share and move to face nasty bugs

WP3 ACTION PLAN DEFINITION
D3.4 ASSET TOOL BOX

ASSET Project • Grant Agreement N°612236

ASSET

Action plan on SiS related issues in Epidemics and Total Pandemics

7th RTD framework programme

Theme: [SiS.2013.1.2-1 Sis.2013.1.2-1]

Responsible partner: **THE INTERNATIONAL EMERGENCY MANAGEMENT SOCIETY (TIEMS)**

Contributing partners: **DBT, EIWH, IPRI, NCIPD, PROLEPSIS, ZADIG**

Nature: **Report**

Dissemination: **PU**

Contractual delivery date: **2016-03-31 (m27)**

Submission Date: **2016-08-19 (m32)**

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 612236

co-funded by the EU. GA: 612236

DOCUMENT MANAGEMENT

PROJECT FULL TITLE	Action plan on Science in Society related issues in Epidemics And Total Pandemics
PROJECT ACRONYM	ASSET
	Coordination and Support Action: project funded under Theme SiS.2013.1.2 "Mobilisation and Mutual Learning (MML) Action Plans"
GRANT AGREEMENT	612236
STARTING DATE	01/01/2014
DURATION	48 months

Delivery: D3.4 ASSET Tool Box

Task: T3.4 ASSET Tool Box

Leader: THE INTERNATIONAL EMERGENCY MANAGEMENT SOCIETY (TIEMS)

Other contributors: DBT, EIWH, IPRI, NCIPD, PROLEPSIS, ZADIG

History of changes:

Vn	Status	Date	Organisation / Person responsible	Reason for Change
V1	Draft	2016-07-14	The International Emergency Management Society (TIEMS)/ Kailash GUPTA	Modification of Checklists for Researchers
V2	Draft	2016-08-17	The International Emergency Management Society (TIEMS)/ Kailash GUPTA	Merging of Tools with the Tool Box
Vf	Final	2016-08-19	The International Emergency Management Society (TIEMS)/ Kailash GUPTA	

Table of Contents

EXECUTIVE SUMMARY

The response to 2009 H1N1 influenza pandemic was inappropriate and created mistrust towards authorities, despite preparedness and huge expenditures. To promote resilience against the next pandemic, the European Union is promoting cooperation among different stakeholders. This is being achieved through Science in Society initiatives to foster Mobilization and Mutual Learning and Responsible Research and Innovations.

Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics (ASSET) is a European Union co-funded transdisciplinary, Mobilisation and Mutual Learning Action Plan project under execution by 14 consortium partners from 11 countries involving 70 researchers during 2014 to 2017. The aims of the project are:

- To forge a transdisciplinary partnership to effectively address epidemics and pandemics
- To explore and map science in society related issues in epidemics and pandemics
- To define and test a participatory and inclusive strategy for successful action
- To identify resources necessary to make the action sustainable after project completion.

ASSET consists of 10 Work Packages (WP). The 10 WP are divided in 43 Tasks (T) and there are 58 deliverables (D). WP3 Action Plan Definition aims to design an action plan and its main components. One of its four components is T3.4, which produced this D3.4 ASSET Tool Box. D3.4 contains eight Tools. Each Tool details processes described in the D3.3 Action Plan Handbook.

Three of the Tools are directly related to learning. These are: (i) Reporting health issues by journalists, (ii) Response to radiological, biological, and chemical threats by healthcare professionals, and (iii) Online interactive continuing medical education course on infectious outbreaks. Two of the Tools are checklists: (i) Awareness of healthcare workers for influenza vaccination, and (ii) Checklist for patient and public involvement in research along with checklist for basic research considerations. Two of the Tools are how to do something: (i) How to organize citizen participatory meetings, and (ii) how to conduct data visualization. Considering the focus of the ASSET project, a glossary of epidemics, including Zika and other emerging virus infections is also a Tool included in this tool box.

A summary of each of the Tool is given in Section 3. A reader may freely access this Tool Box with Tools by going to the ASSET website www.asset-scienceinscociety.eu, selecting Outputs menu, then Deliverables and finally clicking on D3.4 ASSET Tool Box. From within this Tool Box, a viewer may click on the hyperlink of the Tool of his interest to reach the selected Tool and use it.

1. INTRODUCTION

International organizations predicted huge numbers of mortality and morbidity from the 2009 H1N1 influenza pandemic. European countries prepared risk response and risk communication plans. Governments, politicians, administrators, researchers, healthcare workers, and pharmaceutical industry worked overtime, producing huge stocks of vaccines, most of which were not used. Media and cautious officials created a fear among the people of extensive sickness and death. However, the actual situation turned out to be much less severe. This created mistrust of the authorities among the people, which was fuelled by questionable practices in the pharmaceutical industry and among politicians. To promote resilience against the next pandemic, the European Union is working to improve cooperation among different stakeholders. This is being achieved through Science in Society initiatives to foster Mobilization and Mutual Learning and Responsible Research and Innovations.

1.1 ASSET

Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics (ASSET) is a European Union co-funded transdisciplinary, Mobilisation and Mutual Learning Action Plan project being executed by 14 consortium partners from 11 countries involving 70 researchers during 2014 to 2017. ASSET combines disciplines including public health, vaccine and epidemiological research, social and political sciences, disaster and emergency management, law and ethics, gender studies, science communication and media, in order to develop an integrated, transdisciplinary strategy, which will take place at different stages of the research cycle, combining local, regional and national levels. The consortium partners are from Belgium, Bulgaria, Denmark, France, Greece, Ireland, Israel, Italy, Norway, Romania, and Switzerland. The aims of the project are:

- To forge a transdisciplinary partnership to effectively address epidemics and pandemics
- To explore and map science in society related issues in epidemics and pandemics
- To define and test a participatory and inclusive strategy for successful action
- To identify resources necessary to make the action sustainable after project completion.

ASSET consists of 10 Work Packages (WP) and 10 Milestones. The 10 Work Packages are divided in 43 Tasks (T) and there are 58 deliverables (D).

1.2 WP3 Action Plan Definition

The third work package among the ten, titled Action Plan Definition, aims to design an action plan with four components. Its components were developed through four tasks and four deliverables, as shown in Figure 1 below.

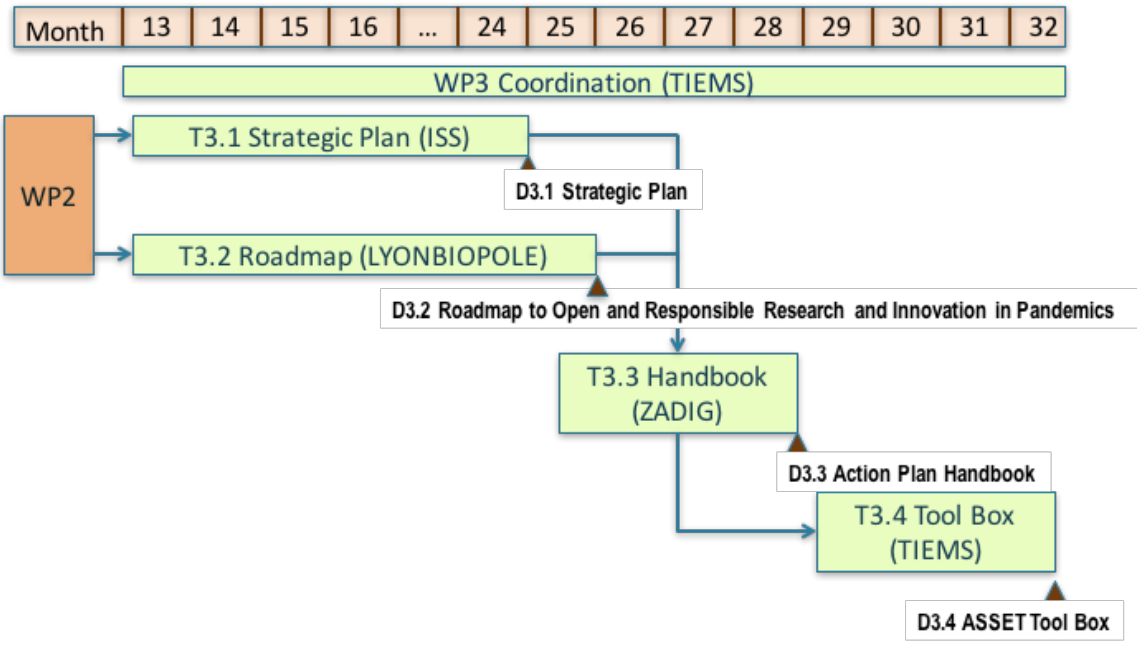


Figure 1. ASSET Work Package 3 Tasks

T3.1 produced D3.1, the Strategic Plan that gives the overall architecture of the Action Plan. T3.2 produced D3.2, a Roadmap towards the user-driven open and responsible research and innovation for pandemic preparedness and response. T3.3 produced D3.3, a Handbook of the actions required to implement the Strategic Plan and Roadmap, including a detailed timetable. D3.3 Action Plan Handbook is also one of the 10 milestones of the ASSET project. Lastly, T3.4 created D3.4, this ASSET Tool Box, which supports carrying out the actions described in the Handbook. As shown in Figure 2, the Handbook and Tool Box work together to improve resilience to pandemics.

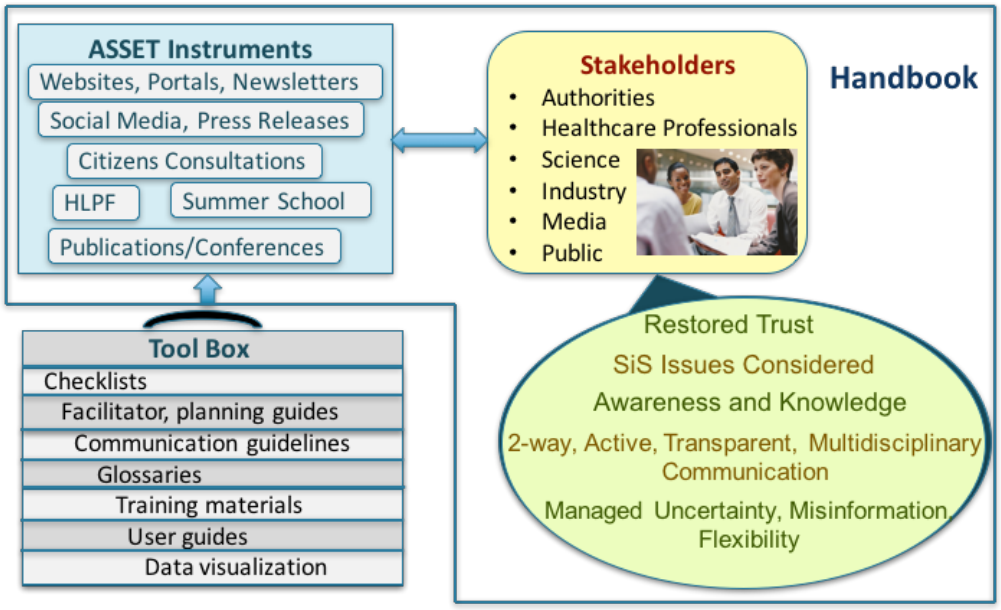


Figure 2. ASSET Action Plan Improving Pandemic Resilience

2. D3.4 ASSET TOOL BOX

A described above, the last task in the WP3 Action Plan Definition is task T3.4 ASSET Tool Box. T3.4 produced the delivery D3.4 ASSET Tool Box. This ASSET Tool Box contains a number of tools. Each tool details processes described in the D3.3 Action Plan Handbook. As implied by the words, Science in Society in the ASSET project title (Action Plan in Science in Society related Issues in Epidemics and Total Pandemics), and the Mobilization and Mutual Learning concept upon which the project is based, these tools are meant for use by the various stakeholders concerned with pandemics.

A reader may freely access the individual tools in the Tool Box by going to the Deliverables portion of Outputs from the Home page of ASSET website www.asset-scienceinscociety.eu and clicking on the D3.4 ASSET Tool Box. This Tool Box is then opened. You do not have to register and do not need a user name and password to open the Tool Box. Once you click on the Tool Box and it opens, you will know what tools are available within the Tool Box. A short description of each tool will also be available to help in choosing a tool of your interest. Once you select a tool and click on the hyperlink of the tool, you will reach the selected tool.

This virtual Tool Box mimics a real hardware toolbox a handyman carries. The handyman (or even a householder) in his professional practice carries a Tool Box and opens it to take out a hammer, or pliers, or a file or whatever is needed.

The tools contained in this Tool Box are described in next section.

3. SUMMARY OF TOOLS

The tools within the Tool Box are mainly meant for pandemics, the focus of the ASSET project. However, with some ingenuity and modifications by the user, the tools may be more generally applicable. A tool may be a document, a check list, a template, training material, a knowledge resource, or something else that may be useful.

The development of the tools was led by The International Emergency Management Society (TIEMS), Belgium. Out of the remaining 13 ASSET consortium partners, six contributed to the development of the tools. These are:

- Danish Board of Technology (DBT), Denmark
- European Institute of Women's Health Limited (EIWH), Ireland
- International Prevention Research Institute (IPRI), France
- National Center for Infectious and Parasitic Diseases (NCIPD), Bulgaria
- Institute of Preventive Medicine, Environmental, and Occupational Health (PROLEPSIS), Greece
- ZADIG SRL, Italy.

