share and move to face nasty bugs

WORK PACKAGE 6 POLICY WATCH
HIGH LEVEL POLICY FORUM REPORT 2

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: **TIEMS**

Contributing partners: **ISS, DBT, FFI, NCIPD, EIWH**

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V3	Draft	2016-12-31	TIEMS	Draft Report of activities through December 2016
V4	Final	2017-1-26	TIEMS	Final Deliverable D6.2

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EXECUTIVE SUMMARY

This is the report of the activities from July 2015 through December 2016 of the High Level Policy Forum (HLPF) established under Task 6.1 of the ASSET program. This report contains the minutes of the second physical HLPF meeting held in Copenhagen on Friday January 15, 2016 (Section 4 below), the HLPF Terms of Reference (Annex 3), which were discussed during the meeting, and a description of activities from July 2016 through December 2016.

This period saw continuing expansion of the HLPF membership. At the time of this report there are 13 HLPF members, representing Norway, Sweden, UK, Denmark, Italy, France, Israel, Bulgaria, Luxembourg, Romania, and Ireland. We have requested ASSET partners to recruit members from Switzerland and Greece. We continue to place a high priority on expanding HLPF membership to more broadly represent member states, and to engage a wider range of stakeholder sectors, such as the pharmaceutical industry, networks of general practitioners, and associations of consumers.

While the basic vision of the HLPF was clear at the first HLPF meeting, and the value of the forum evident, there was a question at that time of how best to focus the activities of the HLPF, given the wide range of issues associated with pandemic preparedness, and the large number of organizations and projects in Europe that are working in this area. In the period prior to the second HLPF meeting, the ASSET program produced new results that provide a focus for the activities of the HLPF, including a Strategic Plan and a Roadmap for research and innovation. These two documents identify requirements for specific HLPF activities, including consultation, review, and endorsement of ASSET results and plans. These requirements have been reflected in the HLPF Terms of Reference (Annex 3), which was approved by the HLPF members during the approval of the minutes for the second ASSET HLPF meeting.

Discussions that took place during the second HLPF meeting confirmed the value of the forum. For example, a presentation on gender issues brought out how low vaccine uptake among women, especially pregnant women, is a significant problem across Europe. During the discussion, the attendees learned that Norway has managed to achieve high vaccine uptake among women, including pregnant women, opening the way for sharing lessons learned that might have a significant impact in Europe.

Four members of the ASSET/HLPF team were invited by DG Santé to participate in a conference “Lessons Learned from the Ebola Outbreak in West Africa – How to Improve Preparedness and Response in the EU for Future Outbreaks”. This conference, held 12-14 October 2015 in Luxembourg, proved to be not only an excellent opportunity to gain valuable insights and contribute to workshops to inform EU Health Council Conclusions, but also a chance to talk about ASSET and HLPF activities and explore collaboration and membership with the 350 participants from all over the EU.

The third and last physical meeting of the ASSET HLPF is now agreed to take place in Brussels 28th of April 2017, at Norway House, Rue Archimede 17, 1000 Brussels. Since the ASSET Consortium meeting will take place the same week in Brussels, we expect representatives from all partners in ASSET to be participating in the meeting.

The ASSET HLPF members and their substitutes are invited to the meeting, and we are now starting the electronic communication with the ASSET HLPF members prior to this meeting, with the aim of discussing and concluding the topics we have decided to focus on, in this third ASSET HLPF meeting.

The three topics selected are:

1. Participatory Governance Policy in European Public Health
2. How to improve considerations of ethical issues in the influenza pandemic plans that every EU country needs to prepare and update
3. Vaccination hesitancy and the possible option of compulsory immunisation

The three topics have been introduced to ASSET HLPF members, and articles for these have been published to provide brief overviews of the topics (Annexes 14, 15 and 16). In addition to these introductory articles, a one-page introduction focusing on the main issues for the topic and questions to be discussed and concluded by ASSET HLPF members, has been prepared for topic 2 (Annex 17), with one-page introductions for topic 1 and 3 under preparation.

Discussion of these topics is intended to take place on the ASSET Community of Practice (COP) online platform, and all ASSET HLPF members are invited to log in and be active on the COP before we send the introduction to the topics and questions. The goal is to have all members active on the COP before the end of 2016, and then use the first 4 months of 2017 prior to the third ASSET meeting for the discussion of the three topics, and aim for achieving policy recommendation for all three topics from the ASSET HLPF members.

Beyond the "inward" focus to help the ASSET program achieve its objectives, the HLPF has a very important "outward" focus – to help carry ASSET results to the broader European community, and to establish itself as a forum valuable enough to continue beyond the end of the ASSET program. To further this outward focus, we have been seeking partnerships and collaborations with established institutions that share ASSET/HLPF goals. Through these partnerships we hope to find avenues and resources enabling implementation of ASSET results and continuing HLPF activity. It is also hoped that such a partnership might provide a "home" for a continuing version of the HLPF. At the second ASSET meeting we explored collaborations with activities associated with Decision 1082/2013 EU, the EU Health and Safety Committee (EU HSC) and with Académie Academique Internationale (ADI). ADI will not be further involved because their focus has changed, while we will continue our outward approach towards HSC.

1. INTRODUCTION

This report is Deliverable D6.2 (High Level Policy Forum Report 2) of the ASSET program's Task 6.1 High Level Policy Forum (HLPF), of Work Package 6 Policy Watch. It provides a report of Forum activity during months 19 through 36 of the ASSET program (July 2015 through December 2016), an updated list of Forum participants, the HLPF Terms of Reference, and the minutes of the Forum's second physical meeting, which took place on January 15, 2016 in Copenhagen. The organization of this report has been made consistent with Deliverable D6.1 (High Level Policy Forum Report 1).

Draft versions of this report were created by the HLPF Secretary, and circulated to Forum participants for comments, additions, and continued discussion. The report thus represents not only a description of activities, but also a means to further the work of the Forum and to record its consensus.

2. FORUM ACTIVITY REPORT July 2015 THROUGH DECEMBER 2016

2.1 Recruiting HLPF Members and Partnerships

To fully achieve HLPF objectives, it is important to have a forum membership that is representative across member states and across public, research, and commercial sectors. Consequently, several activities were undertaken to recruit additional members to the HLPF:

- Each of the 14 organizations of the ASSET project consortium was asked to identify candidates for HLPF membership
- Four members of the ASSET project team were invited to participate in the European Commission's conference "Lessons learned from the EU response to the Ebola outbreak in West Africa", held in Luxembourg 12 – 14 October 2015. During this conference, we had an opportunity to announce the formation of the HLPF and meet a number of potential HLPF members. After the meeting, we have been following up with attendees to identify potential HLPF members.
- We have reached out to organizations whose participation in the HLPF might help further their own objectives, including members of the EU Health Security Committee (HSC) and the the Académie Diplomatique Internationale (ADI). ADI will not be further involved because their focus has changed, while we will continue our outward approach towards HSC.

So far these activities have led to HLPF membership totalling thirteen members. The current HLPF membership is shown in the updated HLPF Introduction (Annex 1) and summarized in Section 3.1 below.

2.2 HLPF Logical Framework

As a part of ASSET project activities, specific objectives and success metrics were developed for the HLPF, and reflected in the ASSET Logical Framework for Work Package 6. Annex 2 is the ASSET Form 1 for this work package, which reflects the following objectives for the HLPF:

- The HLPF is **representative** of regional, national, and EU levels across health agencies, the pharmaceutical industry, and civil society
- The HLPF **endorses** the ASSET Strategic Plan's six action lines
- The HLPF is made into a forum that will be **sustainable** after the completion of the ASSET program.

2.3 ASSET Strategic Plan

A Strategic Plan has been developed under ASSET Task 3.1 to guide ASSET activities, and it states that the HLPF will:

- Recommend guidelines to avoid **conflicts of interest** due to policymakers or members of national vaccine and medical advisory committees having received salary, stock, or funding from industry
- Recommend how to make official meetings more **transparent**
- Make recommendations relative to ASSET "**unsolved scientific questions***"
- Review ASSET **citizen-driven activities** and recommend how to scale-up

- Make recommendations relative to use of **social media** to prepare for and respond to pandemic/epidemic crises
- Recommend how to promote interest and motivation of **health professional and research community**, responsive to values and feelings of **general population**
- Recommend how to improve **vaccine uptake among women**, and to improve inclusion of **women in clinical trials and research**
- Recommend policies to balance security/individual rights, secrecy/transparency for **risky research and intentional outbreaks.**

The following have been suggested on the ASSET Community of Practice online forum, as research areas where civil society could interact with industry and public funding bodies to set research agendas, in order to reduce the impact of influenza epidemics/pandemics:

- Better studies on the efficacy of influenza vaccines in different age groups and between men and women.
- Better studies on the use of adjuvants in influenza vaccines both on efficacy and adveres effects
- More studies on the possible adverse effects of influenza vaccines (more studies on why one vaccine appeared to increase the risk of narcolepsy)
- More studies on the efficacy of medications such as oseltamivar (Tamiflu) and others.
- More studies on the current use of medications such as oseltamivar (timing, underuse, overuse, etc.).
- More studies on the causes of fatal influenza.
- More studies on early warning systems for influenza epidemics/pandemics
- More studies on improving risk communication
- More studies on non-pharmacological methods for reducing the spread and impact of influenza (e.g. does hand-washing really have an impact?).

2.4 Roadmap to Open and Responsible Research and Innovation in Pandemics

This Roadmap has been developed under ASSET Task 3.2 and it includes several recommendations for action by the HLPF

- Include in HLPF activities representatives of civil society, including from **networks of general practitioners** and **associations of consumers**
- Discuss how to implement **bidirectionality** in the making of public health decisions
- Begin **rethinking the research pipeline** and sensitizing stakeholders to systematically implement **Public and Patient Involvement (PPI)**, including how to promote user involvement as intellectual co-owners at the beginning and throughout the research process, incorporating sufficiently diverse representation and cultural sensitivity
- Discuss mitigation of the possible **negative side effects of PPI**, including intrinsic increases of cost and time with respect to the traditional research pipeline
- Assess whether the heterogeneous communities represented in the HLPF **differ in their perception** of the orphan problems in the field of pandemics
- Explore what **lessons from the H1N1 pandemic** we have not yet learned from civil society

- Discuss how to help citizens identify trustable sources of information, what types of information they most need, and **guidelines to build websites** that are informative, trustable, and comprehensible.

2.5 Second Forum Meeting

The second Forum meeting was held in Copenhagen on January 15, 2016. The minutes of this meeting are in Section 4 of this report.

3. FORUM PARTICIPANT LIST AND TERMS OF REFERENCE

3.1 Forum Participants

HLPF Members

Bjørn Guldvog (Norway), Director General of Health and Chief Medical Officer, The Norwegian Directorate of Health

Karl Ekdahl (Sweden), Head of Public Health Capacity and Communication, European Centre for Disease Prevention and Control (represented at the second Forum meeting by Massimo Ciotti)

Jeff French (UK), CEO at Strategic Social Marketing (Substitute: **John French**)

Thea Kølsen Fisher (Denmark), Section Chief/Professor, University of Southern Denmark, The Serum Institute, University of Copenhagen

Ranieri Guerra (Italy), Head of Office, Instituto Superiore di Sanita (did not participate in second forum meeting) (Substitute: **Stefania Iannazzo**)

Bruno Lina (France), Head of the National Influenza Centre (South France) and Head of the Virpath Lab

Itamar Grotto (Israel), Director of Public Health Services, Ministry of Health (Substitute: **Udi Kaliner**)

Angel Kunchev (Bulgaria), Chief State Health Inspector, Ministry of Health

Tencho Tenev (Bulgaria), Deputy Executive Director, Bulgarian Food Safety Agency, Ministry of Agriculture and Food

Germain Thinus (Luxembourg), Former Policy Officer, Crisis Management and Preparedness for Health, European Commission

Adrian Ionel (Romania), General Director, Institutul National de Cercetare

Gabriella Lazzoni (France), Program Director for New Diplomacy Initiative, Académie Diplomatique Internationale (ADI)

Máire Connolly (Ireland), Professor at School of Medicine, National University of Ireland Galway (NUIG)

Participants in the January 15th Meeting

Bjørn Guldvog (Norway), Director General of Health and Chief Medical Officer, The Norwegian Directorate of Health

Massimo Ciotti (Sweden), Deputy Head of Unit Public Health Capacity and Communication/Head of Section Country preparedness Support, European Centre for Disease Prevention and Control (Met as alternate for Karl Ekdahl)

Angel Kunchev (Bulgaria), Chief State Health Inspector, Ministry of Health

Tencho Tenev (Bulgaria), Deputy Executive Director, Bulgarian Food Safety Agency, Ministry of Agriculture and Food

Germain Thinus (Luxembourg), Former Policy Officer, Crisis Management and Preparedness for Health, European Commission

Gabriella Lazzoni, Communication and New Diplomacy, Académie Academique Internationale

K. Harald Drager, The International Emergency Management Society (Chair)

John Haukeland, The Danish Board of Technology Foundation (Host)

Vanessa Moore, European Institute of Women Health

Alberto Perra, Istituto Superiore di Sanita

Thomas V. Robertson, The International Emergency Management Society (Secretary)

Eva Benelli, Zadig

3.2 Terms of Reference

The Terms of Reference (TOR) in Annex 3 were drafted and reviewed at the second HLPF meeting, and further refined and approved during the review of this report by Forum participants. The TOR addresses four elements:

- Vision, objectives, scope, and deliverables
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods.

4. APPROVED MINUTES OF FORUM MEETING JANUARY 15, 2016

4.1 Agenda

This was the second meeting of the ASSET High Level Policy Forum (HLPF). It was held at the Danish Board of Technology (DBT), Toldbodgade 12, 1253 Copenhagen, following the agenda below:

1. *Opening and welcome to new members of ASSET HLPF* (Harald Drager)
2. *ASSET Summary Video* (Eva Benelli)
3. *Minutes of the last meeting of ASSET HLPF. Review and approval* (Thomas Robertson)
4. *Terms of Reference for ASSET HLPF members* (Thomas Robertson)
5. *Each member of ASSET HLPF should appoint a substitute member from his/her organization* (Harald Drager)
6. *ASSET project progress and ASSET Strategic Plan for comments and priority suggestions by ASSET HLPF* (Alberto Perra)
7. **Lunch**
8. *Vaccination and Gender Issues findings in the ASSET Project for information and comments by ASSET HLPF* (Vanessa Moore)
9. *Preparations for Citizens consultations in the ASSET Project for information and comments from ASSET HLPF* (John Haukeland)
10. **Coffee break with a bite**
11. *Review of the EU Health Security Committee and relevance to HLPF* (Germain Thinus)
12. *Review of Académie Diplomatique Internationale (ADI) and potential collaboration with ASSET HLPF* (Gabriella Lazzoni)

13. *Dialogue with ASSET HLPF members between meetings in ASSET HLPF* (Eva Benelli)
14. *Any other business and closing* (Harald Drager)

4.2 Meeting Summary and Discussion Notes

1. **Opening and Welcome** (slides see Annex 4)
    - John Haukeland welcomed us to the Danish Board of Technology, which provided excellent meeting facilities and kept us well nourished during breaks and lunch
    - It was noted that the meeting Secretary will take notes and draft meeting minutes, that will be circulated for additions and refinement by meeting attendees. The minutes will identify the meeting attendees
    - New HLPF member Angel Kunchev was welcomed, as was Massimo Ciotti, who was attending as Karl Ekdahl's alternate
    - Observers Germain Thinus and Gabriella Lazzoni were also welcomed. (After the meeting Mr. Thinus became a member of the HLPF. Ms. Lazzoni was also invited to become a member of HLPF, to foster collaboration with her organization ADI.)
    - It was noted that six HLPF members were unable to attend this meeting, mainly because of last-minute obligations
    - The agenda was reviewed, and it was emphasized that we would pursue fruitful discussions and adapt the schedule as required.
2. **ASSET Summary Video**
    - Eva Benelli presented a short video summarizing the ASSET program. This and subsequent discussions provided useful orientation for attendees less familiar with ASSET.
3. **Minutes of the first HLPF meeting** (slides see Annex 5)
    - The minutes had previously been circulated to meeting attendees for correction, addition, and approval
    - The content of the minutes was summarized by Thomas Robertson, and the complete minutes were uploaded to the HLPF Document area in the ASSET Community of Practice (COP) website
    - The attendees had no changes or questions, and we confirmed approval of the minutes.
4. **HLPF Terms of Reference (TOR)** (slides see Annex 6)
    - This presentation had two parts: one was a discussion of elements and content of the formal HLPF TOR, and the second part was a description of how the HLPF could serve as a link between EU policymakers and the ASSET program, and as a means to help collaborating organizations such as the the Health Security Committee (HSC) and the Académie Diplomatique Internationale (ADI) accomplish their objectives
    - During the review of TOR elements, the objectives of the HLPF were reviewed, as identified by the ASSET Description of Work (DOW), the ASSET Logical Framework, and the ASSET Strategic Plan. Subsequent to the meeting in Copenhagen, an ASSET Research Roadmap was published, which identified additional HLPF objectives; these have been incorporated into the TOR in Annex 3
    - The TOR also incorporates elements describing membership, roles, and responsibilities; resource, financial, and quality plans; and working methods, adapted from materials published as the HLPF was formed
    - **Discussion**

        Q: Isn't what ASSET and the HLPF are trying to do, already being done?

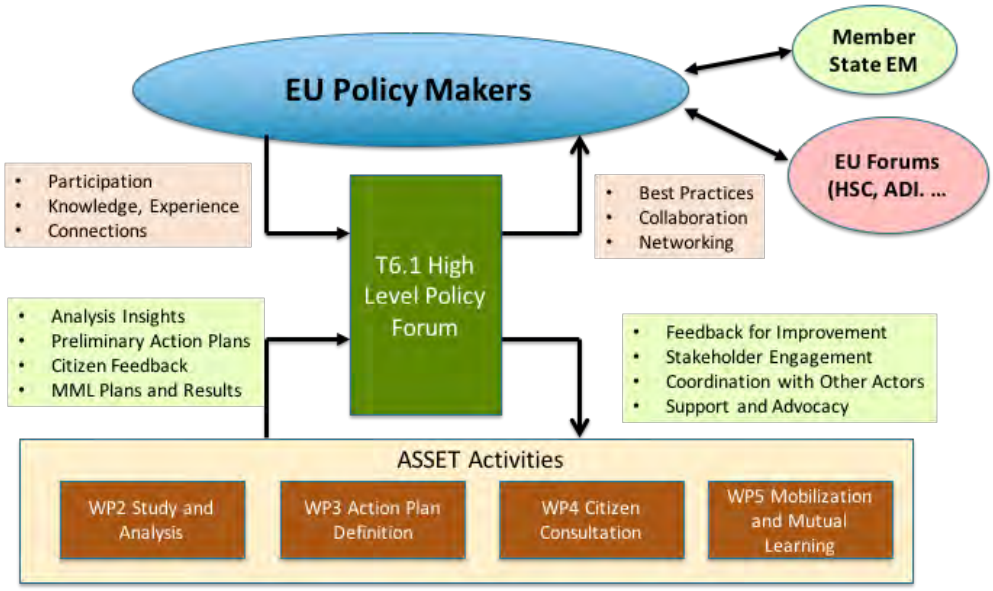
        A: The ASSET approach differs from what has been tried before, in that it is based on a Mobilization and Mutual Learning Action Plan (MMLAP) that engages citizens and all

stakeholders in activities that have previously been closed or one-sided, such as policy making, research, and response planning. This new approach is intended to address the real need to improve trust, compliance, and effectiveness in pandemic preparation and response.
A: As a high level policy maker, I am glad to be participating in this forum – I think the opportunity to discuss these important issues in this diverse group is valuable and can improve pandemic response in my country and across the EU

Q: Wouldn't it be better to fund participant participation, and routinely reimburse travel?
A: While that might make recruiting easier, the ASSET budget for the HLPF is very constrained, so we have adopted a reimbursement policy that we feel is consistent with other EU activities.

- No other comments or suggestions were made for the HLPF TOR, and the Secretary agreed to circulate the TOR document for approval by the participants (draft see Annex 3)

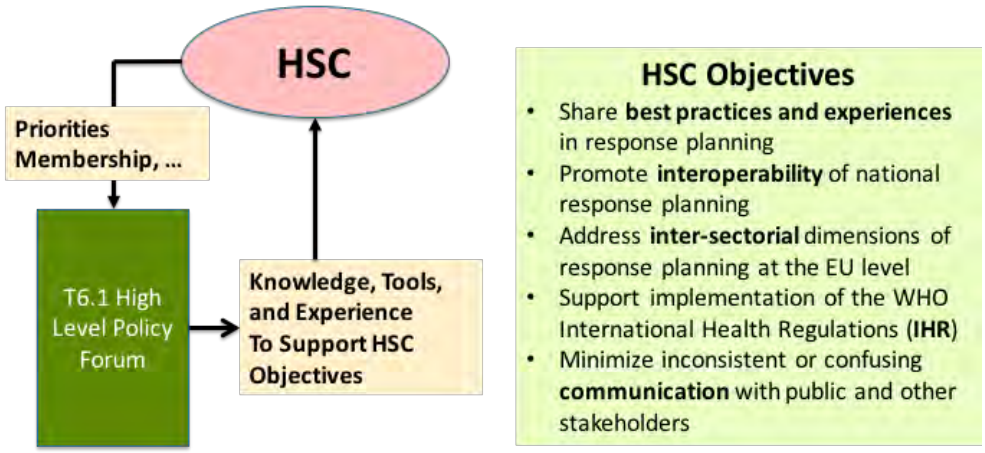
- A graphic was developed to show the role of the HLPF as a link between the ASSET program and EU pandemic preparedness activities, and the HLPF as a continuing forum for policy makers:



- **Discussion**

  Q: What is the scope of emergencies ASSET concerns itself with?
  A: Originally the focus of ASSET was on flu pandemics (like H1N1), however the Ebola experience has led the program to look more broadly at other infectious outbreaks. ASSET does not address the full breadth of EU CDC interests.

- Reflecting another dimension of the role HLPF seeks to play, the HLPF has been seeking partnerships with organizations than share its goal of enhancing EU pandemic preparedness and response through collaboration among inter-sectorial policy makers across Europe. By partnering with these organizations, the HLPF hopes to enlist members who can justify HLPF participation as part of their main work, furthering the aims of both the HLPF and their home organizations. An example of a proposed partnership is shown below:



- **Discussion**
  A: It is not appropriate to think of collaborating with the HSC in this way. While it is fine to have HSC members participate in the HLPF (as individuals and in their own capacity), and to refer to the HLPF sharing objectives with Decision 1082-2013 (which formalized the HSC), the HSC itself is a consulting body whose particular charter is not consistent with working with the HLPF. The HLPF can benefit from networking opportunities afforded by HSC-related events such as the recent Ebola conference in Luxembourg.

5. **Each HLPF Member will appoint a substitute member**
   - The HLPF benefits greatly from the participation and interaction of members with high levels of responsibility and busy schedules. To allow the forum to function in spite of inevitable schedule conflicts, each member is asked to designate a substitute who can participate in their place. This will become increasingly important as forum activity increases through online virtual meetings
   - Massimo will check to see if he will be a regular substitute member
   - Bjørn will identify a substitute member.

6. **ASSET Progress and Strategic Plan** (slides see Annex 7)
   - ASSET is **A**ction plan on **S**cience in **S**ociety related issues in **E**pidemics and Total pandemics
   - 48-month program (24 months left), under EU Seventh Framework Program, 14-organization consortium
   - Use Mobilization and Mutual Learning Action Plan (MMLAP) approach to remedy mistrust seen during 2009 H1N1 pandemic: Connect, Communicate, Democratize for better preparedness
   - ASSET is following a strategy based on six lines of action
     i. Improving governance to increase trust between policy makers, the media, and the public
     ii. Engaging the research community with the public and other stakeholders to establish priorities based on appropriate values, and to provide open and understandable access to scientific outcomes
     iii. Increasing influenza pandemic awareness among healthcare workers, and among the broader public, especially high-risk groups
     iv. Engaging the public, policy makers, and other stakeholders to promote ethical best practices in the event of public health emergencies, balancing fundamental personal

rights, duties and responsibilities, societal issues and priorities, and political considerations

v. Improving vaccination rates among women, and better representing women in research and clinical trials
vi. Promoting policies across Europe to coordinate and standardize research into and response to intentionally caused outbreaks, engaging the public to develop approaches that balance security, personal freedom, and community perceptions and priorities.

