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**TITLE: CITIZEN CONSULTATION**  
**SUBTITLE: Policy Report**

ASSET Project • Grant Agreement N°612236

# ASSET

Action plan on SiS related issues in Epidemics And Total Pandemics

7<sup>th</sup> RTD framework programme

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

Responsible partner: **DBT**

Nature: **Report**

Dissemination: **PU**

Contractual delivery date: **2016-12-31 (m36)**

Submission Date: **2017-03-17 (m39)**

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



co-funded by the EU. GA: 612236

[www.asset-scienceinsociety.eu](http://www.asset-scienceinsociety.eu)

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

## DOCUMENT MANAGEMENT

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

### D4.3 Report

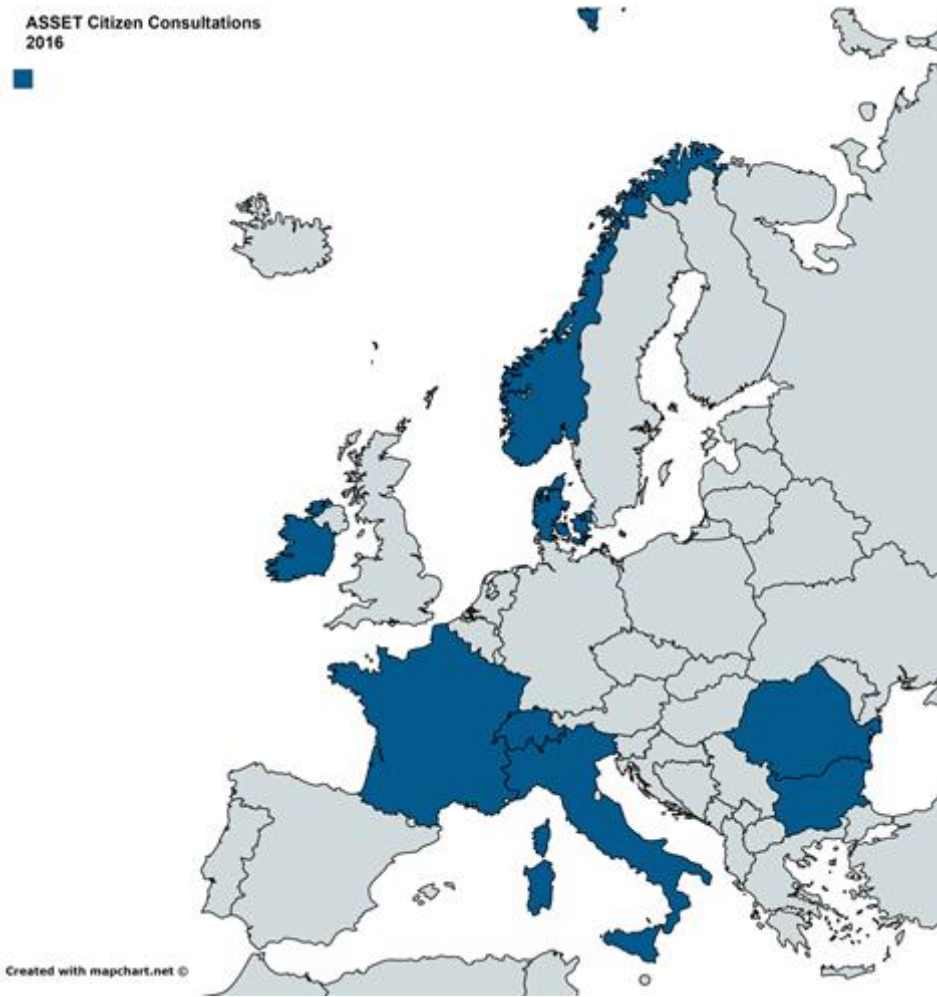
**Task:** 4.3

**Leader:** DBT – **Other contributors:** LYON, DMI, EIWH, FFI, ISS, NCIPD, UMFC

### History of changes:

Vn	Status	Date	Organisation / Person responsible	Reason for Change
V1	Draft	26/02-2017	DBT/ John Haukeland	
Vf	Final	17/03-2017	DBT/ John Haukeland	Partner input

# Participating countries



Bulgaria (67 participants)

Ireland (51 participants)

Romania (51 participants)

Denmark (58 participants)

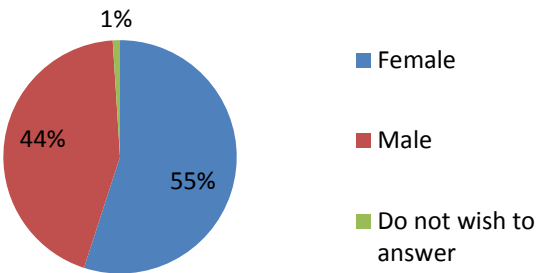
Italy (66 participants)

Switzerland (35 participants)

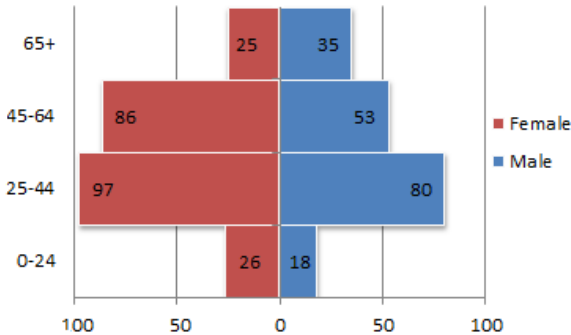
France (47 participants)

Norway (50 participants)

## Gender distribution



## Population Pyramid



## Preface

Health authorities face multiple challenges when responding to epidemic or pandemics treats. Oftentimes they are faced with the challenge of making decisions in conditions of sparse and uncertain information, and available options for action are often less than ideal. In addition, authorities struggle with disseminating information to relevant communities, and they struggle with rumors, parallel information systems, and bridging gaps in cultures, traditions and understandings of health care practices. The present report is a deliverable of the ASSET (Action Plan of Science in Society related issues in Epidemics and Total pandemics) project, and it collects on results from eight day-long citizen consultations in countries across Europe on policy options and issues in epidemic preparedness and response. The ASSET Project is born in the wake of the H1N1 pandemic in 2009-2010, which most of the citizens could remember. However, 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.

This is the ASSET Policy Report.

Its purpose is twofold.

1. In the first part of the policy report, we will account for the rationale behind involving citizen in complex decision-making, and how we did so;
2. In the second part of the policy report, we will analyze and present the results based on the citizen's input deliver six concrete policy recommendations to politicians and decision-makers across Europe.

We hope you will enjoy this report, and if you only were to take one thing away from it, we hope it will be a better understanding, of the merits of citizen participation.

Copenhagen, February 2017

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## Executive Summary

The ASSET citizen consultations show that citizens across Europe are willing to follow the advice from health authorities. In an emergency situation, citizens even supported the infringement of individual rights for the collective good. However, citizens emphasized that public health authorities must communicate in an honest and transparent manner. Citizens do not want to be protected from the realities of a situation; rather they want to know what the uncertainties and risks are. Participants in the meeting urged general practitioners (GPs) and authorities to increase their online presence and to engage in dialogue with their publics. The public desire clear and updated information on vaccination and pregnancy and believe that improved communication and dialogue can restore trust and build better relationships between health authorities and publics. Finally, citizens in the meetings expressed a desire for opportunities to provide input for policy development and action in the case of epidemic or pandemic crisis. The method used in the ASSET citizen consultations present an integrated and participatory strategy for the purpose.

