on how to put into practice one or more aspects vital to RRI. Aspects that matter in this regard are rather wide-ranging. They include the requirements that R&I processes should fulfil to promote responsibility, various types of outcomes characteristic of responsible research and innovation, the policy agendas that the European Commission has identified (Ethics, Gender, Governance, Open Access, Public Engagement, and Science Education), and the Grand Challenges that have likewise been singled out by the European Commission (in short, Health, Food security, Energy, Transport, Climate, Europe in a changing world and Security).

FOCUS: Industry in the process of preparedness and response to epidemic & pandemics

ASSET wants to communicate and mobilise **all the actors** involved in the processes of preparedness and response to epidemic and pandemics, but language, tools and contents of these actions **need to be diverse**. We have defined six groups of possible stakeholders, even if some of them include different actors with different roles in epidemics and pandemics. An actor may be included in more than one group, as well. However, here we are concerned with the groups, and not individual actors.

Pharmaceutical industry is an important stakeholder in the management of an infectious crisis. Especially in a historical phase when public research funding is increasingly being cut by governments because of scarcity of resources, the role of private companies is the key not only for producing and supplying, but also for developing new antivirals and vaccines.

Modern technologies, such as reverse vaccinology, could further accelerate the process in case of an emerging virus, when time is the key for efficacy and effectiveness of vaccination. In 2009, for example, vaccines could be supplied only after the peak of the pandemic, making them less useful. Now, it would be easier to have them in a shorter time.

Clear and transparent agreements with big firms currently working on vaccines are therefore essentials for WHO, but should also be signed by any country. A coordinated effort by all EU Member states, with a common negotiation, could obtain better conditions in terms of costs and flexibility.

Since the public always considers relationships between big pharma and public health authorities with suspect, **a strict policy on potential conflicts of interests** should be developed and transparency should be always pursued.

At last, in a Science-with-and-for-society perspective, along with pharma industry, also **diagnostics sector, airlines, farming, livestock, and many other economic activities** could be possibly impacted in different ways and cases by an infectious outbreak and should be therefore addressed in complete and integrated preparedness plans.





BEYOND THE ASSET PROJECT

Zika, the burden of uncertainty

R. Villa. Clin Ter 2016; 167 (1):7-9.

In the first phases of an infectious outbreak, health authorities have to face the challenge of communicating uncertainty. Just when the attention of the public is at the top, information about what is going on is usually still missing. This is the case of Zika crisis in Latin America, where an association with microcephaly in newborns and neurological complications have been described, but not yet confirmed. Despite this, and even if the risk would be mainly limited to pregnant women, Zika threat is perceived by the general public as greater than others, such as those from dengue or flu. Some peculiarities of this outbreak explain such a gap between real and perceived risk. Nevertheless, in such a situation, WHO and other health authorities have the duty to act out of an abundance of caution, aware of the lose-lose game they are going through: if they raise alarm, and this subsided, they could be accused to fuel people's fears because of economic interests, as it happened in 2009 A (H1N1) pandemic; if they underestimate the threat, they could find themselves in front of a global tragedy.

More information here

ASSET PROGRESS: CREATION OF CONCRETE RRI TOOLS

Strategic plan lines of actions:

The ASSET partners implemented an extensive and inclusive process to develop a strategic plan aimed to outline in the field of Pandemics or Infectious Emergencies the priorities for the Mobilisation and Mutual Learning Plan of Action following 6 main cross cutting themes indicated by the RRI. For the aspects considered as priority, a strategy action line has been consequently developed:

- Improving **governance** to increase trust between policy makers, the media, and the public
- Engaging the **research community** with the **public** and other stakeholders to establish priorities based on appropriate values, and to provide open and understandable access to scientific outcomes
- Increasing influenza pandemic **awareness** among healthcare workers, and among the broader public, especially high-risk groups
- Engaging the public, policy makers, and other stakeholders to promote **ethical best practices** in the event of public health emergencies, balancing fundamental personal rights, duties and responsibilities, societal issues and priorities, and political considerations
- Improving **vaccination rates** among women, and better representing women in research and clinical trials
- Promoting policies across Europe to coordinate and **standardize** research into and **response to intentionally caused outbreaks**, engaging the public to develop approaches that balance security, personal freedom, and community perceptions and priorities.