- Pilot and test an MMLAP approach that leads to multi-country standard
- Several types of instruments are being developed and tested by ASSET
  i. Face-to-face interactions – HLPF, Citizens interactions, Summer School, Geneva Music and Science Festival, Local Initiatives
  ii. Online forums – Stakeholder Portal, Best Practices Platform, Pandemic Preparedness and Response Bulletin, Research and Innovation Newsletter, Science Communication, Gender Issues Platform, ASSET Website
  iii. Media and Social Media – Social Media Mobilization, Media Office
- The HLPF is asked to review, improve, endorse, and promote the MMLAP tools and approaches ASSET is developing. Four priority issues were brought to the HLPF members attention:
  i. The commitment of the Research Community for carrying out more studies aimed to citizen empowerment
  ii. Building effective structures for listening and talking to citizens
  iii. Establishing conditions for transparent governance
  iv. Better engage health personnel in promoting immunization and effective pandemic response
- **Discussion**

  Q: Where does testing come into the ASSET program?

  A: Having spent the first year of the program organizing and the second year planning, we are now ready to test

  Q: The HLPF could better add value if we better understood what is being tested. It still seems kind of fuzzy.

  A: We will probably not have time today to go into more detail; however, we will be talking today about continuing the discussion on the ASSET Community of Practice (COP) online platform – this will be a good way to clarify this question.

7. **Gender Issues in Pandemics and Epidemics** (slides see Annex 8)
   - Literature review carried out to look at gender differences affecting exposures to infectious diseases as well as access to, information on, and use of, vaccinations in pandemics and epidemics
   - Males and females differ in immune function, antibody response to seasonal flu vaccines (women need half the dose), and women report worse reaction to vaccinations
   - Women are underrepresented in clinical trials
   - Pregnant women are more at risk when contracting flu, yet many are not vaccinated due to unfounded concerns about vaccine risk (more research needed)
   - Health workers, many of whom are women, have high risk of illness or death during a pandemic, yet vaccination compliance is low – not clear why
   - Women are particularly affected by lack of vaccination in hard to reach groups such as immigrant communities

- Women make up the largest proportion of the older population, but are generally excluded from clinical trials
- Questions for HLPF
  - **i.** Were you/your organization aware that there was such a thing as gender issues in pandemics/epidemics? Have you/your organization considered gender as a specific issue in pandemics/epidemics?
  - **ii.** What issues strike you/your organization as particularly urgent in terms of pandemic preparedness?
  - **iii.** What role do you/your organization play in addressing some of these issues?
- **Discussion**

  A: Gender discrimination may differ depending on the vaccination being tested

  A: EU is about 20 years behind US in regulating the inclusion of women and minorities in trials

  A: Vaccination uptake isn't the only problem – sometimes producing sufficient quantities a big problem

  A: These recognized as very important topics in Norway. Vaccination rates in Norway are high, especially for pregnant women. Norway has a vaccination registry. It is important to discuss what went well during pandemics, as well as what the issues were

  A: A New England Journal of Medicine article reported lower rates of fetal problems in vaccinated women compared to women who contracted the flu

  A: Good information – new to me! Roma population particularly interesting. Evolving refugee population creates added challenges

  Q: Why don't healthcare workers get vaccinated? This is a big issue affecting vaccination credibility with the public!

  A: Multiple reasons. Some worry about becoming sick after a vaccination, and not able to work

  A: Some may be sceptical about pharmaceutical companies

  A: This sounds like a key "unsolved issue"- both biological and sociological. People may have unresolved questions about effectiveness; lack of good science is replaced by judgement of healthcare workers. Some believe it is good for general immunity to get sick once in a while.

8. **Citizen Participation** (slides see Annex 9)
   - Historically, citizen participation has been embraced in the EU to reduce a "democratic deficit" in policy making with environmental and social impacts; to better tailor decisions to localities; and to enhance legitimacy and acceptance
   - The ASSET citizen participation events will be pre-outbreak, so will take advantage of time available to have physical as digital engagement: 1 day, 8 countries, 50 citizens at each site
   - Specific themes will be
     - i. Two-way communication between citizens and public authorities
     - ii. Citizen access to knowledge and information
     - iii. Personal freedom and public health safety
     - iv. Transparency between citizens and public authorities
   - Questions for the HLPF
     - i. Which policy forums would benefit from citizen input?
     - ii. Which existing debates would ASSET citizen consultations fit into?

iii. Which topics or questions should explicitly be addressed to an existing agenda?

- **Discussion**

A: SECID, a regional organization concerned with communicable disease surveillance, would benefit from citizen participation

A: ADI may have some good outlets for citizen participation

Q: What are we looking for from citizen participation?

A: To voice citizen concerns, inform policy makers, and inform about ASSET

Q: How does the ASSET method compare against other methods, such as those used in Norway? How do results compare?

A: Polling informed citizens works better than usual opinion polls (ref: research done on deliberative polling). When polls are carried out by NGOs, the results may not be representative. Sometimes complementary methods could be used – deliberative polling combined with focused regular polling

A: Need input from HLPF to know what inputs would be most helpful

9. **ASSET and the Lessons Learned from Ebola** (slides see Annex 10 – not presented at meeting due to time limitations)
   - ASSET personnel invited to participate in EU DG Santé conference "Lessons learned for public health from the Ebola outbreak in West Africa – how to improve preparedness and response in the EU for future outbreaks", 12-14 October 2015, in Mondorf les Bains, Luxembourg
   - The conference featured general sessions and four workshops, addressing inter-sectorial cooperation, treatment and prevention best practices for health workers, communication strategies for the public and health professionals, and global health security
   - A conference summary report with workshop conclusions can be found at Ebola Conference
   - Of particular note is the recommendation that Emergency Risk Communication be embedded in all preparedness and response programmes, and coordinated across Europe
   - ASSET may be a useful resource for the Health Security Committee Communicators Network

10. **Decision 1082/2013 EU** (slides see Annex 11 – ad hoc presentation by Germain Thinus)
   - Addresses serious cross-border threats to health; in force since 6 November 2013
   - Scope covers biological (e.g., communicable disease, antimicrobial resistance, bio toxins), chemical, and environmental threats, as well as threats of unknown origin
   - Promotes collaboration, coordination, and standardization of preparedness and response across the EU
   - Two committees
     i. Health Security Committee – forum of consultation and coordination between member states, for public health response to all threats, and for risk and crisis communication
     ii. Committee on serious cross-border threats to health – regulatory function for the adoption of implementing acts

11. **Académie Diplomatique Internationale (ADI)** (slides see Annex 12)
   - Founded 1926, devoted to reflection and debate on global issues
   - Historically published significant works, e.g. First Report on Legal Status of Women Around the World, The Rights of Men and Citizens, Dictionaire Diplomatique

- Current activities include training, conferences, briefings, and projects
- ASSET activities may offer synergies with ADI in the consultation phase leading to ADI briefings and projects
- ADI and the HLPF share the goal of bringing together the health community, scientists, pharmaceutical representatives, high-level policy makers, and civil society organizations to advance cooperation and reflection on pandemic issues
- ADI can help us connect with the international community in Paris
- **Discussion**

  Q: Is there documentation available to show the results of ADI activity?

  A: There is limited documentation available because of the nature of ADI's work: outputs are usually confidential to the member states, and results of training reside in the students

  Q: How are ADI activities funded?

  A: Activities are funded by member states through partner participation

  Q: How might ADI and the HLPF work together?

  A: Let's think about that – it looks like there may be good possibilities.

12. HLPF Dialog Between Meetings (slides see Annex 13)

- The ASSET Community of Practice (COP) is a platform that supports online conversations and sharing of documents; it has been used effectively by the ASSET project over the past two years
- A special HLPF area has been created in the COP, that includes relevant documents and a forum that allows members to initiate conversations on any topic, which can result in a thread of back-and-forth replies that is archived for future reference
- Members can receive by email a daily digest of new entries, and they can log into the COP at any time to review or contribute
- Log in information and further instructions will be provided to HLPF members

13. Concluding remarks

- We are making progress; however, it is important to work on ASSET and HLPF plans so that broad objectives are detailed to the point that they are clear and practical
- We look forward to using the ASSET COP to accelerate the progress of the HLPF
- All attendees are encouraged to identify potential HLPF new members
- We look forward to exploring collaboration with ADI, and other partner organizations with whom share common or complementary objectives
- Thanks to all for their attentive participation and valuable insights!
- Thanks to DBT for hosting the meeting and for their excellent hospitality!

5. CONCLUSIONS AND RECOMMENDATIONS

The experience of the HLPF through ASSET month 36 has confirmed the value of the forum as a useful exchange of information for the participants.

We have been adding new members, but we seek still broader representation, across Europe, its regions and localities, and across sectors, including government, civil society, research and innovation, and the

pharmaceutical industry. We need to continue to reach out through ASSET, current HLPF members, and partner organizations to find new members.

Our members have important positions in Europe – this makes them very valuable to the forum, but also very busy. As a consequence, a physical meeting on any particular date will have partial attendance. For example, only three of nine HLPF members plus one alternate were represented at the second meeting in Copenhagen. We are taking steps to better engage the full membership.

The third and last physical meeting of the ASSET HLPF is now agreed to take place in Brussels 28th of April 2017, at Norway House, Rue Archimede 17, 1000 Brussels. Since the ASSET Consortium meeting will take place the same week in Brussels, we expect representatives from all partners in ASSET to be participating in the meeting.

The ASSET HLPF members and their substitutes are invited to the meeting, and we are now starting the electronic communication with the ASSET HLPF members prior to this meeting, with the aim of discussing and concluding the topics we have decided to focus on, in this third ASSET HLPF meeting.

The three topics selected are:

1. Participatory Governance Policy in European Public Health
2. How to improve considerations of ethical issues in the influenza pandemic plans that every EU country needs to prepare and update
3. Vaccination hesitancy and the possible option of compulsory immunisation

Discussion of these topics is intended to take place on the ASSET Community of Practice (COP) online platform, and all ASSET HLPF members are invited to log in and be active on the COP before we send the introduction to the topics and questions. The goal is to have all members active on the COP before the end of 2016, and then use the first 4 months of 2017 prior to the third ASSET meeting for the discussion of the three topics, and aim for achieving policy recommendation for all three topics from the ASSET HLPF members.

Beyond the “inward” focus to help the ASSET program achieve its objectives, the HLPF has a very important “outward” focus – to help carry ASSET results to the broader European community, and to establish itself as a forum valuable enough to continue beyond the end of the ASSET program. To further this outward focus, we have been seeking partnerships and collaborations with established institutions that share ASSET/HLPF goals. Through these partnerships we hope to find avenues and resources enabling implementation of ASSET results and continuing HLPF activity. It is also hoped that such a partnership might provide a “home” for a continuing version of the HLPF. At the second ASSET meeting we explored collaborations with activities associated with Decision 1082/2013 EU, the EU Health and Safety Committee (EU HSC) and with Académie Academique Internationale (ADI). ADI will not be further involved because their focus has changed, while we will continue our outward approach towards HSC.

ANNEXES

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

ASSET
share and move to face nasty bugs

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

ASSET
share and move to face nasty bugs

ASSET HIGH LEVEL POLICY FORUM

Introduction, Mission & Focus, Agenda and Members

Introduction

The 2009 H1N1 influenza pandemic revealed a breakdown in the communication between decision makers, their scientific institutions and the European public. This communication failure led to unwanted effects, such as the failure of a large part of the population to adopt adequate preventive measures, and the scientific sector not taking into account important information coming from the population. The objective of **ASSET** (**A**ction plan in **S**cience in **S**ociety in **E**pidemics and **T**otal pandemics) is to create the blueprint for a better response to pandemics, through improved forms of dialogue and better cooperation between science and society at various stages of the research and innovation process. **ASSET** is a four-year, European Commission funded **M**obilization and **M**utual **L**earning **A**ction **P**lan (**MMLAP**) project, which started 1st January 2014 and will end on 31st December 2017. The perspectives developed by the **ASSET** project will flow into Horizon 2020. See ASSET Project Web-site for more information of the project: *http://asset-scienceinsociety.eu/*.
See the ASSET Brochure for a quick overview of the ASSET Project:
http://tiems.info/images/Asset%202015%20brochure.pdf

The project objectives are:

1. Forge a partnership with complementary perspectives, knowledge and experiences to address scientific and societal challenges raised by pandemics and epidemics, and associated crisis management.
2. Explore and map SiS (Science in Society) related issues in pandemics and epidemics.
3. Define and test a participatory and inclusive strategy to improve bi-lateral communication aimed to succeed with crisis management.
4. Identify necessary resources to make sustainable the actions after the project completion.

ASSET combines public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media. The aim is to develop an integrated, trans-disciplinary strategy, which will take place at different stages of the research cycle, combining local, regional and national levels. One of the ASSET project tasks is to establish an **ASSET High Level Policy Forum** (**ASSET-HLPF**).

ASSET High Level Policy Forum

Tackling pandemics and epidemics is an intricate process, which necessitates effective interaction among many stakeholders. As this interaction must happen very quickly and under intense public scrutiny, preparedness is essential. The network of stakeholders can only be prepared well through building trust and good working relationships prior to the incident. In addition, identifying and discussing important policy issues and examining how they can be improved, can only be done comprehensively through considering the points of view of all the main stakeholders. The ASSET-HLPF is intended to provide this opportunity at the highest level in various European countries. It is a place for stakeholders to meet, learn from each other, and come up with better policy proposals.

ASSET-HLPF Mission & Focus

Mission:

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

Focus:

- The Forum will consider and revise specific issues related to EU strategic priorities in pandemic preparedness, including communication and other responses.
- The Forum may produce recommendations - however its primary role will be to create mutual trust, improve communication, and provide a "safe" environment to address questions which are otherwise difficult to discuss.

- The forum aims to strengthening the perception that further dialogue among the participants is going to be fruitful due to increased insights into each other's perspectives, and the sense that conversation between the concerned parties has intrinsic value.
- The participants will not participate in any official position, but it is hoped that they might influence policy decisions in a variety of ways.

ASSET - HLPF Basic Rules

The basic rules for the forum are:

1. The forum promotes dialogue, not debate. Participants are not being asked to defend their own views or to find the weakness in others' positions, but rather to explain their own perspectives.
2. Parties speak for themselves only and not as representatives of groups, institutions, or governments.
3. Conversation will be carried out under the Chatham House rule: "When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed".

Questions to ASSET-HLPF

- What and how can we improve (any) systems capacities to make European citizens (and their representatives) timely informed of the next infectious disease crisis?
- How can we help them to identify trustable and accredited information sources?
- What can we do to ease citizen' access to correct and timely information?
- What can we do to create channels to enable citizens to ask questions and receive timely answers from government officials and accredited sources?
- How can we develop a European Scientific network to promote and support such processes?
- Is it possible to draft a general strategy to pursue, in the coming years, the defined objectives through Horizon 2020?
- What is the role of the European institutions in supporting this process?

ASSET - HLPF First and Second Physical Meetings

The ASSET project partners have started the recruitment process, by identifying potential participants to join the ASSET HLPF, from all stakeholders concerned with public health, such as policy makers, decision makers, companies, civil society organizations, media and others, in order to achieve a multidimensional discussion in the forum.

The ASSET-HLPF first meeting took place in Brussels 12th March 2015.

Minutes from the first meeting is found at:

http://tiems.info/images/ASSET%202015%20HLPF%20Report%201%20draft%20minus%20annexes.pdf

The second ASSET HLPF meeting took place in Copenhagen, Denmark, 15th January 2016.

Minutes from the second meeting is found at:

http://tiems.info/images/ASSET2016HLPFReport2a.pdf

ASSET HLPF secretary is Thomas Robertson, TIEMS USA

ASSET-HLPF Next Meeting

The ASSET HLPF next meeting will be arranged 28th April 2017 in Brussels, but a virtual communication with the members of ASSET HLPF over ASSET Community of Practise (COP) platform will take place in the period up to this meeting.

ASSET-HLPF Contacts

If interested in ASSET-HLPF and being a member of the forum, please, contact:

- Alberto Perra, alberto.perra@iss.it
- Valentina Possenti, valentina.possenti@iss.it
- K. Harald Drager, khdrager@online.no
- Thomas Robertson, tvrobertson@yahoo.com

PRELIMINARY LIST OF ASSET-HLPF MEMBERS

Name	Position	Organization	Country
 **Bjørn Guldvog** https://www.linkedin.com/pub/bj%C3%B8rn-guldvog/42/35b/b1a	Director General of Health and Chief Medical Officer	The Norwegian Directorate of Health (A professional agency under the Ministry of Health In Norway)	Norway
 **Karl Ekdahl** http://linkd.in/1BCMtTt	Head of Public Health Capacity and Communication at European Centre for Disease Prevention and Control (ECDC)	European Centre for Disease Prevention and Control (ECDC)	Sweden
 **Jeff French** http://linkd.in/1BmQoRl	CEO at Strategic Social Marketing	Strategic Social Marketing	UK
 **Thea Kølsen Fisher** https://www.linkedin.com/pub/thea-k%C3%B8lsen-fischer/4/7b5/b54	Section Chief/Professor	University of Southern Denmark The Serum Institute University of Copenhagen	Denmark

 **Ranieri Guerra** http://bit.ly/1LSt4UF	General Director of Health Prevention, Ministry of Health	Ministry of Health	Italy
 **Bruno Lina** http://bit.ly/1Q2VbfW	Head of the National Influenza Centre (South France) & Head of the Virpath lab	Hospices Civils de Lyon & Université Claude Bernard Lyon1	France
 **Itamar Grotto** https://www.linkedin.com/in/itamar-grotto-b306036	Director of Public Health Services	Ministry of Health	Israel
 **Angel Kunchev** http://bit.ly/1NxS2GJ	Chief State Health Inspector	Ministry of Health	Bulgaria

 **Tencho Tenev** http://bit.ly/1MCSVtT	Deputy Executive Director	Bulgarian Food Safety Agency under the Ministry of Agriculture and Food	Bulgaria
 **Germain Thinus** http://bit.ly/1JxFd12	Policy Officer Unit C3 – Crisis Management and Preparedness for Health	European Commission	Luxembourg
 **Adrian Ionel** http://bit.ly/2bI0pHm	General Director	Institutul National de Cercetare	Romania
 **Gabriella Lazzoni** http://bit.ly/2dvxPp5	Program Director for New Diplomacy Initiative	Académie Diplomatique Internationale (ADI)	France

 Máire **Connolly** http://bit.ly/2g2awmM	Professor at School of Medicine	National University of Ireland Galway (NUIG)	Ireland

More ASSET-HLPF members under recruitment!

Quality Assurance Plan

Form 1 Task/WP requirements

WP	Beneficiary Leader Number
WP6 Policy Watch	8
Tasks	**Beneficiary Leader Number**
6.1 High Level Policy Forum (ASSET- HLPF)	10
6.2 Pandemic Preparedness & Response Bulletin (ASSET-PPRB)	8
Contributors:	
6.1 DBT, EIWH, FFI, ISS, NCIPD, TIEMS	**6.2** HU, NCIPD, UMFCD

WP description (as from the DOW)

WP6 will

- ensure a reflection on EU strategic priorities about pandemics and a regular monitoring other EU related initiatives and policy developments at local, national and European levels, in order to better connect with policy cycles;
- also aim to liaise with Research or Policy EC services involved in Challenges 1 (Health, demographic change and wellbeing).

Strategies

This WP about "Policy watch" is made of two tools: the High Level Policy Forum (HLPF) and the Pandemic Preparedness & Response Bulletin (PPRB). They both are intended to involve relevant stakeholders in the field.

Objectives

The main WP aim concerns an interactive dialogue to be activated in order to promote an ongoing reflection on EU strategic priorities about pandemics in terms either of policy initiatives devoted to pandemics and related crisis management, or of policy developments at local, national and European levels. Specific issues related to EU strategic priorities in pandemic communication, preparedness, and response in fact are here considered and revised.

Outputs (Expected results – Intermediate objectives)

The two tasks foresee three deliverables each by the end of the Project. The HLPF should meet three times face-to-face; the PPRB has to be issued in seven editions.

Methods

Both the HLPF and the PPRB are supposed to be developed as really collaborative tasks, standing for a cooperation not only internally the ASSET Consortium but also with relevant stakeholders who have already been involved such as the EU Health Security Committee (EU HSC) or the Académie diplomatique internationale (ADI).

Main activities

The HLPF is mainly based on recruiting members, developing three physical meetings and virtual others, studying conditions for sustainability after the project completion. The PPRB activities are divided in two main groups that are: processing/development of seven Bulletin issues and then its circulation/spreading within the stakeholder community.

(Optionally) If you consider that could help, please, try to set up a Logical Framework Analysis following the table in the scheme below

	Definition	Indicator	Source of information	Risks and assumptions
Specific objective1	**EU strategic priorities and policy developments about pandemics highlighted**	**Number of EU Pandemic plans incorporating ASSET policy insights**	**ECDC website**	**Openness towards ASSET outcomes**

	at local, national and EU levels			
Result1.1	**Key policy/decision-makers at regional, national and EU levels, in health agencies and pharmaceutical industry, and civil society organizations positively influenced by HLPF experts**	**60% increase of representativeness degree for ASSET participating countries in the HLPF**	**D6.1, D6.2, D6.3**	**Policy makers and other high-level stakeholders use and promote ASSET findings and conclusions**
Activity1.1.1	Three HLPF physical meetings arranged	1 HLPF physical meeting by 2015, 1 by 2016, 1 by 2017	Reports with meetings' and virtual communications' minutes	Effective interest in participating by international policy-makers
Result1.2	**International SHs reached about pandemics and related crisis management, policy developments**	**15% annual increase of SHs receiving the Bulletin**	**D6.4, D6.5, D6.6 report**	**European policies interested in Pandemic Preparedness and Response**
Activity1.2.1	7 Bulletins Produced	2 Bulletins by 2015; 2 by 2016; 3 by 2017	ASSET CoP web platform	Availability of materials on Infectious Diseases Emergency Preparedness and Response
Activity1.2.2	7 Bulletins Disseminated	2 Bulletins by 2015; 2 by 2016; 3 by 2017	ASSET website	Permanence of stakeholders' roles and responsibilities
Specific objective2	**Research or Policy EC services involved in Challenges 1 (Health, demographic change and wellbeing) engaged**	**A new project in H2020**	**EC website**	**Effective possibility for positioning in Challenge 1**
Result2.1	**Consensus achieved within the HLPF on the main strategic lines identified in the SP**	**Strategic Plan 6 action lines endorsed by HLPF**	**HLPF reports**	**The majority of the MS participating in ASSET are represented within the HLPF**
Activity2.1.1	HLPF made into a sustainable forum after the finalization of the ASSET project	HLPF as a group/committee /forum of another EU organization like EU Health and Security Committee	ASSET website	Availability of EU Institutions to sustain the HLPF

Finally, in any case, for the results and activities that you consider as qualifying your task you should define the quality requirements	
R1.1	**Policy initiatives/briefs include ASSET inputs**
A1.1.1	Efficient meeting arrangement to allow the most of participation
R1.2	**Impact on policy developments on pandemics and related crisis management**
A1.2.1	Evidence-based literature material
A1.2.2	Quickness and efficient ICT delivery

R2.1	**Most of the HLPF members give their consensus to ASSET Strategic Plan**
A2.1.1	HLPF has matured conditions for future sustainabilty

Propose a list of potential feedings towards other tasks/work packages	
WP6	Internally to the WP6 – HLPF and PPRB
WP3	WP6 tools are indicated in the Strategic and Action Plans
WP4	The HLPF and PPRB will be relevant, and thus involved, to the end of the organisation of the Policy Workshop at the European Parliament.
WP5	The HLPF and PPRB will have to cooperate above all with 5.2 that is made of a Stakeholder Portal and a Best Practice Platform.
WP7	These two WP6 tasks feed a lot of WP7 elements/structures: the web portal (7.3) and media office (7.4), the gender portal (7.9) but also other activities and events addressed to professionals and practitioners like the Summer School (7.6) and the SiS Best Practice award (7.7), or to the lay public such as the Geneva Festival (7.11), or to specific project stakeholders (i.e. the Final Conference; 7.12).
WP9	The HLPF is a milestone and it is important in the economy of sustainability in general

Propose a list of potential feedings necessary for your task accomplishments from other tasks/work packages	
WP6	Internally to the WP6 – HLPF and PPRB
WP2	HLPF and PPRB have to consider the six thematic issues analyzed.
WP3	The Strategic Plan indicates where and how HLPF and PPRB enter in action.
WP4	WP4 that is the citizen consultation so that there are elements society-driven.
WP5	WP5 "MML" is the other key-component of societal challenge/empowerment.
WP8	The internal and external evaluations can make the WP6 progress on better.