The policy recommendations from the ASSET citizen consultation relate to specific thematic areas of action, and each recommendation is therefore grouped under its attendant area. The six concrete policy recommendations were:

- Trust in information
  - The GPs should be trained to adapt to the changing society, and decision-makers should be urged to be visible and present at the internet, as the use of the internet is increasing.
- Risk Communication
  - Build a transparent and clear risk communication to restore trust towards society
- Pregnancy and vaccination
  - Update, clarify and standardize influenza vaccination advice materials for pregnant women
- Ethics
  - In an emergency situation, public health interests should infringe upon the individual freedom
- Citizens' voices
  - The citizens believe that honesty and transparency can increase the public trust (no matter how bad the situation is), and that it is their right to know and understand the accurate situation.
- Lessons learned and Citizen Participation

Public health authorities should devote more resources to collect citizen input to policies on epidemic preparedness and response

### Citizens' voices

"Open and honest communication from the authorities. Say what you know and what you are uncertain about. Full disclosure."

Danish citizen

### Citizens' voices

"There should be two-way communication between citizens and the government not only in crisis! During a crisis, information given in advance is the most important thing."

Bulgarian citizen

# The ASSET Project

## Background

ASSET is a four-year European research project. The project combines experts with many different backgrounds, e.g. public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media. The aim of the project is to develop a participatory and integrated, transdisciplinary strategy to preparedness measures.

A milder than expected evolution of the H1N1 pandemic led to mistrust between the public and public health authorities, with the public in particular questioning the relationship between the industry and authorities. International public health authorities still struggle with this mistrust evident from the Ebola epidemic and the Zika Virus outbreak.

The aim of the public consultation in the ASSET project is, therefore, to engage European citizens in the debate of pandemic crisis prevention and management. Citizen meetings with around 50 people each was held in eight countries: Bulgaria, Denmark, France, Ireland, Italy, Norway, Switzerland and Romania.

The project objective and WP4 objectives:

- 1) Make a concrete and policy-relevant example on EU level coordinated public consultation with a link to parliaments;
- 2) Give input to policy-making about policies on pandemic crisis, in terms of expression of informed ideas and opinion from near-representative samples of citizens;
- 3) Engage citizens in the debate of pandemic crisis prevention and management.

### Why 50 citizens?

Statistical theory tells us that by  $n=30$ , the sample will roughly have a normal distribution, meaning that the sample is representative of the population, assuming randomness.

For each additional citizen added to the sample of 30, the sample will become more representative.

For further information: <http://www.asset-scienceinsociety.eu/>

## The design

The design underlying the ASSET citizen consultations was developed in response to the practical challenges of making multi-site citizen participation possible. The following criteria were considered essential:

- Clear link to policy-making: It had to address issues of immediate relevance to policy-makers
- Both international and national: It had to pertain to both international and national decision-making.
- Clear and comparable results: Results had to be comparable across countries and they had to be easy to communicate to policy-makers
- Informed citizens: Citizens had to be provided with balanced information required to understand the issues debated among policy-makers

- Deliberation: Citizens should be given the opportunity to discuss their views with each other before reaching their own conclusions

In order to meet these objectives, groups of citizens (approximately 50) met in their respective countries to deliberate on an identical set of questions, using identical meeting designs and information material. The different meetings and their results are linked through an online web tool.

The method provides policy-makers with in-depth information about trends in national and international opinions, but differs in important ways from conventional opinion polls. Unlike opinion polls, the method provides respondents with balanced and scientifically based information as well as an opportunity to deliberate for a full day with other citizens prior to rendering their judgments. Thus, it encourages the exploration of more substantive questions and well-considered responses, allowing policy-makers to assess which policies will be well received if people are properly informed about the rationale behind them.

The method used for citizen consultation is inspired by the WWViews method (<http://wwviews.org/>). The method has been adjusted in various ways, based on evaluations from partners participating in WWViews on Global Warming in 2009, WWViews on Biodiversity in 2012 and WWViews on Climate and Energy and scientific observations published in the following years. The most essential break from the WWViews method is that the ASSET design allowed for citizen input already prior to the consultations. This came about by systematically applying digital methods to scope public debate online on issues related to the ASSET objectives. This in turn inspired the ASSET information material.

### Questions and information material for the citizens

The questions posed to the citizens across Europe were selected to be of direct relevance to the policy-makers concerned with policies on pandemic crisis or threats and to provide decision makers with information about public opinion on different policy measures to do so. The questions had to be identical in all countries in order to allow for cross-national comparisons. To ensure comparability of results and clear communication to policy-makers, the questions and response choices were predefined in all sessions but the open policy recommendation session. The questions were clustered in six themes:

1. Personal freedom and public health safety;
2. Communication between citizens and public health authorities;
3. Transparency in public health;
4. Access to knowledge;
5. Qualitative policy recommendations (open session);
6. Evaluation

Prior to the citizen consultations, participants received balanced information from a 20-pages booklet written by the Danish Board of Technology in close collaboration with the ASSET project partners. The booklet provided basic information about the controversies on pandemic preparedness and response and different points of view on how to deal with it.

Information videos (each 4-10 minutes long) were made by the Danish research and science communication company GoVisual for the four closed themes, repeating the most essential information available in the booklet and ensuring that all citizens would participate in the meetings with the necessary information. All information material was translated into local languages.

## Selecting the participating citizens

Guidelines for selecting the participating citizens were made in order to ensure the reliability of the results. The citizens at each meeting should reflect the demographic distribution in their country with regards to age, gender, occupation, education and geographical zone of residency (i.e. city and countryside). A further criterion was that they should not be experts on public health issues, neither as scientists nor as stakeholders. Where appropriate, the national partners added further demographic criteria of relevance to their national context. Finally, citizens were asked if they were members of a health organization, this was also used as selection criteria in order to avoid an overrepresentation of participants more concerned with, e.g. vaccination than the population at large.

Based on reports from the partners, the guidelines have been followed, albeit with some local variation due to economic and other practical limitations. While some meetings ended up with fewer than 50 citizens, most ended up with more than 50 citizens on the ASSET Day. The European average was 53 citizens per meeting. Some countries or regions recruited citizens from their entire geographical area, whereas others recruited from a smaller area in order to cut expenses.

Nevertheless, the sample of citizens consulted in ASSET is large and diverse enough to give a clear sense of general trends in national and international public opinion.

## The ASSET Day

All citizen consultations followed the same schedule: the citizens, divided into tables of 5-8 people, were led through a program, divided into four thematic sessions and an open session, by a head facilitator and a number of group facilitators.