A set of relevant tools (toolbox) is being developed, including standard operating procedures (SOPs), checklists, templates, detailing the processes described in the Action Plan Handbook.

The toolbox will be available soon.

Give us your opinion on the RRI Newsletter to improve it:

Is it bringing to you useful information about RRI?

What would you like to add or modify?

Visit the [ASSET website](#) to discover more about the activities of the project!



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EDITORIAL – What is at stake about citizens’ consultation on epidemics?

EVENTS & NEWS

3rd Edition of the ASSET Summer School from 30th May to 1st June 2017 Roma, Italy

The aim of our annual Summer School is to establish an interactive learning space for professionals involved in Science in Society (SiS) related issues in Pandemics; share and exchange issues related to conducting and communicating research in SiS according to a transdisciplinary perspective, ranging from public health to social science and communication; address and critically discuss current discourses on research methodologies and findings as well as on practice-based cases.

Look at the 2nd course [report](#) of the 2015 edition.

ASSET High Level Policy Forum - brings together selected European policy-makers at regional, national and EU levels, key decision makers in health agencies, the pharmaceutical industry, and civil society organisations, in a unique and interactive dialogue to promote on-going reflection on EU strategic priorities about pandemics. The second meeting was organized in Copenhagen 15th January 2016. Here is the detailed [agenda](#). Minutes from the second meeting coming soon!

Have a look at the ASSET Pandemic Preparedness and [Response Bulletin](#) *“Share and move”* an updating tool on policy initiatives concerning pandemics and related crisis management, developed at local, national and international levels.

In epidemics and pandemics rumors and parallel informal information systems have challenged effective risk communication by health workers and authorities. Research studies have shown that rumors perpetually surface in situations that entail power asymmetries. Such situations often arise when knowledge is contested or is left to a small group of highly technical experts to unravel. Individuals or groups left outside such confined knowledge-hubs often produce their own version of the reality, in effect creating ‘rumors’. Such rumors constitute parallel information systems which are linked to the application of top-down communication systems and absence of genuine two-way communication systems.

The loss of confidence in international and national health authorities has had a strong impact on vaccination too, affecting not only flu, but also other infectious diseases. Since 2009, false myths about risks of vaccines have changed attitudes of many families, contributing to reduced immunization rate in some areas, leaving clusters of children unprotected, i.e. against polio, and preventing the achievement of important goals, such as measles eradication from Europe.

Rumors form rapidly during the outbreak of a crisis. Despite efforts by the authorities to deliver correct information, a social reality has arguably already been formed, which rational information is unable to alter. However, whereas rumors are an answer to a call for information from citizens, Crisis Participatory Governance practices, such as citizens’ consultation, might answer this call with better information and alter the spread of rumors.

The challenges confronting policy-makers and health practitioners’ today call for more inclusion of citizens and civil society in risk communication and organized response to epidemic and pandemics threats, in such a way that rumor will not be the main information channel.

Crisis Participatory Governance starts with effective risk communication that is entirely contingent on successfully identifying the cultural dimensions and priorities of the targeted groups. In doing so, it is critical that the identification is a result of an upstream and downstream, two-way communication process.



FOCUS: The eight citizens' consultations of the ASSET project

The example of [CoReVac](#) consultation in France:

CoReVac gathers partners from research institutes and units involved in vaccine researches, involving basic, pre-clinical, translational, clinical, epidemiological and societal researches, as well as industries, stakeholders funding those R&D efforts and public health bodies involved in vaccine implementation.

