



**ASSET**

share and move to face nasty bugs

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

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**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 15<sup>th</sup> 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](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.