Timetable of the main activities

HLPF		**PPRB**	
What	**When**	**What**	**When**
1st Forum meeting	March 2015	1st Bulletin	April 2015
1st Deliverable	**June 2015**	**1st Deliverable**	**June 2015**
2nd Forum Meeting	January 2016	2nd Bulletin	September 2015
Arrange virtual discussions between the physical forum meetings	January 2016 – January 2017	3rd Bulletin	January 2016
		4th Bulletin	July 2016
2nd Deliverable	**December 2016**	**2nd Deliverable**	**December 2016**
3rd Forum Meeting	January – March 2017	5th Bulletin	January 2017
Arrange virtual discussions between the physical forum meetings	March 2017 – December 2017	6th Bulletin	July 2017
		7th Bulletin	December 2017
3rd Deliverable	**December 2017**	**3rd Deliverable**	**December 2017**
Deliver ASSET HLPF as a sustainable forum	December 2017		

ASSET High Level Policy Forum

Terms of Reference

January 26, 2016

1. Vision, Objectives, Scope, and Deliverables

The ASSET Program

The 2009 H1N1 influenza pandemic revealed a breakdown in the communication between decision makers, their scientific institutions and the European public. This communication failure led to unwanted effects, such as the failure of a large part of the population to adopt adequate preventive measures, and the scientific sector not taking into account important information coming from the population. The objective of **ASSET** (**A**ction plan in **S**cience in **S**ociety in **E**pidemics and **T**otal pandemics) is to create the blueprint for a better response to pandemics, through improved forms of dialogue and better cooperation between science and society at various stages of the research and innovation process. **ASSET** is a four-year, European Commission funded **M**obilization and **M**utual **L**earning **A**ction **P**lan (**MMLAP**) project, which started 1st January 2014 and will end on 31st December 2017. The perspectives developed by the **ASSET** project will flow into Horizon 2020. The project objectives are:

- Forge a partnership with complementary perspectives, knowledge and experiences to address scientific and societal challenges raised by pandemics and epidemics, and associated crisis management
- Explore and map SiS (Science in Society) related issues in pandemics and epidemics
- Define and test a participatory and inclusive strategy to improve bi-lateral communication aimed to succeed with crisis management
- Identify necessary resources to make sustainable the actions after the project completion.

ASSET combines public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media. The aim is to develop an integrated, trans-disciplinary strategy, which will take place at different stages of the research cycle, combining local, regional and national levels. One of the ASSET project tasks is to establish an **ASSET High Level Policy Forum** (**HLPF**).

ASSET High Level Policy Forum

Tackling pandemics and epidemics is an intricate process, which necessitates effective interaction among many stakeholders. As this interaction must happen very quickly and under intense public scrutiny, preparedness is essential. The network of stakeholders can only be prepared well through building trust and good working relationships prior to the incident. In addition, identifying and discussing important policy issues and examining how they can be improved, can only be done comprehensively through considering the points of view of all the main stakeholders. The HLPF is intended to provide this opportunity at the highest level in various European countries. It is a place for stakeholders to meet, learn from each other, and come up with better policy proposals.

The HLPF brings together selected European policy-makers at regional, national and EU levels, key decision makers in health agencies, the pharmaceutical industry, and civil society organisations, in a unique and interactive dialogue to promote on-going reflection on EU strategic priorities about pandemics. The Forum will consider and revise specific issues related to EU strategic priorities in pandemic preparedness, including communication and other responses. The Forum may produce recommendations; however, its primary role will be to create mutual trust, improve communication, and provide a "safe" environment to address questions which are otherwise difficult to discuss. Another important goal of the HLPF is to strengthen the perception that further dialogue among participants is going to be fruitful due to increased insights into each others perspectives, and the sense that conversation is worthwhile.

HLPF objectives, scope and deliverables are defined below with reference to documents produced by the ASSET programs.

HLPF and the ASSET Logical Framework

The ASSET Logical Framework (LogFrame) identifies a set of objectives and success metrics for the ASSET program. The HLPF contribution to the ASSET LogFrame is summarized in the following table:

Objective	Indicator	Source of Information
Key policy/decision-makers at regional, national and EU levels, in health agencies and pharmaceutical industry, and civil society organizations positively influenced by HLPF	60% increase in countries represented in the HLPF	HLPF Interim and Yearly Reports HLPF COP Forum
Three HLPF physical meetings arranged	One HLPF physical meeting by 2015, one by 2016, one by 2017	HLPF Interim and Yearly Reports
Consensus achieved within the HLPF on the main strategic lines identified in the SP	Strategic Plan 6 action lines endorsed by HLPF	HLPF Interim and Yearly Reports HLPF COP Forum
HLPF made into a sustainable forum after the finalization of the ASSET project	HLPF becomes a group/committee/forum of another continuing EU organization	ASSET website

HLPF and the ASSET Strategic Plan

The ASSET Strategic Plan specifies the following activities and outputs as responsibilities of the HLPF:

- Recommend guidelines to avoid conflicts of interest due to policymakers or members of national vaccine and medical advisory committees having received salary, stock, or funding from industry
- Recommend how to make official meetings more transparent
- Make recommendations relative to ASSET "unsolved scientific questions"
- Review ASSET citizen-driven activities and recommend how to scale-up
- Make recommendations relative to use of social media to prepare for and respond to pandemic/epidemic crises

- Recommend how to promote interest and motivation of health professional and research community, responsive to values and feelings of general population
- Recommend how to improve vaccine uptake among women, and to improve inclusion of women in clinical trials and research
- Recommend policies to balance security/individual rights, secrecy/transparency for risky research and intentional outbreaks.

HLPF and the ASSET Roadmap to Open and Responsible Research and Innovation in Pandemics

The ASSET Roadmap to Open and Responsible Research and Innovation in Pandemics requires the HLPF to perform the following activities:

- Include in HLPF activities representatives of civil society, including from networks of general practitioners and associations of consumers
- Discuss how to implement bidirectionality in the making of public health decisions
- Begin rethinking the research pipeline and sensitizing stakeholders to systematically implement Public and Patient Involvement (PPI), including how to promote user involvement as intellectual co-owners at the beginning and throughout the research process, incorporating sufficiently diverse representation and cultural sensitivity
- Discuss mitigation of the possible negative side effects of PPI, including intrinsic increases of cost and time with respect to the traditional research pipeline
- Assess whether the heterogeneous communities represented in the HLPF differ in their perception of the orphan problems in the field of pandemics
- Explore what lessons from the H1N1 pandemic we have not yet learned from civil society
- Discuss how to help citizens identify trustable sources of information, what types of information they most need, and guidelines to build websites that are informative, trustable, and comprehensible.

2. Membership, Roles, and Responsibilities

The International Emergency Management Society (TIEMS), a member of the ASSET project consortium, will serve as Secretariat of the HLPF. They will organize and facilitate meetings and publish Minutes.

The HLPF seeks membership representing European policy-makers at regional, national and EU levels, including key decision makers in health agencies, the pharmaceutical industry, and civil society organisations. An initial core membership was recruited by the HLPF Secretariat, and these core members together with ASSET partners are requested to help recruit additional members. A broad and representative HLPF membership will enhance the value of the forum to the EU, the ASSET program, and to the individual participants.

Potential members can apply or be invited, and their admission to membership is approved by the HLPF Secretariat and the ASSET Technical Coordinator.

HLPF members shall designate a person to serve as their alternate for attending meetings and engaging in forum discussions when the primary member is not available.

3. Resource, Financial, and Quality Plans

The HLPF is sponsored by the ASSET program, under Work Package 6, Task 6.1. The funding for this task supports Secretariat activities, but does not allow compensating HLPF members for their time participating in HLPF activities.

Concerning coverage of travel costs, the policy is that, since the ASSET project has limited funds for covering costs in the ASSET project for the ASSET HLPF Forum meetings, it is hoped that members have an organization who will cover the cost for participating in the meetings.

However, the ASSET project will cover travel cost, if the candidate does not have the support of travelling costs from his/her own organization for participating in ASSET HLPF meetings. ASSET project will then cover economy class tickets and make the timing of the day for the meeting, such that it is possible to travel and return same day. If no convenient flights make that possible we will cover one-night accommodation. Since lunch and coffee is served at the forum, no per diem is offered for participating in the forum meetings.

To insure quality, publications of the HLPF will be reviewed, refined, and agreed to by HLPF members. HLPF deliverables to the ASSET program will be subject to ASSET quality procedures.

4. Working Methods

By linking different policy levels both virtually through the ASSET Community of Practice (COP) on-line platform, and physically during a yearly seminar, the ASSET-HLPF will consider and revise specific issues related to EU strategic priorities in pandemic communication, preparedness and response.

The forum promotes dialogue, not debate. Participants are not being asked to defend their own views or to find the weakness in others' positions, but rather to explain their own perspectives. Parties speak for themselves only and not as representatives of groups, institutions, or governments.

Conversation will be carried out under the Chatham House rule: "When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed".

ASSET

share and move to face nasty bugs

Welcome to the Second Meeting in ASSET High Level Policy Forum

K. HARALD DRAGER
THE INTERNATIONAL EMERGENCY MANAGEMENT SOCIETY (TIEMS)

Copenhagen 15/01/2016

www.asset-scienceinsociety.eu

co-funded by the EU, GA: 612236

10:15: *Opening and welcome to new members of ASSET HLPF: 5 minutes Harald*

10:20: *Minutes of the last meeting of ASSET HLPF. Review and approval:10 minutes Tom*

10:30: *Terms of Reference for ASSET HLPF members: 30 minutes Harald & Tom*

11:00: *Each member of ASSET HLPF should appoint a substitute member from his/her organization: 10 minutes Harald & Tom*

11:10: *Update from the ASSET project: 15 minutes Alberto*

11:25: *ASSET Strategic Plan for comments and priority suggestions for focus items by ASSET HLPF: 90 minutes Alberto*

12:55: Lunch: *60 minutes*

13:55: *Vaccination and Gender Issues findings in the ASSET Project for information and comments by ASSET HLPF: 45 minutes Vanessa*

14:40: *Preparations for Citizens consultations in the ASSET Project for information and comments from ASSET HLPF: 60 minutes John*

15:40: Coffee break with a bite: *15 minutes*

15:55: *Conclusions from HSC Conference and Workshop in Luxembourg on Lessons Learned from the Ebola Crisis: 20 minutes Eva and/or Germain Thinus*

16:15: *Cooperation between HSC and ASSET HLPF: 15 minutes Harald & Tom and Germain Thinus*

16:30: *Cooperation between ADI and ASSET HLPF: 15 minutes Harald & Tom and Gabriella Lazzoni*

16:45: *Potential new ASSET HLPF members to be suggested by present members: 15 minutes Harald & Tom*

17:00: *Next ASSET HLPF meeting: 5 minutes Harald & Tom*

16:05: *Dialogue with ASSET HLPF members between meetings in ASSET HLPF: 10 minutes Eva*

17:15: *AOB: 10 minutes Harald & Tom*

ASSET HLPF Members

Name	Country	Position	Substitute
Bjørn Guldvog	Luxembourg	Director General of Health and Chief Medical Officer at The Norwegian Directorate of Health	Steinar Straume (?)
Karl Ekdahl	Sweden	Head of Public Health Capacity and Communication at European Centre for Disease Prevention and Control (ECDC)	Massimo Ciotti (?)
Ranieri Guerra	Italy	General Director of Health Prevention, Ministry of Health	Stefania Iannazzo
Jeff French	UK	CEO at Strategic Social Marketing	John French
Thea Kølsen Fisher	Denmark	Section Chief/Professor at University of Southern Denmark - The Serum Institute	
Lina Bruno	France	Head of the National Influenza Centre (South France) & Head of the Virpath lab	
Itamar Grotto	Israel	Director of Public Health Services at Ministry of Health	Udi Kaliner
Angel Kunchev	Bulgaria	Chief State Health Inspector at Ministry of Health	
Tencho Tenev	Bulgaria	Deputy Executive Director Bulgarian Food Safety Agency under the Ministry of Agriculture and Food	

Observers

Name	Country	Position	Organization
Germain Thinus	Luxembourg	Policy officer @ European Commission	DG SANTE
Gabriella Lazzoni	France	Responsable de Communication at ADI	Académie diplomatique internationale

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T6.1 High Level Policy Forum

Minutes Review

HLPF Meeting Brussels

March 12, 2015

THOMAS V. ROBERTSON

THE INTERNATIONAL EMERGENCY MANAGEMENT SOCIETY (TIEMS)

Copenhagen 15/01/2016

www.asset-scienceinsociety.eu

co-funded by the EU. GA: 612236

ASSET

Objective of this Agenda Item

Review and confirm approval of the minutes of the First HLPF meeting held in Brussels on March 12, 2015

History

- Draft circulated to attendees for review and approval March 24, 2015
- Comments received and incorporated into a final version uploaded to ASSET COP as D6.1 High Level Policy Forum Report 1

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EXECUTIVE SUMMARY

This is a report of the activities through June, 2015 of the High Level Policy Forum (HLPF) established under Task 6.1 of the ASSET program. During this period the first members of the HLPF were assembled, and the first HLPF meeting was held in Brussels on Thursday March 12, 2015.

As this was the first meeting of the HLPF, considerable time was spent discussing how to focus the activities of the Forum to maximize its value, considering the many aspects affecting pandemic response, the many organizations involved, and the limited resources of the Forum. While it will certainly be valuable for the participants to share best practices, it will probably be even more valuable for the group to take advantage of its unique structure to address what is needed beyond best practices to improve pandemic response.

The ASSET program can provide a means to act on the insights developed in the Forum. This might begin by having the HLPF review the conclusions of ASSET Work Package 2 Study and Analysis, which is intended to identify the gaps and opportunities in pandemic response that will be addressed by the Strategic Plan, Roadmap, Workbook, and Tool Box to be created by ASSET Work Package 3.

Subsequent to the March 12 meeting, recruiting for HLPF members continued, and one new member was added (Lina Bruno). ASSET HLPF brochures and introductory material were distributed by HLPF member Bjørn Guldvog at the meeting of EU Chief Medical Officers and Chief Nursing Officers in Riga during April, to support recuiting of addtional members. We also contacted EU SANTE Policy Officer Germain Thinus to begin coordination of HLPF activities with the EU Health Security Committee. We have been invited to participate in their next conference, and we plan to hold the second HLPF meeting adjacent to this conference in Luxembourg (mid October), to enable a good exchange of information.

Questions?
Confirm Approval?

ASSET

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T6.1 High Level Policy Forum
Terms of Reference

THOMAS V. ROBERTSON

THE INTERNATIONAL EMERGENCY MANAGEMENT SOCIETY (TIEMS)

Copenhagen 15/01/2016

www.asset-scienceinsociety.eu

co-funded by the EU. GA: 612236

ASSET

Objective of this Agenda Item

- Review and Discuss proposed **Terms of Reference (TOR)** for the ASSET High Level Policy Forum (HLPF)
- After this discussion, a TOR document will be drafted and circulated for approval

Elements of TOR

- Vision, objectives, scope, and deliverables
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods

Background for HLPF TOR

- HLPF objectives from ASSET Description of Work (**DOW**)
- ASSET Logical Framework (**LogFrame**)
- ASSET **Strategic Plan**

Elements of TOR

- Vision, objectives, scope, and deliverables
  - Recommendation: adopt DOW, LogFrame, and Strategic Plan elements …
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods

T6.1 Objectives (DOW)

1. The High Level Policy Forum (ASSET – HLPF) objective is to **bring together** selected European policy-makers at regional, national and EU levels, key decision makers in health agencies and pharmaceutical industry, and civil society organizations, in a **unique and interactive dialogue** to promote on-going reflections on EU strategic priorities about pandemics
2. The primary goal of ASSET – HLPF is to create mutual trust, improve communication, and provide a "safe" environment to **address questions which are otherwise difficult** to discuss
3. Another important goal of ASSET – HLPF is to strengthen the perception that further dialogue among participants is going to be **fruitful due to increased insights** into each others perspectives, and the sense that conversation is worthwhile

Key HLPF LogFrame Results

- HLPF **represents** regional, national, and EU levels across health agencies, pharmaceutical industry, and civil society
- HLPF **endorses** the ASSET Strategic Plan's six Action Lines
- HLPF is made into a **sustainable** forum after the ASSET project

HLPF Contributions in ASSET Strategic Plan

- Recommend guidelines to avoid **conflicts of interest** due to policymakers or members of national vaccine and medical advisory committees having received salary, stock, or funding from industry
- Recommend how to make official meetings more **transparent**
- Make recommendations relative to ASSET "**unsolved scientific questions**"
- Review ASSET **citizen-driven activities** and recommend how to scale-up
- Make recommendations relative to use of **social media** to prepare for and respond to pandemic/epidemic crises
- Recommend how to promote interest and motivation of **health professional and research community**, responsive to values and feelings of **general population**
- Recommend how to improve **vaccine uptake among women**, and to improve inclusion of **women in clinical trials and research**
- Recommend policies to balance security/individual rights, secrecy/transparency for **risky research and intentional outbreaks**

Elements of TOR

- Vision, objectives, scope, and deliverables
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods

Membership, Roles, and Responsibilities

- Membership by invitation or application, approved by HLPF Secretariat and ASSET Technical Coordinator (other criteria?)
- Members shall designate an alternate to participate when they are not available
- As Secretariat, The International Emergency Management Society (TIEMS) will organize and facilitate meetings, and publish minutes

Elements of TOR

- Vision, objectives, scope, and deliverables
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods

Resource and Financial Plans

- The HLPF is sponsored by the ASSET Program, which will provide meeting facilities and support Secretariat services and ASSET staff participation
- Members will not be reimbursed for time spent on HLPF activities, and they are asked to pay their own travel expenses
- Funding may be available to support member travel expenses on a limited, special case basis

Quality Plan

- Publications of the HLPF will be reviewed, refined, and agreed to by all HLPF members
- HLPF deliverables to the ASSET program will be subject to ASSET quality procedures

Elements of TOR

- Vision, objectives, scope, and deliverables
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods
  - Recommend adoption of DOW language ….

T6.1 Methods

1. By linking different policy levels both virtually through the ASSET Community of Practice (COP) on-line platform, and physically during a yearly seminar, the ASSET-HLPF will consider and revise specific issues related to EU strategic priorities in pandemic communication, preparedness and response
2. The forum promotes dialogue, not debate. Participants are not being asked to defend their own views or to find the weakness in others' positions, but rather to explain their own perspectives
3. Parties speak for themselves only and not as representatives of groups, institutions, or governments
4. Conversation will be carried out under the Chatham House rule: "When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"

Other TOR Considerations?

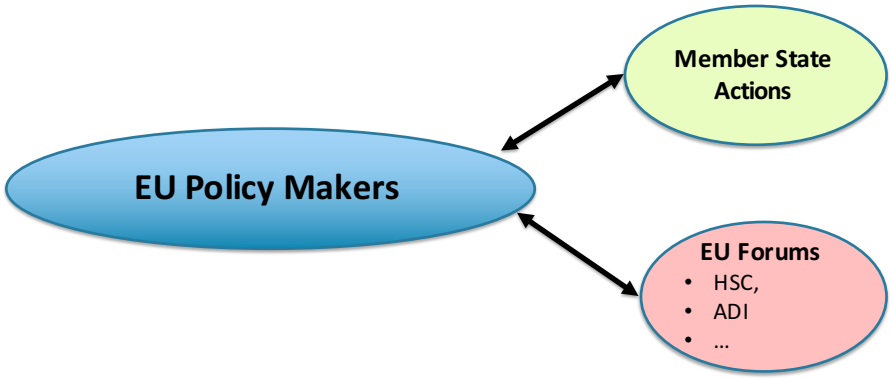
- Vision, objectives, scope, and deliverables
- Membership, roles, and responsibilities
- Resource, financial, and quality plans
- Working methods

Next Steps

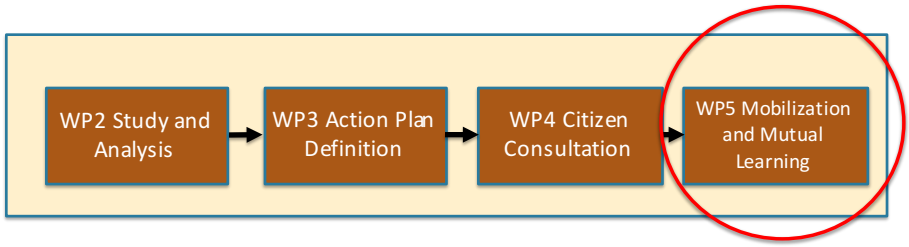
- TIEMS will draft a TOR document reflecting today's discussion
- HLPF members and ASSET participants will review and comment on the draft
- A final TOR document will be circulated for approval

Framework for Discussing Role of HLPF

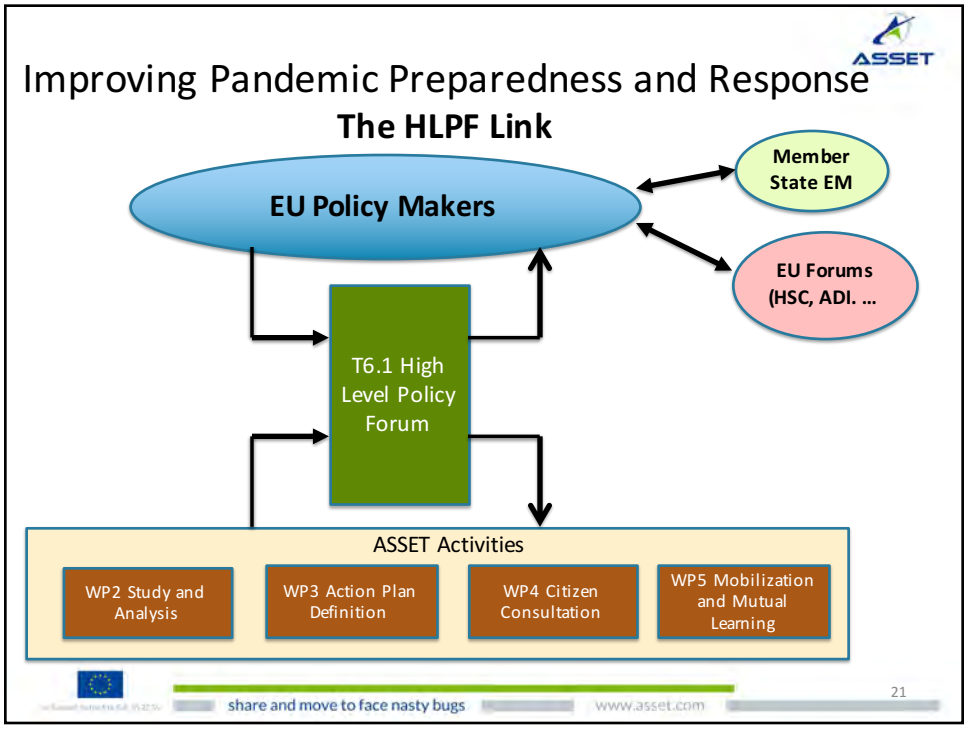
Improving Pandemic Preparedness and Response
EU Policy Makers



