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**Asset paper series**  
**Epidemics and Pandemics: The response of Society**

*Issue No. 6 October 2017*

**The role of citizens in times of  
an epidemic or pandemic**

John Haukeland.

- *Not how, but why citizens could be included in policies on public health?*
- *The role of citizens in epidemic preparedness and response.*

Rebecca Moore, John Haukeland, Lise Bitsch, Valentina Possenti

- *Views from the general public on communication and information in dissemination during a pandemic; results and experiences from the 2016 Irish citizen consultation.*

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## SUMMARY

This issue of the ASSET paper series, titled “The Role of Citizens in times of an Epidemic or Pandemic”, is dedicated to the discussion of citizen participation in the response to a public health crisis such as an epidemic and furthermore, to the role of citizens in shaping public health policy. Specifically, the articles included in this issue present information from two European countries, Denmark and Ireland, based on the experience of the relevant ASSET project partners, who organised a number of citizen consultations in their respective country.

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## Not how, but why citizens could be included in policies on public health?

by John Haukeland<sup>1</sup>

<sup>1</sup>*Danish Board of Technology Foundation, Copenhagen, Denmark*

In the ASSET project we have a participatory and inclusive approach to foster a partnership between science and society. Actually most of our communication focuses on how to increase citizen participation. In this editorial we will reflect on why we do it, and why you should do it!

In this editorial we will put forward three arguments for the value of citizen participation. It is a powerful tool to (1) bridge the gap between people and politics, (2) create robust solutions that meet society's needs and (3) more normatively citizens are the ones that will live with the consequences of the polices, and therefore deserves to participate.

### Bridging the gap between people and politics

You do not have to be a professor in current affairs to realise that a rift exists between the public and politics. A number of prominent commentators have highlighted last year's Brexit vote and the election of multimillionaire Donald Trump as US President as a testimony to this. The anti-austerity movements across Southern Europe following the Global Financial Crisis add to this [1].

Citizen participation is a very powerful tool aiming to involve citizen in the political process, even if it presents complex challenges. Such engagements are attributed with building trust between citizens and authorities as well as empowering citizens to act in democracies [2].

With opinion polling seemingly unable to provide the public with reliable information on public opinion, particularly about complex societal challenges, citizen participation methods enable decision-makers to get exactly this, in an informed and near-representative manner. This empowers politicians to address society needs and concerns based on informed input from the public, rather than based on ever-changing opinion polls.



### Creating robust solutions that meet society needs

Ensuring that politicians and public authorities work for the public good requires informed, organised and active citizen participation. We are past questioning that citizens can contribute with just as significant and valuable input as professionals.



It is only citizens that can ensure that research & innovation truly respond to societal challenges and take into account the social and environmental consequences from the outset.

An acknowledgement hereto is the recent proliferation of participatory budgeting across Europe. With online public engagement methodologies paving the way Lisbon and Paris are noteworthy case-studies on how citizen are placed center stage at the political decision-making: the budget.

However, at the same time there is significant literature on how Non-Governmental Organizations (NGOs) and Civil Society Organizations (CSOs) can misrepresent citizens and be vested interest groups themselves.[3]

## They deserve it

Inasmuch as citizens will have to live with the decisions made about all from how to address climate changes and energy transition to policies on epidemic preparedness and response, we believe it would be only fair to consult them [4].

As mentioned above, it is not enough to include CSOs or NGOs in the decision process, as, at best, they do not represent the whole spectrum of opinions from citizens.

Finally, citizen participation should be regarded equally as a right, as well as an obligation of living in a democracy.

## Conclusions

Reading our editorial a reasonable question would be: are then all kinds of citizen participation beneficial? The answer is clear: No. Citizen consultation can in fact be counter-productive, if not organised properly. We know for example of town-hall meetings creating tension and fury, and people storming out [5].