In this Section 3 a brief description of each tool within this Tool Box is given. Each tool is stand-alone, which means it is complete in itself. Each tool has been prepared in a similar "Template for Tool" format, which starts with a summary of the tool, followed by its purpose, for whom it is meant, a description of the tool, the challenges the tool addresses, the benefits of the tool, example(s) of its use, and where to get further information or resources. The Template for Tool is a modified version of the standard ASSET "Delivery Template", used for deliverables of the ASSET program. In a sense, Template for Tools is itself a tool.

This Tool Box document summarizes the online ASSET Tool Box, and it is presented in the ASSET Delivery Template. All ASSET deliverables that you may view at http://www.asset-scienceinsociety.eu/outputs/deliverables follow the same formatting style as this document with regard to layout, margins, fonts, font size, spacing, etc. We hope this document is a useful guide for use of the Tool Box with Tools.

This Tool Box currently contains the following tools. Additional tools are expected to be added during the remainder of the ASSET program.

1. Checklist - Awareness of Healthcare Workers for Influenza Vaccination
2. Glossary - Epidemics, Including Zika and other Emerging Virus Infections
3. Infectious Outbreaks Continuing Medical Education Online Interactive Course
4. Data Visualization
5. Citizen Participatory Meetings

6. Reporting Health Issues by Journalists
7. Response to Radiological, Biological, and Chemical Threats by Healthcare Professionals
8. Checklists for Researchers.

A brief description of each tool follows:

3.1 Checklist - Awareness of Healthcare Workers for Influenza Vaccination

Note: A hyperlink is provided at the first word "Checklist" in the title above, to take you to the Checklist Tool. Similarly, hyperlinks have been provided for each of the other tools that follow.

This checklist is intended to help healthcare workers who have direct contact with patients to assess their knowledge, attitude, and willingness to facilitate their preventive activities, and to improve the quality of their work in the field of vaccine prevention of influenza.

3.2 Glossary - Epidemics, Including Zika and other Emerging Virus Infections

The usage of terms related to epidemics and emerging epidemics differs largely between different disciplines. The goal of the glossary is to facilitate communication, avoiding linguistic misunderstandings with so many different disciplinary, geographical, and cultural backgrounds, and to contribute to overall coherence, through a shared, transdisciplinary language.

3.3 Infectious Outbreaks Continuing Medical Education Online Interactive Course

This is a continuing medical education online interactive course related to infectious outbreaks, that may be completed at your own speed, as and when time is available to you, and from anywhere Internet access is available. This has different modules and case studies, with an evaluation at the end of each module. You progress to next module if you answer 80% of the questions correctly. On completion of the course, you may download a certificate of completion.

3.4 Data Visualization

With data visualization (dataviz), existing data can be compared, superimposed, and made easily visible and understood by everybody. This can lead to the emergence of hidden information and raise debates on issues related to different aspects. The tool is generic in nature and innovative approaches may be adopted by users according to different needs and using different means. The tool is illustrated by an example of an analysis that compares rates of immunization in all EU/EAA countries with their policies on mandatory vaccinations. Analysis of three vaccines (pertussis, polio and measles), showed that vaccination rates are not necessarily better when preventative measures are compulsory.

3.5 Citizen Participatory Meetings

Citizen participatory meetings are becoming increasingly popular. The meetings are a good way to enter into

a dialogue with citizens in order to understand their views, and learn from their everyday experiences. Citizen meetings are a tool in the participatory governance approach to governance. Engaging with citizens through dialogue is a necessary requirement for an equitable and sustainable development of our societies. Participatory governance means including citizens in decision making that has implications for their wellbeing, and transparency in the decision making and implementation processes. However, it is extremely difficult, time consuming, and costly to include all citizens directly in a decision-making process or via citizen meetings. Therefore, the preferred approach is to use a near-representative sample size (may or may not be statistically significant) of citizens at participatory meetings. This tool explains the citizen participatory meetings methodology with an example of face-to-face ASSET citizen participatory meetings. The ASSET citizen meetings are planned in eight countries across Europe for one full day on September 24, 2016.

3.6 Reporting Health Issues by Journalists

This online e-learning tool aims to advance training in health reporting. It summarizes public health issues and how to communicate about them to the public by journalists. The tool is valuable not only for journalists, but also for media officers, and communication and press officials working at the community level. The tool is available in English, Estonian, German, Greek, Finish and Romanian. Each language-specific section includes issues of importance for specific countries. The courses include issues on global health and communicable diseases, including influenza, Hepatitis and AIDS/HIV.

3.7 Response to Radiological, Biological, and Chemical Threats by Healthcare Professionals

The aim of this tool is to provide knowledge and training material to empower health professionals and organizations, governments, civil authorities, security agencies and armed forces, to rapidly recognise clinically, and adequately respond to, new public health threats, such as deliberate or terrorist attacks with biological, chemical, and radiological agents. Institutions, universities, or public health authorities may use the tool for training. The tool includes necessary information and guidelines that different stakeholders will need to disseminate to front-line health professionals in emergencies caused as explained above, as well as a guide for actions to be undertaken.

3.8 Checklists for Researchers

The purpose of these checklists is to support implementation of an ideological shift within which patients and civil society representatives have a formal and recognized role to effectively get involved in research that concerns their health-related issues. This shift would result in research being carried out ‘with’ or ‘by’ members of the public rather than ‘to,’ ‘about,’ or ‘for’ them.

ANNEX 3 is a specialized checklist to guide researchers in following the D3.2 Roadmap to Open and Responsible Research and Innovation in Pandemics. The primary goal of this Roadmap (http://www.asset-scienceinsociety.eu/outputs/deliverables) is to improve Public and Patient Involvement (PPI) in pandemic research. In this context, “Public and Patient” refers to patients, care givers, health researchers, and patient organizations.

ANNEX 4 is a checklist of basic research considerations, which applies to research on pandemics as well as other topics. This checklist shows how ANNEX 3 fits into the broader context of research methodology, and also serves as a basic reference for intermediate level researchers.

3.9 Navigating to Tools

We now present each of the above tools in individual Sections 4 to 11. If you want to go to a particular tool directly, please click in the first word of the tool name from the list above, and with the help of the hyperlink you will be taken there.

4. CHECKLIST - AWARENESS OF HEALTHCARE WORKERS FOR INFLUENZA VACCINATION

This checklist is intended to help healthcare workers (HCWs) who have direct contact with patients to assess their knowledge, attitude, and willingness to facilitate their preventive activities, and to improve the quality of their work in the field of vaccine prevention of influenza.

4.1 Purpose

Healthcare workers' knowledge, attitudes and willingness to recommend and give influenza vaccines are different in different medical practices. This checklist is intended to help HCWs who have direct contact with patients to assess their attitude, knowledge and willingness to facilitate their preventive activities, and to improve the quality of their work in the field of vaccine prevention of influenza.

4.2 Target Group

HCWs - especially physicians and nurses who have direct contact with patients.

4.3 Description

In the concept and objectives of the ASSET project are enshrined issues related to low coverage with influenza vaccines, and the need for active involvement of HCWs with increased knowledge in the field of vaccine prophylaxis. The 2009 influenza H1N1 pandemic raised the issue of limited compliance with vaccination plans by HCWs. For instance, in the US, 2009 H1N1 vaccination coverage among HCWs only reached 37.1% against a fixed target of 60%. In Europe, HCWs accepting immunization were consistently under 50%. The results are fairly consistent everywhere, e.g., Germany, the United Kingdom, Spain, Italy, Turkey, confirming previous findings that HCW's tend to have a negative attitude towards flu vaccination. Even more telling is a 2010 study about HCWs, showing that parents were likely to under-vaccinate their children against the H1N1 virus. Needless to say it is difficult to convince the public to get vaccinated when the people administering the vaccines demonstrate mistrust by not getting their children or themselves vaccinated.

ASSET is furthermore related to the challenge named "Health, demographic change and well-being" in Horizon 2020. More specifically it aims to address "the need to ensure high levels of human health protection", "the lifelong health and wellbeing of all and therefore on the effective prevention, treatment and management of disease", "emerging epidemics", "drug and vaccine development processes", and "access to effective and competent health systems".

Influenza causes substantial morbidity and mortality annually, particularly in high-risk groups such as the elderly, young children, immunosuppressed persons, and persons with chronic diseases. Healthcare-associated transmission of influenza also contributes to this burden. HCWs, especially physicians and nurses having direct contact with patients or patient's' specimens, are at increased risk of contracting infections and further transmitting them to their patients and colleagues. Immunization against influenza would protect HCWs themselves, acting as a barrier against the spread of infection and maintaining healthcare

delivery during epidemics. Therefore, it is very important to increase the awareness of medical professionals in the field of the influenza vaccination, and support their efforts to convince patients of the usefulness and benefits of influenza vaccines.

4.4 Challenge Addressed

The need for increasing HCWs' knowledge in the field of influenza vaccination.

4.5 Benefits

The awareness of HCWs to perform influenza vaccination will increase their vaccination coverage against influenza, and support their efforts to convince patients of the usefulness and benefits of influenza vaccines.

4.6 Example

This checklist allows HCWs to assess their knowledge, attitudes, and willingness to recommend and give influenza vaccine. However, this example may be modified to make checklist in other healthcare areas. This checklist was developed by National Center of Infectious and Parasitic Diseases, Bulgaria, one of the consortium partners of ASSET.

4.7 How to Use

To assess your knowledge, attitudes, and willingness for influenza vaccination, please answer the questions given in Annex 1 honestly (There is a hyperlink at "Annex 1," which will take you to the Annex 1 that follows. Similarly, there are hyperlinks to other Annex numbers). The answers will help you identify the areas where you need to upgrade your skills or reconsider your practices.

ANNEX 1: CHECKLIST - AWARENESS OF HEALTHCARE WORKERS FOR INFLUENZA VACCINATION

HCWs' knowledge, attitudes, and willingness to recommend and give influenza vaccines are different in different medical practices. This checklist is intended to help you assess your attitude, knowledge, and willingness, to facilitate your preventive activities and to improve the quality of your work in the field of vaccine prevention of influenza. Please rely only on your own judgment while answering the following questions.

- Do you have credentials (license / certificate) for vaccination?
- Is your knowledge of vaccination up-to-date?
- Are you sufficiently skilled for vaccination?
- Are you aware of the influenza preventive measures?
- Are you aware of the possible consequences and complications, after getting infected with influenza virus?
- Do you know which influenza vaccines are available in the pharmacies in your area before the start of the influenza season?
- Do you know which months are most appropriate for influenza vaccination of your patients?
- Do you know the immunity duration following influenza vaccination?
- Are you aware of the risk groups for which influenza vaccination is highly recommended?
- Do you recommend influenza vaccination to your patients with chronic medical conditions?
- Do you have material related to influenza vaccine prophylaxis for distribution before the start of the influenza season?
- Do you distribute material related to influenza vaccine prophylaxis to your patients, before the start of the influenza season?
- Do you get the influenza vaccine to protect yourself from infection?
- Do you get the influenza vaccine to protect your patients from infection?
- Do you know the contraindications for getting influenza vaccine?
- Do you know the ways and options for reporting adverse reactions following vaccination?
- Do you know where to get updated information about the influenza incidence and the spread of influenza viruses?

- Do you know the latest composition of influenza vaccines?
- Have you attended a scientific forum that includes the subject of influenza vaccine prophylaxis during last year?
- Do you receive medical journals, brochures etc. containing updated information about influenza and its prophylaxis?

5. GLOSSARY - EPIDEMICS, INCLUDING ZIKA AND OTHER EMERGING VIRUS INFECTIONS

The usage of terms related to epidemics and emerging epidemics differs largely between different disciplines. The goal of this glossary is to facilitate communication, avoiding linguistic misunderstandings with so many different disciplinary, geographical, and cultural backgrounds, and to contribute to overall coherence, while forming a shared, transdisciplinary language.

5.1 Purpose

The purpose of this tool is to provide a glossary of concepts and terminology related to science in society in epidemics and pandemics. At the time of this writing, with the 2016 Olympic Games approaching and the Zika virus infection in Rio de Janeiro, Brazil is a hot topic. More than 150 scientists have made an appeal to postpone the games due to the Zika virus, and a number of sports persons have withdrawn from the games. Therefore, it is important that the general public know the terminology required to discuss Zika and other emerging virus infections.

This tool is provided to benefit the general public, although the Glossary was originally developed for use by the 14 ASSET consortium partners. One of the main aims of the ASSET project is to build a common approach to problems among partners from different disciplinary, geographical, and cultural backgrounds, and to pave the way for a deeper cooperation and integration among members of the project. These objectives were accomplished through collaboration among partners on a common Glossary of Terminology, which includes terms and concepts from all fields, relevant to ASSET. Work on the Glossary of Terminology is continuing, as new terms and definitions are added to reflect constantly changing conditions and the emergence of new threats to public health.

