



share and move to face nasty bugs

## **ENJOY READING THE ASSET NEWSLETTER**

**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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co-funded by the EU. GA: 612236

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## EDITORIAL: Citizens' involvement and public participation in pandemic governance

### Event & NEWS

#### 3<sup>rd</sup> 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!*