Each thematic session was introduced by the head facilitator and an information video. The participants then engaged in moderated discussions at their tables, the purpose of which was to give all participants time to listen to other opinions and reflect prior to voting. Group facilitators were trained in advance to provide unbiased facilitation at the tables. Each thematic session concluded with citizens casting their votes anonymously on alternative answers to a total of 24 questions (five to six questions in each thematic session). Votes were counted by the staff and immediately reported to <http://citizenconsultation.asset-scienceinsociety.eu/en-gb/results> thereby enabling international, quantitative comparisons.

Most meetings were either opened or closed by ministers or high-level government officials. The citizens were apprised of the means by which policy-makers would be informed of the results.

## Follow-up

Following the ASSET day, the data was analyzed by the partner based on the output of the web-tool and a two-day workshop.

In addition to the quantitative data from the closed-ended questions in the first four sessions in the questionnaire, we added an open-ended question in session 5 to provide the citizens with the opportunity to express their personal opinions and include themes that were not embraced in the former sessions. More specifically, the citizens were asked to write policy recommendations as an answer to the following question: *“Considering the issues debated today, what is your most important recommendation to national and international policy-makers?”*



To analyze the qualitative data from session 5, we used and developed a new analytical strategy based on the use of digital methods. The use of digital methods makes it possible to visualize complex datasets. More precisely, the different set of techniques provides the opportunity to gather, organize and visualize issues to create an overview of the complexity and to observe, explore and investigate the relations within. The two-folded function of visualizations is both suitable for analysis and representation.

### **Making the citizens' views heard**

The outcomes of the ASSET Project and its citizen consultations are being disseminated on a European level. The target groups for receiving the ASSET results are politicians, international and non-governmental organizations and interest groups engaged in policy-making about pandemic preparedness and response. The ASSET results are especially significant for policy-makers and stakeholders because they represent the informed and considered views of a broad range of citizens from across Europe concerning complex issues about policies on pandemic crisis or threats.

The ASSET partners have set up a comprehensive dissemination strategy aimed at presenting and discussing the results of the citizen consultations with the relevant policy-makers and stakeholders. Dissemination already began in January 2016, 8 months prior to the citizen consultation, with a workshop with ASSET's High-Level Policy Forum in Copenhagen to secure stakeholders' interest in the project and its results and to guide the process to be most relevant to the target group. Next, the results will be presented at the European Parliament in April 2017. This will then be followed by a presentation and discussion of the results with the High-Level Policy Forum.

In addition to the presentations made by the partners at a European level, all national ASSET partners have employed their own strategies to reach key target groups. The goal is to make those engaged in public health policy-making aware of the results and to take them into consideration.

## Policy Recommendations

The key findings in this report highlight the results from the citizen consultations that the partners find to be most significant and interesting to policy-makers. We invite others to explore the results to see what they find to be significant on our [web-tool](#). The key findings were selected during the policy workshop in Copenhagen with the partners.

The key findings were identified in the workshop and subsequently developed and refined by an editorial group. The key findings are structured in the following way: first, a clear message to decision-makers (the key finding); second, factual observations from the ASSET voting results that underpin the message (sometimes the same observations underpin more than one key finding); and third, an assessment drawn from the observations. The key findings are structured in six messages:

- Trust in information
  - The general practitioners (GPs) should be trained to adapt to the changing society, and decision-makers should be urged to be visible and present at the internet, as the use of the internet is increasing
- Risk Communication
  - Build a transparent and clear risk communication to restore trust towards society
- Pregnancy and vaccination
  - Update, clarify and standardize influenza vaccination advice materials for pregnant women
- Ethics
  - In an emergency situation, public health interests should infringe upon the individual freedom
- Citizens' voices
  - The citizens believe that honesty and transparency can increase the public trust (no matter how bad the situation is), and that it is their right to know and understand the accurate situation
- Lessons learned and Citizen Participation
  - Public health authorities should devote more resources to collect citizen's input to policies on epidemic preparedness and response

## Trust in information

### Clear message

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.

### Observations

One of the topics discussed at the citizen consultations was trust in authorities and information before and during a pandemic or epidemic outbreak. The results are showing that the most trusted and used source of information are GPs. When the participants were asked who they consult first when they get ill 57 % answered their GP (Figure 1). The pivotal role of health care workers (HCW) and GPs is underlined by people's opinion on the distribution of scarce resources, where 64 % answered that priority should be given to HCW and other people working in the fields important for society. After the GPs, the internet is the most used source of information, but at the same time the results show that people trust the internet less than any other source of information apart from newspapers. There is also a clear finding when asking what information people need from the public health authorities in the case of an epidemic. People want do's and don'ts for how to act.

Figure 1. When you are ill who do you consult first? n. 425

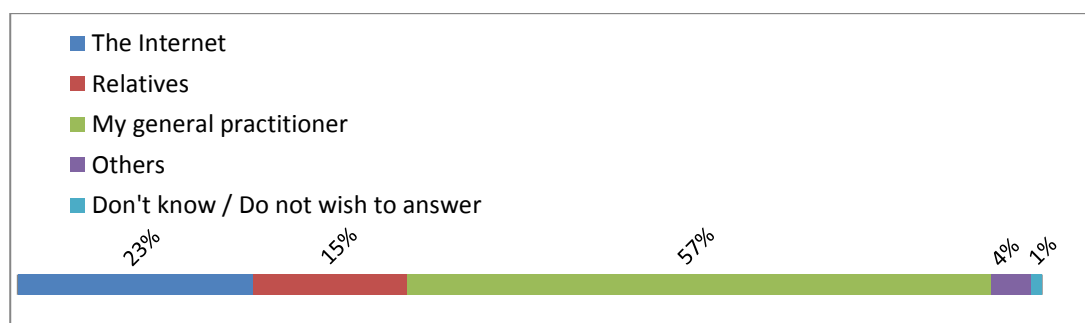
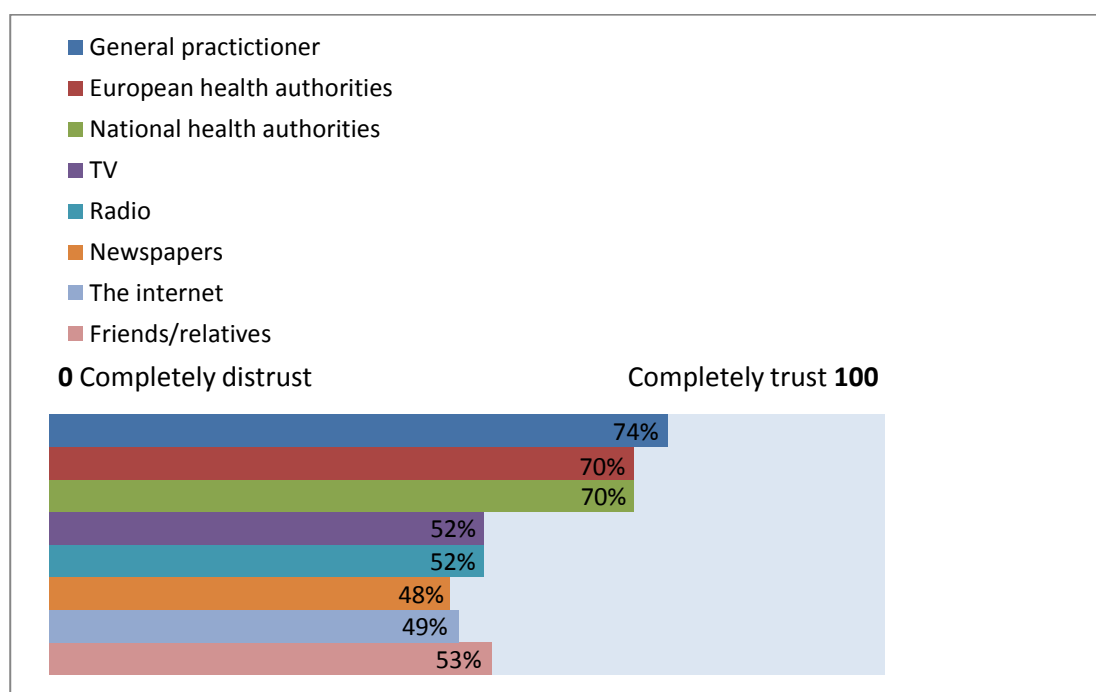