5.2 Target Groups

General public, including from different disciplinary, geographical, and cultural backgrounds.

5.3 Description

National Centre of Infectious and Parasitic Diseases (NCIPD), one of the 14 members of the ASSET consortium, led a task to compile a glossary with the help of all the other partners. A glossary of about 400 concepts and terminologies is available on the ASSET website (see Section 2.7 How to Use).

The outbreak of Zika virus infection began in April 2015 in Brazil, and has spread to other countries in South America, Central America, Mexico, and the Caribbean. Specific areas where Zika is spreading are often difficult to determine and are likely to change over time. On February 1, 2016, the World Health Organization declared the Zika virus a Public Health Emergency of International Concern. Inter sectorial collaboration and efficient public communication strategies to ensure community participation are required for a sustainable disease control program. The spread of the disease has created the need for new terms and concepts to be defined and explained.

To formulate term definitions, a mix of sources was used, where the definitions had to first and foremost come from trustworthy sources. Sometimes the wording was changed for better clarity, and more popular sources were used if these sources kept the accuracy of the definition.

5.4 Challenges Addressed

To provide to the general public concepts and terminology related to epidemics, including Zika and other emerging virus Infections.

5.5 Benefits

The glossary is expected to remove the confusion about the different terminologies related to epidemics and promote common understanding among different disciplinary scientists.

5.6 Example

This example is only one out of about 400 concepts and glossary items; however, we give the example of Ebola to illustrate a typical entry.

2.6.1 Ebola

Ebola haemorrhagic fever is caused by a virus. It is a severe and often fatal disease. It can affect humans and other primates. Researchers believe that the virus first spreads from an infected animal to a human. It can then spread from human to human through direct contact with a patient's blood or secretions.

Symptoms of Ebola may appear anywhere from 2 to 21 days after exposure to the virus. Symptoms usually include

- Fever
- Headache
- Joint and muscle aches
- Weakness
- Diarrhea
- Vomiting
- Stomach pain
- Lack of appetite

Other symptoms including rash, red eyes, and internal and external bleeding, may also occur.

The early symptoms of Ebola are similar to other, more common, diseases. This makes it difficult to diagnose Ebola in someone who has been infected for only a few days. However, if a person has the early symptoms of Ebola and there is reason to suspect Ebola, the patient should be isolated. It is also important to notify public health professionals. Lab tests can confirm whether the patient has Ebola.

There is no cure for Ebola. Treatment involves supportive care such as fluids, oxygen, and treatment of complications. Some people who get Ebola are able to recover, but many do not.

See also: Viral haemorrhagic fever.

Ebola virus is a possible weapon for bioterrorism (category A). However, the General Accounting Office, the investigative arm of the US Congress, in a 1999 report considered Ebola virus to be an "unlikely" biologic threat for terrorism, because the virus is very difficult to obtain and process, unsafe to handle, and relatively unstable.

The 2014 Ebola virus disease (EVD) outbreak that began in Guinea in December 2013 is the largest one ever recorded. For up-to-date information regarding the outbreak, we suggest NIH Medline Plus, WHO website and the Science magazine open access area, which includes a selection of research articles on the topic and feature articles. The web links of these sites are given below:
NIH Medline Plus: Ebola (https://medlineplus.gov/ebola.html)
WHO: Disease outbreak news: Ebola virus disease (http://www.who.int/csr/don/archive/disease/ebola/en/)
Science Magazine: Ebola (http://www.sciencemag.org/site/extra/ebola/)

5.7 How to Use

The glossary of concepts and terminology related to epidemics may be accessed at http://www.asset-scienceinsociety.eu/sites/default/files/d1.2_glossary_and_terminology.pdf. The glossary contains about 400 items from pages 7 to 91. The glossary about Zika and other emerging virus infections is given in the ANNEX 2.

ANNEX 2: GLOSSARY - EPIDEMICS, INCLUDING ZIKA AND OTHER EMERGING VIRUS INFECTIONS

This Annex provides the latest addition to the glossary regarding Zika and other emerging virus Infections. Terms are in alphabetical order. For other about 400 items of glossary please go to web site http://www.asset-scienceinsociety.eu/sites/default/files/d1.2_glossary_and_terminology.pdf and see pages 7 to 91.

A

Antibody titer - the concentration of antibodies circulating in the bloodstream of an individual. Antibody titers are used to establish the diagnosis of some infectious diseases: a rising titer indicates a recent exposure to a specific infectious antigen.

Autochthonous - formed or originating in the place where found (an autochthonous infection), endemic

Autochthonous cases - contracted in the area where reported, indigenous or endemic to a region

Autochthonous transmission means refers to the transmission of a communicable disease from one case to another, in the same place. The relevance of this is that some diseases are spread by vectors such as mosquitoes. Climate change means that particular species of mosquitoes now survive in places where they didn't previously survive, or have spread to areas where they were not previously found or had previously been eliminated.

P

Persistent viremia - virus can be isolated from the blood for periods longer than a few days

Primary viremia is an invasion of viruses into the blood from the initial site of infection.

S

Secondary viremia - viruses can infect various organs, like the lymph nodes or liver, and spread into the blood again after some days or weeks

Sepsis (blood infection) is a serious health condition, in which microbes invade the blood (usually from existing severe infection) and trigger high fever, rapid breathing and heartbeat

T

Travel-associated transmission - infection associated with travel to an area with local transmission of the pathogen

V

Vector control - programs designed to reduce or eliminate a disease-carrying insect or rodent population (vectors of diseases)

Viremia - the presence of viruses in the blood (form of sepsis). In generalized virus infections there may be local invasion, proliferation in regional lymph nodes, followed by primary viremia with dissemination to other tissues. For some infections there may be a secondary viremia followed by increasing tissue damage and severe clinical disease sometimes including spread of virus to the central nervous system.

Z

Zika Virus – the Zika Virus infection is a mosquito-borne infection caused by Zika virus. Most infections are either asymptomatic or cause a mild illness with a transient maculopapular rash. The Aedes aegypti mosquito is the main vector but other Aedes species can also transmit the virus. Zika Virus infection during pregnancy can cause a serious birth defect called microcephaly, as well as other severe fetal brain defects.

REFERENCES AND RESOURCES

Many different sources are available for glossary on epidemics, including Zika and other emerging virus infections. Examples of useful sources, found and used during our work are the WHO website and documents, the ECDC website and documents, the transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence (TELL ME) project website and documents, NIH Medline Plus, and Me

6. INFECTIOUS OUTBREAKS CONTINUING MEDICAL EDUCATION ONLINE INTERACTIVE COURSE

This is a continuing medical education online interactive course related to infectious outbreaks, that may be completed at your own speed, as and when time is available to you, and from anywhere Internet access is available. This has different modules and case studies, with an evaluation at the end of each module. You progress to next module if you answer 80% of the questions correctly. On completion of the course, you may download a certificate of completion.

6.1 Purpose

To improve awareness, knowledge, attitudes and actions in healthcare workers during epidemics, including seasonal flu.

6.2 Target Group

Healthcare workers, mainly in primary care.

6.3 Description

"Action Plan on Science in Society Related Issues in Epidemics and Pandemics" (ASSET) project is a follow-up project of "Transparent Communication in Epidemics: Learning Lessons from Experience, Delivering Effective Messages, Providing Evidence" (TELL ME). Within the TELL ME project, the feasibility of an e-learning course for Healthcare Workers (HCWs) was studied. ZADIG (one of the 14 consortium partners) staff developed a prototype, followed by a specific course on Ebola, prepared in a very short time when the outbreak happened, which was adopted by the Italian Federations of Doctors' and Nurses' Associations (FNOMCeO – Federazione Nazionale Ordini Medici Chirurghi e Odontoiatri- and IPASVI - Infermieri Professionali, Assistenti Sanitari, Vigilatrici d'Infanzia).

The course is made of:

- One or more files with basic information on the **disease/s and/or vaccines** and non-pharmacological preventative measures, based on reliable sources such as peer-reviewed scientific literature, WHO, CDC, ECDC and links to their websites in order to get updated information. It is mandatory to read all of the sources before tackling the interactive activities
- One file with basic notions about **counselling and communication strategies**
- One file with basic explanation of the huge impact of **societal issues** on the dissemination or the control of infectious diseases (i.e. ethics, gender, law, stigma . . .)
- A few **case histories** where healthcare professionals face everyday situations. These histories are made of blocks. After each block a multiple choice quiz challenges the reader on questions to which he/she should be able to answer after studying the file. At the end of each step, one gets his/her score; the step is passed if at least 80% of correct answers have been given. Each case history is a prerequisite for the next. When a case history is passed, an explanation of right answers is given. At this point, it is possible to return to course's activities summary or proceed to the next case with the navigation menu.

- **A forum for discussion** at the end of each case.
- **Final evaluation** of the number of correct answers.
- A **certificate** can be achieved when all case histories have been passed.

The course can be done in several sessions, by logging on at different times.

6.4 Challenges Addressed

- Lack of knowledge, awareness and involvement of HCWs on pandemics
- Negative attitudes towards vaccines
- Lack of communication skills
- Lack of awareness on stigma issues related to infectious outbreaks.

6.5 Benefits

- Busy healthcare workers can take online courses whenever and wherever they can (this is especially relevant when dealing with an ongoing outbreak and/or when living or working in remote places).
- Online courses can be easily linked to continuously updated sources such as international organizations and authorities.
- Realistic case histories make learning more useful and concrete, involving HCWs more than just providing information far from their practice.
- Interactive activities involve professionals and help them to self-evaluate their own learning.

6.6 Examples

As of May 2016, the model has already been used in producing three courses:

- **The first** is focused on seasonal flu, vaccination and other preventative measures, but also considers other emerging infectious threats, such as MERS. It highlights the related risk of stigma and its impact, while providing some clues on counselling and communication strategies (i.e. to face vaccination hesitancy) (in English).
- **The second** was produced in response to 2014 Ebola outbreak in Western Africa, both in English and in Italian, since it was adopted by the Italian Federations of Doctors' and Nurses' Associations (FNOMCeO and IPASVI). It highlights the related risk of stigma and its impact as well.
- **The third** was produced in the wake of Zika crisis in South and Central America and consider the gender specific risk related to pregnancy. It is in Italian, but could be translated if some other international association or authorities would ask for it.

The model has therefore been demonstrated to be flexible and useful in different outbreak situations, providing information and guidance to HCWs for their own behaviour and for answering their patients' doubts.

6.7 How to Use

Are you interested in taking Pandemic Continuing Medical Education Online Interactive Course for yourself, your family, and your patients? Yes. Good. Then go to http://elearn.tellmeproject.eu, register

yourself without payment of any fee and complete the course at your speed and time available. On completion of the course, you may download the certificate of completion.

REFERENCES AND RESOURCES

http://elearn.tellmeproject.eu

7. Data Visualization

With data visualization (dataviz), existing data can be compared, superimposed, and made easily visible and understood by everybody. This can lead to the emergence of hidden information and raise debates on issues related to different aspects. The tool is generic in nature and innovative approaches may be adopted by users according to different needs and using different means. The tool is illustrated by an example of analysis that compares rates of immunization in all EU/EAA countries with their policies on mandatory vaccinations. Analysis of three vaccines (pertussis, polio and measles), showed that vaccination rates are not necessarily better when the preventative measure is compulsory.

7.1 Purpose

To improve lack of awareness of Science-in-Society issues related to infectious outbreaks.

7.2 Target Group

All stakeholders, public included.

7.3 Description

Within the ASSET project, ZADIG (one of the fourteen consortium partners) staff performed some of these analyses of existing data, comparing and visualizing them in graphical representations. Other data visualization will be performed by ASSET in the future, but any stakeholder can use the same model to focus on specific points under debate. This tool is illustrated by an example of analysis performed by ZADIG.

7.4 Challenges Addressed

Lack of awareness of Science-in-Society issues related to infectious outbreaks.

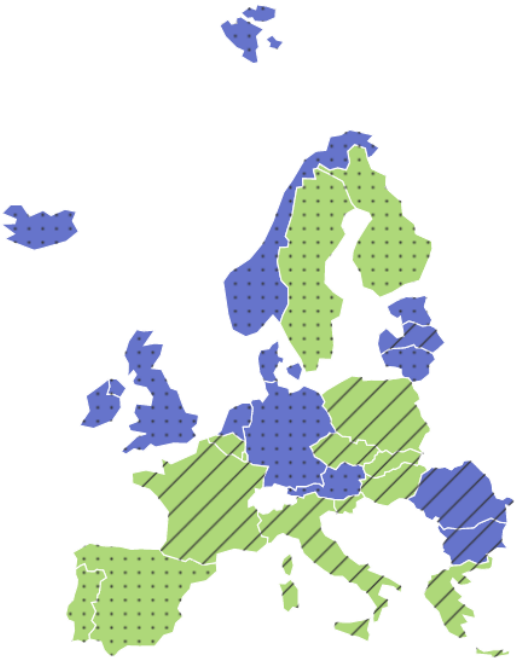
7.5 Benefits

- Any stakeholder can focus on a question by analysing existing data
- Comparing and superimposing data can provide new information
- Visualization makes information easier to understand and disseminate
- Pictures and graphs are considered “appealing” and circulated very well by new social media, so that the message will be delivered more effectively.