Improving Pandemic Preparedness and Response
ASSET Contribution



ASSET Provides a Unique Opportunity to
- Develop policies, tools, and approaches informed by multi-sectoral stakeholders
- Engage civil society to improve trust and communication
- Improve coordination of research, policy, and public values
- Better serve underserved populations


Improving Pandemic Preparedness and Response
The HLPF Link
EU Policy Makers
Member State EM
EU Forums (HSC, ADI. ...
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ASSET Activities
WP2 Study and Analysis
WP3 Action Plan Definition
WP4 Citizen Consultation
WP5 Mobilization and Mutual Learning
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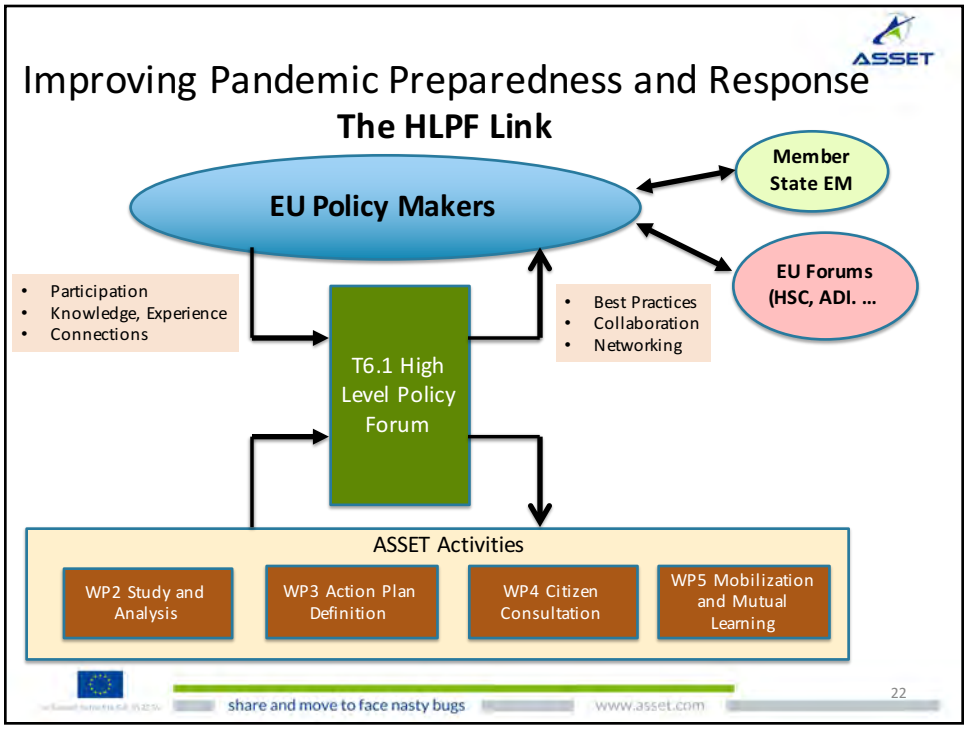
Improving Pandemic Preparedness and Response
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Participation
Knowledge, Experience
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Best Practices
Collaboration
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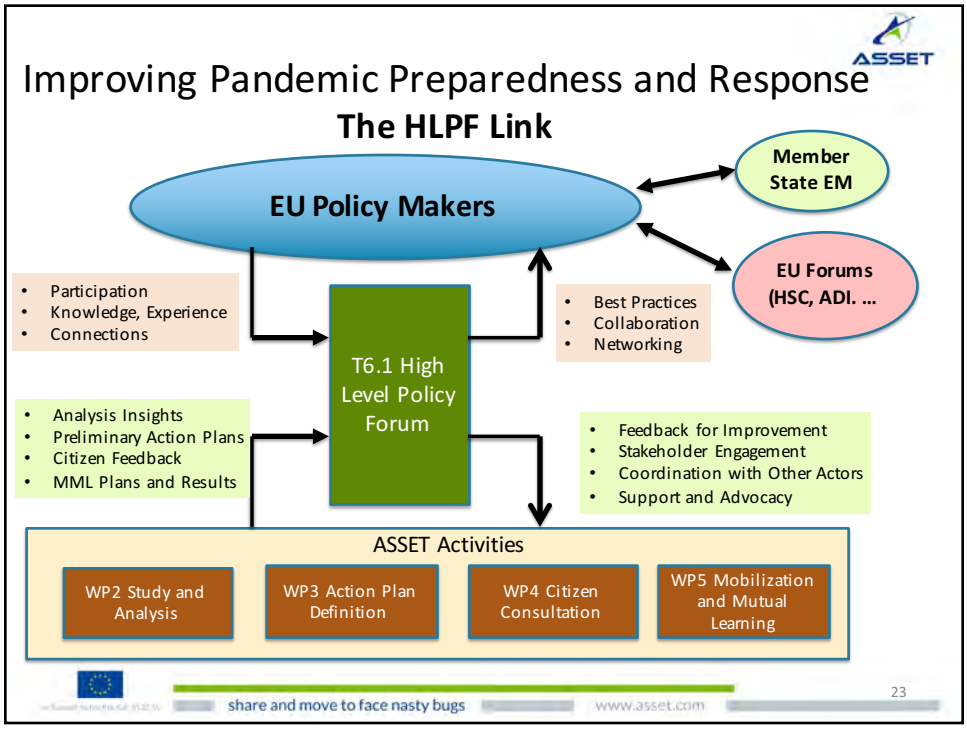
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Best Practices
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Networking
Analysis Insights
Preliminary Action Plans
Citizen Feedback
MML Plans and Results
Feedback for Improvement
Stakeholder Engagement
Coordination with Other Actors
Support and Advocacy
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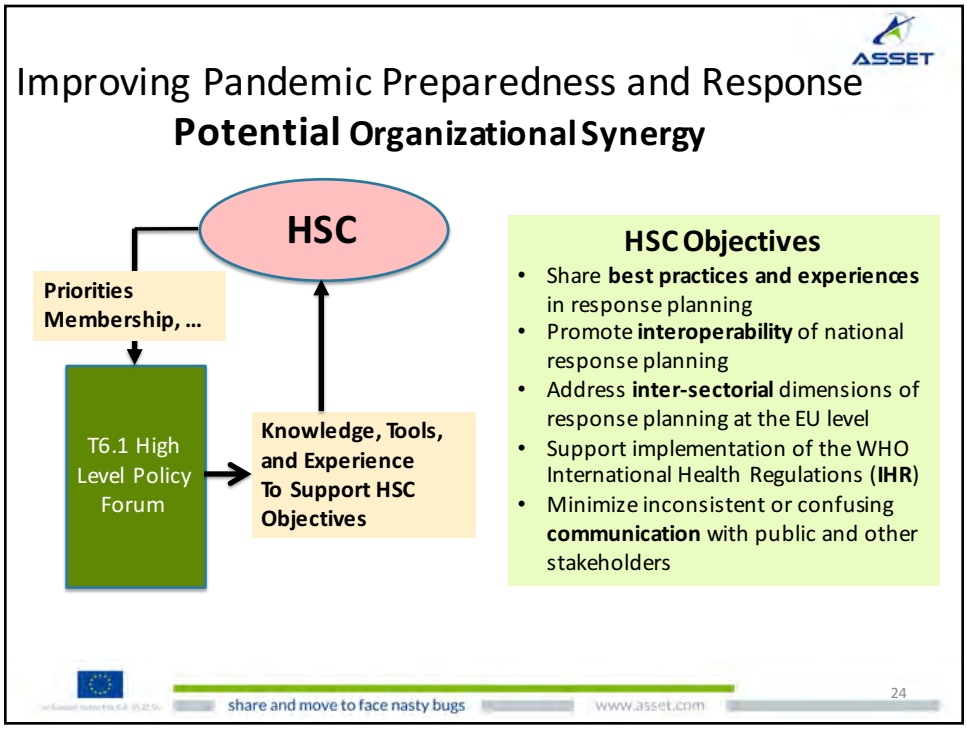
Improving Pandemic Preparedness and Response
Potential Organizational Synergy
HSC
Priorities
Membership, ...
T6.1 High Level Policy Forum
Knowledge, Tools, and Experience To Support HSC Objectives
HSC Objectives
Share best practices and experiences in response planning
Promote interoperability of national response planning
Address inter-sectorial dimensions of response planning at the EU level
Support implementation of the WHO International Health Regulations (IHR)
Minimize inconsistent or confusing communication with public and other stakeholders
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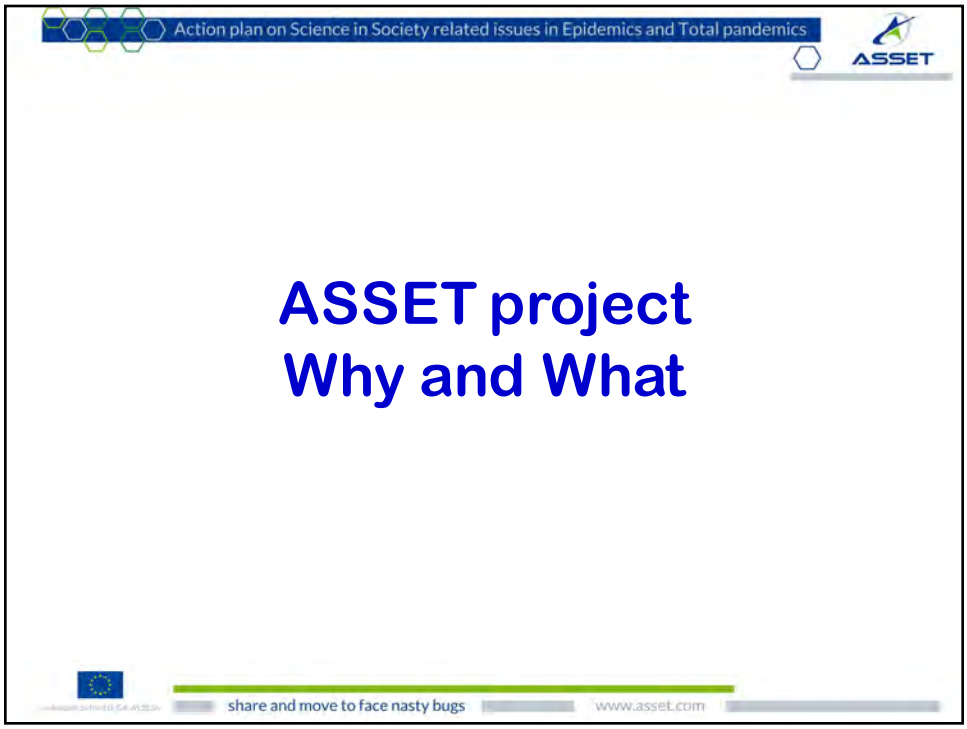
ASSET project progresses and strategic plan
II HIGH LEVEL POLICY FORUM MEETING
ALBERTO PERRA, SCIENTIFIC COORDINATOR,
ISTITUTO SUPERIORE DI SANITA' - ITALY
Copenhagen, 15 . 01 . 2016
www.asset-scienceinsociety.eu
co-funded by the EU. GA: 612236
ASSET Action plan on Science in Society related issues in Epidemics and Total pandemics


Action plan on Science in Society related issues in Epidemics and Total pandemics
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ASSET project
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(Action plan on SiS related issues in Epidemics and Total Pandemics)

- Funded by the European Union's Seventh Framework Program
- 48-Month Mobilization and Mutual Learning Action Plan (MMLAP) Project
- Starting date: 01/01/2014

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

Country	% Informed (1)		% Distrust in information sources (2)				
	'Well'	'Not well'	Health professionals	National health authorities	European authorities	Media (TV, radio, newspapers)	Internet
Slovenia	91	8	26.7	35.0	39.6	56.3	39.6
Norway	87	12	10.7	13.2	17.4	69.6	44.8
Switzerland	87	13	13.3	24.9	36.6	69.1	51.9
Finland	87	13	7.4	14.2	24.8	39.6	43.6
Portugal	84	15	10.1	19.8	16.9	46.2	33.2
Malta	85	15	6.0	14.9	14.6	41.2	33.3
Luxembourg	84	15	14.0	31.0	37.3	68.4	56.1
United Kingdom	83	16	8.1	18.3	36.4	65.1	44.5
Iceland	83	16	3.5	6.6	20.4	54.2	43.3
HU: Hungary	83	17	29.0	43.4	33.7	70.7	40.2
IE: Ireland	83	17	7.1	22.1	21.2	49.6	43.5
Belgium	82	17	7.7	21.4	24.3	64.4	55.8
Sweden	82	17	11.0	14.9	23.2	72.8	47.7
Denmark	81	19	7.8	10.6	17.1	56.3	38.3
Netherlands	80	20	8.7	16.0	22.4	64.3	48.9
France	77	22	19.5	48.1	48.0	73.7	59.0
Austria	77	22	15.5	29.7	42.9	66.6	48.6
Germany	75	25	17.2	36.1	45.8	65.8	47.8
Italy	75	25	23.1	42.9	40.5	66.7	48.9
Cyprus	72	29	19.7	24.6	24.0	49.7	33.4
Slovakia	71	28	18.6	24.3	26.8	44.2	36.4
Bulgaria	70	29	21.1	35.6	25.5	39.8	21.2
Spain	69	30	12.8	41.7	38.7	62.3	48.9
Greece	67	33	26.5	43.1	36.8	74.1	35.4
Czech Rep.	66	34	15.3	25.8	32.3	42.4	37.9
Romania	66	34	15.0	34.9	29.4	44.5	31.0
Poland	66	35	23.6	52.0	44.3	57.5	44.5
Estonia	57	42	16.2	24.7	24.4	45.0	34.9
Latvia	51	48	27.4	56.4	48.5	53.8	42.3
Lithuania	43	54	25.4	36.5	25.0	39.3	27.4
EU-27	**75**	**24**	**16.6**	**35.5**	**38.2**	**62.8**	**46.3**

European citizens perceptions : Information level and distrust responses (2009)

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Primary Aims of ASSET

- Forge a partnership with complementary perspectives, knowledge and experience to address scientific and societal challenges raised by pandemics
- Explore and map SiS-related issues in global pandemics
- Define and test a participatory and inclusive strategy
- Identify resources to make the project sustainable

The ASSET Consortium

1. ABISKEY CP (ABSISKEY)	8. NATIONAL CENTER OF INFECTIOUS AND PARASITIC DISEASES (NCIPD)
2. ASSOCIATION LYON BIOPOLE (LYONBIOPOLE)	9. THE INTERNATIONAL EMERGENCY MANAGEMENT SOCIETY AISBL (TIEMS)
3. EUROPEAN INSTITUTE OF WOMEN'S HEALTH LIMITED – (EIWH)	10. UNIVERSITATEA DE MEDICINA SI FARMACIE'CAROL DAVILA' DIN BUCURESTI (UMFCD)
4. FONDEN TEKNOLOGIRADET (DBT)	11. UNIVERSITY OF HAIFA (HU)
5. FORSVARETS FORSKNINGINSTITUTT (FFI)	12. ZADIG SRL (ZADIG)
6. INTERNATIONAL PREVENTION RESEARCH INSTITUT-IPRI MANAGEMENT (IPRI)	13. DATA MINING INTERNATIONAL SA (DMI)
7. ISTITUTO SUPERIORE DI SANITA (ISS)	14. INSTITUTE OF PREVENTIVE MEDICINE ENVIRONMENTAL AND OCCUPATIONAL HEALTH (PROLEPSIS)

Project development

- **The first phase** focused on the **constitution of a sound part**nership and, given the elevated number of consortium partners, of an effective approach to the internal communication and mutual understanding (WP1)
- **The second phase** (WP2) has provided the **baseline knowledge** according to the 6 main components of RRI concerning pandemics and global emergencies crisis management (governance, unsolved scientific questions and open access to scientific outcome, participatory governance and science education, ethics, law and fundamental rights. gender issues and inclusiveness, intentionally caused outbreaks)
- **The third phase** (WP3), fed by the previous ones, has designed the **strategic and action plans**, polarizing on the development of citizens' awareness, empowerment and action, by implementing instruments and tools typical of the mobilization and mutual learning approach. Central to this phase is the RRI perspective, including citizen-driven innovation.
- **The fourth phase** (essentially the WP4) will be devoted initially to
- **The fifth** (WP5, and partially the WP6 and 7) aimed to **stakeholder and social media mobilization, mutual learning exercises, policy watch, and external communication**.
- **The last phase** (WP 9) will focus **legacy** while WP8 and 10 (**monitoring** and **evaluation**) will encompass all the other WP activities along the entire duration of the project.

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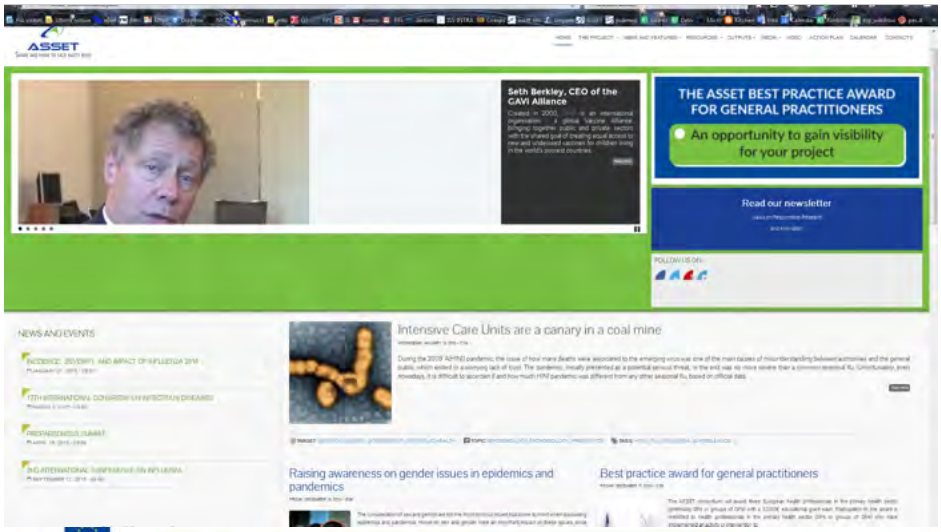
The ASSET site



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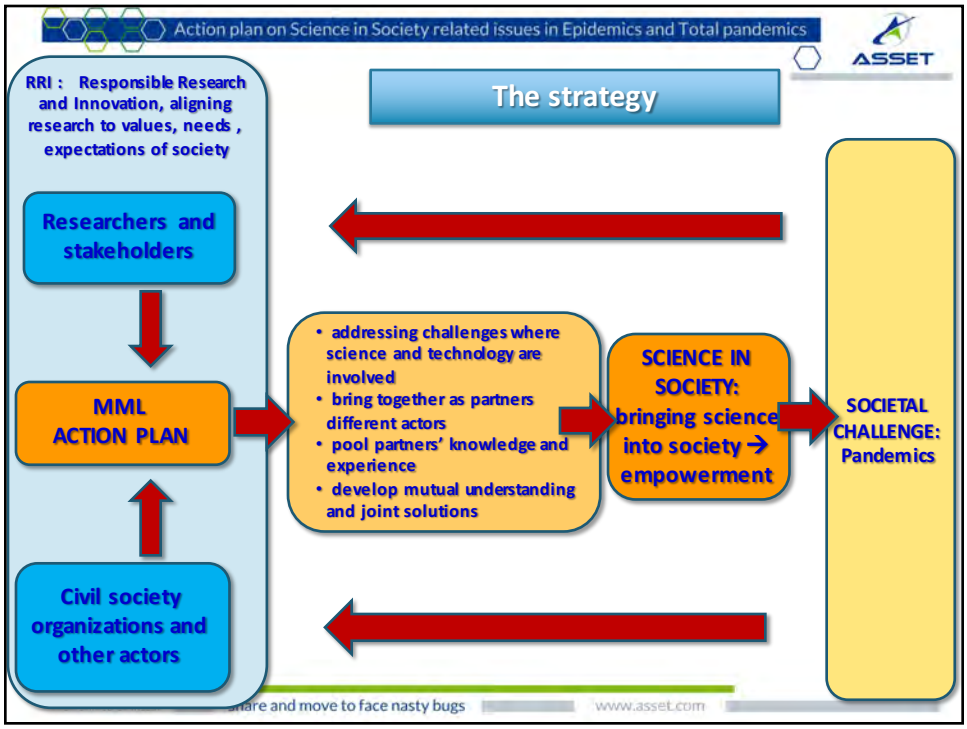

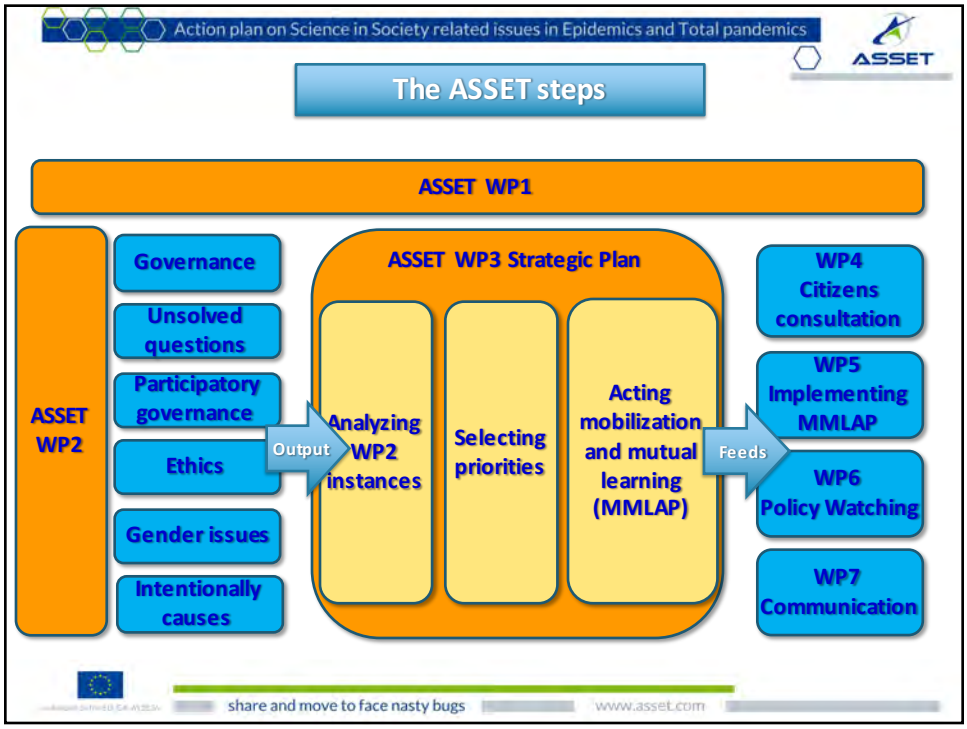
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Governance
Unsolved questions
Participatory governance
Ethics
Gender issues
Intentionally causes
Output
ASSET WP3 Strategic Plan
Analyzing WP2 instances
Selecting priorities
Acting mobilization and mutual learning (MMLAP)
Feeds
WP4 Citizens consultation
WP5 Implementing MMLAP
WP6 Policy Watching
WP7 Communication
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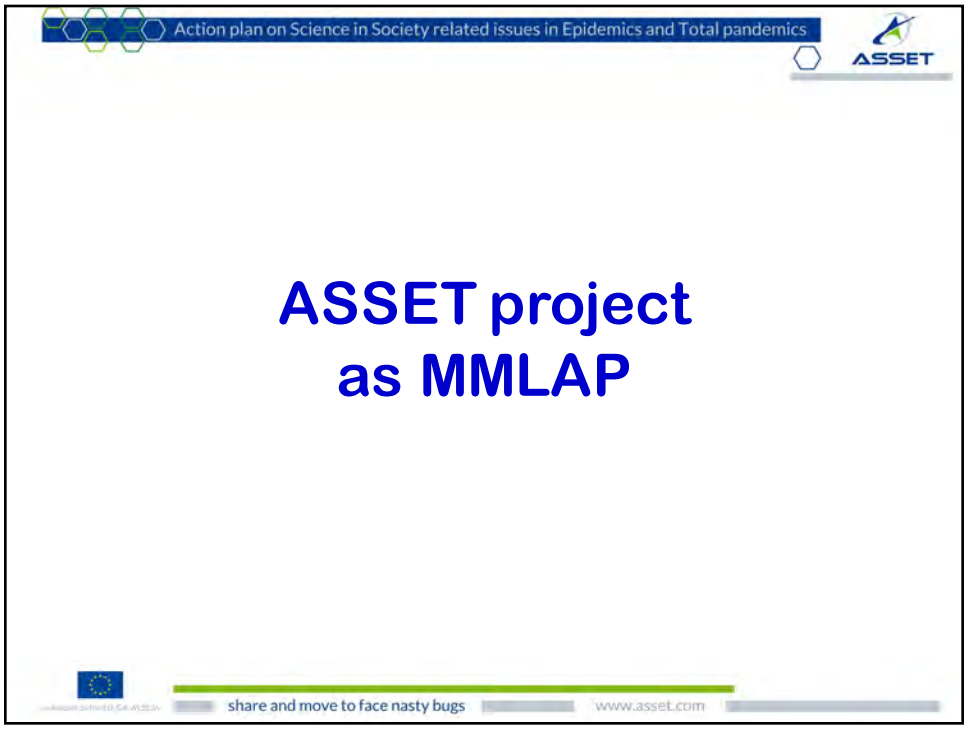
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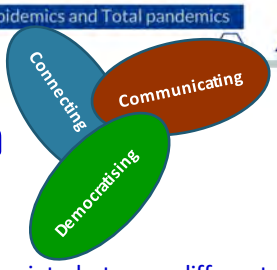
Essential functions of MMLAP approach