Figure 2. How much do you trust each of the following sources of information regarding the recent Zika epidemic? n. 425



## Assessments

GPs are the most used source of information followed by the internet. There is a decreasing trend with age for the internet as a source of information. However, the data shows that citizens do not really trust the internet. As the case of the Zika was used as an example, the level of trust could perhaps be different for other examples, but the trend in the discussions was that people use the internet even though they want a second opinion afterwards. This may be referred to as “the dilemma of the internet”: People use it, but do not trust it<sup>1</sup>.

Considering the results, GPs should be involved in the planning and response for epidemics. They should play a stronger role in prevention and build a stronger preparedness system. Gender differences and age differences are not significant for trust in GPs, and it is therefore recommended that GPs should be engaged in informing people.

<sup>1</sup> See ASSET Background Material: <http://www.asset-scienceinsociety.eu/outputs/deliverables/citizens-meeting-national-materials>

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.

In a case of emergency, it is clear to people what they want. The public health authorities should be present in social media and have clear, visible and identifiable official webpages.

## Risk communication

### Clear message

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

### Observations

#### *General comment:*

Almost 60% of the citizens are not satisfied with the information from public health authorities during epidemic threat, showing that there is a need for more communication from the governments.

#### *Clear message:*

71 % are in favor of a clear one-way communication from public health authorities and, according to 81% of the citizens, they should dedicate more resources to gather data on people's opinions, thoughts, questions etc. With regards to the idea of having another citizen's consultation, 58% of them think that such a dialogue process is a good idea.

When asked about the most important content of the message, the citizens answered at 67% that governments should provide information about "What to do / not to do" during an epidemic threat.

#### *Transparency:*

50% of the citizens feel comfortable with the idea that not all information is publicly available for security reasons during an outbreak. Moreover, 53% of the citizens agree for publishing scientific studies even if there is a large uncertainty about the results.

Finally, 88% are in favor of all relationships with vaccine manufacturer being declared. Public authorities should be transparent on this issue.

#### *Trust:*

The results of voting show that 70% of the citizens trust the European Health Authorities regarding epidemics, and 74% trust their general practitioner whereas only 11% trust social media for example. So, these are the sources of information identified as credible and through which the trust should be built.

Figure 3. Are you satisfied with the information from public health authorities during epidemic threats like Zika? n. 425

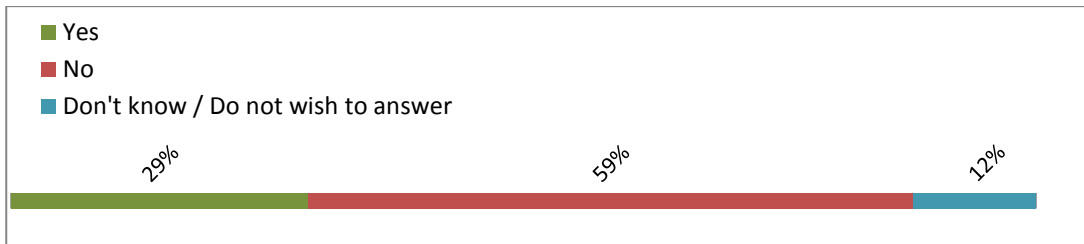


Figure 4. What is the best way to provide information in times of pandemics/epidemics? n. 425

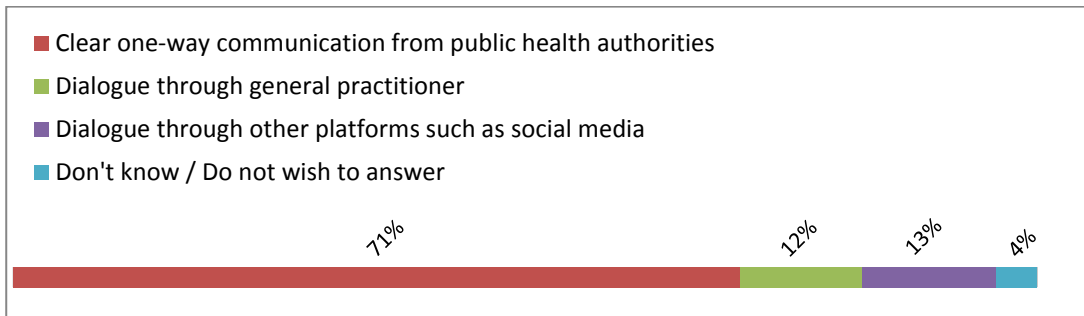
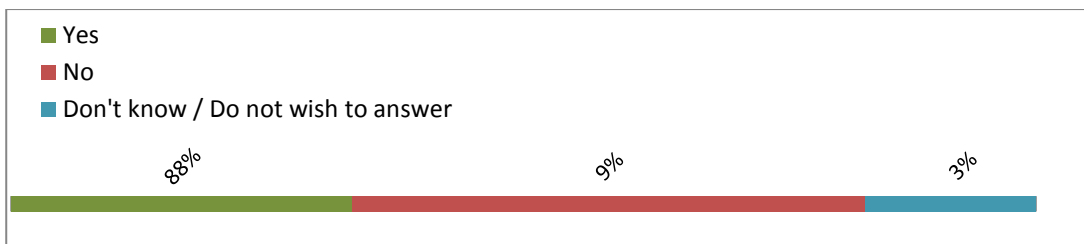


Figure 5. Do you think that all relationships with vaccine manufacturers should be declared and publicly available? n. 425.



## Assessments

Citizens prefer the information to come from the public health authorities but need to be consulted too. Indeed, it is essential to stay tuned with the risk perception of the public and adapt the communication consequently. The message must be clear and focused on how the citizens should act concretely.

Public health authorities should be honest and transparent when dealing with scientific and economic aspects during an epidemic. Indeed, citizens want to be informed on the scientific details of the epidemic even if this information may change during the outbreak period. So, it seems to indicate that a careful communication of uncertainty is positively appreciated. On the other hand, if for security reasons some aspects are being hidden from the public, citizens understand it. It is very important however that any link with the vaccine industry is acknowledged to avoid the “sensation of conspiracy”. Thereby, the vaccine industry will probably avoid the rumors and their recommendations will be followed by implementation because they are trusted.