7.6 Example

Within ASSET project two data visualizations have already been performed and one of them is explained below:

The data visualization compares rates of immunization in all EU/EAA countries with their policies on mandatory vaccinations. ASSET staff considered only three vaccines (pertussis, polio and measles), showing that vaccination rates are not necessarily better when the preventative measure is compulsory. The analysis raised the interest of editors of the Vaccines Today journal, and in the European Centre for Disease Prevention and Control (ECDC) staff, which started a deeper study on this issue.



Polio vaccination coverage in EU/EEA.

- Blue/green countries are below/above the European average. (Data UNICEF)
- Mandatory vaccination has been marked with a lined background. (Data VENICE)

To get a fuller understanding of this example please click on the web link given in References and resources section.

7.7 How to Use

Anyone can use open data and cross them, providing a graphical representation.

REFERENCES AND RESOURCES

http://www.asset-scienceinsociety.eu/reports/page1.html

8. CITIZEN PARTICIPATORY MEETINGS

Citizen participatory meetings are becoming increasingly popular. The meetings are a good way to enter into a dialogue with citizens in order to understand their views, and learn from their everyday experiences. Citizen meetings are a tool in the participatory governance approach to governance. Engaging with citizens through dialogue is a necessary requirement for an equitable and sustainable development of our societies. Participatory governance means including citizens in decision making that has implications for their wellbeing, and transparency in the decision making and implementation processes. However, it is extremely difficult, time consuming, and costly to include all citizens directly in a decision-making process or via citizen meetings. Therefore, the preferred approach is to use a near-representative sample size (may or may not be statistically significant) of citizens at participatory meetings. This tool explains the citizen participatory meetings methodology with an example of face-to-face ASSET citizen participatory meetings. The ASSET citizen meetings are planned in eight countries across Europe for one full day on September 24, 2016.

8.1 Purpose

The purpose of this tool is to explain how to organize citizen participatory meetings. Citizen meetings are a tool for democratisation of (political) decision-making processes. The tool described in the present guide is generic, and may be used to address a variety of topics such as crisis participatory governance, traffic improvement, urban infrastructure investments, solving local administrative problems, etc.

8.1.1 Importance of Citizen Participatory Meetings

The importance of citizen participation in decision-making is illustrated by an example here, although there are many such examples around the world. The 1993 Latur earthquake in the Maharashtra state of India killed 7,928 people. Fifty-two villages in 13 districts around Latur were affected with 30,000 houses fully collapsed and 211,000 houses partially damaged. The government of Maharashtra with the government of India, along with technical and financial support of the World Bank and the Asian Development Bank rebuilt the houses. However, these houses remain unoccupied by villagers. Instead, the houses now house animals. The new houses do not accommodate the culture, traditions, and the life style of local villagers, and therefore the villagers do not use the new houses. Including the local villagers in the decision-making process on the design of the new houses, could probably have prevented the houses ending up as animal shelters instead of as human lodgings.

8.2 Target Group

The target group for this tool includes all stakeholders, to name a few: politicians, policy makers, city mayors, administrators, activists, academicians, businesses, citizen groups, civil society organizations, faith organizations, and non-profit organizations.

8.3 Description

Citizen participation in meetings about decisions that affect them is not something new. Such meetings are generally known as town hall meetings. Politicians and administrators generally call town hall meetings

to present their decisions or policies to the people and ask their comments. Generally, these are held to market their ideas and are held for less than two hours. A few articulate dominant people are given a chance to speak, and the conclusion is often drawn that the people have agreed to the authorities' point of view. Sometimes the authorities may even plant people to support them or ask questions that will support the point of view of the authorities. It is rare that a decision is changed after a town hall meeting.

The citizen participatory meeting methodology propagated in this tool is different from the tradition town hall meeting. We propose holding citizen participatory meetings only after sufficient research and issue identification is performed, and after citizens are invited well ahead of time. Citizens who agree to come to the meetings are given transport to the meetings and food during the meetings. The meetings last for one full day. Citizens are divided into different groups, each issue is thoroughly discussed in small groups, and a consensus or majority view is attempted in the closing plenary session. In the citizen participatory model as propagated here, the organizers refrain from giving their opinion on the issues.

This methodology of citizen participatory meetings has been developed by one of the ASSET consortium partners, The Danish Board of Technology Foundation. The methodology is explained in Sub-section 2.6 with a real-life detailed example of ASSET citizen participatory meetings to be held simultaneously in eight countries on September 24, 2016.

8.4 Challenges Addressed

- Citizen consultations
- Give input to policy-making in terms of informed ideas and opinions from near-representative samples of citizens
- Engaging citizens in the debate on important issues that affect them
- Confirmation bias of authorities.

8.5 Benefits

- Decisions taken with involvement of citizens are easy to implement
- Citizen cohesion
- Happiness among citizens
- Sustainability of projects implemented
- Motivation of citizens to improve other areas of their daily living.

8.6 Example: ASSET Citizen Participatory Meetings on September 24, 2016, in Eight Countries

In Section 1.1, it was stated that ASSET project has ten work packages. WP4 is citizen consultations. The purpose of citizen consultations is to give inputs to European Parliament for policy-making on pandemics. The inputs will evolve from an eight nation (Bulgaria, Denmark, France, Ireland, Italy, Norway, Romania, and Switzerland) citizen consultation with simultaneous face-to-face, one full day meetings. Local ASSET consortium partners will coordinate these meetings. Citizens' at all national meetings will receive the same

information (before and during the meeting), will be given identical facilitated processes, and will answer the same questions. ASSET consortium partners over long deliberations and a two-day workshop developed four themes on which questions will be asked:

1. Personal freedom and public health safety: This theme addresses the inevitable conflict between public health safety and personal freedom and how citizens attach importance to each concern.

2. Communication between citizens and public health authorities: This theme addresses risk and crisis communication channels and conflicts, which are an integral part of any public health emergency response, as a dynamic process of sharing and responding to information about a public health threat.

3. Transparency in public health: Within this theme, we will ask the citizens to reflect on need for transparency in public health policymaking and what public health authorities need to do, to work effectively during an outbreak.

4. Access to knowledge: This last closed theme addresses various sources to acquire knowledge, and asks how to deal with the frontiers of research in public health communication.

The outcome of these meetings will be the messages that citizens want to send to policy-makers.

This Section contains scripts for the citizen consultation to guide the project manager, head facilitator, group facilitators, and technicians. If you have little experience in citizen consultation facilitation of this kind, we strongly recommend that you practice the facilitation. You could invite all staff to an exercise day before the citizen consultation, so you can try the program together. It is important to make sure that ALL members of the citizen consultation staff (especially the group facilitators) are well educated before the citizen consultation. This is to minimize the amount of possible faults and uncertainties during the citizen consultation.

8.6.1 The Project Manager

PROGRAMME	TASK	NOTES
Staff briefing	- Gather the staff. - Make sure that everybody is there, and if not find substitutes. - Hand out nametags in a special colour to all members of the staff. - Together with the head facilitator, you encourage everyone and call for team spirit. - Repeat (very briefly) the roles and tasks of everyone. - Clarify uncertainties and answer questions. - Make sure that all material and equipment is there	This is only meant as a short follow up on previous training and briefings to make sure that the staff are present and familiar with their tasks during the day. Use some extra time to repeat the role of

	and is functioning. - Remember to provide breakfast to staff members.	group facilitators. All items should be placed correctly in the room, at the tables, at the entrance, etc.
Citizen check in	– Make sure that you have staff placed at the entrance to help and guide the citizens and to make sure they receive papers and their nametags with table numbers. – Make sure that only invited people enter the room. – Make sure that people have some breakfast. – Make sure that members of staff assist participants to be seated at the right tables (max 7 + group facilitator). – Make sure that visitors (journalists, politicians, the prominent speaker, and others) are taken care of and are seated (not at the group tables). – Make sure group facilitators go to their table	Participants should get a folder including a short programme for the day, voting papers, and the information material (has been delivered to citizens before). When this session ends all citizens and group facilitators should be seated at round tables.
Introduction	– Start the programme by letting the prominent speaker begin. – Make sure that the speaker keeps the time. – Introduce the head facilitator who will lead the plenary sessions from now on.	Even though you give the platform to the head facilitator, you will still be the person responsible for taking decisions about possible issues that arise during the day.
First thematic session;	– Make sure that the programme and time schedule is followed. – Make sure that all members of the staff actively fulfil their tasks. This implies that video clips are ready on time; that results are reported correctly, etc. – Answer questions from the tables related to the information material that the group facilitator could not answer. **NO QUESTIONS IN PLENUM**.	During the group discussions you should circulate discretely around the room and make sure that the group facilitators fulfil their task and that discussions goes successfully. Keep an eye on the voting procedure and assist if necessary. This part is very important.

Second thematic session;	Same as above – Make sure that the vote reporters have started to type in the results	
Third thematic session;	Same as above – Make sure that the vote reporters have started to type in the results	When lunch is available, you help facilitators to make sure that not everybody collects their food at the same time, but that lunch pass off smoothly without interrupting the sessions.
Fourth thematic session;	Same as above – When you (together with the head facilitator) find it appropriate (for example before third thematic session) you should start the physical exercise. – The physical exercise instructor should arrive in good time before the exercise takes place. It is possible that the instructor is bringing a tape or CD with exercise music. Make sure that the vote reporters have started to type in the results – Make sure that the vote reporters have started to type in the results	Be sure that the technical staff supplies the instructor with the equipment he needs (for example, a microphone, CD-player, etc.).
Fifth thematic session;	Same as above – Make sure that the vote reporters have started to type in the results	
Closing remarks	– Enter the platform and tell citizens about procedures to follow up from the citizen consultation. Citizens need to know: – How they can keep themselves updated with the results. – How the results are communicated to policy makers. – Practical issues (home transportation, take away food, etc.). – You can inform about results from other countries (for example screen shots from the website.) – You and the head facilitator say thank you to the participants.	

	– Maybe some of your staff members could make video interviews with a few citizens about their participation.	

8.6.2 The Head Facilitator

This script concerns the task for the head facilitator at September 24, 2016. You have also other tasks related to preparing the citizen consultation, for example, practice the program together with the other staff members and briefing the group facilitators (together with the project manager) etc. In order to lead the citizen consultation you will need to know the scripts and tasks for all other staff as well. The project manager could as well carry some of the tasks in this script. You can arrange with the project manager (beforehand) who is doing what. In all circumstances, you need to go over the program and script with the project manager.

PROGRAMME	TASK	NOTES
Staff briefing	– Gather all staff. You assist the project manager in this session to encourage everyone and call for team spirit. – Make sure you are familiar with everyone's role and tasks during the day.	Important that all staff members get confident with you as you are the one to lead them during the day.
Citizen check in	Preparations: – Get microphone from tech staff and do a sound test – Organize your papers at the platform – Welcome people and help to make sure that everybody gets their intro-package, name badges and that they are seated at the right tables etc.	
Introduction	After the prominent speaker leaves the platform you lead the citizen consultation. – Introduce yourself and tell about the roles of the different staff members (especially the group facilitators). – Give practical information (where are the toilets, where to get coffee, tea or water, rules for smoking, mobile telephones should be turned off etc.) – Speaks about the principles and purpose of deliberation and you introduce the citizen consultation programme (only main points; thematic sessions, no common breaks but they should arrange this at the tables)	You should have prepared yourself carefully for this session as it is crucial that people in the room feel confident with you and that the participants gets energy and drive. **No questions in plenum**, all questions should be given to group facilitators who can call for assistance. When you explain

		deliberation the proposed text at the end of this script is good to use.
First thematic session;	First you give an overview of the procedure with the three steps (the procedure is the same for all thematic sessions): Step 1, Introduction of the theme and a video presentation. Step 2: Discussions at round tables. Step 3: Voting (voting papers in intro-packages). (Max 10 minutes for this total overview). Then you start the procedure: – Step 1: You introduce the theme of the first session (1 minute) and you show the video clip (normally about 5 minutes, but in this 1st. session about 8 minutes). – Step 2: You start the round table discussions and request the group facilitators to start with an introduction round, where everybody tells who they are and what their first impression is about what they saw at the video (45 minutes). – Step 3: You announce the voting and repeat the voting procedure (about 15 minutes).	When you explain the procedure you should have an overhead / power point showing the 3 steps. There should be no questions in plenum but make sure that members of staff help the group facilitators when needed (especially regarding the voting procedure). You should have a power point showing the questions that structure the discussions (NB: not the same questions as the voting questions) Sometime before step 2 (table discussions) ends you should remind the group facilitators to make sure all main elements are touched upon.
Second thematic session;	You start the procedure as above (the 3 steps), but now without the overview of the procedure	Results presentation: It will be an advantage if you can present the voting results on power point. If results from the 1st session have been

		reported in good time (30 min before) via the web tool, you can show participants the results on the webpage. (Simply go to the results page and select your own country and language, and a graphical presentation of results will be available).
Third thematic session;	You start the procedure as above (the 3 steps), but now without the overview of the procedure – Step 1: 5 minutes – Step 2: 45 minutes (including time to get lunch) – Step 3: 15 minutes (including results - see below) – Introduce that lunch will be available from a buffet and should be taken to the tables when people are ready to eat - not simultaneously. Emphasize that there's no break involved, citizens are supposed to dine while the session is running. – Before step 3 (voting) you present the results from the voting in first and second session (about 5 minutes included in step 3).	
Fourth thematic session;	– You start the procedure as above. – When you have the feeling that people get tired you arrange with the project manager to start the 10 minutes physical exercise. You give the floor to the instructor. - Before step 3 (voting) you present the results from the voting in third session (5 minutes).	10 minutes exercise; will take about 15 minutes before people have returned to the tables and you can continue.
Closing remarks	You thank the participants for their active contribution to the project, and then you give the platform to the project manager.	You should actively support the project manager during the rest of the program.