COREVAC organised a citizens' consultation on vaccine and established a [report](#), published the 30th November 2016.

Presided over Professor Alain Fischer, the committee of this large concertation aimed at identifying the civil society questions about vaccination and to give concrete propositions towards the very important problematic: restore trust towards vaccines.

To sum up, the committee recommends to improve the communication about vaccines by the implication of health care workers, schools and the medias. One of the major recommendation of the committee is to extend the obligation to vaccinate to include 11 diseases and not 3 as it is the case now.

Good governance is the backbone for equitable and sustained development and effective participation by all people have come to be viewed as a necessary requirement. Participatory governance means including citizens in decision making that has implication for their wellbeing, and transparency in the decision making and implementation processes. This is particularly important during the time of crisis, as people become the center of both providing aid and receiving it.

In that framework, the ASSET partners organized at the same time **citizens' consultations in 8 different European countries** (Italy, Switzerland, Ireland, Denmark, Norway, France, Bulgaria and Romania). In total 424 European citizens participated.

The aim of the ASSET Citizen Consultations was to **understand how European citizens think about epidemic and pandemic preparedness and response**.

Citizens participating in the project reflected the demographic distribution of the general population in each country with regard to the following parameters:

age, gender, geographical zone (city and countryside, specific region), educational level, occupation, other criteria of national relevance.

It was also important that all participating citizens were lay people, meaning that they should not be people working professionally with health care. Neither could politicians or officials working for the government with public health.

Round tables of 10 participants were organised and the debates were framed by one "round table facilitator" whose role was to be neutral and keep people focused on the subject of each session. In France, PhD students from different backgrounds were recruited. They are used to reflect on different subjects, analyse and write about them while keeping neutral. So, it was a real added value to get them involved in that experience and citizens gave them much credibility as "university students".

Four themes all relevant to epidemic and pandemic preparedness and response have been determined beforehand by the project partners to provide the citizens with background information on the themes that were discussed during the ASSET citizen consultations: 1- Balancing individual rights and the common good in the event of epidemics or pandemics; 2- Communication between citizens and public health authorities; 3- Transparency in crisis situations; 4- Trust, Action and Access to Knowledge.

Once at the meeting they have been asked to vote on questions related to each topic. The questions and the information material were the same at all eight citizen consultations.

Following the meetings, ASSET partners then compared the results to see similarities and differences among countries. The analysis will be the object of a Policy Report that is on the process of drafting now. It will contain recommendations that have been identified by the citizens.

In April 2017, ASSET partners will hold a **workshop in the European Parliament** during which the consultations process and results will be presented and discussed.





ASSET PROGRESS: Mobilisation and Mutual Learning: ASSET Local Initiatives

BEYOND THE ASSET PROJECT

Population consultation, two-way communication and decision – good practice from the USA.

In 2009, in USA, the Association of State and Territorial Health Officials (ASTHO) [surveyed the population](#) on their attitude towards vaccination, in order to adapt their communication messages and clearly and accurately promote the benefits of vaccination in ways that resonate with family decision makers. A total of 1,278 parents and guardians were interviewed using an online established survey panel.

The collected information was afterwards used to create a toolkit for communication for health officers to use, including methods of effective communication about vaccines, key messages to communicate, but also personalized messages depending on the target audiences. In 2010, draft messages issued from the toolkit were tested in focus groups of mothers in Atlanta, Washington D.C. and Seattle. Feedback from these focus groups was incorporated in the final messages.

RRI is an inclusive approach to research and innovation, to ensure that societal actors work together during the whole research and innovation process. It aims to better align both the process and outcomes of Research & Innovation, with the values, needs and expectations of European society.

In that framework, ASSET is putting in place 12 local Initiatives (to be developed in: Rome, Milan, Paris, Lyon, Dublin, Athens, Brussels, Oslo, Sofia, Bucharest, Geneva, Haifa) and aim to promote mobilization and mutual learning at local level and to enhance the transferability of the most effective policies and practices.