We have elsewhere developed a ten-step guide before starting a citizen consultation, which is presented in Table 1. [6]

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<ol style="list-style-type: none"> <li>1. Be clear in your purpose and objectives from the outset.</li> <li>2. Start as early as possible in the policy/decision/research process.</li> <li>3. Create a culture of openness, transparency and participation.</li> <li>4. Have sufficient resources in terms of time, skills and funding.</li> <li>5. Cover both the aspirations and concerns held by the public, scientists in the public and private sector, and policy makers and involve as many perspectives as possible.</li> <li>6. Be clear about the extent to which participants will be able to influence outcomes.</li> <li>7. Ensure that policy makers and experts promoting and/or participating in the dialogue process are competent in their own areas of specialization and/or in the techniques.</li> <li>8. Employ techniques and processes appropriate to the objectives. Multiple techniques and methods may be used within an engagement process, where the objectives require it, including offline and online discussions where possible.</li> <li>9. Encourage collaboration, networking, broader participation and co-operation in relation to engagement with science and technology.</li> <li>10. Build in evaluation at every stage of your process.</li> </ol>
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Table 1. 10 step guide for organising citizen consultations



# The Role of Citizens in Epidemic Preparedness and Response

by John Haukeland<sup>1</sup>

<sup>1</sup>*Danish Board of Technology Foundation, Copenhagen, Denmark*

## Abstract

**Risk communication forms the basis of effective management of emergencies during epidemics or pandemics. It is an inherent and exceedingly important component of successfully combating uncertainties and fears during times of crisis. This paper will first explain the basics of risk communication and, second, identify and suggest potential methods and techniques that can be adopted in order to improve risk communication especially during times of pandemics and epidemics.**

## 1. Introduction

Health authorities face multiple challenges when responding to epidemic or pandemics threats. Often times they are faced with the challenge of making decisions in conditions of sparse and uncertain information, and available options for action are less than ideal. In addition, authorities struggle with disseminating information to relevant communities, and the spreading of rumors, parallel information systems, as well as the need to bridge gaps in cultures, traditions and understandings of health care practices. The ASSET (Action Plan of Science in Society related issues in Epidemics and Total pandemics) project aims at engaging citizens across Europe in epidemic preparedness and response, and at

delivering policy-options to European policy-makers. The ASSET Project is born in the wake of the H1N1 influenza pandemic in 2009-2010, which most of the citizens could remember.

In the framework of the ASSET project, eight day-long citizen consultations on policy options were organized in 8 countries across Europe, discussing issues in epidemic preparedness and response. For more than 100 young people taking part in the citizen consultations, this summer's debate on the Zika virus, or last year's Ebola epidemic were their main references.

## 2. Methodology

### The rationale for citizen participation

The citizen consultation has been instrumental to the ASSET project. It has answered the European Commission's (EC) call for inclusive and transparent participatory governance and improves citizen participation in epidemic and pandemic response and preparedness.

Two are the main central reasons for investing time and resources in citizen participation:

- Social robustness of scientific knowledge and improvement of health literacy to enable appropriate decisions;
- Transparency and Fairness.

When explaining the need for scientific knowledge to have a strong bond with society, Naubauer (2015) states that: "societal engagement should not only alter the face of research but also improve public confidence and support in research and innovation, lead to more creative and real-world inputs, improved policy decision making and the development of more



appropriate, effective and robust solutions for pressing issues”.

It is true for research and policy-making alike that in order to have the most robust results they need to engage the public, and to integrate societal needs in the process of innovation.

The second dominant argument for citizen participation is fairness: As citizens are the ones that are going to live with the consequences of policies it is only fair that they should be consulted in the process (Bedsted et al 2015). The latter has been furthered in democratic debate lately (for instance the Participatory Budgeting experiences across Europe, e.g. STOA 2017).

### Method

We developed and tested a participatory and inclusive method for engaging citizens in epidemic preparedness and response planning, a field normally dominated by technical experts. In fact, the field has very clear normative components, involving obvious conflicts and ethical dilemmas, combined with a well-documented scientific knowledge base, and a need for political action, which are ideal conditions for citizen participation.

We involved 425 citizens across Europe in day-long deliberations (in Bulgaria, Denmark, France, Ireland, Italy, Norway, Romania and Switzerland). The day was designed to take the citizens through the same discussions and questions at the same time across Europe.

For a detailed description of the methodology and the information material and questions posed to the citizens, please visit: <http://www.asset-scienceinsociety.eu/work-packages/citizen-consultation>

## 3. Results and Discussion

At a policy workshop in Copenhagen in November 2016, the partners of the ASSET project discussed the results of the European citizen consultations. The analysis below is based on this discussion.

The most striking result from the citizen consultation was that only 29 % of participants are satisfied with the information provided from public authorities during epidemic threats (Fig.1). The result is of course a huge problem for national public health authorities as well as European public health authorities. The consequences for risk communication are grave. Therefore, this can easily lead to mistrust towards public health authorities, and we can assume that this mistrust will challenge the advice from the public health authorities.