Example of how head facilitator can introduce the idea about deliberation without using the technical term "deliberation":

Dear participants,

Today you are going to share your views on epidemic and pandemic preparedness and response.

In order to give you the best thinkable basis for stating your views, we have gathered a lot of different information from different sources pointing in different directions. We have sent you information material that you received before the citizen consultation and we will show you some videos today.

We have invited a broad variety of citizens, broadly representing all parts of society. We invited you as citizens because you all come with different experiences on and knowledge of epidemics and pandemics and you all have different stories to tell.

Today you will listen to and discuss different facts and statements. You may agree with some and disagree with others. You do not need to reach a common agreement at the table as you will all vote individually, but it is important that you listen to each other and respect each other's opinions. At this citizen consultation, everyone is equal, free of hierarchy, meaning that anyone can put forth proposals, criticize, and support measures.

We believe that the best way to discuss and consider an issue is to look upon and assess as many aspects of the issue as possible. That is the reason why we bring so many differences into play.

At your table, you have a group facilitator. His/her job is function as a neutral moderator of the dialogue at the table, and they are not allowed to state their own opinion.

8.6.3 The Group Facilitators

This script concerns both a part describing the role of the group facilitators and a part with the tasks for the group facilitators on September 24, 2015.

The group facilitators should read the role description, the script (table with tasks below) and the information material given to the citizens thoroughly before the citizen consultation.

The whole idea with the dialogue at the table is not to get everybody to agree, but that the citizens hear different perspectives and different points of views in order to reflect on their own view.

Group facilitators' role

As the name indicates, the group facilitator will have to manage (facilitate) a discussion between a group of 6-7 participants. The four thematic sessions will each consist of discussions followed by voting sessions.

The group facilitators have an important role in the discussion process. The group facilitators make sure that the discussions sticks to the point and progress in a good and matter-of-fact form. The facilitators should not influence the process with personal points of view and should avoid using their knowledge about the subject to promote their own views in the table discussion.

The group facilitator is in charge of the table and should act like that. Dominant citizens have been seen to take control over the table, which is why the group facilitator should be able to maintain the facilitator role and demonstrate who is participant and who is running the debate. It is your most important job to make

sure that everyone at the table gets a chance to state their opinion. This means that you have the right to stop a discussion in order to give room for somebody to be heard.

The debates at the tables should start out relatively open discussing the overall theme for the session. Then the table facilitator should move the discussion more towards the voting questions. The citizens should not look at the voting questions before the last third of the discussion, and you should not go through the questions and answers options from one end to another, but the group facilitator must structure the deliberations so that all questions in the thematic session are properly debated. If the debate dries out, e.g. the participants agree on the subject within short time; it might be necessary for the group facilitator to use prompting questions to start the debate again. This could be by asking the citizens to look at the theme from a different perspective or by playing the devil's advocate and ask critical question.

Tasks

The group facilitator's tasks are:

- Keep the group focused on the task.
- Ensure participants treat one another with respect.
- Enable everyone to participate.
- Handle the speech list order.
- Give every citizen a chance to express his or her views on the questions.
- Encourage the shy and cautious citizens not accustomed with deliberations like this to express their views.
- Moderate eager citizens and to limit their time to speak, so that everybody can get a fair chance to speak.
- Make sure you stick to the timetable.
- Explain the citizens what the main objectives of the tasks are in case they are in doubt.
- Maintain neutrality.
- Moderate the discussions without promoting your own view.
- Listen and be aware of your authority as a moderator. It is important that you do not influence the discussion by telling about your own point of view or perspectives.
- Remember that the participants are here as lay people on the topic and therefore they will express themselves on that background. This is the main idea of the project, so it is important that you do not use valuable time from the group discussions to enlighten/educate the citizens or answer questions on the content.
- Collect votes and counting in cooperation with the group.

You should go through the "Rules for good dialogue" (available on every round table) together with participants.

A way to include all citizens and make sure that everybody is heard is to start the session by giving the citizens a minute or two to reflect on the theme and their own point of view, and then give them 1 minute each to tell about their thoughts. No one is allowed to comment or ask questions before everybody have presented their thoughts. When everybody has had his or her turn, you can open/start the free discussion.

PROGRAMME	TASK	NOTES
Staff briefing	– Attend staff briefing:	The group facilitators

	– It is helpful for the group facilitators to have repeated: ○ Practical information such as location of toilets, cloakroom etc. ○ The time schedule for the citizen consultation. ○ The group facilitator's role: manage discussions, prioritize the time, make sure that all citizens have a say, make sure that all questions have been addressed in the discussions, see to that participants are ready for voting. ○ The procedure about voting.	(and other staff) will receive a name badge to put on the clothes, showing firstly that they are an authority and secondly that they are different from the participating citizens. It is very important for the group facilitator to be familiar with the programme of the day. As there are no scheduled breaks during the day, it is you job to coordinate the breaks at your table.
Citizen check in	Find your table and help citizens find their seat at the right table (a seating plan is made for this purpose).	Introduce yourself and make sure that all participants at your table know that you are the group facilitator. Make sure citizens present themselves towards each other (shake hands) thus a friendly atmosphere is established.
Introduction		If participants at your table have questions, you need to answer these after the introduction**. Make sure that questions are not asked in plenum**.
First thematic session;	After the introduction, the video presentation, and the head facilitators presentation of the questions, you start the discussion:	Make sure that the discussion questions in this session have been

	Discussion: The group facilitators start the discussion at the table with an introduction round, where every participant one by one presents themselves and say what their first impression is about what they saw at the video – max 1 minute each**.** After that you should **lead the discussion** as prescribed in the group facilitator's role description above. **Voting:** At the end of the discussion, you go through the voting procedure.	discussed within **45 minutes.** (NB: the discussion questions are not the same as the voting questions) The citizens should discuss together – not ask questions towards you. If they ask questions, you should make answers corresponding with the information material. As a last way out, you should call for the project manager to answer.
Second thematic session;	– Same procedure as first thematic session	Make sure that every discussion question in this session has been discussed and voted on within **45 minutes.**
Third thematic session;	– Same procedure	Make sure that the discussion questions in this session have been discussed within **45 minutes.** Lunch is served at the buffet. People consume at the round tables while the thematic sessions are running. No definite break involved. **Make sure this will happen smoothly, with least interruption for the citizen consultation.**
Fourth thematic	– Same procedure	Make sure that every

session;		discussion question in this session has been discussed and voted on within **45 minutes.** After the exercise, you have to make sure that the participants find their seat right away.
Fifth thematic session;	For question 5 we have developed a method for analyzing the answers from the citizens. After answering the question citizens will be instructed to encircle the 2-5 most central words in their answers. Our reason for this choice is that it provides us with an opportunity to go through the answers from the citizens more quickly than if we have to read through all the answers and then try to structure them. We have made instructions for the citizens on how to encircle the answers and what constitutes central words in an answer. Having encircled specific words in their answers the citizens answer data will then be inputted in a table.	
Closing remarks	When the citizen consultation is finished thank the citizens at your table for a pleasant day.	

8.6.4 The Technician

The technician should be familiar with the software and hardware used at the citizen consultation, and should be the one to make sure that all technical equipment is running perfectly during the entire citizen consultation. Please find out what technical equipment is necessary. The technician must prepare and test all equipment before the citizen consultation will start. If you decide on having a trial run of the event, the technician should of course participate.

Some issues that should be addressed before the event starts could be: Is the computer used for the power point and video presentations able to work with the projector and audio system? Do the microphones work probably and with good sound quality? Do the sound from the introduction videos is audible? **Does the internet connection work?** Are you able to connect to the web-tool? Is the printer able to print out copies of the results for all citizens? Questions like these are good to think through so that you are well prepared for the citizen consultation.

PROGRAMME	**TASK**

The day before	– ***Technical Set-Up***: If it is possible computers and audio & visual equipment should be set up the day before and tested. Please test as much as possible the day before, such as; correct connection to the internet, computer batteries should be fully charged or plugged in, proper set-up of video-playing-equipment to the screen or TV, good set-up of the microphone to the audio system, power-points should be put on the computers used, and printer able to print 100 copies of the citizen consultation results.
Staff briefing	– Attend the briefing
Citizen check in	– Make sure that all technical equipment is ready. What technical equipment has to be ready next?
Introduction	– The **microphone** and **audio system** as well as the **computer** and **projector** for power point presentations should be ready.
First thematic session;	– The **projector + computer with power points** should be ready for the head facilitator presentation. – The **video to the first thematic** session and **microphone** should be ready. – Procedure explained by head facilitator, (5 – 10 minutes). – The 3 steps: o Introduction of the theme and **video presentation** (15 minutes); o Discussions at round tables via **discussion questions** (50 minutes); o Voting (15 minutes). – During the second session the **voting data** should be **uploaded to the web-tool.**
Second thematic session;	– The **video to the second thematic** session and **microphone** should be ready. – The **results from first session** should be made ready for presentation. – The **projector + computer with power points** should be ready for the result presentation. – The 3 steps: o Introduction of the theme and **video presentation** (5 minutes); o Discussions at round tables via **discussion questions** (45 minutes); o Voting and **result presentation from first session** (15 minutes). – During the third session the **voting data** should be **uploaded to the web-tool.**
Third thematic session;	– The **video to the third thematic** session and **microphone** should be ready. – The **results from second session** should be made ready for presentation. – The **projector + computer with power points** should be ready for the result presentation. – The 3 steps:

	○ Introduction of the theme and **video presentation** (5 minutes); ○ Discussions at round tables via **discussion questions** (45 minutes); ○ Voting and **result presentation from second session** (15 minutes). – A **portable microphone** for the exercise instructor should be ready. – *Exercise:* Halfway through the sessions (the day) there should be 10 minutes of physical exercise. – During the fourth session the **voting data** should be **uploaded to the web-tool**.
Fourth thematic session:	– The **video to the fourth thematic** session and **microphone** should be ready. – The **results from third session** should be made ready for presentation. – The **projector + computer with power points** should be ready for the result presentation. – The 3 steps: ○ Introduction of the theme and **video presentation** (5 minutes); ○ Discussions at round tables via **discussion questions** (50 minutes); ○ Voting and **result presentation from third session** (15 minutes). – During the recommendation session the **voting data** should be **uploaded to the web-tool.**
Fifth thematic session:	– The **results from fourth session** should be made ready for presentation. – The **projector + computer with power points** should be ready for the result presentation. – During the recommendation session the **voting data** should be **uploaded to the web-tool.**
Closing remarks	– The **screen shot from the website of the European results** should be ready. – World perspective: **Screen shots from the website, for transnational gathered results, should be monitored (if possible).** – Information about follow-up: What will happen now, how will the results be communicated. – Explain how the participating citizens reach today's national and World results. – Practical issues (transportation etc.) – The project manager and the main facilitator give a terminal speech and thank the citizens for their participation (max 5 minutes). – Take away food (sandwiches or similar) is served. – **Hard copies** of the results from the thematic sessions are distributed to all citizens at the exit if possible. – **Video** interviews with citizens.

8.7 How to Use

Different stakeholders may use this Citizen Participatory Meetings Tool for getting true insights from a cross-section of citizens on varieties of themes that affect the daily lives of citizens. It is important that thorough homework and proper planning is done, including who will do what, before a citizen participatory meeting is called. We recommend writing a detailed script for the meeting as explained in the example given above. The example given above is applicable across geographical boundaries for pandemics. You may easily modify it for your functional focus area.

REFERENCES AND RESOURCES

Work Package 4 Citizen Consultations of Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics pp. 17 to 20 available at http://www.asset-scienceinsociety.eu/about/dow

Section 3 Participatory Governance in D2.3 Crisis Participatory Governance Report of Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics pp. 10-19 available at http://www.asset-scienceinsociety.eu/outputs/deliverables/crisis-participatory-governance-report

9. REPORTING HEALTH ISSUES BY JOURNALISTS

This online e-learning Tool aims to advance training in health reporting. It summarizes public health issues and how to communicate about them to the public. The Tool is valuable for journalists and media officers, as well as for communication and press officials working at the community level.