They will be based on a fourfold strategic approach:

- 1) Share valid and all relevant information;
- 2) Combine advocacy with scientific inquiry and innovation processes;
- 3) Jointly design ways to test disagreements between stakeholders;
- 4) Always promote reflective practices to enlarge the portfolio of ideas.

The overall goal of this investigation is

- to experiment an effective two-way communication;
- to conduct a dialogue according to a methodological process and relational skills (empathy, self-awareness, active listening);
- to try capturing the “spirit of the place” about infectious outbreaks, the specific way(s) in which people living in a given city or region perceive, and react to, the pandemic threat;
- to involve local stakeholders to share information, decisions and policies/practices;
- to provide an opportunity to local actors and stakeholders to feed the action with their contents and to co-design the action itself.

Local initiatives will be based on a **participatory** communication approach and conducted for example in hospitals towards health care workers asking them about their perception of vaccination and also towards students who are often not familiar with flu vaccinations and channels to be used in case of epidemics.

They will be **women**-friendly balanced guaranteeing gender representations, culturally appropriate, and delivered at a place and time allowing women’s participation.

Visit the [ASSET website](#) to discover more about the activities of the project!





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EDITORIAL: Citizens' involvement and public participation in pandemic governance

Event & NEWS

3rd Edition of the ASSET Summer School in Roma, Italy

From May 30 to June 1, 2017, the Third ASSET Summer School was held at the National Centre for Disease Prevention and Health Promotion of the Italian Institute of Public Health in Rome. Thirty people worked on thematic focuses such as vaccination and current vaccine hesitancy; an intentionally caused outbreak of botulism; Zika virus and gender related issues; etc. Read the [details](#) on the ASSET website

Publication of the Policy Report

The aim of the report is to present the results of the citizen consultation focusing on concrete policy recommendations. Find the complete report [here](#)

ASSET final conference in Autumn

"A mobilization and mutual learning event at local, national and international levels on Science in Society related issues in epidemics and pandemics". The concluding conference will be held in autumn in order to present the main outcomes of the action to a selected audience of EU stakeholders and policy makers.

More info to come soon!

During the third ASSET Summer School, a specific session was dedicated to the concept of Public Participation and the citizens' involvement in pandemic governance.

Before focusing on their involvement in health governance, it has firstly been recalled what the **concept of public participation** (PP) is and why it is becoming always more relevant. As reminder and according to Nabatchi and Leighninger definition, "*Public participation is an umbrella term that describes the activities by which people's concerns, needs, interests, and values are incorporated into decisions and actions on public matters and issues*". The PP is relevant in many dimensions: (1) **Morally** because citizens have a right to be involved in decisions and discussions that affect them; (2) **Instrumentally** by increasing the legitimacy of a process; (3) **Substantially** through the valuable knowledge held by the public. After a short exercise, the participant agreed on the fact that a good PP should be **transparent, inclusive, adaptive, well-timed, well proportioned**, and should have a plan for political buy-in. Diverse forms of PP have been listed in two categories: **Indirect participation** (voting, donating money...); **Direct participation** (Thick participation, Thin participation, conventional participation...)

During the second part of the session, the **concepts has been applied to PP in public health** and especially in epidemic or pandemics governance. Considering the challenges faced by Health Authorities (such as making decisions in conditions of sparse and uncertain information, struggling with disseminating information to relevant communities, with rumors, parallel information systems, bridging gaps in cultures, traditions and understandings of health care practices...), the involvement of citizens in the definition of epidemic and pandemic governance is more than relevant.

In this respect, the ASSET partners have launched a public consultation, involving more than 400 hundred citizens from 8 European countries (see Focus in [Newsletter – Issue 4](#)). A follow-up strategy has been designed to provide relevant Institution with the results of this citizen consultation at the European (see next article for the dissemination of the results at the European Parliament) and National governance levels.



