



share and move to face nasty bugs

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



co-funded by the EU. GA: 612236

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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

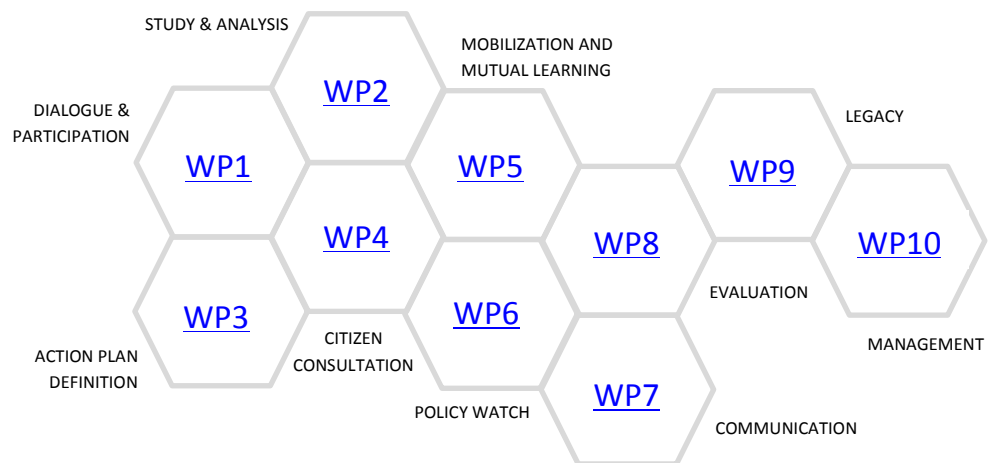
The ASSET Summer School aims at establishing an interactive learning space for researchers and practitioners in the field of Science in Society (SiS) related issues in Pandemics. It focuses on sharing and exchanging issues related to conducting and communicating research in SiS according to a transdisciplinary 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.