- **Connecting**
  - local to global issues
  - researchers to benefit from links to civil society between different stakeholders from academia, policymakers, civil society and the private sector
  - general public to access data
- **Communicating**
  - doing more for communication at national level
  - example: Communicating with policy makers to share developments in research agendas and progresses in investigation
- **Democratizing**
  - allowing different categories of stakeholders, and particularly marginalized social groups, to have a voice in decision-making processes
  - "fully embedding CSOs in research processes"

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

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Challenges of MMLAP

- **Social inclusion**
  - the democratization of scientific agendas and activities
  - bringing science out of its 'ivory tower' and promoting a 'methodology for action'
  - collaborative approaches with a diverse range of stakeholders
  - to explore the day to day obstacles involved in doing so
- **Mutual learning**
  - enable to share good collaborative practice and ideas
  - research processes more critically self-aware
  - reducing institutionalized prejudice against working in collaboration with non-scientific partners
  - development of new forms of knowledge and unexpected outcomes
- **Policy relevance**
  - valuable stimulus for innovation and for the development of potentially 'world-changing ideas'
  - supporting knowledge based decision making processes

In practice for the European citizen:

- Timely and adequate information
- Easy identification of trustable information sources
- Communication channels between citizens and researchers/health authorities
- ……

Preparedness and response for the next pandemics or epidemics

ASSET as MMLAP, in summary

- **What went wrong during the last pandemic?**
  - Broad themes review indicated by the RRI frame carried out by WP2 and the evidence whereof is produced in the 6WP2 reports
- **What can we do for making things going smoothly for the next pandemic?**
  - Strategic plan identifies what is the role, objectives, output and outcomes for each ASSET MMLAP tool (Citizen consultation, HLPF, PPRB, Web and SH portals, Media office….) to be effective
- **Does this complex machine work?**
  - through continuous monitoring and evaluation we will ensure it
- **What is the last project "deliverable" at the end of 2017?**
  - a reproducible model to be implemented to improve PPR
- **And beyond that time (end 2017)?**
  - a new project aimed to broadening and strengthening approach and effectiveness of PPR

ASSET project "Complementarity"

Action plan on Science in Society related issues in Epidemics and Total pandemics
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Conference "Lessons learned for public health from the Ebola outbreak in West Africa – how to improve preparedness and response in the EU for future outbreaks" Luxemburg, 2015, October

- Workshop 1: The Ebola outbreak as a complex crisis: the EU response and inter-sectorial cooperation
- Workshop 2: Best practices for treatment and prevention including protection of health care workers, medical evacuation, diagnostic methods and vaccines
- Workshop 3: Communication activities and strategies addressed to the public and health professionals
- Workshop 4: The Ebola epidemic from a local challenge to a global health security issue.

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Communication activities and strategies addressed to the public and health professionals: recommendations

- Emergency Risk Communication is an integral part of any emergency response and the crucial role of the EC
- Information and communications activities and materials as well as lessons learned for EU countries in any major health emergency should be coordinated at EU level, with the support of the each MS MoH
- The framework for health communications between EU/EEA Member States and the European Commission is the Health Security Committee's Communicators' Network (HSC ComNet)
- Timely development of communication materials, repository, common communication platform, perceptions, knowledge and behaviors of European citizens during a health crisis
- Multifaceted communication strategy

ASSET added value

- **Testing** and accounting by for a multi country standardized approach grounded on the EU "Science with and for Society"
- Leading to **stable** changes in Society (empowerment)
- Promoted by the principles of RRI, where progresses are expected by means of **aligning (and promoting) research** to "questions", needs and values of the citizens
- Supported by creating multiple 2-way communication settings where different stakeholders "***mobilize and mutually learn***" about governance, unsolved questions, participatory governance, ethics, law and fundamental rights, gender issues, intentionally caused outbreaks concerning pandemic or large crisis like Ebola

ASSET project Progresses

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

Asset objectives' progress

- Initial delay
- 15 months actual activities
- First phase investing in internal communication: is well running
- Second phase external communication: is growing up and differentiating

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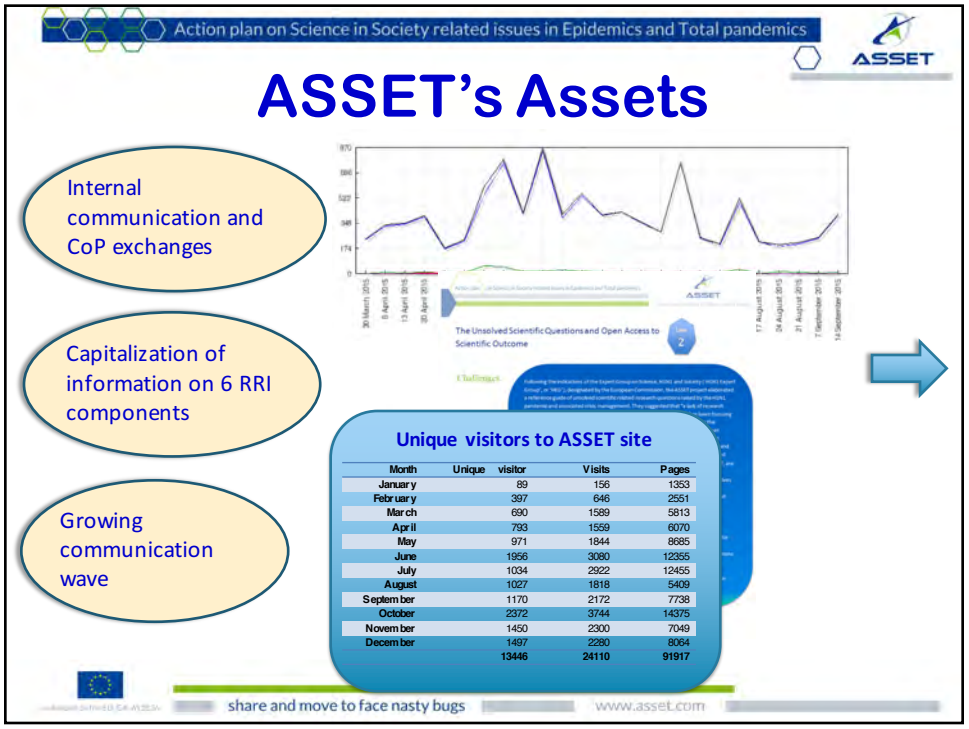
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ASSET's Assets
Internal communication and CoP exchanges
Capitalization of information on 6 RRI components
Growing communication wave
The Unsolved Scientific Questions and Open Access to Scientific Outcome
Unique visitors to ASSET site
Month | Unique visitor | Visits | Pages
January | 89 | 156 | 1353
February | 397 | 646 | 2551
March | 690 | 1589 | 5813
April | 793 | 1559 | 6070
May | 971 | 1844 | 8685
June | 1956 | 3080 | 12355
July | 1034 | 2922 | 12455
August | 1027 | 1818 | 5409
September | 1170 | 2172 | 7738
October | 2372 | 3744 | 14375
November | 1450 | 2300 | 7049
December | 1497 | 2280 | 8064
13446 | 24110 | 91917
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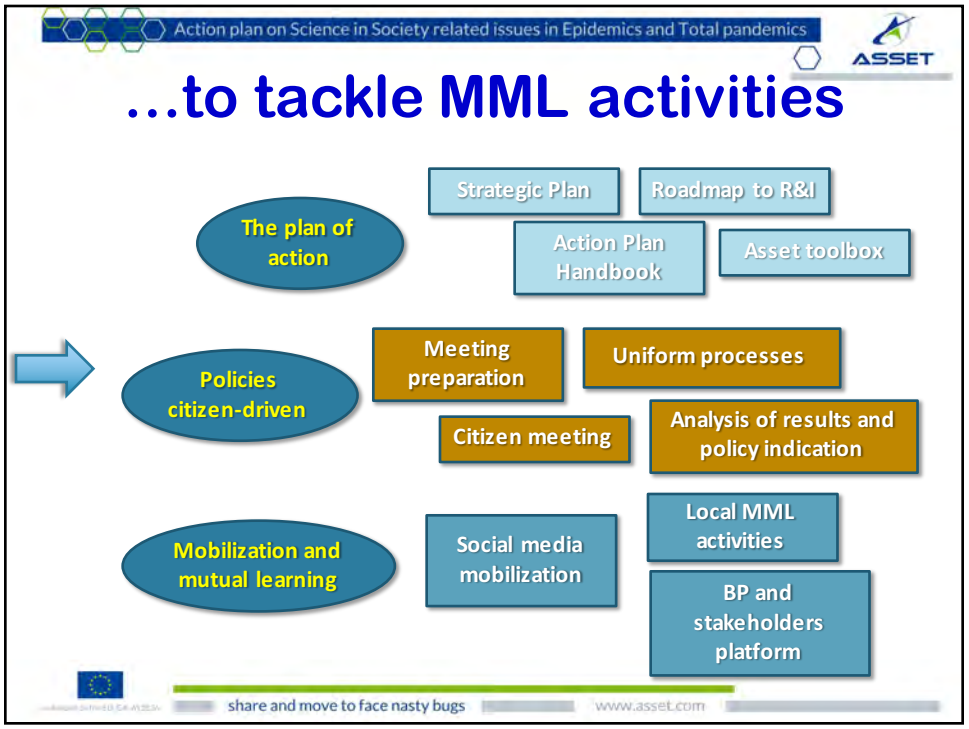
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...to tackle MML activities
The plan of action
Strategic Plan
Roadmap to R&I
Action Plan Handbook
Asset toolbox
Policies citizen-driven
Meeting preparation
Uniform processes
Citizen meeting
Analysis of results and policy indication
Mobilization and mutual learning
Social media mobilization
Local MML activities
BP and stakeholders platform
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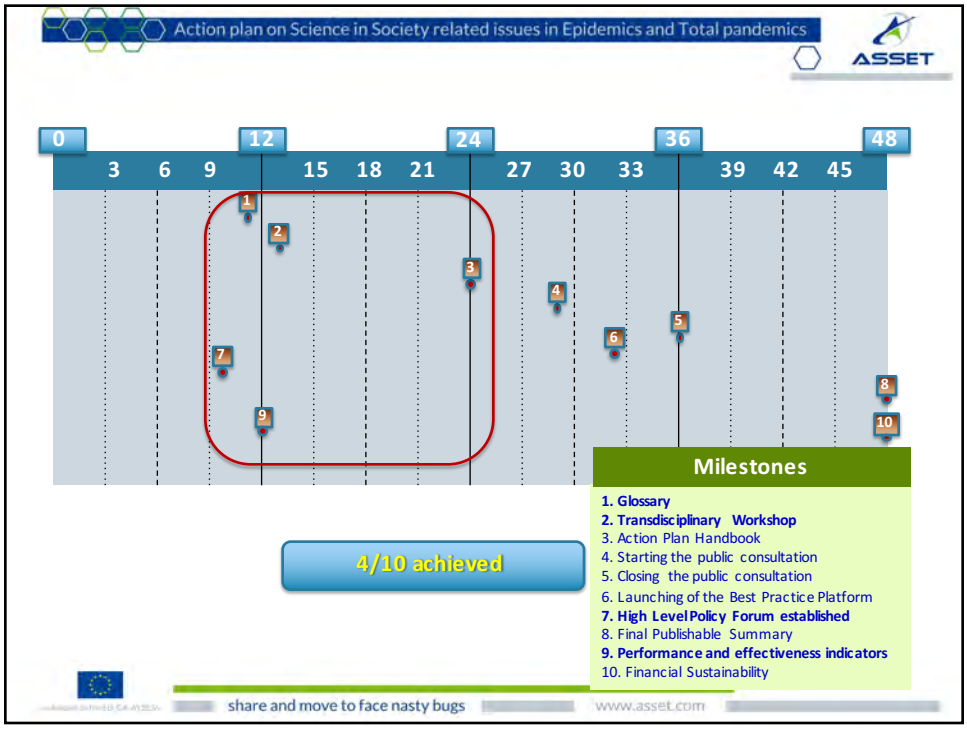
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0 3 6 9 12 15 18 21 24 27 30 33 36 39 42 45 48
Milestones
1. Glossary
2. Transdisciplinary Workshop
3. Action Plan Handbook
4. Starting the public consultation
5. Closing the public consultation
6. Launching of the Best Practice Platform
7. High Level Policy Forum established
8. Final Publishable Summary
9. Performance and effectiveness indicators
10. Financial Sustainability
4/10 achieved
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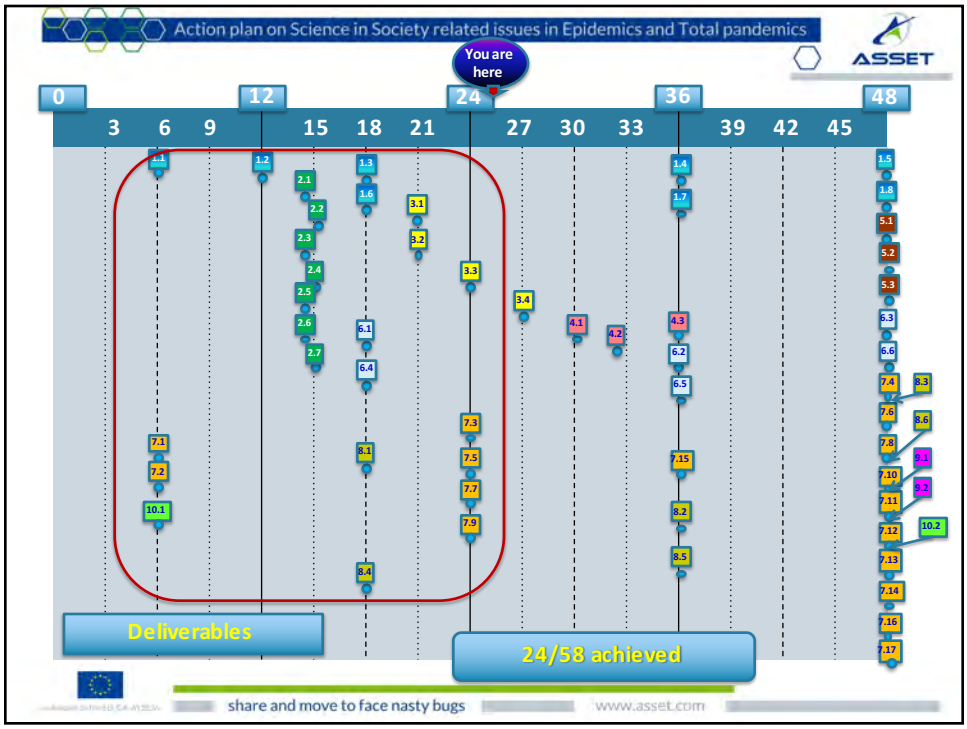
Action plan on Science in Society related issues in Epidemics and Total pandemics
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You are here
0 3 6 9 12 15 18 21 24 27 30 33 36 39 42 45 48
Deliverables
24/58 achieved
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ASSET project Strategic Plan

Action plan on Science in Society related issues in Epidemics and Total pandemics
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What is a MMLAP Strategic Plan

- A high-level plan to provide a framework for MML strategy and, consequently, for the actions and activities to be included in the MML action plan
- To define a clear focus not only for the actions to be carried out by ASSET members but also for relevant stakeholders
  - to engage societal actors in the research and innovation process,
  - to create equal conditions for citizen's engagement, possibly also including specific strategies into pandemic policies in the European members states

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ASSET mission and vision

- to connect decision makers and researchers with citizens by trust-building processes in order to facilitate science in society (SiS) and responsible research and innovation (RRI) in the field of pandemics and crisis management

- to promote mobilization and mutual learning (MML) among decision makers, researchers, healthcare workers, and citizens to increase participatory and evidence based preparedness and response capacity in the field of pandemics and crisis management

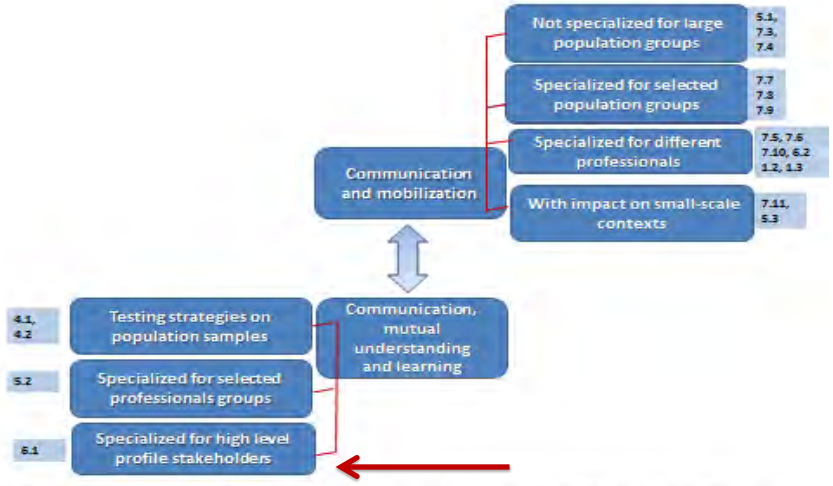
Objective of the MML Strategic Plan

To propose **a model of change** so as to make easier acquiring the mastery in terms of knowledge, attitudes and behaviours in case of a threaten conditions, like a pandemic, to build a more resilient society

Main steps to set up the SP:

- Definition of the **ASSET mission**, as from the DoW and the main ASSET goals;
- The **Problem Setting for selected action lines** emerged by the 6 specific WP2 reports in form of a priority list of main issues inventoried;
- Consequential **Strategy lines** to be developed with specific action by the ASSET MML action Plan;
- all ASSET actions to be encompassed by the overall approach of **mobilization and mutual learning**

ASSET MML TOOLS



Approaches, characteristics, targets and related tasks (N.N) of the ASSET project

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

Challenges

General approach

- not only a matter of reaching the population (and the entire population) with an appropriate risk communication campaign, but also of raising the level of EU citizens' participation and promoting responsible research in different fields

- promote conditions more favorable for changes connecting governments and population, stakeholders and scientists, particularly by the so called mobilization and mutual (understanding and) learning approach.

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Challenges

Contents

- A great deal of information to be processed and priorities to be selected
- Difficult priority identification in terms of strategic lines
- Preparation of a text as useful reference for many project tasks fed by the strategic plan

Methods

- Tuning in of actions and tools typical of the MMLAP
- Multifaceted tasks for the large number of interweaves with other WPs
- Scaling up and Evolution into H2020 established starting from here

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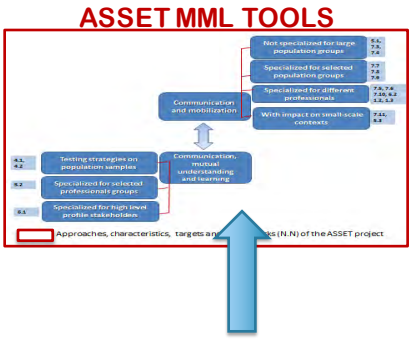

High Level Policy Forum

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Selected priority issues to be brought to the HLPF members attention - 1

The commitment of the Research Community for carrying out more studies aimed to citizen empowerment

To what extent is this a problem in EU MS?

Best practices or relevant positive experiences?

Possible strategies?

How to share and translate in plans such strategies?

Specific indications for ASSET?

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

Selected priority issues to be brought to the HLPF members attention - 2

Building effective structures to listening to and talking to citizens

To what extent is this a problem in EU MS?

Best practices or relevant positive experiences?

Possible strategies?

How to share and translate in plans such strategies?

Specific indications for ASSET?

Selected priority issues to be brought to the HLPF members attention - 3

Establishing conditions for transparent governance

To what extent is this a problem in EU MS?

Best practices or relevant positive experiences?

Possible strategies?

How to share and translate in plans such strategies?

Specific indications for ASSET?

Selected priority issues to be brought to the HLPF members attention - 4

Establishing and promoting health personnel role

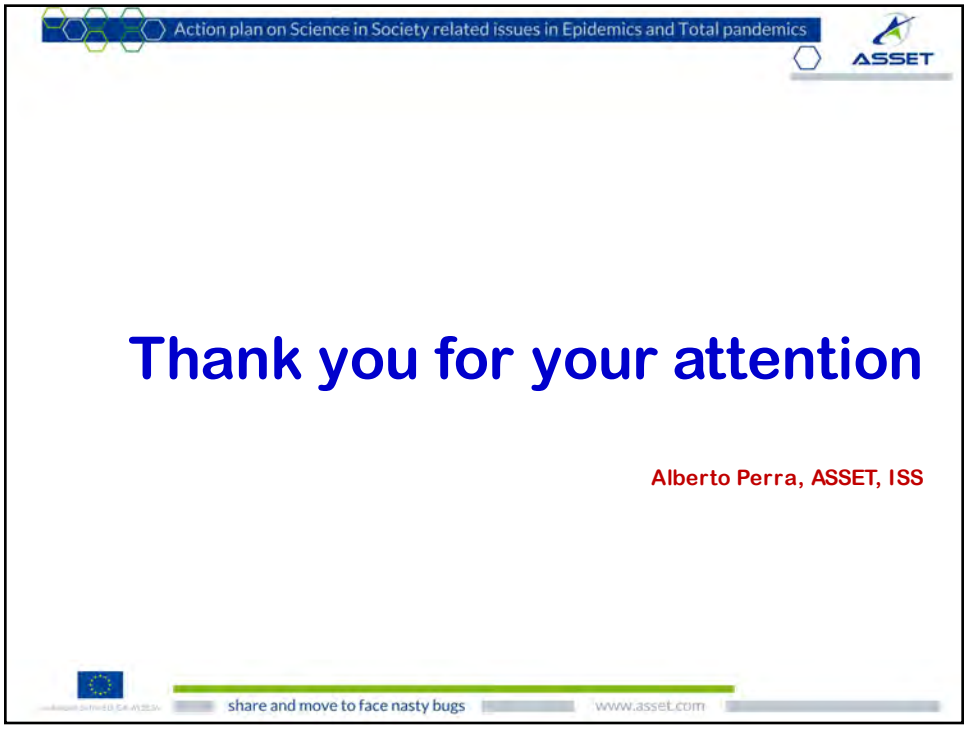
To what extent is this a problem in EU MS?

Best practices or relevant positive experiences?

Possible strategies?

How to share and translate in plans such strategies?