FOCUS: The Citizen Consultation presented at the European Parliament

Have a look at the **ASSET Pandemic Preparedness and Response Bulletin** published in February 2017, an updating tool on policy initiatives concerning pandemics and related crisis management, developed at local, national and international levels.

ASSET Scientific publications in the pipeline

Two articles have been submitted for publication by the ASSET partners related to:

- News insights on Unsolved Scientific Questions related to Pandemic and Epidemics
- Roadmap towards responsible and open, citizens-driven research and innovation

A third article is being prepared related to:

- Vaccine Hesitancy, Vaccine Refusal and Mandatory Vaccination

News in the Journal of Responsible Innovation

A new paper has been published offering some first thoughts regarding the current Zika virus outbreak and the immediate response it generated in health and research policy:

“On irresponsibility in times of crisis: learning from the response to the Zika virus outbreak”, Marko Monteiro, Clare Shelley-Egan, and Jim Dratwa

Read the full paper [here](#)

The ASSET partners have presented the results of the citizen consultation that took place in eight countries on September 2016 at the European Parliament. The partners have raised different **findings of the consultations** showing for example that citizens across Europe are willing to follow the advice from health authorities. Furthermore, in an emergency situation, citizens even supported the infringement of individual rights for the collective good. However, citizens emphasized that public health authorities must communicate in an honest and transparent manner. Participants in the meeting urged general practitioners and authorities to increase their online presence and to engage in dialogue with their publics. The public desires clear and updated information on vaccination and pregnancy and believe that improved communication and dialogue can restore trust and build better relationships between health authorities and publics. Finally, citizens in the meetings expressed a desire for opportunities to provide input for policy development and action in the case of epidemic or pandemic crisis. Find more about the consultation in the ASSET [Policy Report](#).

The consultation has highlighted six concrete policy recommendations:

Trust in information

The GPs should be trained to adapt to the changing society, and decision-makers should be urged to be visible and present at the internet, as the use of the internet is increasing

Risk Communication

Build a transparent and clear risk communication to restore trust towards society

Pregnancy and vaccination

Update, clarify and standardize influenza vaccination advice materials for pregnant women

Ethics

In an emergency situation, public health interests should infringe upon the individual freedom

Citizens' voices

The 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

Lessons learned and citizens participation

Public health authorities should devote more resources to collect citizen's input to policies on epidemic preparedness and response

Bringing citizen consultation results to the attention of public institutions and decisionmakers at different level of governance is a major objective of the ASSET project, as well as encouraging dialogue and development of an integrated and transdisciplinary strategy by combining expertise in public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media.

All the detailed results of the consultation are available on our [web tool](#).



ASSET PROGRESS: Update on the ASSET Local Initiatives

BEYOND THE ASSET PROJECT

Other RRI initiatives produced in Horizon 2020 projects:

- **Citizen in Medicine Hackathon**

[Sparks](#) is a project engaging European citizens with the concept and practice of RRI through the topic of technology shifts in health and medicine. Sparks promotes RRI by inviting key stakeholders to actively question, experiment and play with science in a way that makes it relevant to today's society. The hackathon brought together doctors, designers, engineers, artists, students of technical faculties, material scientists and researchers from different fields in order to find ways of improving a medical procedure implemented by foetal surgeons to save the lives of babies with diaphragmatic hernia in the foetal period.

- **Training for industrial actors**

[SMART-map](#) project aims to define and implement concrete roadmaps for the responsible development of technologies and services in three key game-changing fields: precision medicine, synthetic biology and 3D printing in biomedicine. The project develops a new format for open and collaborative dialogues between industry and societal actors (Industrial Dialogues) which will allow the co-design of a tool (a smart map) that helps companies to address questions of social and environmental responsibility they face in their innovation processes.

The ASSET project aims to promote mobilization and mutual learning at local level and to enhance the transferability of the most effective policies and practice. As presented in the last newsletter ([Issue 4](#)), 12 local initiatives are currently being developed in the ASSET partners' cities.