European health authorities and general practitioners are the most trusted sources of information. They should reassure the citizens on the government preparedness and coordinate themselves to agree on the message to give when asked about more details on the epidemic.



## Pregnancy and vaccination

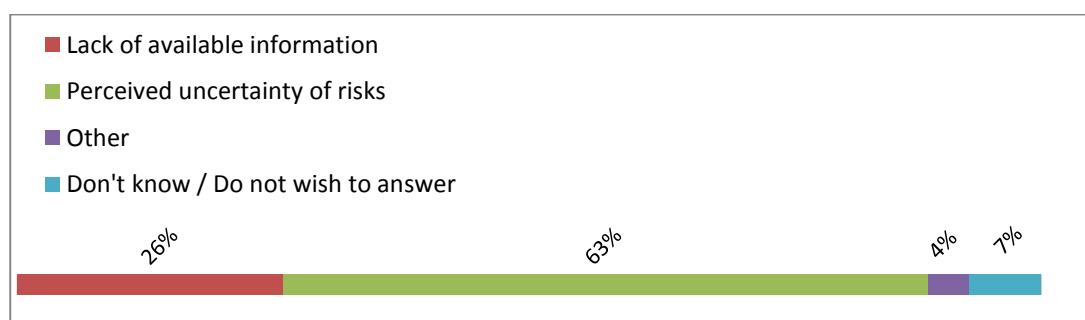
### Clear message

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

### Observations

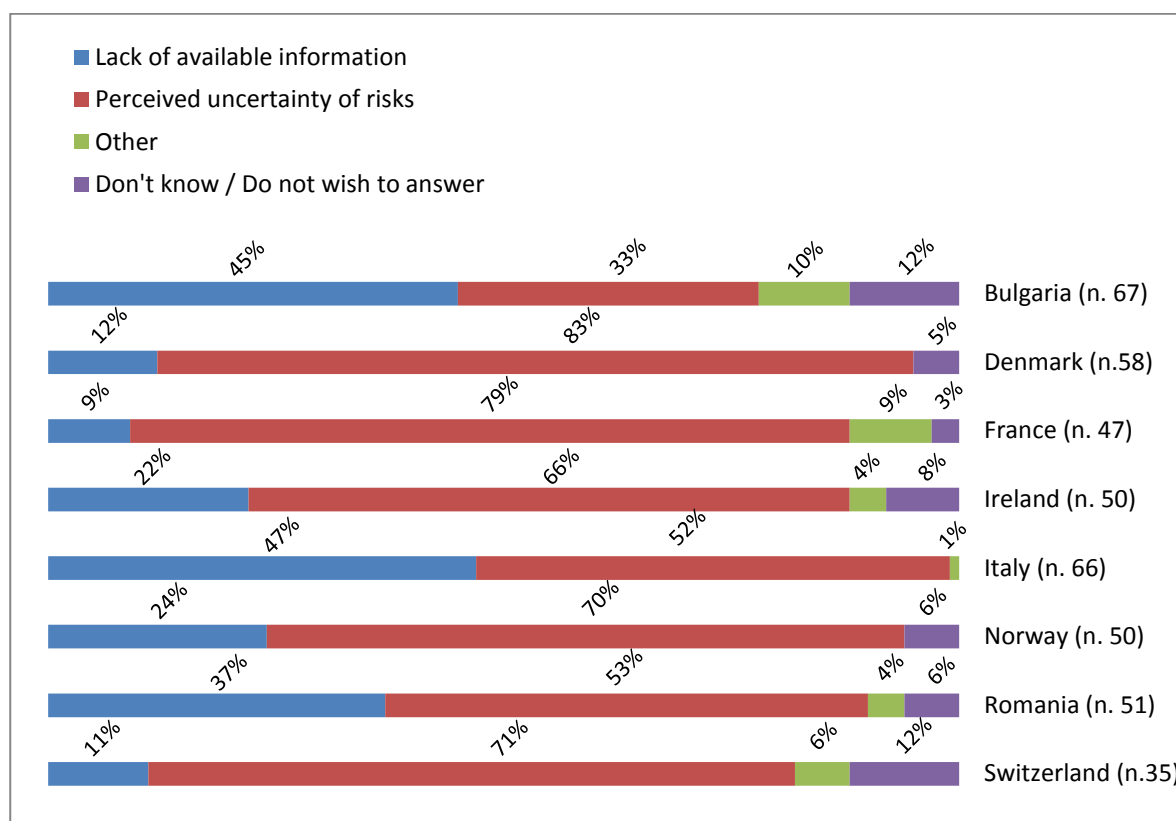
*Perceived uncertainty of risks* was overwhelmingly the main opinion of the participants in the voting, as can be seen in the figure below. This shows all the responses from all age groups and genders from the eight participating countries.

**Figure 6. What do you think is the main reason that vaccine covers of pregnant women tend to lag behind the general population? n. 424**



However, when broken down by country, Bulgaria chose *Lack of available information* as the main reason for the low vaccination, and Italy and Romania had a large number of participants also choosing *Lack of available information*.

Figure 7. What do you think is the main reason that vaccine covers of pregnant women tend to lag behind the general population?



Broken down by gender, the results were slightly different, with more men than women choosing the option *Lack of available information*, perhaps inevitably as they might not know much about it as it may be considered a ‘woman’s health’ issue only. Nevertheless, the male respondents, apart from those in Bulgaria and Romania, put *Perceived uncertainty of risks* as the main reason vaccination of pregnant women tends to lag behind that of the general population.

In terms of age difference, the data shows us that all four age cohorts in the eight participating countries also voted for *Perceived uncertainty of risks* as the main reason for poor vaccination rates for pregnant women. Broken down by age and gender, the responses show us that males under 24 years of age were more likely to choose *Perceived uncertainty of risks* than their older counterparts, but this was nevertheless the majority response for all age groups. Among women, the response did not change significantly across the age groups.

### Assessments

The Citizen Consultation data shows us that most respondents considered the *Perceived uncertainty of risks* as the main barrier for vaccination uptake among pregnant women. While not a majority, the high number of participants choosing *Lack of available information* as their reply makes it clear that vaccination in pregnancy is still an issue many people feel they do not know enough about to make an informed decision.

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 (WHO 2012). There is limited research done on vaccine safety in pregnant women, however, studies suggest that the vaccine is safe, and there are no indications that vaccination causes harm (ECDC 2012). In general, vaccination of pregnant women serves to protect both the woman and the fetus (Klein et al 2010). Existing studies on pregnant women who have taken the influenza vaccine show no adverse risks or side effects on the mother, fetus, or the child once it is born – rather, there is a good record of administering the vaccine, particularly in the second and third trimester (WHO 2010).

Despite the strong emphasis from the WHO and national health care authorities on the need for pregnant women to vaccinate against influenza, the message is not reaching the target audience. Existing information and communication efforts have not brought with them the intended effect, and the Citizen Consultation data shows us that the apprehension toward taking any sort of vaccination while pregnant still lingers. Also, a significant minority do not feel that they have access to relevant and appropriate information.