Specific indications for ASSET?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Alberto Perra, ASSET, ISS
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Gender Issues in Pandemics and Epidemics

Vanessa Moore
European Institute of Women's Health
High Level Policy Forum
Copenhagen 15 January 2016

www.asset-scienceinsociety.eu

co-funded by the EU. GA: 612236

ASSET

EIWH

Overview

- Introduction to EIWH
- Sex difference
- Pregnancy
- Health care workers and carers
- Hard to reach groups
- Older women

About the EIWH

- The European Institute of Women's Health is a health NGO launched in 1996
- The EIWH **advocates** for a gender-sensitive approach to health and research policy, prevention, treatment, care in order to reduce health inequalities and improve quality
- **Organisation**:
  - Extensive multi-national, multi-disciplinary network of patient groups, health NGOs, researchers, gender experts, politicians, and medical professionals
  - Expert Advisory Board.

EIWH target audience

- European Commission: DG Santé
- DG Research, DG Justice, DG Connect
- DG Employment/Social/Inclusion
- European Parliament
- European Medicines Agency (EMA)
- The Council Presidencies and EU Member States
- Public Health NGOs, researchers, health professionals, and academic organisations
- Patient organisations and healthy people, especially more marginalised vulnerable groups.

Literature review

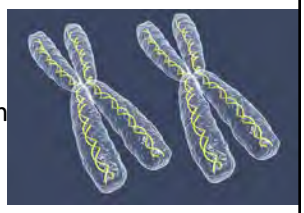
- Objective: to look at gender differences affecting exposures to infectious diseases as well as access to, information on, and use of, vaccinations in pandemics and epidemics
- This was done by applying a targeted gender and life course approach
- Searches of databases were conducted to identify papers in peer-reviewed journals on the topic of gender, epidemics, and pandemics
  - Grey literature was also consulted.

Sex vs. Gender – what is the difference?

- Sex – the biological and physiological characteristics that define men and women. Used as a classification, generally as male or female, according to the reproductive organs and functions that derive from chromosomal complement

- Gender – socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women. Used to refer to a person's self-representation as male or female, or how that person is responded to by social institutions on the basis of the individual's gender presentation.

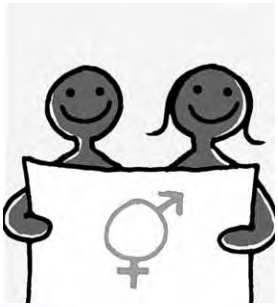
Sex Difference



- Sex differences in immune function are well established – for example, several genes that are responsible for immunological proteins are on the X chromosomes, and studies have shown that inflammatory immune responses are generally higher in females than in males
- Biologically, females and males differ in their immunological responses to seasonal influenza virus vaccines
- Women, whether adult or as older persons, have higher antibody responses to influenza vaccinations – the antibody response of a woman to half a dose of influenza vaccine is equivalent to the antibody response of a man to the full dose
- Women also report a worse reaction to vaccinations than men do.

Sex difference in research

- Women are underrepresented in clinical trials
- While women participate in all phases of study development, participation is especially low in early Phase I and I-II studies
- Another problem stemming from the paucity of women in clinical trials is the lack of awareness among doctors and health care professionals about the importance of sex-specific differences across the lifespan.



Pregnancy and Vaccinations

Women who are pregnant are more likely to have severe disease and hospitalisation with either seasonal or pandemic influenza, compared to the general population or compared to non-pregnant women of the same age group

- During pandemics, the mortality rate for pregnant women is higher than non-pregnant women
- A number of reasons why pregnant women are more at risk
- The WHO recommends all pregnant women to receive vaccinations during the influenza season, and that they should be given highest priority among all the risk groups.

Pregnancy and Vaccinations

- Vaccine covers of pregnant women tend to lag behind those seen in the general population
- Evidence points to pregnant women not knowing of the increased risks associated with pregnancy and influenza
- Many health care providers do not recommend pregnant women to take influenza vaccine due to concerns over giving a vaccine to a pregnant woman
- Data on pregnancy and vaccinations is scarce – in terms of drivers and barriers for pregnant women, there is little evidence-based research

- There is limited research done on vaccine safety in pregnant women, however studies suggest the vaccine is safe.

Health case workers and carers

- These groups tend to be predominantly female – for example, 92% of nurses in Ireland are female
- Front line workers face disproportionate risks of illness and death during a pandemic; yet compliance rates are as low as 10% to 40-50% among health care workers, with no clear pattern as to why this is
- Care giving in the home is a large risk factor for influenza; also, caregivers often delay seeking treatment due to their caring responsibilities (WHO 2012).

Hard to Reach Groups and Vaccination

- Gender (social) is one of the most critical variables in terms of health outcomes
- Hard to reach groups may have adverse health outcomes - the complex interplay of social/economic marginalisation makes this a particular issue
- There are a number of minority groups in society which have adverse health outcomes and where women are particularly affected, for example
  - -Roma community
  - -Isolated immigrant communities
  - -Lower socioeconomic groups
- Need for an integrated interdisciplinary programme where systematic surveillance of trends in influenza uptake by hard to reach groups is implemented.

Hard to Reach Groups and Vaccination

- Obstacles for Roma health prevention
- Roma women are more likely to experience social exclusion than Roma men and suffer the added disadvantages of limited access to education, employment, health services and social services, and are discriminated against on the basis of both ethnicity and gender
- Limited MMR vaccination of children in Somali community in Sweden – only 70% of two-year olds in this community vaccinated against MMR
- Importance of intersectional research to address this.

Older People and Vaccinations

- Persons over the age of 65 have a higher risk for severe influenza-related complications and have the highest risk of mortality from influenza – this includes both men and women
- Life expectancy for women in the EU was, on average, 5.5 years longer than that for men in 2013
- The gap is smaller in terms of healthy life years than for overall life expectancy – just 0.1 years difference in favour of women
- Women make up the largest proportion of the older population – but older people are generally excluded from clinical trials
- Older women who due to multimorbidities and increased longevity take many medications must be included in clinical trials.

Older People and Vaccinations

- Older people are more likely to be poor than other groups, and women are more likely to be poor than men
- As mortality is higher for men than for women, more older women than men live in one-person households
- The loneliness and depression that may accompany widowhood can lead to increased risk of physical and psychological illness

- The older woman may find herself at a worse financial status due to the loss of spousal income.

HLPF discussion

- Were you/your organisation aware that there was such a thing as gender issues in pandemics/epidemics? Have you/your organisation considered gender as a specific issue in pandemics/epidemics?
- What issues strike you/your organisation as particularly urgent in terms of pandemic preparedness?
- What role your you/your organisation play in addressing some of these issues?

ASSET

The Danish Board of Technology Foundation

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

- The Danish Board of Technology
- Introduction to citizen participation
- The ASSET Method for citizen participation
- HLPF Input
  - Group work and poster presentations
- Conclusion

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The Danish Board of Technology

- The DBT Foundation offers a variety of participatory processes that provide decision makers with valuable insight into the attitudes of the citizens with regard to political priorities.
- We are internationally recognized for the development of citizen engagement methods, which are used both locally and globally.

@DBT_Foundation

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Introduction to citizen participation

- "The idea of citizen participation is a little like eating spinach: no one is in principle against it because it is good for you". Arnstein 1969

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Introduction to citizen participation

- **Brief history (1/3)**
- Born out of a growing concern for the environmental and societal consequences of industrialization in the 1960's

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Introduction to citizen participation

- **Brief history (2/3)**
- Technology Assessment institutes in the 80's and 90's

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Introduction to citizen participation

- **Brief history (3/3)**
- RRI pushed by the Commission
  - "A need for an engaged public"

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Introduction to citizen participation

- **The Rationale (1/2)**
- Response to the 'democratic deficit' in policy-making
- Local information is increasingly essential for policy makers as governance systems expand and consequently become more distant from its constituencies

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Introduction to citizen participation

- **The Rationale (2/2)**
- The legitimacy of political decision-making is strengthened as more voices are heard
- Rule of law (Ex. Public Hearings)

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Introduction to citizen participation

- **Different method, different outcomes**
- CIVISTI
- World Wide Views
- Consensus Conference

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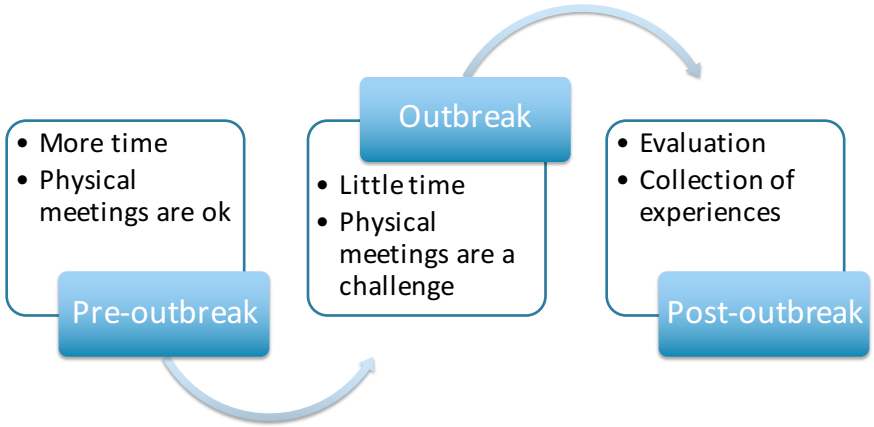
The ASSET Method for citizen participation



Contextual demands on method

Post-Outbreak

Pre- outbreak

The ASSET Method for citizen participation

- Adapted to pre-outbreak situation, and;
- Ad hoc organisation
- A combination of digital and face-to-face approaches to engagement
- Practically: 1 day, 8 countries, with 50 citizens at each site
- Citizens will receive the same information, go through the same procedures, deliberate the same questions

The preparation phase

- Development of information material
- Scientifically informed and well-balanced information, how?
  - The scientifically informed: ASSET experts
  - For a 'good balance', ASSET experts are not enough!
  - We need representation of topics discussed in different 'publics'
- Where do we find 'publics' discussing epidemics, pandemics and preparedness? Online!

Specific themes

1. Two way communication between citizens and public authorities
2. Citizen access to knowledge and information
3. Personal freedom and public health safety
4. Transparency and between citizens and public authorities

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HLPF Input

- Two minutes to discuss among yourself:
  * Which policy forums would benefit from citizen input?
- * Which existing debates would ASSET citizen consultations fit in to?
- * Which topics or questions should explicitly be address to speak into an existing agenda?

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Conclusion
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ASSET AND THE LESSONS LEARNED FROM EBOLA

Eva Benelli – Zadig Ltd
Italy

15 January 2016

www.asset-scienceinsociety.eu

co-funded by the EU, GA: 612236

EU DG SANTÉ

Conference: "Lessons learned for public health from the Ebola outbreak in
West Africa – how to improve preparedness and response in the EU for future outbreaks"

Mondorf les Bains, 12-14 October 2015

THE CONFERENCE PROFILE

Over **350** participants, including:

- ✓ health authorities
- ✓ experts from EU Member States
- ✓ EU bodies
- ✓ non-governmental organisations
- ✓ projects working in risk and crisis management and communication who have been involved in the response in West Africa as well as in preparedness and response in the EU (as ASSET)

Journalists has been invited to participate to the main sessions

FOUR WORKSHOPS:

1. The Ebola outbreak as a complex crisis: the EU response and inter-sectorial cooperation
2. Best practices for treatment and prevention including protection of health care workers medical evacuation, diagnostic methods and vaccines
3. **Communication activities and strategies addressed to the public and health professionals**
4. The Ebola epidemic from a local challenge to a global health security issue.

WORKSHOP 3 MAIN CONCLUSIONS

- Health Security Committee Communicators network fully operational and active
- Emergency Risk Communication: an **integral part** of any emergency response
- Consider deployment of trained communication experts to affected countries

RECOMMENDATIONS FOR ACTION

- Emergency Risk Communication (ERC) is an integral part of any emergency response and crucial to its management and coordination. Communications planning and training **need to be embedded in all preparedness and response** programmes.
- Information and communications activities and materials as well as lessons learned for EU countries in any major health emergency should be coordinated at EU level.
- Other organizations networks such as those of the Global Health Security Initiative (GHSI) and the World Health Organization (WHO) can also play a key role in exchanging information.
- **All networks need to be connected and all the relevant partners need to be included in the exchanges from the beginning of an emergency.**

RECOMMENDATIONS FOR ACTION/2

Possibilities for joint communications between EU/EEA Member States, the EU, civil society and key stakeholders (such as NGOs and health professionnals organisations) to **more systematically** communicate have to be explored.

Coordinating joint communications activities at the national and EU level should include **engagement with stakeholders such as the civil society**, relevant sectors, and partner agencies including but not limited to WHO, the European Centre for Disease Prevention and Control (ECDC), the European Food Safety Authority (EFSA), the European Medicine Agency (EMA).

LAST, BUT NOT LEAST

The Ebola outbreak revealed that the Commission and some national Health authorities lack the rapid access to budgets for communication during a crisis and that the contractual procedures are too complex and cumbersome to produce communication material at short notice.

Rapid procurement processes should be put in place at the EU and or national levels so that in case of a public health emergency, a **responsive and effective allocation of resources** can be facilitated.

To read more: **Conference summary report** and the **Council conclusions on 'Lessons learned for Public Health from the Ebola outbreak in West Africa** (released on 17/12/15)

Web address: http://ec.europa.eu/health/preparedness_response/

ABOVE ALL…

- As a pre-condition, the Health Security Committee (HSC) communicators network needs to be operational and active.
- EU Member States and EEA Member states should be actively encouraged to contribute to the network activities.

ASSET: A RESOURCE FOR THE HSC COMMUNICATORS NETWORK?

ASSET, ACTION PLAN IN SCIENCE AND SOCIETY IN EPIDEMICS AND TOTAL PANDEMICS is a EU funded, 48 months (2014-2017) Mobilization and Mutual Learning Action Plan (MMLAP) project whose aim is to develop an **integrated, transdisciplinary strategy** for pandemic and epidemic preparedness at local, regional and national levels.

ASSET provides research, experiences, proposal and tools that could be useful to incorporate **Science in Society issues** into Preparedness Plans.

Moreover ASSET picked up the legacy from TELL ME: Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, Providing Evidence (www.tellmeproject.eu)
TELL ME had the purpose to provide evidence and develop models for improved risk communication during infectious disease crisis.

RESEARCH ON COMMUNICATION AND OTHER SCIENCE-IN-SOCIETY ISSUES

NEW SOCIAL MEDIA

GENDER ISSUES

ETHICS AND HUMAN RIGHTS

As the Ebola crisis has recently shown, these factors need to be kept well in account when preparing national and transnational emergency plans, not only as a matter of principle, but also because **they can have an enormous impact** on the spread of the disease itself

PHILOSOPHY HAS CHANGED

HEALTH AUTHORITIES

ASSET

NEW MEDIA

STAKEHOLDERS

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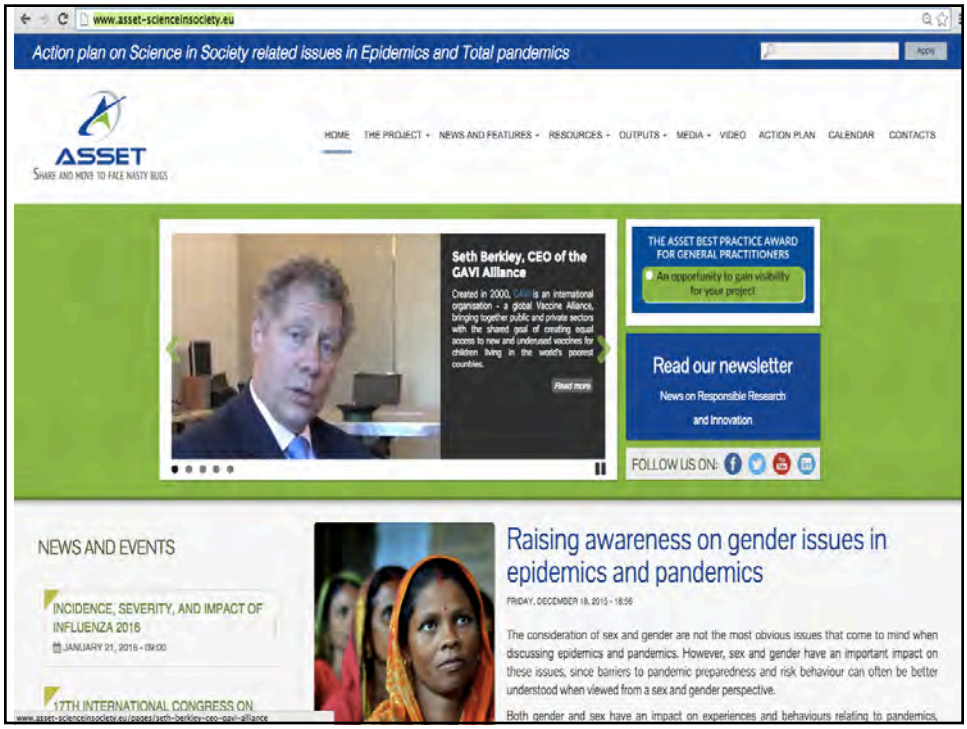
THE LEGACY OF TELLME TO ASSET

TELL ME products:

- a new framework model for risk communication
- a communication practical guide
- two online courses (basic and ebola)
- a proposal for a new pandemic threat index.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NEWS AND FEATURES
RESOURCES
OUTPUTS
MEDIA
VIDEO
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CALENDAR
CONTACTS
Seth Berkley, CEO of the GAVI Alliance
THE ASSET BEST PRACTICE AWARD FOR GENERAL PRACTITIONERS
An opportunity to gain visibility for your project
Read our newsletter
News on Responsible Research and Innovation
FOLLOW US ON:
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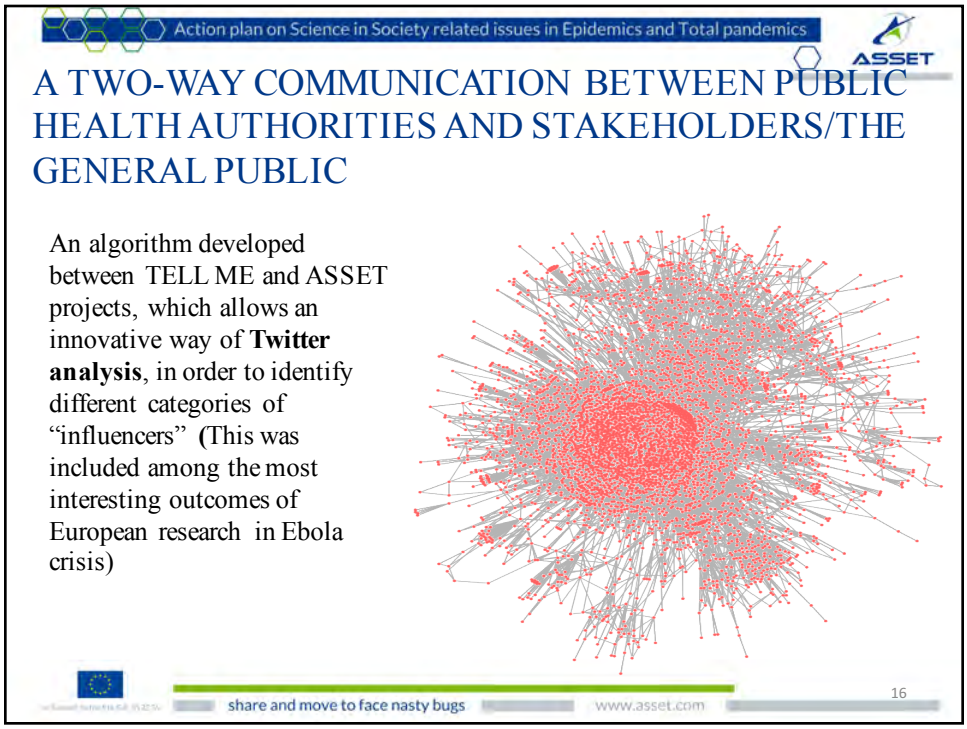
INCIDENCE, SEVERITY, AND IMPACT OF INFLUENZA 2016
JANUARY 21, 2016 - 09:00
17TH INTERNATIONAL CONGRESS ON
Raising awareness on gender issues in epidemics and pandemics
FRIDAY, DECEMBER 18, 2015 - 18:56
The consideration of sex and gender are not the most obvious issues that come to mind when discussing epidemics and pandemics. However, sex and gender have an important impact on these issues, since barriers to pandemic preparedness and risk behaviour can often be better understood when viewed from a sex and gender perspective.
Both gender and sex have an impact on experiences and behaviours relating to pandemics,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A TWO-WAY COMMUNICATION BETWEEN PUBLIC HEALTH AUTHORITIES AND STAKEHOLDERS/THE GENERAL PUBLIC
An algorithm developed between TELL ME and ASSET projects, which allows an innovative way of **Twitter analysis**, in order to identify different categories of "influencers" (This was included among the most interesting outcomes of European research in Ebola crisis)
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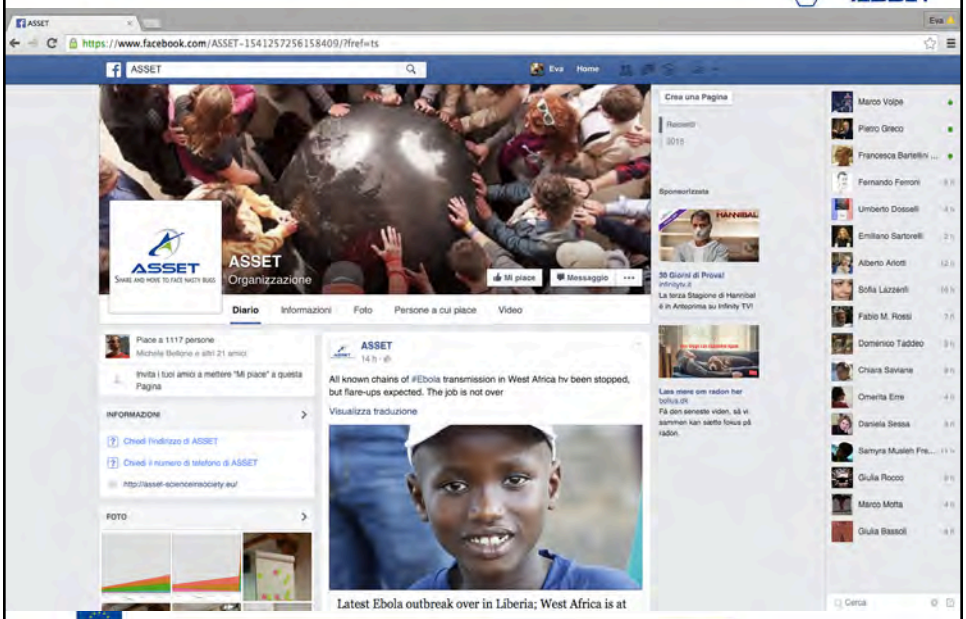
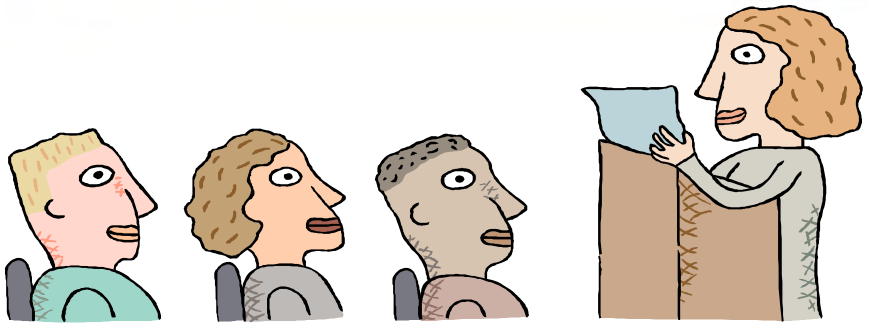


ASSET TOOLS

- The results of ASSET project **transnational citizens' consultations**
- Other activities within the project aim to **involve stakeholders** and the general public through different interventions in schools, cultural events and so on
- ASSET **website (http://www.asset-scienceinsociety.eu/)**
- **New social media analysis and contents production**
- An Action Plan handbook written to advice on open and **responsible research** and **communication** in pandemics
- **An active network with a new philosophy about the risk and crisis communication: mobilization and mutual learning**



THANK YOU FOR YOUR ATTENTION

benelli@zadig.it

A strengthened European framework on health security:

New Decision 1082/2013 EU on serious cross-border threats to health

LÜKEX 2013
27-28 November 2013

1998	• **Decision 2119/98/EC of the European Parliament and of the Council**
2001	• **EU Health Security Committee** (informal)
2005	• **European Centre for Disease Prevention and Control** • Surveillance • Threats and risk assessment
2007	• **International Health Regulations (IHR)** • All-inclusive threats approach; core capacities

2009	• **Lisbon Treaty** – Article 168 – Monitoring, early warning of and combating serious cross-border threats to health
2011	• Commission's **legal proposal** of serious cross-border threats to health
2013	• **Approval** of the proposal by the co-legislators
Future	• **Implementation** of the legal proposal: EU assessment and management of serious cross-border threats to health

Decision 1082/2013 EU

on serious cross-border threats to health of 22 October 2013

- In force since 6 November 2013

Main elements of the Decision

Broader scope

- Threats of biological origin, including
  - communicable diseases, antimicrobial resistance, health care-related infections, non-communicable diseases caused by bio toxins or other biological agents,
- Threats of chemical origin
- Threats caused by environmental factors
- Threats of unknown origin
- Events which may constitute public health emergencies of international concern determined pursuant to the IHR (2005)

Preparedness and response planning

- Mutual information and consultation to strengthen preparedness by supporting coherence and common approaches
- Create a basis for Member States to put in place comparable preparedness plans

Joint Procurement

Establishment of a mechanism for joint procurement of medical countermeasures

Communicable diseases

- Decision 1082/2013/EU reflects the mandate of the ECDC given by its founding regulation and repeals Decision No 2119/98/EC
- ECDC will still provide the risk assessment of threats caused by communicable diseases and outbreaks of unknown origin
- Strengthened cooperation with WHO reporting mechanisms

Other serious cross border threats to health

Ad hoc monitoring
Put in place monitoring of threats only when they are notified and for the duration of the incident

Notification of alerts
Extended EWRS

Risk assessment
Use the Scientific Committees of the Commission

Crisis management
Health Security Committee for coordination of
- Public health response to all threats
- Risk and crisis communication

Emergency situations at Union level

Recognition of a situation of public health emergency to accelerate the process for marketing authorisation of vaccines and medicines.