**Figure 1: ASSET Citizen Consultation questionnaire-1, 2016**



As argued in ‘the rationale for citizen participation’, this process leads to more socially robust solutions, for research and policy-making alike, because it integrates societal needs into policy-making in a democratic manner.

Our results highlight this as well, as >8/10 participants think that public health authorities should devote more resources to collect





information and input from citizens during epidemic / pandemic threats (Fig 2).

**Figure 2:** ASSET Citizen Consultation questionnaire-2, 2016

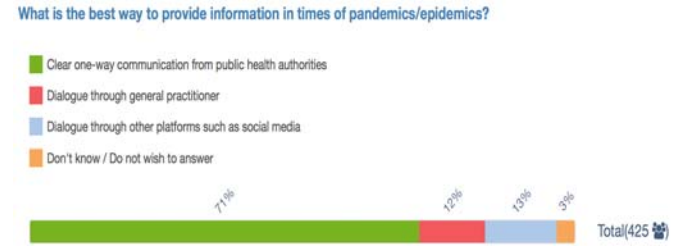


Citizen inputs could take many forms; some institutionalized as citizen panels on epidemic response issues or citizen participation in preparedness planning under the International Health Regulations (IHR); some could be more ad-hoc as this project has been or take the form of opinion polls on public health policies in Europe.

According to Bedsted et al (2015), in democratic and functional terms, policies will not work effectively if they do not enjoy public support.

However, there is an interesting paradox – and the last of our results that will be highlighted in this brief paper – that when asked: “What is the best way to provide information in times of pandemics/epidemics?” a staggering 71% of the participants in the ASSET Citizen Consultations believes in clear one-way communication from public health authorities to the citizens.

**Figure 3:** ASSET Citizen Consultation questionnaire-2, 2016



The paradox – that public health authorities should devote more resources to collect information from citizens, but on the other hand the citizens prefer clear one-way communication – can be explained by the citizens wanting to be heard, yet, at the same time relying heavily on expert advice during times of crisis such as during an epidemic or pandemic.

### 4. Conclusions

From the analysis it is clear that citizens across Europe are not satisfied with communication from public health authorities, they want the authorities to collect more input from and engage with the public. However, at the end of the day, citizens prefer a clear one-way communication from public health authorities during the response to threats.

The implications of these findings, also discussed in the ASSET Policy Report (2017) (Fig.4), are calling for an inclusive and participatory approach, with advice

to include citizens in the planning of preparedness and response, and in that way strengthen the robustness of the policy process.

Based on the ASSET project, and the discussions in the ASSET High-level Policy Forum (2017), we suggest two possible approaches. Both approaches can work together





with international standardization organizations, e.g. ISO.

The first approach is a continuation of the experience gained through the ASSET project: Include standardized citizen consultations as a mandatory part of preparedness plans developed for the IHR under WHO. The methodology would be based on the approach described above, with minor adjustments according to local context, as needed.

The main advantage of this approach is that it is an effective way to make citizens aware of the dilemmas and conflicts concerning the planning of response to a threat. A shortcoming is, of course, that the approach is neither agile nor ideal during a crisis, such as a pandemic or epidemic threat.

**Figure 4: The ASSET Policy recommendation**

*The ASSET Policy Recommendation,  
Source: ASSET Policy Report 2017*

**Trust in information**

- **The GPs should be trained to adapt to the changing society, and decision-makers should be urged to be visible and present at the internet, as the use of the internet is increasing.**

**Risk Communication**

- **Build a transparent and clear risk communication to restore trust towards society.**

**Pregnancy and vaccination**

- **Update, clarify and standardize influenza vaccination advice materials for pregnant women.**

**Ethics**

- **In an emergency situation, public health interests should infringe upon the individual freedom**

**Lessons learned and Citizen Participation**

- **Public health authorities should devote more resources to collect citizen's input to policies on epidemic preparedness and**

A second approach would be to have a “citizen jury” institutionalized as part of the public health response plan. The citizen jury would be comprised of a small number of lay citizens, which would be chosen/elected for a single term of 2 years, to avoid from being institutionalized and keep them at arm’s length in relation to policy-makers.

Both the above suggested methods would answer the call for an inclusive and participatory approach, while still allowing for public health authorities to communicate a clear message to citizens in times of crisis.

The value of citizen participation is widely recognized in many policy areas and public health policy should do more to adapt policy-making in a more inclusive and participatory manner. The above is a suggestion on how to do so.