While the Citizen Consultation data results are not statistically representative of the participating countries, it does give insight into barriers and concerns that general populations face. The message received from the respondents is that the idea of pregnant women vaccinating against influenza is met with reticence or lack of knowledge – this insight presented by the data provides us with an opportunity to address these issues through targeted policy initiatives. We wish to suggest the following recommendations:

- Update, clarify and standardize influenza vaccination advice materials for pregnant women
- Health literacy should be considered in the development of all such materials and communication efforts - plain language should be the foundation of all materials and the ability required to understand and process the information
- Educate and promote increased awareness among health professionals of the benefits of vaccination for pregnant women
- Provide clear communication strategies at the EU, national and regional level on pregnancy and vaccination -clear, consistent, unequivocal communication is essential to successfully provide information
- Use more evidence-based research to address the concerns that pregnant women have

## Ethics

### Recommendation

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

### Observations

Mandatory vaccination could help to contain the spread of infectious diseases. Regardless of age and gender, 54% of citizens say that health authorities should make the flu vaccination mandatory in case of epidemics or pandemics. This percentage rose to 68% and 71% in Italy and Romania respectively. In Norway and Ireland, less than 40% of participants would agree to make the flu vaccination compulsory.

The large majority of citizens (85%) think that for health care workers vaccination should be rather compulsory. Note that the answer was uniform when analysing by country, age group or gender.

Non-pharmaceutical interventions such as closing public services (i.e. kindergartens, offices and schools) and cancelling large international events such as Olympic game has been reported by 82% and 69% of respondents respectively as efficient measure to contain epidemics or pandemics. France turned to be the more reluctant with regard to such preventive measures.

Figure 1 represents the results of our survey concerning priority setting during epidemics or pandemics. Overall, 64% of participants want the public health authorities to give priority access to vaccines or other medications to health care workers and other professional categories such as firemen, army and police. High risk populations (e.g. people with comorbidities, children, etc.) were reported as the most prioritized group to receive scarce resources by 29% of participating citizens. Only 4% of respondents declare that there should not be discriminatory distribution, meaning first come, first served. The results for Switzerland were different as high-risk group was identified as the most important category for receiving vaccines. In Ireland, 46% of citizen voted for health care workers as primacy group while another 46% reported the high-risk group as the main category to be vaccinated first.

Another ethical consideration during epidemics and pandemics is how to use new drugs and vaccines. Overall, 43% of participating citizens were in the favour of priority fast track trail of the most promising treatments and vaccines. In total, 30% declared that public health authorities should allow patients to receive treatment with experimental drugs while 22% would follow through established guidelines and procedures (Figure 2).

Figure 8. Should public health authorities make flu vaccination mandatory in case of a pandemic or epidemic risk?

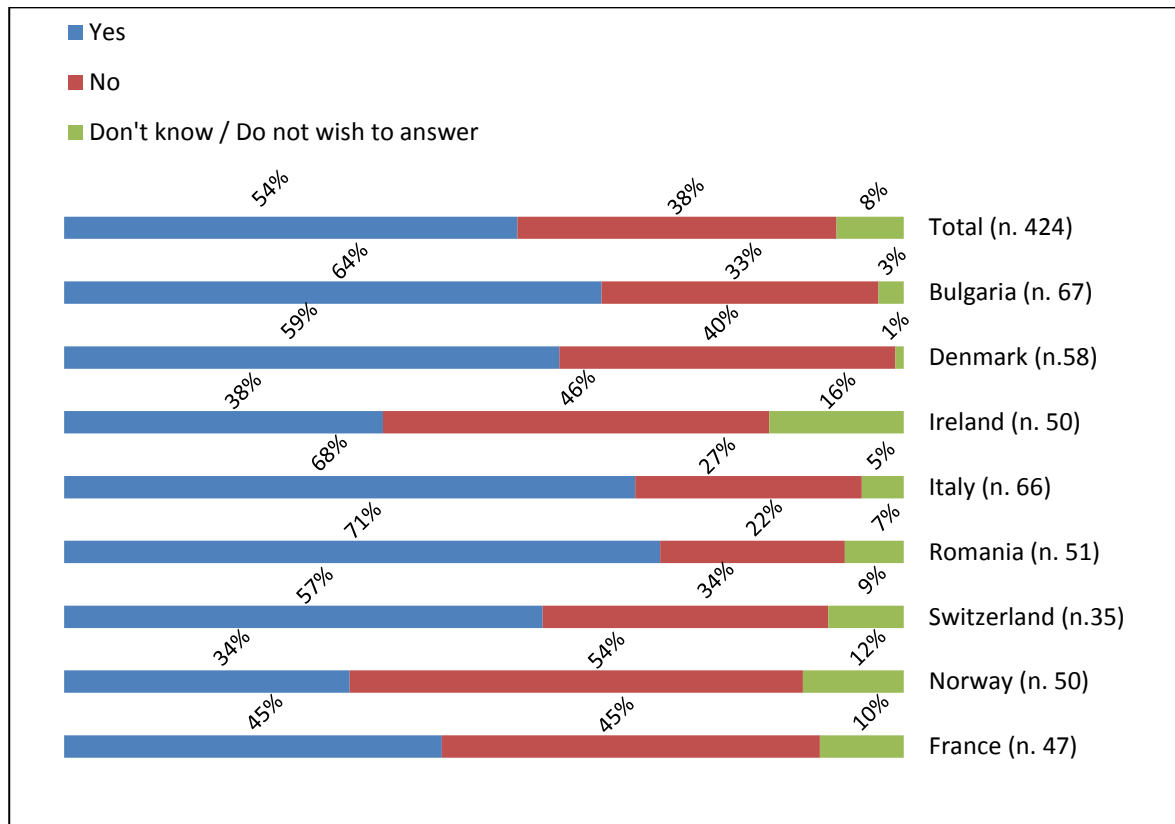
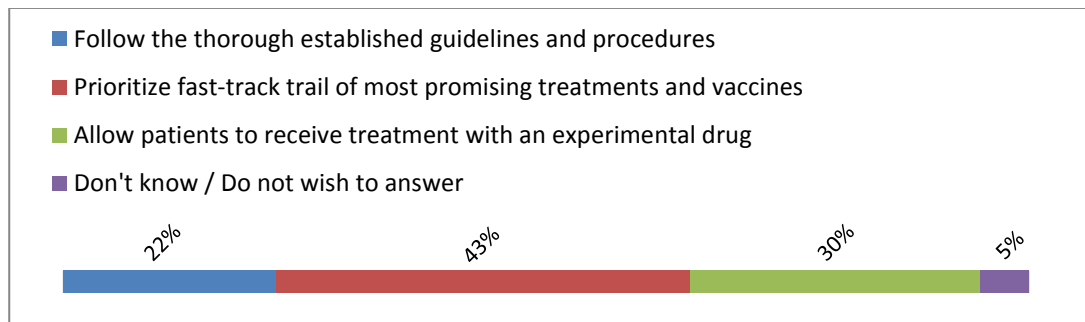
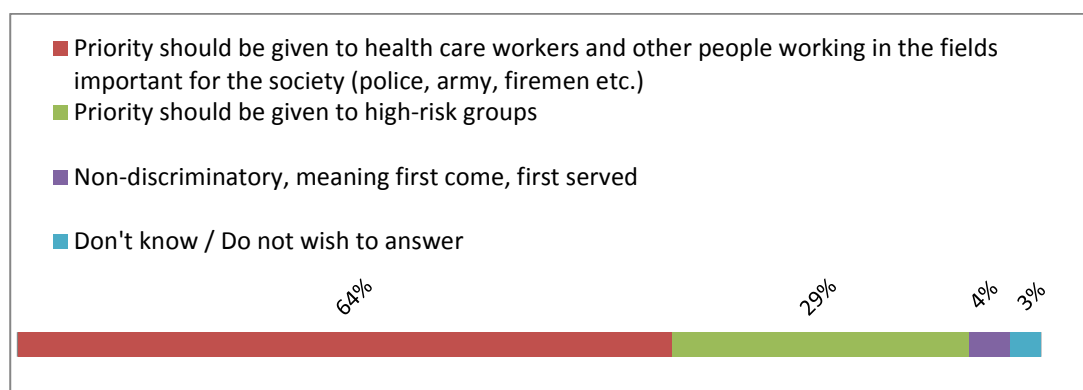