In this respect, the European Institute of Women's Health based in Ireland was responsible for liaising with local schools to disseminate the activities of the ASSET project. The Institute started a collaboration to teach the students more about infectious diseases epidemics and pandemics. As results, in terms of their knowledge of infectious diseases, pandemics and epidemics, the students presented a mixed picture. They were overall fairly familiar with epidemics/pandemics, especially more recent ones (especially Ebola).

Regarding the communication aspects, an overwhelming number of students stated that their chief mode of communication was social media and the internet. It was the communication channel they used the most, the one they would prefer public health authorities to use during a pandemic/epidemic, and the one they would use to get information regarding pandemics and epidemics. In terms of the type of social media used, Facebook was the most popular one, followed closely by Snapchat. Interestingly, only 2 students said they use Twitter the most.

Learn more about the results of this initiative [here](#).

Other local initiatives already took place in the following cities:

- Milan, Italy (May, 25) – Malpensa International Airport: Management of emerging infectious diseases crises in an airport setting
- Rome, Italy (March, 15) – ISS in the framework of School-Workplace alternation
- Sofia, Bulgaria (March, 29) – Health Care Workers opinions on key themes, such as vaccination, communication channels.
- Kfar Saba, Israel (from January 2016 to June 2016) – involvement of students from 13 classes of the Katznelson High School

A final, comprehensive report presenting all the results of the 12 local initiatives will be delivered at the end of the project life time, stay tuned!

Visit the [ASSET website](#) to discover more about the activities of the project!



share and move to face nasty bugs

ENJOY READING THE ASSET NEWSLETTER

Providing you with news on RRI in the field of antiviral drugs and vaccines, in the framework of the ASSET project!

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ASSET Action plan on Science in Society related issues in Epidemics and Total pandemics



EDITORIAL: Final Event of the ASSET project in Rome, October 30-31

Events & News



New Horizon 2020 Work Programme “Science with and for Society” The [SWAFS Work Programme](#) 2018-2020 has been developed to reflect and support the evolution of science and society and the increased emphasis on their interplay at national and EU levels. There is recognition that co-design with citizens, stakeholders and end-users needs to be promoted in all policy instruments.

Register to the Infoday and brokerage event [here](#), on January 29th in Brussels.

Best Practice Platform: voices from coordinators In order to improve the effectiveness of the Best Practice Platform, interviews of the coordinators of some relevant initiatives have [been uploaded to the database](#). These interviews provide further information related to the European Immunization Week (EIW), Immuniser Lyon, the French Citizen Consultation on Vaccination, and the Health mediation program in Bulgaria.

The ASSET Final Event was held on October 30-31 and structured in order to reflect the ASSET Project Action Plan focusing on the six main Science in Society (SiS) themes for a Responsible Research and Innovation (RRI) applied to the field of pandemic and epidemic preparedness and response. The ASSET Final Event included the brokerage event (with electronic and paper poster displays, videos, interviews, social media corners, etc.) and the conference (3 plenary sessions and two slots of 3 parallel sessions each).

During the first plenary session on October 30th, the ASSET project has been presented to the stakeholders. In line with the European research programme, Michael Sulzner (European Commission, DG Health) presented relevant strategical topics and projects related to vaccination at the EU level, such as the Influenza preparedness in the context of the One Health Strategy, the challenges related to seasonal influenza vaccination, and the Joint Action on vaccination currently under preparation (starting early 2018).

In the afternoon, 3 parallel sessions took place on the following issues: “Unsolved questions and open access”; “Participatory governance and Science education”; “Ethical issues”.

The second plenary session, on October 31st, aimed to discuss vaccine hesitancy based on the Italian experiences and perspectives. In this respect, the Italian national and local level were represented by Stefania Iannazzo from the Italian Ministry of Health, and by Alberto Perra from a Local Health Unit.