9.1 Purpose

Media play a key role when it comes to health, by:

- informing the general public about health,
- maintaining important issues on the public agenda, and
- promoting health literacy.

Journalists reporting on health can influence health-related behaviors of patients, clinicians and policy makers (Dentzer, 2009). However, as research also shows, the lack of specialized training and understanding of complex scientific subjects can result in inaccurate reporting (Dentzer, 2009), posing a risk of creating false ideas and negatively influencing policy makers. In a recent survey, only 18% of the journalists had specialized training. Only 6.4% reported that a majority of their readers change health behaviors based on their reporting.
Previous EU initiatives have shown that journalists recognize their need for training. However, specialized training opportunities appear to be limited. As shown by the European Guide to Science Journalism Opportunities (2008), training in some countries, e.g. Portugal and Finland, is scarce, while in others, e.g. Greece, it does not exist. Furthermore, a large amount of science coverage in EU focuses on what is being conducted in the US.

The purpose of this Tool is to offer guidance concerning communication issues faced by journalists and others who report on health issues. In particular, this Tool aims to improve the accuracy, clarity, and the effectiveness of communications about health issues, including issues related to epidemics and pandemics.

9.2 Target Group

The training tool primarily targets journalists who report on health issues and aims at improving their skills and capacities to report in an efficient and scientifically optimal way. However, the tool is also useful for media officers and communication and press officials working at the community level. It can be used by both professionals (journalists, media officials) and by other community stakeholders who are concerned with communicating health issues to the general public.

9.3 Description

This tool has been adapted for the ASSET Tool Box from the HeaRT Project.

Health Reporting Training Project (HeaRT project):

HeaRT was an EU co-funded two-year project completed in October 2012 that aimed to develop vocational

training on health reporting for journalists. HeaRT identified health journalism education opportunities around Europe, reviewed existing literature and knowledge, conducted original research among journalists, and developed educational tools on health reporting. HeaRT had six consortium partners led by the Institute of Preventive Medicine, Environmental and Occupational Health (PROLEPSIS) in Greece. PROLEPSIS is also one of the 14 ASSET consortium partners, and they contributed to developing this ASSET Tool from the HeaRT results.

The tool developed within the HeaRT project:

- Identified and made easily accessible all existing training opportunities on health reporting,
- Developed new training tools
- Conducted courses in several European countries
- Built an informative web site to serve as an EU health journalism platform and a valuable resource.

The tool is available in English, Estonian, German, Greek, Finish and Romanian. Each language-specific section includes issues of particular importance in each country. For example the Greek version has a section on crisis management and preparedness. The e-learning platform offers courses on global health, including communicable diseases like influenza, Hepatitis and AIDS/HIV.

The English section includes the following modules:

- Medical research and science
- The business - Economics of healthcare
- Health policy
- Reporting on health policy
- Healthcare quality and performance
- Global health
- Consumer - Lifestyle health
- Health disparities
- Global health inequalities
- How to understand statistics
- How to do multimedia reporting
- Public Health & the politics of healthcare
- How to evaluate conflicts of interest
- Reporting
    - Reporting medical research and science
    - The trouble with medical news stories
    - Understanding Hospital and Other Financial Documents
    - Data mining with Excel or other analytical software
    - How to map health conditions
    - How to search for medical information online
    - How to report public opinion polls and surveys
    - Reading and general advice on how to understand statistics

9.4 Challenges Addressed

This tool addresses the lack of specialized training of journalists reporting health issues, and it also provides information useful to others communicating with the general public about health issues.

9.5 Benefits

This Tool promotes better communication to the general public by journalists who report on health issues, media officers and communication and press officials working at the community level. Improved health communication can lead to better understanding and health outcomes in the general public.

9.6 How to Use

The e-tool is freely available to all interested through the HeaRT project website - http://www.project-heart.eu

To enter the e-learning platform, please click on the icon e-learning tool - http://www.project-heart.eu/index.php/projectheart/tools/elearning and then register your email address and contact details so as to access the e-learning tool.

REFERENCES AND RESOURCES

Dentzer, S. (2009). Communicating medical news—pitfalls of health care journalism. *New England Journal of Medicine,* 360(1), pp. 1-3.

European Commission, Directorate-General for Research and Innovatio, Communication Unit. (2008). *European Guide to Science Journalism Training.* Brussels: Author

10. RESPONSE TO RADIOLOGICAL, BIOLOGICAL, AND CHEMICAL THREATS BY HEALTHCARE PROFESSIONALS

The aim of this tool is to provide knowledge and training material to empower health professionals and organizations, governments, civil authorities, security agencies and armed forces to rapidly recognise clinically and adequately respond to new public health threats, like deliberate or terrorist attacks with biological, chemical, and radiological agents. Institutions, universities, or public health authorities may use the tool for training. The Tool includes necessary information and guidelines that different stakeholders will need to disseminate to front-line health professionals in emergencies caused as explained above as well as the algorithm guide of actions to be undertaken.

10.1 Purpose

The purpose of this tool is to providing training material to front-line health care professionals and emergency medical responders in case of a radiological, biological, and chemical threat for responding effectively.

10.2 Target Group

The target group for this tool includes front-line health professionals, including physicians and nursing staff in civilian or military facilities, especially those working in emergency departments or in primary healthcare. Second target group is public health officials at the local level and Emergency Medical Services personnel. Third target group is the institutions, medical colleges, organizations, administrators, security agencies, armed forces, and first responder trainers imparting training in this area.

10.3 Description

Public health professionals are increasingly facing serious threats and are worried about the possibility of the international spread of communicable diseases and intentionally caused biological attacks. Predictions based on climatic changes, as well as the global socioeconomic situation indicate that humanity as a whole is going to face in the future an increasing number of international outbreaks, as humans on one hand invade more and more tropical forests and come in contact with new agents, and on the other travel long distances in large numbers.

Front-line health professionals such as emergency medical services, emergency departments, and primary health care personnel, as well as regional public health personnel should be aware of the basic issues regarding new health threats to public health and radiological, biological, and chemical threats. Front-line health professionals form the first vital link for the detection of any incident. Astute clinicians are usually the first to understand and notice new clinical syndromes (e.g., West Nile virus encephalitis) and the reporting of these to the regional public health authorities is the first step towards the recognition of the problem.

European Training for Health Professionals on Rapid Response to Health Threats (ETHREAT)

ETHREAT was a EU funded three-year project launched in 2005 to plan and develop an educational package

containing information and training material necessary to empower European health professionals, including armed forces health personnel, to rapidly recognise clinically and adequately respond to new public health threats, like attacks with radiological, biological, and chemical agents. ETHREAT had seven consortium partners including the Institute of Preventive Medicine, Environmental and Occupational Health (PROLEPSIS), Greece. PROLEPSIS is also one of the 14 ASSET consortium partners and contributed to developing this Tool from ETHREAT.

The ETHREAT project developed a *"How to Respond to Radiological, Biological, and Chemical Threats: A Guide for the European Front-Line Health Professional*." The handbook includes the following sections:

- Introduction: overview of the new public health threats and basic principles of planning for public health emergencies
- Biological Agents: overview of the biological agents of high threat, their clinical symptoms and the principles of their clinical management
- Infection Control: outline of the transmission based infection control guidelines
- Chemical Agents: overview of the groups of chemical agents of high threat, toxins and Industrial chemicals, their clinical symptoms and the principles of their clinical management
- Radiological Emergencies: overview of radiation exposure, its clinical symptoms and principles of clinical management
- Triage: overview of the triage principles and process and the START triage system
- Management of Contaminated Patients: basics of scene management, overview of the decontamination process and basic principles along with special considerations
- Psychological Effects: overview of the psychological effects of emergencies and terrorist events.

10.4 Challenges Addressed

This Tool addresses the challenges faced by front-line health professionals in emergencies caused by radiological, biological, and chemical threats.

10.5 Benefits

Front-line health professionals, including physicians and nursing staff working in emergency departments and emergency medical services personnel may benefit by learning from this Tool in response to radiological, biological, and chemical threats.

10.6 How to Use

The handbook, *"How to Respond to Radiological, Biological, and Chemical Threats: A Guide for the European Front-Line Health Professional*" is a user friendly basic awareness manual aiming at empowering front-line health professionals to rapidly response to the impending threats. The handbook is available at http://www.cbrne-terrorism-newsletter.com/resources/ETHREAT%20Manual%202009.pdf

REFERENCES AND RESOURCES

ETHREAT Scientific Committee. (2011). *How to respond to radiological, biological and chemical threats: A guide for the European front-line health professional.* Athens: National & Kapodistrian University

European Training for Health Professionals on Rapid Response to Health Threats (ETHREAT) http://euprojects.org/ethreat.info/

11. CHECKLISTS FOR PANDEMIC RESEARCH

ANNEX 3 is a specialized checklist to guide researchers in following the D3.2 Roadmap to Open and Responsible Research and Innovation in Pandemics. The primary goal of this Roadmap (http://www.asset-scienceinsociety.eu/outputs/deliverables) is to improve Public and Patient Involvement (PPI) in pandemic research. In this context, "Public and Patient" refers to patients, care givers, health researchers, and patient organizations.

ANNEX 4 is a checklist of basic research considerations, which apply to research on pandemics as well as other topics. This checklist shows how ANNEX 3 fits into the broader context of research methodology, and also serves as a basic reference for intermediate level researchers.

11.1 Purpose

The purpose of these checklists is to support implementation of an ideological shift within which patients and civil society representatives have a formal and recognized role to effectively get involved in research that concerns their health-related issues. This shift would result in research being carried out 'with' or 'by' members of the public rather than 'to,' 'about,' or 'for' them (INVOLVE, 2012).

The role of patients in health is acknowledged by epidemiologists, who advocate that evaluation of health care services should be based on patients' clinical effectiveness, economical efficiency, and social acceptability. Historically, social acceptability or patient-based evidence has received less attention and limited in giving consideration to the patient's suggestions and rights in clinical practice.

In recent times there has been a paradigm shift toward "patients as co-researchers", accepting the idea that patients have the full capacity and right to be directly involved in biomedical research, although not in technical phases and patients and publics contributions are increasingly being accepted. The level of patients' participation can range from tokenism to joint decision making by professionals and patients.

11.2 Target Group

The target group of these checklists is researchers on pandemics, vaccines, and antiviral drugs.

11.3 Description

Public and Patient Involvement may take several forms:

- Consultation: Patients are consulted for their needs. A critical issue is however that there is no guarantee that their input is taken into consideration in research agendas
- Participation: Patients are involved in the research agenda in a more formal way but again the final decision belongs to health care professionals (HCPs)
- Partnership with real power-sharing between HCPs and patients-partners, and where there are genuine negotiations between patients and HCPs

- Delegated power: Patients have a dominant position in decision-making process
- Patient control: Decision-making in biomedical research belongs to patients.

To achieve effective PPI, each research project must consider what form of involvement will best serve the research and the public. These checklists are intended to stimulate reflection on options and opportunities, within the framework of the ASSET Roadmap's five steps:

- Building the PPI
- Key Players
- Communication and Education
- Neutralizing Negative Side Effect, and
- Implementation.

11.4 Challenges Addressed

There are many challenges to achieve greater PPI in research. These include, "what" should be the role of PPI, "when" should PPI be used, and "how" to achieve PPI.

What is the role of PPI? PPI in the research design stage may achieve greater success by involving patients in decisions such as: the scheduling of visits, blood sampling, and use of invasive devices. Another "what" question is the level of involvement in different phases of the R&D process, i.e. 1) preparation of research topics/ questions; 2) design and execution; 3) analysis; and 4) communication of results/policy making decisions. The involvement of patients and non-research Health Care Professionals (HCPs) needs careful guidance by research HCPs involved in the projects.

"When" is PPI likely to achieve the greatest success? PPI from the beginning and throughout the process is the ideal condition (Caron-Flinterman, 2005). This, however, may not always be feasible.

The "how" challenge of PPI is to find out the way HCPs could come into contact with the targeted population of patients, and vice versa. Essential to this challenge is a cultivated ability for the HCPs to effectively communicate with the public, and to actually hear and understand their perspectives.

11.5 Benefits

The benefits of PPI in research include

- Deciding which are the right research questions to ask
- Difference between research success and failure by understanding the experience of people living with a condition
- Shortening the recruitment time in clinical trials
- Avoidance of waste of time and wrong ways of developing devices
- Better understanding of potential additional benefits of medications after they have reached the market based on data reported by patients

- Feedback strategy and putting mechanisms into place to encourage retention to the studies
- Reduction of the gap between producers' and developers' ungrounded conceptions about vaccines
- Benefitting the patients themselves by helping the development of new therapies.

11.6 Examples

PPI in research has been implemented in practice in Europe and other developed countries. PPI in international health technology assessment activities is also growing. Denmark has the leading position in establishing user-driven innovation as national policy with several projects already completed in different sectors of health (e.g. diabetes, patients in ICU, etc.). In the UK, PPI has become a central part of clinical research with many funding agencies asking information on the extent of PPI involvement in the planned research study (Evans et al., 2013).