Figure 9. During epidemic outbreaks like the Ebola virus disease, how should public health authorities work with new epidemic drugs and vaccines? n. 425



**Figure 10. What should be the principle of distribution of scarce resources (e.g. medicine) during an epidemic/pandemic outbreak? n. 424**



### Assessments

Many ethical questions with respect to fair distribution of vaccines (i.e. equity), priority setting access, personal freedom to get vaccinated or not, and social distancing measures (e.g. isolation, quarantine, border control, etc.) arise in pandemics and epidemics. Moreover, increased health care demands during epidemics or pandemics can exceed the available capacity. Optimizing the use of available therapeutics is therefore a very important step of efficient response. These ethical issues should be properly addressed by public health authorities at national and international levels in planning the response efforts in the event of a pandemic.

Preventing the spread of the disease in the community is the major component of a pandemic management crisis that involves, among other parameters, making decisions related to the target population and infection control measures. At early stages of pandemics, the available resources are often not enough to cover the need of the whole population. In this case, the continuity of essential services such as health care provision, treatments of infected patients and protection of the population are the most important actions to be taken by public health authorities. This requires setting priority to access vaccines to health care workers, police and army at first, followed by other at-risk groups such as children, elderly and individuals with underlying chronic diseases (e.g. diabetes, cancer, immunosuppression, etc.). The results of voting show that the vast majority of participating individuals highly agree on establishing a priority list. Furthermore, the order of priority groups was almost homogenous through participating countries. Indeed, the large majority assigned health care workers, army and police as the first target population for vaccination during epidemics and pandemics.

As far as the mandatory or optional character of vaccination is concerned, communities consider that rendering the vaccine compulsory for these groups is another important factor that could help in keeping the spread of the disease low. The results of voting in Norway and Ireland were not in favor of mandatory vaccination. Further investigations are warranted to better understand this finding.

Enacting of other policies such as social distancing measures can also mitigate the spread of the disease at population level and might be combined with pharmacological interventions. Such preventive measures

were largely reported by citizens as an effective infection control measure to be taken into consideration when facing emergency situations.

Finally, it is worth mentioning that the participating citizens voted that public health authorities should work with new epidemic drugs and vaccines by giving priority to fast-track trailing of most promising vaccines and drugs and by allowing patients to receive treatment with experimental drugs.

In summary, legitimate restrictions on personal freedom may occur if, in exercising one's freedom, one places others at risk. The results of our citizen consultation suggest that during epidemics or pandemics, the community is willing to prioritize the public health interest to detriment of individual freedom.

## Citizens' Voice

The citizens believe that honesty and transparency can increase the public trust (no matter how bad the situation is), and that it is their right to know and understand the accurate situation.

### Observations

- Information and communication is the main theme

The citizens highlighted the need for early, reliable and understandable information and communication from different channels and platforms. Two-way communication and dialogue between the authorities and the citizens has also been embraced and highly recommended, in order to increase the public trust.

- The importance of increasing the public trust through honesty and transparency

Most of the citizens highlighted the importance of increasing the public trust with open communication based on reliable information. Honesty, openness and transparency are fundamental for building trust.

- Objective studies to avoid any conflict of interest

Information from international politicians and other important stakeholders should come from objective studies that are not influenced by the pharmaceutical industry as an example. Some of the citizens have suggested an impartial communication platform to be created and used in case of a crisis.

- Vaccination should be mandatory

Some of the citizens highlighted that the management of vaccinations should be intensified, and that they believe that vaccinations can prevent diseases in spreading. It is important to provide transparent, honest, scientific and accurate information and communication to the citizens regarding the treatments and side effects of vaccinations. Also, vaccinations should be mandatory in time of a crisis, especially for health care workers.

- The use of social media as a communication channel

The citizens have highlighted the need to communicate and make sure that information reaches the entire population (people from different age groups, etc.). In order to do so, they have suggested the use of various communication sources, but primarily social media. Social media can reach out to the world, and clear a lot of the rumours.

- Cross disciplinary collaboration to defeat infectious diseases

The urge for an international and cross disciplinary collaboration in case of an epidemic or pandemic. A couple of citizens stated the need for a collaboration between both national and international health authorities, governments, citizens (through dialogue), doctors and other specialists, to prevent and control infectious diseases.



## Assessments

The citizens' recommendations to the national and international policy-makers mainly evolve around an improvement of the information that the citizens receive and consult before and during an epidemic or pandemic. Within this improvement, there was a general request for information to be understandable and available for everyone at an early state, and that the information was reliable and built on objective and scientific facts. Some of the citizens suggested the creation of an independent and impartial communication platform, as a solution to the problem of bias and corruption. Here, the citizens believe that honesty and transparency can increase the public trust (no matter how bad the situation is), and that it is their right to know and understand the accurate situation. For instance, all information regarding treatments and the side-effects of vaccinations should be available for everyone to access.

Most of the citizens, who wrote about vaccinations in their recommendations, chose to preference the societies' needs over the aspect of personal freedom. Here, they suggested the policy-makers to incorporate mandatory vaccinations, especially for health care workers, in critical situations.

Concerning the discussion of communication channels, they believe that the information should reach out to everyone through the use of a variety of channels and platforms. However, their main proposals are to use and be active on social media, in order to raise awareness, spread information, and encourage a dialogue with the citizens and to avoid the formation of rumours.