Committees

- **Formalization of the Health Security Committee (coordinating role)**
  - Forum of consultation and coordination between the Member States
- **Committee on serious cross-border threats to health (regulatory function)**
  - Committee for the adoption of implementing acts


European Commission
Thank you for your attention.

Académie Diplomatique Internationale

1

1 -

2 -

ADI Historical Legacy

ADI Activities

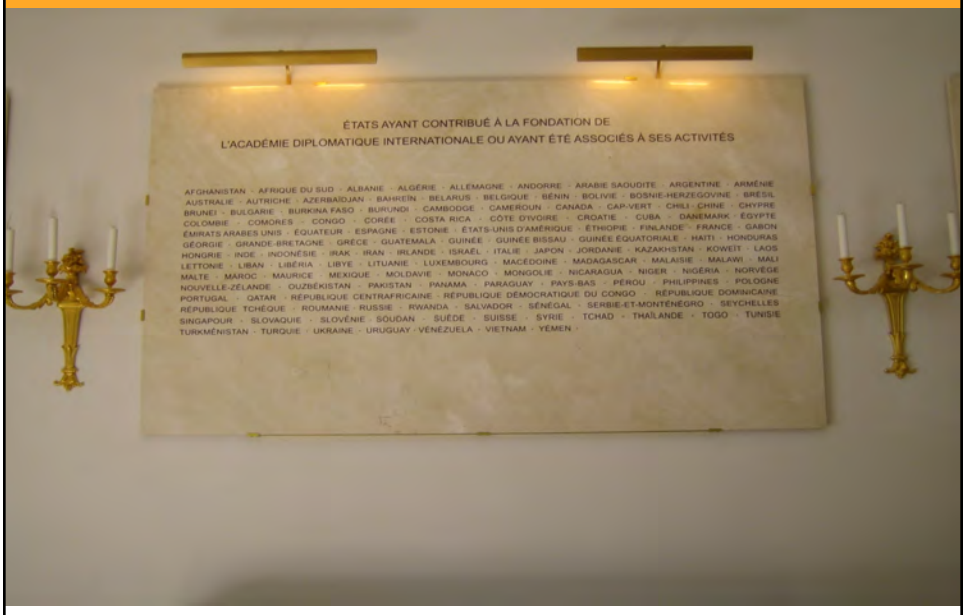
2

1- ADI Historical Legacy

- Prestigious past: Founded 1926
- Founders include Presidents, Prime Ministers and Diplomats
- Devoted to reflection and debate on global issues
- Publications and conferences of international consequence

3

1- ADI Historical Legacy



4

1- ADI Historical Legacy

New York Times
March 24, 1927

The New York Times

DIPLOMATIC ACADEMY IS OPENED IN PARIS

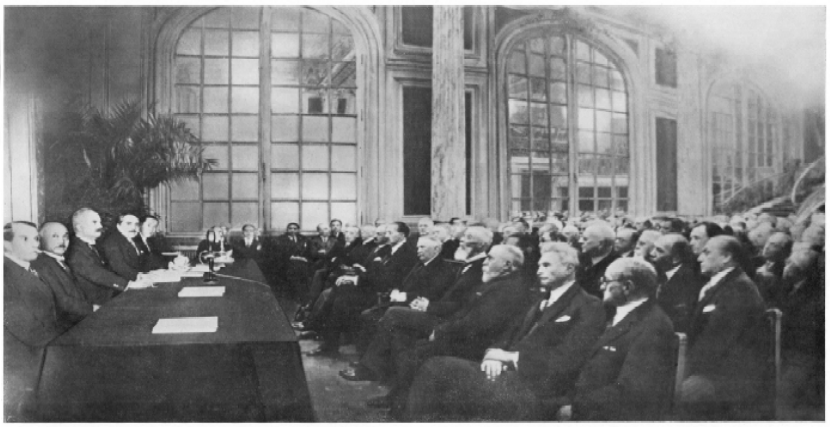
World Organization Is Composed of 150 Envoys Representing Sixty-four Nations.

1- ADI Historical Legacy

Inauguration of ADI offices
October 19, 1929

INAUGURATION DU NOUVEAU SIÈGE DE L'ACADÉMIE DIPLOMATIQUE INTERNATIONALE

(*L'Illustration* du 19 Octobre 1929)



Au Bureau (de gauche à droite) :
MM. GUERRERO, Président de la X^e^ Assemblée de la S.D.N., Vice-Président de l'Académie ;
ADATCI, Ambassadeur du Japon, Vice-Président de l'Académie ;
le Vicomte de FONTENAY, Président de l'Académie ;
FRANCOLIS, Secrétaire Général Perpétuel ;
TITULESCO, Ministre de Roumanie, Vice-Président de l'Académie ;

Au premier rang (de gauche à droite) :
MM. ALESSANDRI, Ministre du Chili ;
CÓRNEJO, Ministre du Pérou, Délégué au Conseil de la S.D.N. ;
FRANÇOIS-PONCET, Ministre des Beaux-Arts et de l'Enseignement Technique ;
le Comte SKRZYNSKI, Ancien Président du Conseil de Pologne ;
S. Exc. GASTON DOUMERGUE, Président de la République Française ;
le Comte ALBERT APPONYI ;
le Sénateur GASTON MENIER ;
SPALAIKOVITCH, Ministre de Yougoslavie ;
CARLOS MANUEL DE CESPEDES, Ministre de Cuba ;

Au deuxième rang (de gauche à droite) :
MM. LOUDON, Ministre des Pays-Bas ;
VILLEGAS, Ambassadeur du Chili ;
le Prince ARFA, Ambassadeur de Perse ;
le Prince FARROUKH, Président en exercice du Conseil de la S.D.N. ;
le Comte ERSERSVARD, Ministre de Suède ;
PUSTA, Ministre d'Esthonie ;
HOLSTIA, Ministre de Finlande, etc.

1- ADI Historical Legacy

ADI initial Board was composed of leading political figures of the era

Latin America

J. G. Guerrero
Vice-President
El Salvador

Eastern Europe

N. Titulesco
Vice-President
Romania

Western Europe

A. F. Frangulis
Secretary General
Greece

North America

R. Dandurand
Member
Canada

Asia

M. Adatci
Vice-President
Japan

1- ADI Historical Legacy

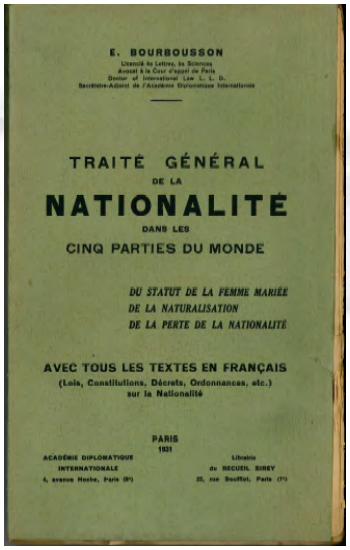
Original mission of the Académie Diplomatique Internationale : "Meet emerging needs brought by the intensity of international life"

"We have no connection with any government and we have no desire to impose our will on anyone"

J. G. Guerrero
First ADI Vice-President

- ➔ To "promote peace and respect for international law"
- ➔ To "study quietly and dispassionately the international maladies which place peace constantly in the balance"
- ➔ To "encourage cooperation and understanding among member states"

1- ADI Historical Legacy


E. BOURBOUSSON

TRAITÉ GÉNÉRAL DE LA NATIONALITÉ DANS LES CINQ PARTIES DU MONDE

DU STATUT DE LA FEMME MARIÉE
DE LA NATURALISATION
DE LA PERTE DE LA NATIONALITÉ

AVEC TOUS LES TEXTES EN FRANÇAIS
(Lois, Constitutions, Décrets, Ordonnances, etc.)
sur la Nationalité

PARIS
1931

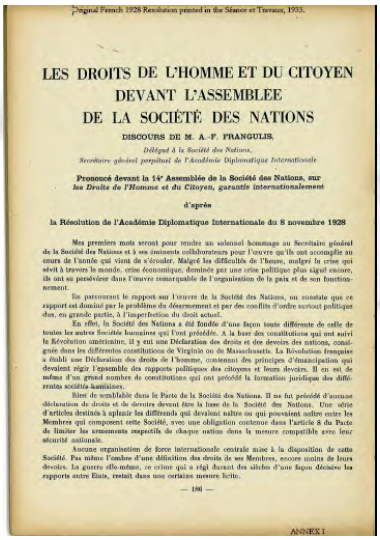
ACADÉMIE DIPLOMATIQUE INTERNATIONALE
Librairie du RECUEIL SIREY

A "Diplomatic laboratory":

First Report on legal status of women around the world

1- ADI Historical Legacy

League of Nations November 1933


Original French 1928 Resolution printed in the Séance et Travaux, 1933.

LES DROITS DE L'HOMME ET DU CITOYEN DEVANT L'ASSEMBLEE DE LA SOCIÉTÉ DES NATIONS

DISCOURS DE M. A.-F. FRANGULIS.

Délégué à la Société des Nations,
Secrétaire général perpétuel de l'Académie Diplomatique Internationale

Prononcé devant la 14e Assemblée de la Société des Nations, sur les Droits de l'Homme et du Citoyen, garantis internationalement

d'après

la Résolution de l'Académie Diplomatique Internationale du 8 novembre 1928

Mes premiers mots seront pour rendre un solennel hommage au Secrétaire général de la Société des Nations et à ses éminents collaborateurs pour l'œuvre qu'ils ont accomplie au cours de l'année qui vient de s'écouler. Malgré les difficultés de l'heure, malgré la crise qui sévit à travers le monde, crise économique, dominée par une crise politique plus aiguë encore, ils ont su persévérer dans l'œuvre remarquable de l'organisation de la paix et de son fonctionnement.

En parcourant le rapport sur l'œuvre de la Société des Nations, on constate que ce rapport est dominé par le problème du désarmement et par des conflits d'ordre surtout politique dus, en grande partie, à l'imperfection du droit actuel.

En effet, la Société des Nations a été fondée d'une façon toute différente de celle de toutes les autres Sociétés humaines qui l'ont précédée. A la base des constitutions qui ont suivi la Révolution américaine, il y eut une Déclaration des droits et des devoirs des nations, consignée dans les différentes constitutions de Virginie ou de Massachusetts. La Révolution française a établi une Déclaration des droits de l'homme, contenant des principes d'émancipation qui devaient régir l'ensemble des rapports politiques des citoyens et leurs devoirs. Il en est de même d'un grand nombre de constitutions qui ont précédé la formation juridique des différentes sociétés humaines.

Rien de semblable dans le Pacte de la Société des Nations. Il ne fut précédé d'aucune déclaration de droits et de devoirs devant être la base de la Société des Nations. Une série d'articles destinés à aplanir les différends qui devaient naître ou qui pouvaient naître entre les Membres qui composent cette Société, avec une obligation contenue dans l'article 8 du Pacte de limiter les armements respectifs de chaque nation dans la mesure compatible avec leur sécurité nationale.

Aucune organisation de force internationale centrale mise à la disposition de cette Société. Pas même l'ombre d'une définition des droits de ses Membres, encore moins de leurs devoirs. La guerre elle-même, ce crime qui a régi durant des siècles d'une façon décisive les rapports entre Etats, restait dans une certaine mesure licite.

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ANNEXE I

"The rights of men and citizens"

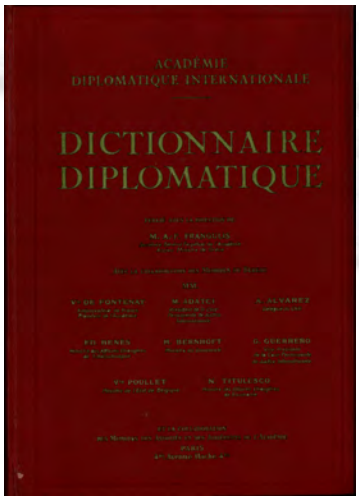
➔ This document represents the first appeal of the 20th century for the protection of individual rights

➔ The project was approved by ADI on November 8, 1928

➔ And presented before the 14th Meeting of the League of Nations in November 1933

1- ADI Historical Legacy

Publication of the Dictionnaire Diplomatique
8 volumes, 1933-1972



LE FIGARO

4 Septembre 1933

LE DICTIONNAIRE DIPLOMATIQUE

Il est des dates qui, dans la vie des hommes comme dans celle des sociétés et des grandes assemblées, constituent une étape décisive. Elles marquent. Tel a été le cas pour la séance solennelle qu'a tenue le 11 juillet dernier l'Académie diplomatique internationale devant une salle comble et qui réunissait l'élite du monde diplomatique et scientifique.

Le vicomte de Fontenay, l'éminent président de l'Académie, présentait, en effet, au gouvernement français et à tous ses collègues, le *Dictionnaire Diplomatique*, véritable travail de bénédictin, chef-d'œuvre d'érudition et de documentation, publié sous la direction de M. Frangulis, secrétaire perpétuel de l'Académie, qui y a consacré sept années et a ainsi élevé un véritable monument, selon la propre expression du chef du gouvernement français, M. Edouard Daladier.

ADI Archives

The ADI has been revitalized under the leadership of His Highness the Aga Khan as president and Jean-Claude Cousseran as Director General.

2- ADI Activities

- Training
- Conferences
- Projects

Académie Diplomatique Internationale

2- ADI Activities

TRAINING PROGRAM

ADI training programs are organized in partnership with major institutions

in partnership with

Liberté • Égalité • Fraternité
RÉPUBLIQUE FRANÇAISE
MINISTÈRE DES AFFAIRES ÉTRANGÈRES ET EUROPÉENNES

ORGANISATION INTERNATIONALE DE LA FRANCOPHONIE

CBRN Centres of Excellence
An initiative of the European Union

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Académie Diplomatique Internationale

2- ADI Activities

CONFERENCES

Designed to provide the international community with an opportunity for reflection, debate and exchange on major issues related to public and foreign policy

- ➔ TRIBUNES
- ➔ DÉBATS
- ➔ RENCONTRES
- ➔ ROUNDTABLES

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2- ADI Activities

FORUM FOR NEW DIPLOMACY

The *Forum for New Diplomacy* is a joint initiative of the Académie Diplomatique Internationale and the *International New York Times*

Kofi Annan, Former Secretary General, United Nations
November 17, 2008
Académie Diplomatique Internationale

FORUM
FOR NEW DIPLOMACY

Senior journalists from the *International New York Times* engage at the *Forum for New Diplomacy,* leading figures in politics, business and civil society, in a discussion on major issues of global concern.

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2- ADI Activities

ADI New Diplomacy Research Projects

The research projects are meant to foster dialog among different stakeholders and derive best practices and guidelines.
The idea is to build trust and good working relationships across sectors

- ➔ **International Justice & Diplomacy**
- ➔ **Internet & Diplomacy**
- ➔ **Protecting Cultural Patrimony**

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BRIEFINGS

The Briefings are events developed in partnership with relevant institutions focusing on issues

SERIES ON HEALTH CRISIS

EBOLA: POLICY RESPONSES TO MEDICAL THREATS
Speaker: Ismail Ould Cheikh Ahmed, Special Representative of the UN Secretary General

BATTLING EPIDEMICS WITH BIG DATA
Speaker: Caroline Buckee, Associate Director, Harvard Center for Communicable Disease Dynamics

EBOLA & MOBILE TECHNOLOGY:
Speaker: Erik Wetter, Co-founder and Chairman, Flowminder

Institut Pasteur-Paris
Ebola Crisis Series-2014

17

BRIEFINGS

SERIES ON EBOLA CRISIS

INSTITUTIONAL PARTNERS

Institut Pasteur

UNMEER

MEDIA PARTNER

International New York Times

18

Académie Diplomatique Internationale

2- ADI Activities

Possible Synergies with New Diplomacy Projects & Events

SCOPE:

Bring together
-health community, scientists, representatives of pharmaceuticals and
-high level policy-makers, civil society organizations and the international community based in Paris
In order to advance cooperation and reflection on pandemic issues

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Académie Diplomatique Internationale

ADI 2016

The Diplomatic Community attending a conference in the Grand Salon of the Académie Diplomatique Internationale

Académie Diplomatique Internationale

4bis avenue Hoche, 75008 Paris
Tél. 01 42 12 82 50 – Fax. 01 42 12 82 51
www.academiediplomatique.org

ASSET

share and move to face nasty bugs

Project infrastructure
THE ASSET COMMUNITY OF PRACTICE

Copenhagen 15/01/2016

Eva Benelli- Zadig

www.asset-scienceinsociety.eu

co-funded by the EU. GA: 612236

ASSET

The ASSET CoP (Community of Practice)

OBJECTIVES

- ✓ To create a virtual, interactive platform for dialogue
- ✓ To connect different universes (stakeholders)
- ✓ To encourage transfer of knowledge
- ✓ To develop new ideas
- ✓ To reframe problems

➢ **To find original solutions**

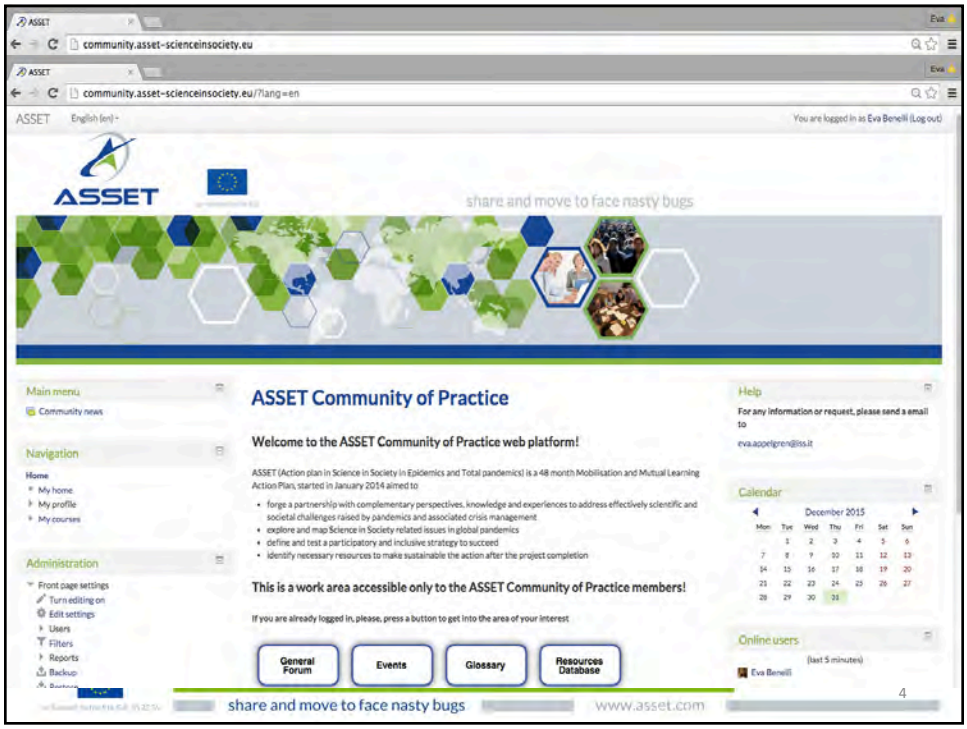
METHODS

- ◆ **CoP (Asset Community of Practice)**

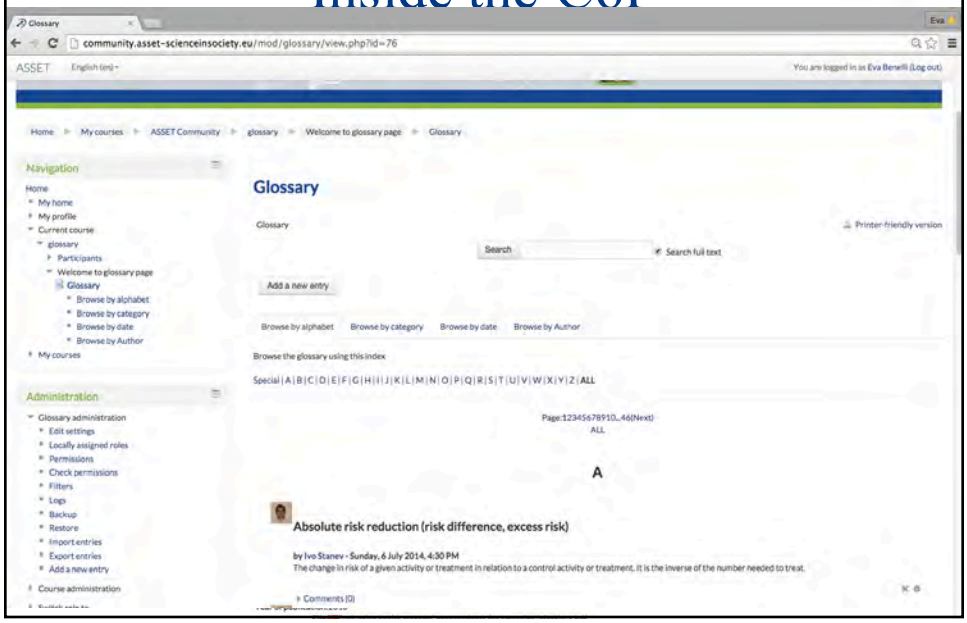
- ✓ Open source software (moodle)
- ✓ General and specific forums for self organized discussion process
- ✓ Custom settings
- ✓ Several tools (resources database, events calendar, work in progress areas, check list and rapid surveys…)
- ✓ Daily report
- ✓ A CoP tutor (Debora Serra)

http://community.asset-scienceinsociety.eu/

- The CoP is a **reserved area** accessible only to the **invited** members
- It's **our internal** communication and sharing tool
- is also our starting point for **external** communication



Inside the CoP

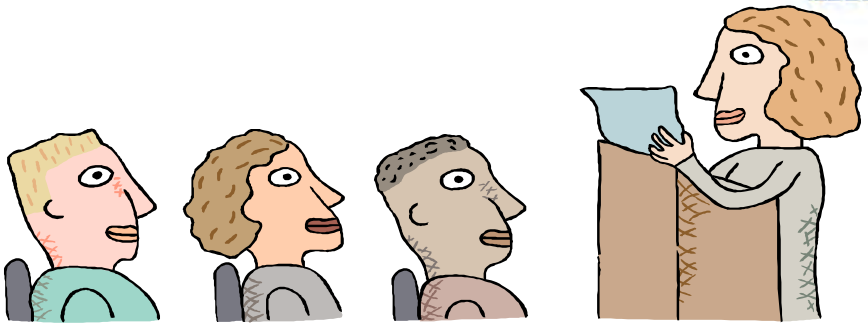


Use of the CoP

As the DoW reminds us: "the main goal is to facilitate a **transparent** and **participatory** discussion, allowing multi-actor cooperation and transfer of knowledge among partners and stakeholders".