Indeed, in January 2017, a new vaccination schedule was adopted at the Italian national level, with an increased planned supply of vaccines, especially during the first year of life, and a recent Law enforcing compulsory immunization with 10 vaccines mandatory. The tangible effect of vaccination hesitancy and influence of the recent law were discussed during the plenary session.

Following this plenary session, 3 parallel sessions took place on relevant RRI issues: “A matter of policy”, “Lay public engagement - let’s be social”, “Gender implications”. Lastly, the third plenary session was based on the perspectives on the European research focusing for example on the open scientific issues.



FOCUS: New insights on unsolved scientific questions related to pandemics

New Vaccines against Epidemic

Infectious Diseases Recently published in the New England Journal of Medicine, this [article](#) presents the newly formed international Coalition for Epidemic Preparedness Innovations (CEPI) which aims to stimulate, finance, and coordinate the development of vaccines against epidemic infectious diseases, especially in cases in which market incentives alone are insufficient.

Risk Communication in times of an epidemic or pandemic

Read our [5th ASSET paper series](#) on the positives and negatives of using modern technology to communicate risk.



European Patients'

Academy on Therapeutic

Innovation is a patient-led initiative that uses training courses, educational material and an online public library for empowering patients to engage more effectively in the development and approval of new treatments and become true partners in pharmaceutical research and development. [Learn more here.](#)

The final event organised by the ASSET consortium was a great opportunity to discuss further the unsolved scientific questions related to pandemics and epidemics and to present the project's results achieved in this field.

Following the proposals of the *Experts Groups on Science, H1N1 and Society*, designed by the European Commission, the ASSET project elaborated a [Reference guide](#) on unsolved scientific questions raised by the H1N1 and the associated crisis management. The aim of this work was to outline – by stressing the viewpoint of Science in Society - the main unsolved scientific questions regarding epidemics and pandemics, focusing on the H1N1 2009 pandemic. We complemented our analysis by means of a questionnaire, sent to experts in the field of pandemics and epidemics, and of a focused workshop.

We observed large heterogeneities across Europe in legal systems, various initiatives taken by the Member States and heterogeneous results obtained in terms of vaccine delivery, vaccination uptake, and infectious controls measures.

The analysis of risk communication (RC) showed the lack of transparency and coherence of the process and the messages transmitted by authorities. Rumors and suspicions regarding adverse effects of vaccines have shaken people's trust in vaccination, contributing to what is known as a post-trust society. The most frequently research areas considered as "vital" for future pandemic preparedness were: effectiveness of antiviral drugs; technology transfer, mechanism of virus emergence; epidemiological tool for early detection of outbreaks; standardization and flexibility of pandemic plans; sociological aspects of vaccination, efficiency of social distancing and how to optimize the use of mathematical models.

In conclusion, establishment of a real framework by the Member States to identify avenues for improvement of future influenza pandemics management is warranted. Re-building the trust in the current "post-trust" society requires effective RC campaigns that consider the social and cultural heterogeneity of the target population. It is also crucial to exploit and anticipate the role of Social Networks and Internet and integrate their use in communication strategies. Risk communication can no more be unidirectional but, to some extent, it ought to be bidirectional.



ASSET PROGRESS: Completion of 15 local initiatives all over Europe

Gender stereotypes in medical and research practices

Down with clichés! is a Web-series available to the public, physicians and researchers. These [6 video-clips](#) alert us about gender stereotypes in medical and research practices to improve health care for women and men. Partners: Inserm, CNRS, MEDSRI, University Paris-Diderot, University Paris II and the Institut universitaire de France.

The big challenge of communicating about vaccines safety

Vaccines are very safe, but occasionally they can cause severe reactions. Patrick Zuber, group leader of the WHO Vaccine Safety team, says that it is very important to explain to the public what we know about this risk and how we can reduce them. However, even more important is to explain the benefits of vaccines. Last but not least, people should be informed of what is in place to monitor and continuously ensure the safety of vaccine.