The United States has a pioneering position in the field of user-driven innovation via the Berkeley based Centre for Information Technology Research in the Interest of Society. Research carried out by this centre is technology and product based and includes a large variety of subjects such as telemedicine, using games to screen for fragile X syndrome, and a small microscope on a cell phone to monitor patient's blood from home.

Online communities by patient organizations, providers, and non-profit organizations are growing. In these virtual forums, patients and caregivers discuss health concerns and exchange information that may be potential drivers of innovation in the field of health, although with some limitations. We give below examples of disease-specific PPI that led to improved participation of the civil society, associations of consumers, and patients in health-related research.

- Breast Cancer: The objective of Europa Donna (http://www.europadonna.org/) is to promotion and direct involvement of women in cancer research. It is active in more than 20 European nations (Cardoso, et al. 2014; Knox, 2011). It is a member of the Scientific Committee of the Breast Cancer International Group (http://www.bigagainstbreastcancer.org/, and http://www.europadonna.org/research) and has directly been involved in the definition of recent ESO-ESMO 2nd International Consensus Guidelines for Advanced Breast Cancer (ABC2) (Cardoso et al., 2012, 2014).

- Rare Diseases: Physicians seldom encounter rare diseases due to their low prevalence, because of that these diseases suffer from a deficit of medical and scientific knowledge. Potentially, PPI could have a significant impact on diagnosis, treatment, and prognosis of rare diseases. Several PPI initiatives for rare diseases are in place. The European Organization for Rare Diseases is the most notable of these initiatives (http://www.eurordis.org/).

- AIDS: The European AIDS Treatment Group (http://www.eatg.org/) 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 in Europe since its foundation in 1991.

11.7 How to Use

The checklists given in the two Annex may be used by answering the questions along with innovative, deep, and creative thinking. If the reply to one or more question(s) is in negative, the researcher needs to do more work and modify the research. A researcher is also recommended to share her or his thoughts, proposed actions, and draft writings with peers and patients and public who are/ were involved in the research.

ANNEX 3: CHECKLIST FOR RESEARCHERS TO INSURE PATIENT AND PUBLIC INVOLVEMENT

The objective of D3.2 Roadmap to Open and Responsible Research and Innovation in Pandemics is to design a roadmap towards responsible and open, citizens-driven research and innovation on vaccines and antiviral drugs. The Roadmap will be accessible from http://www.asset-scienceinsociety.eu/outputs/deliverables. The Roadmap answers 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. The Roadmap indicates best practices for PPI in biomedical research concerning pandemics. This checklist is intended to help researchers who want to involve patient and public in their research. The Roadmap has identified five steps, which may lead to best practices for the PPI in biomedical research concerning pandemics. This Checklist details the items which a researcher may consider before, during, and/ or after research to achieve greater PPI. If the answer to any of the questions in the Checklist is in negative, the researcher needs to do more preparation or modify his research project. The five steps, which are detailed below are: (1) Building the PPI, (2) Key Players, (3) Communication and Education, (4) Neutralizing Negative Side Effect, and (5) Implementation.

A3.1 Building the PPI

A3.1.1 Before the Research

- Are you contemplating PPI from very beginning of the research process?
- Are you sensitizing stakeholders of public and private sectors?
- Are you ensuring that users involved in a research project feel as intellectual co-owners, and not as guests in the project (this checklist item is applicable before the research as well as during the research)?
- Are you ensuring that patients/representative of civil society contribute to design their own agenda without being overly influenced by professionals?
- Are you ensuring that the involvement of patients/civil society representative in research projects is well “designed?”
- Are you ensuring that the participants are as heterogeneous as possible, both in their personal health experience and in their socio-cultural background?

A3.1.2 During the Research

- Are you keeping sustained PPI throughout the research process, although with appropriately variable degree of involvement in different processes?
- Are you ensuring that users involved in a research project feel as intellectual co-owners, and not as guests in the project (this checklist item is applicable before the research as well as during the research)?
- Are you ensuring involvement of patients and care takers in scheduling of visits, blood sampling, and use of invasive devices?

- Are you ensuring that cultural issues are taken into consideration in clinical trials-based research (this is particularly relevant in research aimed at increasing the awareness of the relevance of vaccination with the aim of increasing the vaccination rates)?

A3.1.3 After the Research

- Are you ensuring involvement of civil society representatives in the extraction of key points, as well as in the interpretation of research results, especially those that have impact on their everyday life?

A3.2 Key Players

A3.2.1 Before the Research

- Are you involving a range of associations in PPI research?
- Are you involving EU Association of GPs (this association may allow contacting all EU GPs?
- Are you involving GPs (and especially research networks of GPs), because they act as an interface between professional researchers and civil society representatives?
- Are you involving EU and national associations of consumers?

A3.2.2 During the Research

- Are you establishing a new research network of GPs as an integral part of your project in this area, if your research is in pandemic prevention?

A3.3 Communication and Education

A3.3.1 Before the Research

- Are you educating biomedical scientists and public/ patients to enhance their communication skills, trust, and ability of mutual interaction?
- Are you aware of PPI in research training courses?
- Have you completed a PPI in research training courses?
- Have you checked that the prospective patient and public whom you are thinking of involving in your research have completed a PPI in research training courses?
- If they have not completed a PPI in research training courses, how would you motivate them to complete a course?
- Have you set-up a specific, validated, and official Internet sites as the main communication tool?

A3.3.2 During the Research

- Are you able to communicate science to a large audience and able to understand them?
- Are you able to stimulate the ability to discriminate between a good quality website with scientifically serious content from websites that contain false contents (often written in a Para-scientific style) among the patient and public whom you have involved in your research?
- Are you able to foster an internet-based dialogue with 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?

A3.4 Neutralize Negative Side Effects

A3.4.1 Before the Research

- Are you aware of the negative side effects of PPI?
- Are you prepared to face the negative side effects of PPI?
- Are you willing to take the challenge of user-focused research that might be of less immediate benefit for users, but that might have huge positive benefit to users in a non-immediate future?
- Are you aware of potential risks of PPI?

A3.4.2 During the Research

- Are you able and willing to propagate research on how to prevent and minimize the risks related to a PPI in pandemic research?
- If yes, have you thought of strategy and its implementation?
- Are you psychologically and otherwise prepared to accept time delays and costs due to a process of mutual learning and of planning a new type of collaboration that entails PPI?

A3.4.3 After the Research

- Are you making efforts to avoid limiting the freedom of research of scientists?

A3.5 Implementation

A3.5.1 Before the Research

- Are you involving patient-reviewers for evaluation of project design and grant application?
- Are you aware of specific developed and validated measurement tools that could evaluate what work, and in which circumstances, achieve better results in PPI (this checklist item is applicable before the research as well as after the research)?

A3.5.2 During the Research

- Are you implementing PPI research with collaborative bidirectionality?
- Are you avoiding dissipating the precious heritage of comments and criticisms that civil society has elaborated during and after the 2009 H1N1 pandemics?
- Are you conducting periodic surveys in collaboration of civil society public opinions to measure the fear and expectance concerning pandemics?
- Are you aware of serious obstacles in investigating the nature of PPI due to confidentiality in industrial projects, although information on these projects is essential to enrich methodological research on PPI?

A3.5.3 After the Research

- Are you ready to do frequent and specialized surveys when small epidemics appear and the related information is widely communicated by media?
- Are you seeking support of civil society to become aware of a wide range of pandemic problems to be investigated and that are “orphans” until now?
- Are you involving patient-reviewers for evaluation of scientific articles?

- Are you aware of specific developed and validated measurement tools that could evaluate what work, and in which circumstances, achieve better results in PPI (this checklist item is applicable before the research as well as after the research)?
- Are you evaluating the value and impact of PPI partnerships in your research project?

ANNEX 4: BASIC CHECKLIST FOR RESEARCHERS

This checklist is designed to help an intermediate level pandemic researcher to initiate and execute a research project related to a topic of the selected pandemic by answering some questions and thinking deeply about her or his responses to the questions.

There are differences in approaches to research in different academic disciplines. This checklist is intended to help generally an intermediate level pandemic researcher in initiating a research project and executing it. This checklist for researchers is prepared for any topic related to the pandemics, since the focus of the ASSET project is on pandemics. However, with modifications, this checklist for researchers may be used in any academic discipline.

The target group of this checklist for pandemic researchers is the intermediary level researchers in any field of human endeavour. This checklist is neither designed for people who are beginners in research nor for those who have terminal degrees, like PhD, or who are otherwise advanced researchers. An example of the target group member is a healthcare professional who has basic domain knowledge and wants to do research on a topic related to the pandemic.

Europe 2020 strategy stipulates an investment of 3% of gross domestic product in research and innovation, across the public and private sectors combined, by 2020. Horizon 2020 has a budget of 80 billion Euro and a duration of 2014 to 2020. It aims to make Europe a better place to live and work, by developing and implementing research and innovation policy, to improve Europe's competitiveness, boost its growth, create jobs, and tackle the main current and future societal challenges. This shows research is important. There are opportunities for funding for a good researcher from many other sources, apart from Horizon 2020.

Research is defined by the University of North Texas as a systematic study directed towards fuller scientific knowledge or understanding of the subject studied. Another definition is: research is systematic rigorous investigation into a phenomenon to generate new knowledge or understanding.

Research is done basically to reduce the gap in knowledge. To identify the gaps, a literature review needs to be done. Having identified the gap, a researcher has to frame a clear research question(s) or develop a hypothesis for testing. The research questions and hypothesis determine the research methodology: quantitative, qualitative, or mixed-methods. Research method helps in data collection (primary or secondary). Data analysis leads to findings. Steps in preparing a research study are given below (Magnus, M. (2008) :

- Literature review
- Development of specific and measurable research questions, null and alternate hypothesis
- Development of the research question matrix
- Development of a protocol with multidisciplinary team of investigators (multiple iterations)
- Meet with the community to discuss and ensure community – and culture – appropriateness of study
- Creation / adaptation of instrumentation
- Pre-testing / piloting of instrumentation and study protocols
- Development of a quality assurance plan

- Submission to institutional review boards and relevant organizational, local, state, or federal bodies for approval
- Training of field staff
- Study implementation
- Ongoing data and study quality assurance measures
- Assessment of fidelity to intervention (if applicable)
- Data cleaning
- Data analysis
- Interpretation
- Public health action as needed
- Dissemination
- Recommendations for future study.

This is a simplistic model of research, but in reality it is more complicated, and sometimes it becomes iterative. Research is generally a team effort (except for getting a PhD) that involves peer reviews, feedback, and trade-off.

Please consider the following questions before starting the research, during the research, and after completing the research. This checklist for researchers provides only closed-ended questions to reply in yes or no. If the reply to a closed-ended question is in affirmative, the researcher may proceed to next question (research, particularly qualitative research, is not a linear process, and iterations may be involved). However, if the reply is negative, the researcher has to go back and do some more work. For example, one of the questions in the checklist is: Have you identified proper research question(s) or hypothesis to test regarding the topic within the pandemic? If the reply is in affirmative by the researcher and colleagues, the researcher may go ahead. If the reply is in negative, the researcher has to go back to the drawing board and think of the appropriate research question or hypothesis. How to develop research questions or hypothesis is beyond the scope of this checklist. Similarly, details of other parts of conducting research or elaboration of steps given in Annex_3 are beyond the scope of this Tool. For details a reader may refer to the references and resources section given at the end.

A4.1 Before the research (literature review, planning, writing, funding, and other resources raising)

A4.1.1 Need and Purpose of Research

- Why do you want to do this research on the pandemic?
- What is the importance of the research you want to do?
- Does your contemplated research justify the time and resources that will be dedicated to it?
- Will your research bring about a change in the understanding of the disease process?
- What will be the use of the research findings before or during the next pandemic?
- Who will be the target audiences of your findings and why would they care about your research findings?

- How will you disseminate research findings to make them actionable?
- Are you competent to do the research on the topic related to the pandemic you are contemplating?
- Who may help you in the research and how would you contact them?
- Will the knowledge generated from research question/s or hypothesis testing add to existing knowledge on the pandemic?
- Do you expect your research to bring about a change in current healthcare practices?

A4.1.2 Identifying Knowledge Gap

- Have you done a literature review on the pandemic in general and specifically on the topic of the research you are contemplating?
- Have you identified knowledge gaps within the pandemic on the topic of your interest based on the review?
- Have you identified the leading research scholars doing cutting edge research on the topic within the pandemic and have you read their recent publications?

A4.1.3 Defining Research Question or Hypothesis

- Have you defined proper research question(s) or hypothesis to test regarding the topic within the pandemic?

A4.1.4 Research Design

- Is the research design appropriate for research question(s) or hypothesis testing for the topic within the pandemic?
- Have you designed the questionnaire or written the hypothesis for testing for the topic within the pandemic?
- Have you pilot tested the approach?
- Have you met with the community to discuss and ensure cultural appropriateness of the study?
- Have you delineated geographical area for your responders for your research on the topic?
- What will be your sample size, how will you compute it, and how will you select the responders for your research on the topic?