Even just-following conversations is important. If some information is not immediately useful, it can be useful later.

It 's something like a conversation at the coffee machine: someone speaks, others listen, but **all are part of the group**.



THANK YOU FOR YOUR ATTENTION

benelli@zadig.it

Can citizens be included in epidemic preparedness and response? Yes, and they demand to be!

More than 400 citizens were consulted on epidemic preparedness and response in late September across Europe. The citizens expressed a demand for more transparency and dialogue in both epidemic response and planning, while at the same time they provided policy-makers with thought-provoking insights with the other as; the Internet being the least trustworthy source of information yet the first source citizens consult.

By John Haukeland, Project manager at The Danish Board of Technology

In the wake of the 2009-2010 H1N1-pandemic (the swine flu) a web of mistrust between the public and health authorities was spun. National pandemic plans were usually based on a single scenario that was more severe than the actual 2009 pandemic, and that was extrapolated from the severity of previous outbreaks like SARS and Avian flu (See Box1).

	SARS	Avian flu	Swine flu
Transmissibility	Moderate	Human to Human rare	High
Estimated death rate	10%	60%	<0,03%
Deaths (global)	774	393	18,500
At-risk groups	Older adults, those with underlying health problems	All	Initially, infants, pregnant women, those with underlying health problems; later waves affected older people more

In effect the 2009 pandemic was nicknamed the false-pandemic or 'the pandemic there never was'. However, national health authorities had declared a pandemic and bought vaccines for billions.

The ASSET-project should be EU's counter to this by engaging citizens in the debate of pandemic crisis prevention and management.

Method

The Danish Board of Technology (DBT) was asked to develop and test a participatory and inclusive method for engaging citizens. The method should convince the EU that citizen participation can be done within a field normally dominated by technical experts.

In fact, epidemic response and planning has clear normative components, involving obvious conflicts and dilemmas, combined with a well-documented scientific knowledge base, and a need for political action in the crisis situation and fulfilling all conditions for citizen participation.

We decided to develop a multi-site method, where the citizens received the same information prior and during the consultations at the same time across Europe. Their votes were reported in-real-time into a webtool, were all the results can be seen and analyzed. See Box2 for more information.

ASSET Citizen Consultation

- 8 consultations across Europe
- 400 citizens engaged, with 50 representative sampled citizens at each site
- They provided informed opinions differentiating it from a poll. The received a booklet in their native language prior to the event, saw brief information videos during the events, and discussed an hour with other lay citizen in small groups before voting on pre-defined questions
- The last session was an open session where citizens in their native language could write recommendation or comments to policy-makers.

For more information visit our website here

Results

The citizen were very satisfied with the process, and provided policy-makers with clear demands and thought-provoking insights.

96% were satisfied with the process

While most analytical work still remains some trends are already now striking.

94% would like the process to be repeated on different or similar issues

The citizens want more transparency in the work of health authorities, and are not satisfied with the level of information provided during epidemic threats. Actually less than half of the citizens are confident with information being withheld, even for security reasons by health authorities. Same goes for the satisfaction level during an epidemic threat.

81% would like public health authorities to collect more information from citizen during threats

Source: ASSET Webtool

Figure 1: Result example from the webtool

Some of the more thought-provoking results from the consultation included vaccination and information channels. While half of the citizens found mandatory vaccination as an appropriate tool for public health authorities during epidemic threats, more than eight-of-ten answered that it should be mandatory for health care workers. This discrepancy is very interesting, and we will in the upcoming policy-workshop go more into detail. As mentioned in the lead paragraph, an insight that policy-makers cannot overlook is that the citizen deems the internet as the least trusted information channel, and yet it is the one they consult first. Research has showed that even if this insight, information read online has a subconscious effect on decision-making.

Finally, we organized an open session where the citizens were asked to write policy recommendations in their native language. In addition to their recommendations, they were asked to encircle the most important words from their policy recommendations. The words have been translated and mapped according to the citizens' priorities (Figure 2) through a co-hashtag analysis. What we can see from Figure 2 is that 'information', 'transparency' and 'citizens' are very central in the map, and important to the citizens. By investigating the full recommendations behind the keywords, we can explore the context behind the most popular recommendation. This analysis will be further developed in the months to come, by the DBT's research assistant Wafa El Ghiouane, who can be contacted if you want to know more about the analysis.

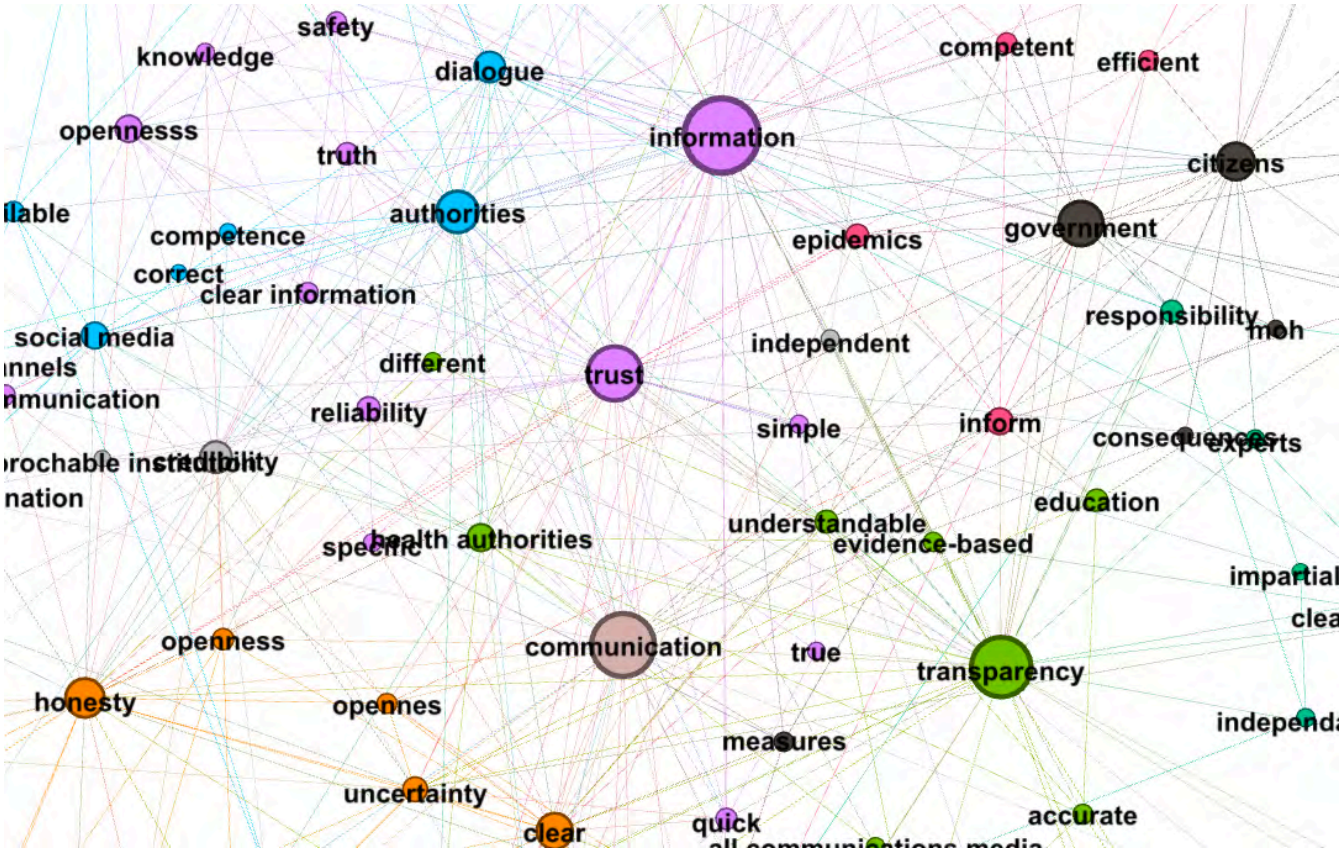


Figure 2: Co-hashtag analysis of policy recommendations

Way forward

The ASSET-project is a 4-year project, which will end in 2017. The citizen consultations and the high-level policy forum, which TIEMS facilitate, will be two of the most important legacies.

In the next months we will pen a policy report, which we will present for decision-makers in Europe at several events and policy-seminars during the next years.

Follow the ASSET web-site for more updates.

Ethics in influenza pandemic planning

by Eva Benelli & Alessandra Craus

Zadig S.r.l (www.zadig.it)

Abstract

This work evaluates the relevance and the application of ethical principles in the development of national pandemic plans. A semantic analysis on ethical issues was conducted of eleven national influenza pandemic plans (10 from European Union (EU) member states (MS) and one from Switzerland), including EU and WHO documents.

The semantic analysis showed a lack of discussion on ethical issues in most European pandemic plans. This work may encourage the discussion on the necessity to update all national influenza pandemic plans in order to include ethical issues.

1. Introduction

Influenza pandemics are unpredictable but recurring events that can have severe consequences on human health and socio-economic life to global level. For this reason, the World Health Organization (WHO) has recommended all countries to prepare a pandemic influenza plan and to keep them constantly updated, following its own guidelines [1].

The WHO guidance – revised in 2009 to help policymakers to balance individual and community interests when dealing with national influenza preparedness plans – stresses the importance of ethical principles such as equity, utility/efficiency, liberty, reciprocity and solidarity. Any measure that limits the individual rights and civil liberties (such as isolation and quarantine) must be necessary, reasonable, proportional, equitable, not discriminatory, and not in violation of the national and international laws.

For such purposes, WHO has developed a framework of detailed ethical considerations, in order to ensure that overall concerns (such as protecting human rights and the special needs of vulnerable and minority groups) are addressed in pandemic influenza planning and response [2]. In 2008, WHO published another document aimed at providing a more comprehensive analysis of the ethical and policy issues [3], and emphasizing that every public health interventions must be implemented within the context of internationally recognized human rights, according to the Siracusa Principles [4].

WHO has highlighted that guidelines included in these documents should be used from all countries to develop or update national influenza preparedness and response plans, in conjunction with the WHO checklist for influenza preparedness planning published by WHO in 2005 [5].

Experts from the ASSET project conducted a study on this issue, performing a semantic analysis of national pandemic plans developed by ten European Union/European Economic Area (EU/EEA) countries (Austria, Croatia, Czech Republic, France, Hungary, Iceland, Ireland, Italy, Spain, United Kingdom) and one by Switzerland, member of European Free Trade Association (EFTA), including EU

and WHO documents [6]. All documents were accessed through the ECDC official website, whenever a translation in English was available [7].

2. Methodology

The semantic analysis was based on two keyword lists: in a first, generic list, keywords represent areas of possible ethical interest; in a second, more specific list, keywords are more precisely related to ethical issues actually addressed in each one of the national plans.

Aim of the research was to assess and compare the occurrence rates of each keyword within both lists, in order to evaluate the relevance of ethical issues and the application of ethical principles in the development of national preparedness and response plans.

The results of the semantic analysis are shown through data visualizations that allow to describe a complex theme and to share it easily on the web in graphics [6].

3. Results

ASSET analysis shows that ethical issues have not been addressed in most national influenza pandemic plans. They are mentioned in some, like in the Italian and Spanish, while ethical concerns have been discussed more extensively in the French, English, Swiss and Czech pandemic plans. However, only UK, France and Switzerland dedicated a specific section – also included in the index – to ethical questions as regards the management of an influenza pandemic.

In all national plans examined, there are issues which are considered ethical. For instance, in the list of keywords generically connected to ethics, the words *isolation* and *quarantine* are mentioned in all documents examined, but mostly as measures aimed at limiting the spread of the disease. However, only some of the plans consider the ethical implications of these measures which limit personal freedom, such as the necessity of a transparent communication and the respect of personal needs and human rights.

Similarly, the word *borders* would also require ethical consideration, especially when a document states that an individual coming from a country at risk should be subjected to screening, facing, for example, the risk of stigma. Although the particular human rights may be limited in exceptional circumstances, the focus on the dignity of the human being must always be a priority [6].

4. Discussion

The semantic analysis of a number of national influenza pandemic management plans in Europe showed little concern for ethical aspects and a lack of true discussion of ethical issues in most with the exception of the UK, French, Swiss and Czech plans [6].

The relative abundance of national guidelines, international policy documents, technical reports and scientific papers that discuss fundamental rights issues and different types of ethical considerations in pandemic preparedness and response reveals the importance and the need to place those issues in the right context and the right proportions.

Beyond WHO guidelines and documents, the CDC has also developed ethical guidelines in 2007, as a foundation for decision making in preparing for and responding to pandemic influenza. In these, the Ethics Subcommittee in a first section addresses general ethical considerations and in a second section

deals with particular ethical issues in pandemic influenza planning such as social distancing and restrictions on personal freedom procedures [8].

The Forum on Microbial Threats of the US Institute of Medicine (IOM) in 2007 has prepared a workshop summary on Ethical and Legal Considerations in Mitigating Pandemic Disease, highlighting that many of the proposed disease mitigation strategies may have unintended ☐ and often undesirable ☐ consequences, such as adverse economic effects or the restriction of civil rights and civil liberties. Through this meeting, participants explored lessons learned from past pandemics, identified barriers to equitable and effective responses to future pandemics, and examined opportunities to overcome these obstacles through research, policy, legislation, communication, and community engagement [9].

On April 2015 in the framework of the EU co-funded project ASSET, experts published an *Ethics, law and fundamental rights report*, for contributing to the accomplishment of a major objective of the ASSET project, which is the establishment of baseline knowledge on Science-in-Society related issues about pandemics. This report identified and drew attention to the various ethical, legal and fundamental rights implications in situations of public health emergencies, such as epidemics or pandemics.

Ethical considerations should not be seen as part of a problem, but rather as part of a solution with shared values for both individuals and key stakeholder groups within society. Policy and decision makers should take into account ethical considerations to inform and colour all aspects of pandemic planning for preparedness and response. More importantly, national governments and local authorities should strive to cultivate a "culture of ethics" across the entire spectrum of societal actors and stakeholders who are likely to be involved – and make or act upon decisions – at different phases of a pandemic [10].

But despite awareness of the relevance of ethical issues, they are still underestimated in national influenza pandemic plans. In fact, our study shows that some of them, like the Italian and Spanish plans, just mentioned them while other MS plans discussed them in more details.

Only 4 national plans (United Kingdom, France, Switzerland and Czech Republic) among those available in English on the ECDC website, have a dedicated section to this topic, including ethical issues among the main principles of a pandemic management plan. This is even more relevant since the analysis revealed multiple areas of possible ethical interest within the different plans, as data visualisations have clearly demonstrated.

This analysis has some limitations, such as the inability to examine all EU/EEA MS national pandemic plans as they were not all available in English and the fact that not all pandemic plans examined are updated in accordance with WHO guidelines revised in 2009. Also, this semantic analysis has used some keywords that are not always matching with the context in which they may occur in the documents examined.

Despite these limitations, however, this work may represent a useful tool to guide future development of influenza pandemic plans. Exceptional circumstances such as public health emergencies in case of epidemics and pandemics must not provide a reason for planners and policy makers to ignore fundamental human rights and ethical issues that can arise at different phases of a pandemic. It aims at

encouraging discussion on the necessity to update all national pandemic plans in order to properly address ethical and other SiS issues, such as gender and participatory governance, which have also proved to be of great relevance in case of epidemics and pandemics [6].

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Vaccine Refusal Revisited — The Limits of Public Health Persuasion and Coercion

James Colgrove, Ph.D., M.P.H.

In recent years, vaccine refusal and associated declines in herd immunity have contributed to numerous outbreaks of infectious diseases, consumed public health resources, and provoked increasingly polarized debates between supporters and opponents of vaccines. Although the prominence of the Internet as a forum for information and misinformation has given these conflicts a distinctly 21st-century character, they have deep historical roots. Many of the scientific, ethical, and political challenges that physicians and public health officials face today in dealing with vaccine refusal would be recognizable to their counterparts of previous eras. The heart of their task entails balancing the use of coercive and persuasive approaches.

Coercion is the older tradition in public health. During the 19th century, many states and localities passed compulsory-smallpox-vaccination laws covering both children and adults. These laws were of a piece with an expansive network of public health regulations that arose in that era concerning practices such as quarantine, sanitation, and tenement construction. Vaccination laws imposed various penalties, including exclusion from school for unvaccinated children and fines or quarantine for adults who refused vaccination. The effectiveness of the laws was soon demonstrated — jurisdictions with them consistently had fewer disease outbreaks than those without — and their constitutionality was upheld in numerous court challenges that culminated in the 1905 Supreme Court case of *Jacobson v. Massachusetts*.

The use of coercion has always raised concerns about state intrusions on individual liberty and the scope of parental control over child-rearing. Compulsory vaccination laws in the 19th century typically contained no explicit opt-out provisions. Today, all states offer medical exemptions, and almost all offer religious or philosophical exemptions. Nevertheless, even a law with an opt-out provision may exert a coercive effect, to the extent that the availability of the exemption may be limited and conditional and the consequence of the law is to make the choice to withhold vaccination more difficult (if only marginally so) for the parent. These laws continue to be the target of antivaccination activism.

Persuasion became an important part of the public health tool kit in the 1920s, with the rise of modern forms of mass media. Health professionals began to draw on techniques from the emerging fields of advertising and public relations to sell people on the importance of childhood immunization against diphtheria and pertussis. Such appeals began to acquire a more scientific basis in the 1950s, after the development of the polio vaccine, when sociologists, psychologists, and other social scientists began to identify the attitudes, beliefs, and social contexts that predicted vaccine-related behaviors. Their efforts brought increasing theoretical and empirical rigor to the study of why people accepted or declined vaccination for themselves and their children, and health professionals used these insights to develop approaches to increase uptake of vaccines, such as enlisting community opinion leaders as allies.[1] Persuasive approaches, because they are less restrictive, are ethically preferable and more politically acceptable, but they are also time consuming and labor-intensive, and evidence indicates that by themselves they are ineffective.

Vaccine refusal has been a heterogeneous phenomenon reflecting a diverse and complex array of attitudes and beliefs, including mistrust of medical and scientific elites, resistance to government authority, and adherence to "natural" or alternative health belief systems. Although religion-

based objections have made up a relatively small part of the overall picture of vaccine refusal, Christian Scientists have been very vocal in their opposition, and some of the most severe disease outbreaks in the United States in recent decades have occurred among isolated or tightly knit religious communities that have spurned vaccination (see the report by Gastañaduy et al. in this issue of the *Journal* on measles in an Amish community in Ohio [pages 1343–54]). The prominence of antivaccination views in public discourse has waxed and waned since the 19th century; eras in which vaccine critics remained on the fringe have alternated with eras in which their ideas enjoyed wide exposure. Our current era is one of the latter.

Today, immunization proponents are attacking the problem of refusal by honing the effectiveness of both persuasive and coercive approaches. Continuing the work begun by social scientists in the 1950s, they are seeking to develop a more nuanced understanding of the phenomenon of vaccine hesitancy — the term given to the spectrum of behaviors that include reluctant, selective, or delayed vaccination as well as refusal of all vaccines — in order to more precisely identify its underlying motivations. A better understanding of these beliefs is a critical step in crafting more effective messages that can be delivered through media channels or in one-on-one encounters with health care workers.

Progress on this front has been mixed. One study demonstrated that relatively subtle alterations in provider communication styles could produce considerably more acceptance among vaccine-hesitant parents during pediatric visits.[2] In contrast, another study testing a variety of fact- and emotion-based messages to counter hesitancy found that all were ineffective and could even be counterproductive.[3] Because of the complexity of vaccine hesitancy and the many biases and heuristics (cognitive shortcuts) that people use to assess and make decisions about risk, it's challenging to use persuasive approaches, and few such interventions have been clearly demonstrated to be effective.[4]

A more promising way forward can be found in the tools of the law. Many immunization proponents also advocate for strengthening compulsory-vaccination laws to narrow the circumstances under which parents may refuse to have their children vaccinated and to make it difficult or impossible for them to claim exemptions on religious or philosophical grounds. In what may prove to be an important bellwether, California eliminated nonmedical-exemption provisions in 2015, becoming only the third state in the country without them.[5] Various health professional groups have recommended that other states follow suit.

Some immunization proponents have argued convincingly that states should retain nonmedical exemptions to avoid inflaming the resistance of antivaccination activists and that legislators and health officials should proceed carefully as they press for change. Nevertheless, vaccination laws have a proven track record over more than two centuries, and strengthening them will probably be the most effective means of achieving higher immunization rates in both the short and long terms. Even the most well-crafted persuasive appeals cannot achieve the nearly universal vaccine uptake needed to maintain herd immunity for highly contagious diseases such as measles.

Both persuasion and coercion are necessary, and neither is sufficient. Laws serve as a critical safety net as well as a powerful symbolic statement of proimmunization social norms. Education and persuasion are needed to maintain public understanding of the value of vaccines and trust in health professionals, both of which are essential to securing compliance with laws. The melding of the two approaches — along with ensuring a stable, accessible, and affordable supply of vaccines for everyone who needs them — is the central challenge for vaccine policymakers. As has been the case since the 19th century, effectiveness, efficiency, ethics, and political acceptability all need to be balanced in a careful calculus.

Disclosure forms provided by the author are available at NEJM.org.

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TIEMS High-Level Policy Forum (HLPF) Focus Topic

Ethical Issues in Pandemic Preparedness

Background

The High Level Policy Forum contributes to ASSET's goal to bring Science-in-Society (SiS) issues into epidemic and pandemic preparedness by "…identifying and discussing important policy issues and examining how they can be improved….". One of the key SiS issues addressed by ASSET is the incorporation of **ethical** considerations in pandemic preparations and response.

To assess the extent that ethics is currently considered in EU pandemic preparation and response, ASSET performed an analysis of national pandemic plans from 10 countries of the European Union/European Economic Area and Switzerland. The report concluded that the national plans "… showed little concern for ethical aspects and a lack of discussion on ethical issues in most pandemic plans from European countries, except for Switzerland, United Kingdom, Czech Republic, and France."

Discussion and Questions

We would like to now initiate a discussion within the HLPF, on the issue of incorporation of ethical considerations in pandemic preparation and response. We would like to start the discussion by asking each HLPF member to comment on the following questions/topics presented on the ASSET Community of Practice (CoP) website:

1. How have the following topics been addressed (or not addressed), in the pandemic plans associated with your nation or region?
    a. Allocation of scare resources, such as diagnostic laboratory testing, influenza vaccines, or antiviral drugs
    b. Compulsory vaccination
    c. Limiting personal freedom through isolation and quarantine
    d. Use of human subjects in research
    e. Other considerations?
2. Do you believe your current plans adequately address ethical issues? What changes do you believe should be made?
3. Would it be appropriate to incorporate international guidelines (e.g., the WHO Checklist) into national pandemic plans? What mechanism do you recommend to enable this?
4. Can you recommend other approaches to improve consideration of ethical issues in pandemic planning across the EU?