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.

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

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.

96% were satisfied with the process

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

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

Source: ASSET Webtool

Should public health authorities make flu vaccination mandatory for health care workers in case of a pandemic or epidemic risk?

■ Yes
■ No
■ Don't know / Do not wish to answer

85%   12%   3%   Total(424 👥)

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.
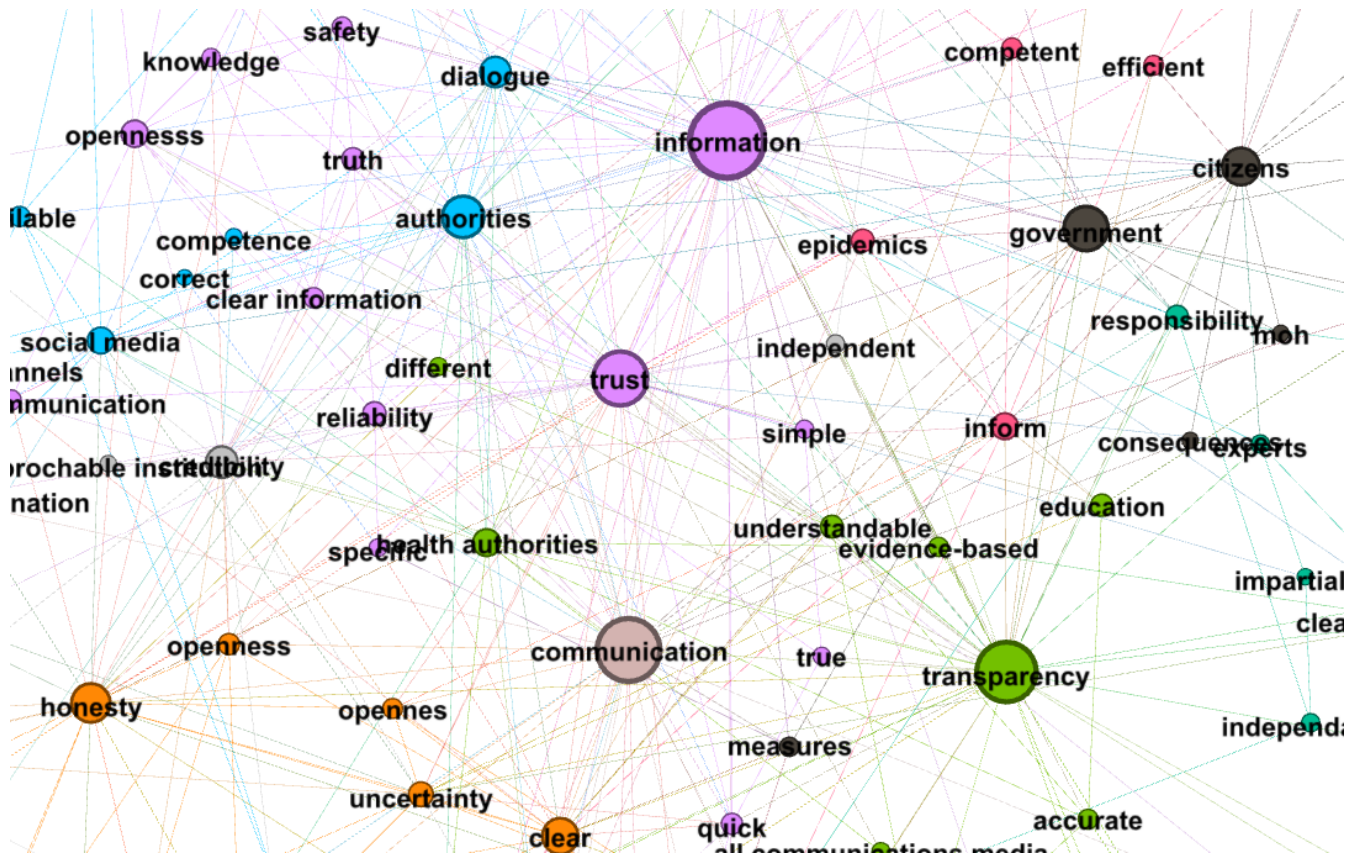
Figure 2: Co-hashtag analysis of policy recommendations

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.