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# Views from the general public on communication and information dissemination during a pandemic; results and experiences from the 2016 Irish citizen consultation

by Rebecca Moore<sup>1</sup>, John Haukeland<sup>2</sup>, Lise Bitsch<sup>2</sup>, Valentina Possenti<sup>3</sup>

<sup>1</sup>European Institute for Women’s Health (EIWH), Dublin, Ireland

<sup>2</sup> Danish Board of Technology, Copenhagen, Denmark

<sup>3</sup> Istituto Superiore di Sanità, Rome, Italy

## Introduction/ Background

Communicating well with the general public is important to disseminate information properly during an epidemic or pandemic.

We collected public views of how to communicate in order to help provide input to policy making for pandemic crises, in terms of expression of informed ideas and opinions from near-representative samples of citizens. We engaged citizens in a debate on pandemic crisis prevention and management.

## Methodology

As part of the ASSET project, funded through FP7, eight citizen consultations were held simultaneously across Europe, following a design created to facilitate this multi-site consultation. The countries participating were

Ireland, Denmark, Norway, Italy, Romania, Bulgaria, France, and Switzerland.

Each country recruited approximately 50 participants, representing demographics of the country and participants were given a unique anonymous ID to facilitate stratification of results by gender, age.

In Ireland 51 people participated. A short film introduced each topic, followed by a set of questions that were discussed in groups. Participants were then asked to fill out questionnaires, where they registered their vote on the questions relating to each topic.

The topics discussed were:

- Personal freedom and public health safety;
- Communication between citizens and public health authorities;
- Transparency in public health;
- Access to knowledge.

## Results

After each voting round, the voting slips were collected and immediately entered into an online tool, which meant that all participating countries could watch the results from other countries come in live. Many questions received similar votes across Europe, however in Ireland the voting results showed at times diverging views from the Irish and the overall data.

For the questions “Should health authorities make flu vaccination mandatory in case of a pandemic or epidemic?”, the total answer for all eight participating countries were 54% in



favour, 38% against, and 8% “do not know”. In Ireland, the results were the opposite – 38% for, 46% against, and 16% “do not know”. The only other country that was not in favour of mandatory vaccination was Norway, with 54% against. However, when it came to mandatory flu vaccination for health care workers in case of a pandemic/epidemic, the Irish consultation agreed with its European counterparts. Overall, 85% of participants were in favour of mandatory vaccination for health care workers – in the Irish consultation, this figure rose to 98% in favour, the highest number of all the participating countries (the closest was Italy with 94% in favour).

In terms of satisfaction with information from public health authorities, the results clearly showed that the public felt that this could be improved. The question specifically concerned the Zika virus: “Are you satisfied with the information from public health authorities during epidemic threats, like the Zika virus?” The overall result was 29% yes, 59% no, and 12% don’t know. In Ireland, this increased to an overwhelming 76% not satisfied, with 14% yes, and 10% don’t know. The only other unhappier country was Italy (80%), followed by Ireland and then Romania (75%) and France (72%).

One area where Ireland also had differing responses was for the question: “How much do you trust each of the following sources of information regarding the recent Zika epidemic?” The citizens were asked to rank in order of importance the following: General practitioner; European health authorities; National health authorities; TV; Radio; newspapers; Internet; and Friends/family. Here, the overall results showed that the General Practitioner was the most trusted source of

information overall, whereas in Ireland it was the European health authorities (84%). This was followed by National health authorities (79%) and General Practitioners only showing up on third place with 75%.

## Conclusions

While not statistically significant, the citizen consultation task within the ASSET Project gave an interesting insight into the thoughts and concerns of citizens of eight European countries on the issue of pandemics, epidemics and risk communication. In addition, the results showed great enthusiasm among citizens and desire to be included in policy development, when possible, – 91% of participants said a similar dialogue should be arranged again in the future.

Overall, the opinion was that public health interests could infringe on individual freedom in an emergency, however the Irish consultation didn’t support mandatory vaccination during epidemics/ pandemics.

In terms of communication, clear one-way communication from health authorities as their source of information during a pandemic and transparency was seen as key to build trust in the public.

Moreover, the preferred type of communication channel proved to be different among the age groups; the difference in age in preferred information source and the evolving social media communication channels makes a continuous dialogue especially valuable for devising effective policy. The citizen consultation thus provided a valuable insight into opinions and concerns that citizens



themselves have, and also showed how these differ from country to country.

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