A4.1.5 Researcher Competency and Resources

- Do you have necessary skills and resources (human, infrastructure, machines and equipment, support from collaborators, financial, time) to conduct the research on the topic within the pandemic?
- Do you have interviewing skills regarding the topic within the pandemic, if your research involves interviewing?
- Will you financially reward the research participants? If not, have you thought of non-monetary ways to motivate research participants for seeking their cooperation in the research?

A4.1.6 Ethical Considerations

- Is there any conflict of interest involved in the proposed research on the topic within the pandemic, if yes, have you made proper disclosures?
- What are the risks of conducting proposed research on the topic within the pandemic and how will you mitigate them?
- Have you considered the potential risks to health, safety and well-being of researcher(s) and research participants in conducting proposed research on the topic within the pandemic and the ways to mitigate them?
- Is it ethical to do proposed research on the topic within the pandemic according to the Institutional Review Board (in US) or other similar organization in other countries? If not, you need to modify your approach or consider some other topic.
- Is your research approved by Institutional Review Board (in US) or other appropriate body in your country on the topic within the pandemic or the medical research authority, as applicable?

A4.1.7 Legal and Regulatory Considerations

- Will your research on the topic within the pandemic comply with health and safety requirements in general, in addition to the researcher(s) and research participants' health and safety mentioned above?
- Have you received legal permission to conduct the research on the topic within the pandemic, if required?
- Will your research on the topic within the pandemic comply with legal and ethical requirements, all applicable guidelines of partner organisations, funding organization, and local laws of the country and place the research will be conducted?
- Will your research on the topic within the pandemic comply with monitoring and audit requirements of the funding and regulatory authorities?

A4.1.8 Agreement with Co-researchers

- Do you have an agreement with co-researchers on the topic within the pandemic about who will do what and by when?
- Do you have an agreement with co-researchers on the topic within the pandemic for intellectual property rights, publications and authorships?

A4.2 During the research (going in the field, field observation, data collection, interviewing)

A4.2.1 Reconfirmation

- Generally, there is a time lag between planning research and starting research. Before starting a research check: Do you still have the resources, human, infrastructure, equipment, financial, and time for doing the research on the topic within the pandemic?

A4.2.2 Entry in the Field

- Have you established local contacts to enter in the field?
- Have you arranged the services of an interpreter, if needed?

A4.2.3 Consent of Participants

- Have you made proper disclosures about the risks involved to the research participants, explained to them the purpose of the research on the topic within the pandemic, and that they may withdraw from the research at any time?
- Have you received the Institutional Review Board (in US) approved Consent Form signed by the research participants or other consent form required for the research on human subjects in the research originating country and/ or the country in which you are doing research?
- Have you received permission of the research participant on the topic within the pandemic before taking pictures or audio or video recording the interview?

A4.2.4 Reward to Participants

- Have you told the participant about the financial reward you will give, if any, for their participation in the research on the topic within the pandemic?
- If you are not giving a financial reward, have you thought of how will you motivate respondents to participate in your research?

A4.2.5 Changing the Research Design

- Are you following the research design and/ or procedure as agreed with the funding, collaborating, and regulatory agency or agencies on the topic within the pandemic?
- Sometimes, during the research, a need becomes clear to change certain aspects of the research. Are any changes needed in the original research design on the topic within the pandemic? If yes, what modifications are needed?
- If you are changing the research design or procedure, have you gotten approval for the changes from the funding, collaborating, and regulatory agency or agencies on the topic within the pandemic?

A4.2.6 Data Collection and Analysis

- Are you following data collection procedures as envisaged on the topic within the pandemic?
- Do you have a data monitoring committee?
- Do you have the data analysis plan ready?
- Have you made necessary arrangements for data entry and analysis?
- Have you put in place processes to ensure data quality?
- Are you preserving the data properly for retrieval while doing research on the topic within the pandemic?

A4.2.7 Adverse Events

- Are you reporting the adverse events diligently to the concerned people?

A4.3 After the research (data analysis, interpretation, findings, report writing, dissemination)

A4.3.1 Data Preservation, Analysis, and Sharing

- Are you preserving the research data in a secure, accessible form, till they are required to be retained for research on the topic within the pandemic?
- Have you started processing data on the topic within the pandemic in a reasonable time after data collection?
- Have you engaged local stakeholders in interpretation of the findings?
- If your data on the topic within the pandemic are collected from publically funded grants, and does not involve state or defence secrets (applicable for advance researchers), are you making them available publically for other researchers?

A4.3.2 Report Writing

- Will you report the research findings accurately and within a reasonable time?
- Have you planned that the draft findings will be discussed with the funding agency and key stakeholders?
- Have you followed the style manual of your discipline in the research report and is it consistent with your research proposal?
- Have you checked that in your research report on the topic within the pandemic you are giving proper credits to the sources you use and that there is no plagiarism?

A4.3.3 Acknowledgement

- Are you acknowledging in the report contributions made by different stakeholders to the research on the topic within the pandemic, who have contributed in any way, howsoever small that may be, and not limited to only funders, co-researchers, or research participants?
- Have you shared the findings with the research participants who gave their time for the research on the topic within the pandemic?

A4.3.4 Compliance of RequirementsA1.3.5 Limitations of the Research

- Have you stated the limitations of your research on the topic of the pandemic in your research report?

A4.3.6 Future Direction of Research

- Have you identified future directions for research based on your topic within the pandemic?

A4.3.7 Dissemination of Findings

- Do you have a plan for dissemination of research findings in place?

- How will the findings reach those who can most benefit?
- What modes of dissemination will you use in addition to conferences and peer reviewed journal articles?

A4.3.8 Conference Presentations

- Have you identified the conferences where you want to present the findings of your research on the topic within the pandemic?
- If you have identified the conferences, are you aware of the dates and places of the conferences, deadlines for abstract and full paper submission, and registration?
- Do you have funding or do you know whom to approach for funding for participation in the conferences of your interest?

A4.3.9 Publication in Journals

- Have you identified the journals in which you want to publish your findings based on the research on the topic within the pandemic?
- Have you written the manuscript for the identified journal following the submission guidelines, including formatting and style manual?

A4.3.10 Utility of Research Findings

- Have you identified who will be able to use your research on the topic within the pandemic and the application of your research?

A4.3.11 So, what's next?

- Congratulations on completing the research on the topic within pandemics. So, what's next?
    - Celebrate!
    - Share your findings.
    - Use findings for action, including policy and practice changes, adjustments, and advocacy efforts.
    - Plan next steps.

REFERENCES AND RESOURCES

Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics (ASSET). www.asset-scienceinsociety.eu

American Psychological Association (2010). *Publication manual of the American Psychological Association* (6th Ed.). Washington, DC: Author

Bailey, S. L., Handu, D. (2013). *Introduction to epidemiological research methods in public practice*. Burlington, MA: Jones & Barlett Learning

Caron-Flinterman F. (2005). A new voice in sience: Patient participation in decision-making on biomedical research. (Doctoral dissertation0. Reterived from http://dare.ubvu.vu.nl/bitstream/handle/1871/9047/7326.pdf;sequence=1

Cardoso F., Costa A., Norton L., Senkus E., Aapro M., André F., Barrios C. H., Bergh J., Biganzoli L., Blackwell K. L, Cardoso M. J., Cufer T., E. l., Saghir N., Fallowfield L., Fenech D., Francis P., Gelmon K., Giordano S. H., Gligorov J., Goldhirsch A., Harbeck N., Houssami N., Hudis C., Kaufman B., Krop I., Kyriakides S., Lin U. N., Mayer M., Merjaver S. D., Nordström E. B., Pagani O., Partridge A., Penault-Llorca F., Piccart M. J., Rugo H., Sledge G., Thomssen C., Van't Veer L., Vorobiof D., Vrieling C., West N., Xu B., Winer E.; European School of Oncology; European Society of Medical Oncology. (2014) ESO-ESMO 2nd International consensus guidelines for advanced breast cancer (ABC2). *Breast, 23*(5):489-502. doi: 10.1016/j.breast.2014.08.009.

Cardoso F., Harbeck N., Fallowfield L., Kyriakides S., Senkus E., ESMO Guidelines Working Group. (2012). Locally recurrent or metastatic breast cancer: ESMO clinical practice guidelines for diagnosis, treatment, and follow-up. *Annals of Oncology*, 23 Suppl 7:vii11-9.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approach* (4th Ed.). Thousand Oaks, CA: SAGE

Dohoo, I. R., Martin, S. W., Stryhn, H. (2012). *Methods in epidemiologic research.* Charlottetown, Prince Edward Island, Canada: VER Inc.

European Commission, Directorate-General for Research and Innovation: http://ec.europa.eu/research/index.cfm?pg=home&lg=en

Evans, B. A., Bedson, E., Bell P., Hutchings H., Lowes L.; Rea D., Seagrove A., Siebert S., Smith G., Snooks H., Thomas M., Thorne K., Russell I.; West Wales Organisation for Rigorous Trials in Health. Involving service users in trials: Developing a standard operating procedure. (2013). *Trials, 14*(219). doi: 10.1186/1745-6215-14-219.

Horizon 2020 in brief: http://ec.europa.eu/programmes/horizon2020/en/news/horizon-2020-brief-eu-framework-programme-research-innovation

INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh Retrieved from http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

Knox S. (2010). The European advocacy perspective on mammography screening. *Breast, 20*(1):93-5. doi: 10.1016/j.breast.2010.07.003.

Magnus, M. (2008). *Essentials of infectious disease epidemiology.* Sudbury, MA: Jones and Bartlett Publishers

Magnus, M. (2009). *Essential readings in infectious disease epidemiology.* Sudbury, MA: Jones and Bartlett Publishers

Porta, M. (Ed.). (2014). *A dictionary of epidemiology*. (6th Ed.). New York: Oxford University Press

World Health Organization. (2001). *Health research methodology: A guide for training in research methods*, (2nd Ed.) Manila: Author. Retrieved from http://www.wpro.who.int/publications/docs/Health_research_edited.pdf

Yen, R. K. (2013). *Case study research: Design and methods* (5th Ed.). Thousand Oaks, CA: SAGE

CONCLUSIONS AND RECOMMENDATIONS

In this ASSET Tool Box we have included eight tools developed by the ASSET consortium partners. Three of the tools are directly related to learning. These are: (i) Reporting health issues by journalists, (ii) Response to radiological, biological, and chemical threats by healthcare professionals, and (iii) Online interactive continuing medical education course on infectious outbreaks. Two of the tools are checklists: (i) Awareness of healthcare workers for influenza vaccination, and (ii) Checklist for patient and public involvement in research along with checklist for basic research considerations. Two of the tools are related on how to do something: (i) How to organize citizen participatory meetings, and (ii) how to conduct data visualization. Considering the focus of the ASSET project, a glossary of epidemics, including Zika and other emerging virus infections is also a tool included in this tool box.

The tools given in this Tool Box are primarily for pandemics, the focus of ASSET project. However, with modifications some of the tools may be used in any domain of knowledge. Visitors to the ASSET website are encouraged to use these tools, give their feedback at email address info@asset-scienceinsociety.eu, and inform people in their network about the existence of these tools.

REFERENCES AND RESOURCES

We have included references and resources for each of the Tool separately along with them in their particular Section 4 to 11. This section on references and resources is for the entire D3.4 ASSET Tool Box. Apart from the selected references and resources given below, some of the useful sources, found and used during our work are the WHO website and documents, the ECDC website and documents, NIH Medline Plus, and Merriam-Webster Dictionary.

American Psychological Association (2010). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author

Citizen Consultations, Work Package 4 of Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics, pp. 17 to 20 available at http://www.asset-scienceinsociety.eu/about/dow

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approach* (4th ed.). Thousand Oaks, CA: SAGE

Data Visualization, an example: *Compulsory Vaccination and rates of Coverage Immunisation in Europe* available at http://www.asset-scienceinsociety.eu/reports/page1.html

Dentzer, S. (2009). Communicating medical news—pitfalls of health care journalism. *New England Journal of Medicine,* 360(1), pp. 1-3.

ETHREAT Scientific Committee. (2011). *How to respond to radiological, biological, and chemical threats: A guide for the European front-line health professional.* Athens: National & Kapodistrian University

European Commission, Directorate-General for Research and Innovation: http://ec.europa.eu/research/index.cfm?pg=home&lg=en

European Commission, Directorate-General for Research and Innovation, Communication Unit. (2008). *European Guide to Science Journalism Training.* Brussels: Author

European Training for Health Professionals on Rapid Response to Health Threats (ETHREAT) http://euprojects.org/ethreat.info/

Horizon 2020 in brief: http://ec.europa.eu/programmes/horizon2020/en/news/horizon-2020-brief-eu-framework-programme-research-innovation

Participatory Governance, Section 3 of *D2.3 Crisis Participatory Governance Report* of Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics pp. 10-19 available at http://www.asset-scienceinsociety.eu/outputs/deliverables/crisis-participatory-governance-report

Transparent Communication in Epidemics: Learning Lessons from Experiences, Delivering Effective Messages, Providing Evidence (TELL ME) project available at http://elearn.tellmeproject.eu

Yen, R. K. (2013). *Case study research: Design and methods* (5th ed.). Thousand Oaks, CA: SAGE