[Watch the video](#)

As explained in our previous newsletters, the aim of the ASSET local Initiatives was to promote mobilization and mutual learning at local level and to enhance the transferability of the most effective policies and practice.

The project's partners have developed 15 local initiatives in many diverse cities (Rome, Milan, Lyon, Dublin, Athens, Brussels, Oslo, Sofia, Bucharest, Geneva, Haifa) involving different kind of stakeholders (family doctors, nurses, educators, health care providers, public health officers, policy-makers, communicators, consumers, students, etc.) The overall goal of this investigation has been set out in order to:

- capture the “spirit of the place” in line with infectious outbreaks, the specific way(s) in which people living in a given city or region perceive and react to the pandemic threat;
- involve the local stakeholders to share information, decisions and relevant policies/practices at community level.

The complete overview (see table on the next page), it is clear that health care workers (HCW) and students are the targets most suitable to mobilization and mutual learning action: 6 local initiatives to professionals and other 6 to the young people. These initiative with young people and children confirmed that collaboration with schools remains a common health promotion practice.

Three local initiatives address peculiar development settings: airport, museum of comics and international stakeholder community. About topics, vaccination represents the core focus of ten local initiatives but is mentioned in the others as well.

Four initiatives are designed to be based on experiences or results of the citizen consultations delivered in 2016, and 3 events dealing with broader concepts such as health emergency preparedness and response.

Furthermore, women were directly involved in 8 initiatives.

The detailed results of those initiatives are fully available in the [Deliverable 5.3](#)



Overview of local initiatives developed by the project's partners:

CITY PARTNER	TARGET(S)	ISSUE(S)
Rome ISS	High school students	Preparedness and response towards epidemics and pandemics
	Professional networks involved in the field	Community resilience
	HCWs, pregnant and/or breastfeeding women	Vaccinations among HCWs in epidemics and/or pandemics
Lyon LYONBIO-POLE, IPRI	Medical students and resident medical doctors at University	Respiratory infectious disease: the role of vaccination and personal behaviours
	Relevant stakeholders of this initiative	Promotion of immunization programs at local level
Dublin EIWH	Pregnant/ recently pregnant women; public health doctor; primary care team; midwifery representative; local women's group	Influenza vaccination in pregnancy
Oslo FFI	Health professionals/ authorities/ agencies working on preparedness and response for epidemics and pandemics	Results of Citizen consultation; Crises- and risk communication; Vaccination with particular concern to HCWs and pregnancy
Athens PROLEPSIS	HCWs, Medical or nursing university students	Vaccine preventable diseases (VPD): role of HCWs; barriers, and appropriate materials; preparing local communities for epidemics and pandemics
Sofia NCIPD	HCWs, Health Care Students	Practical information about prophylactic measures and behaviour during influenza epidemics and pandemic, risk communication; vaccination; citizen consultation.
Brussels TIEMS	Public Health and Civil Protection Authorities and/or manager	Results from citizen consultations, mainly on participatory governance as a management policy
Geneva DMI	General population	Vaccine adherence
Bucharest UMFCD	HCWs, medical students, general population	Knowledge and attitudes towards epidemics and pandemics; Community knowledge, attitude and practice regarding epidemics and pandemics
Haifa HU	High school students	Science-orientation/ education by using artistic tools (comics, painting, photography, etc.): correlation between hygiene, transmission of infectious diseases
Milan ZADIG	Police/army/law enforcement officers	Management of emerging infectious diseases crises in an airport setting
	People visiting the Museum	Vaccine hesitancy

Thank you for having followed the main RRI achievements of the ASSET project!

All project's results are available on our website: <http://www.asset-scienceinsociety.eu/>

Don't forget to read our report summarizing all the project objectives and its achievements
<http://www.asset-scienceinsociety.eu/pages/final-summary-report>