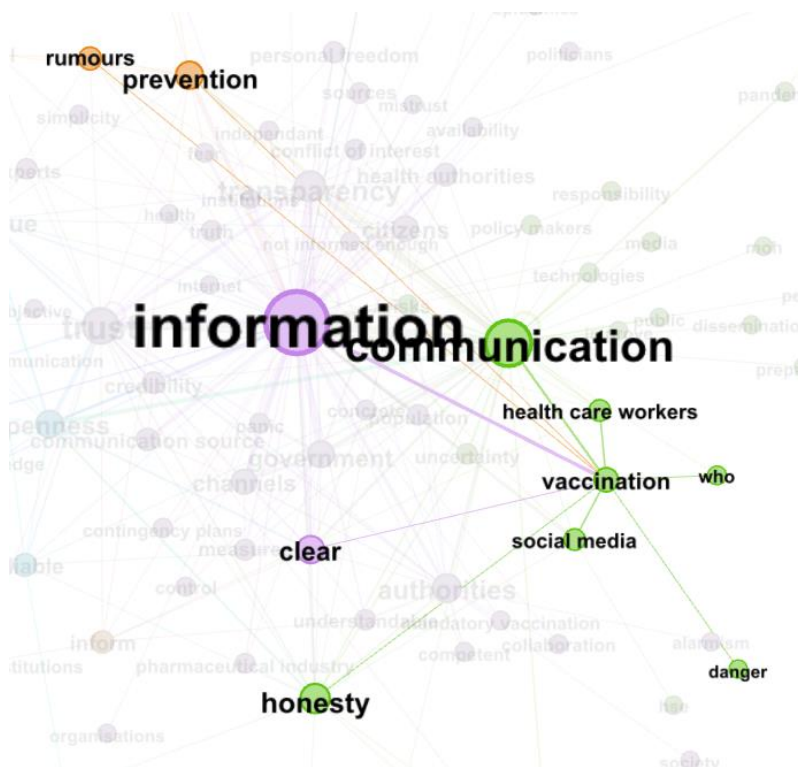


Figure 11: Links between and with vaccination

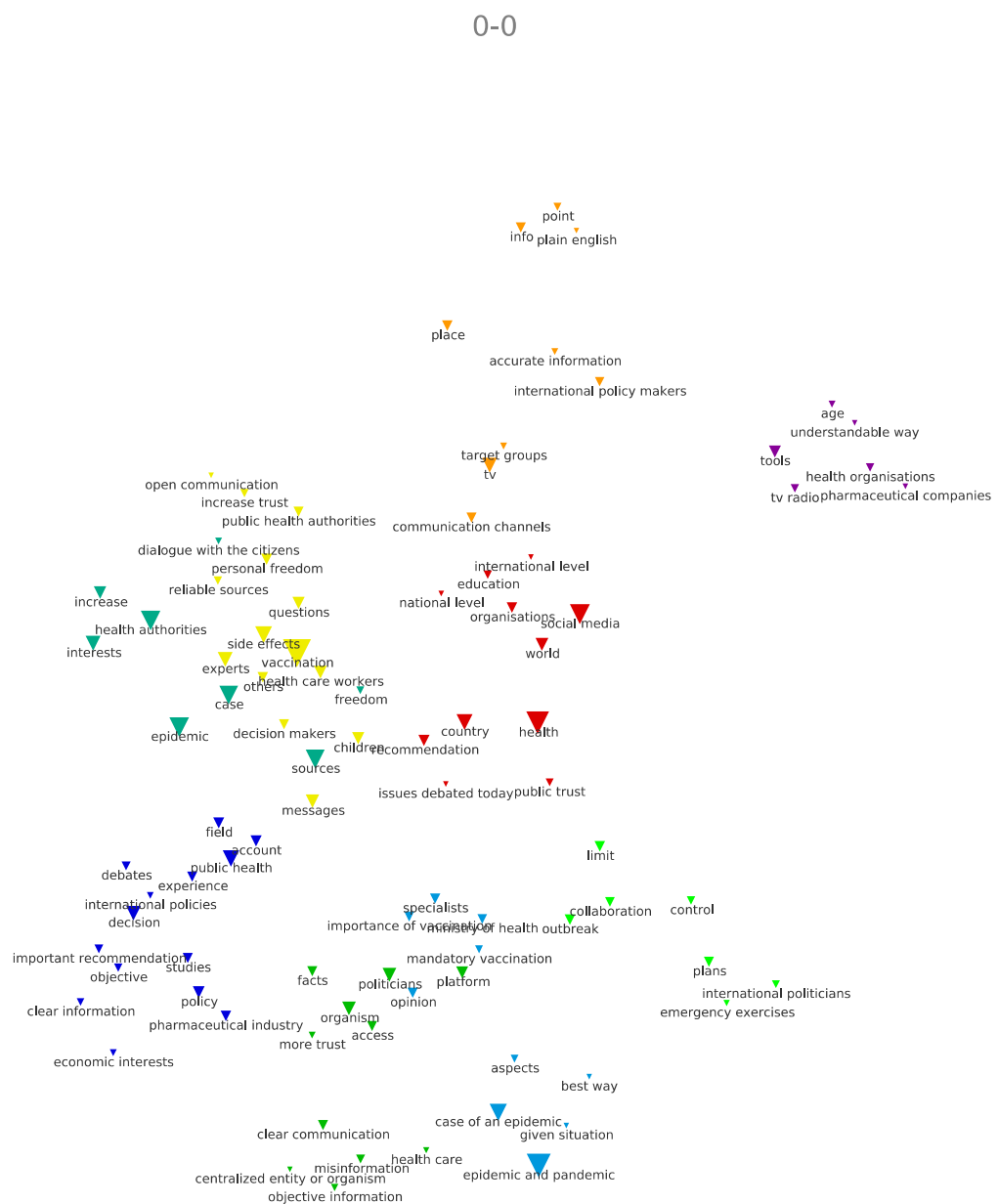


Figure 12: Clustering of citizens keywords

## Lessons learned and Citizen Participation

### Clear message

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

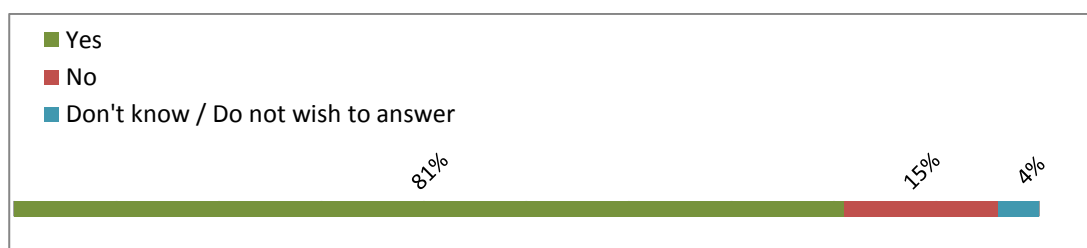
### Observations

More than 8-out-of-10 citizens in Europe want public health authorities to devote more resources to collect worries and input from citizens.

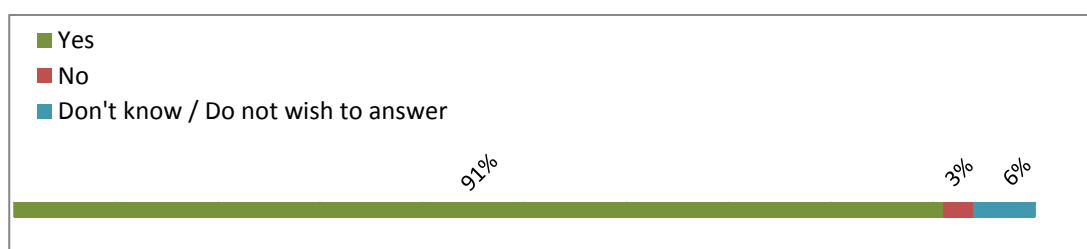
And 91% of the citizens think that global dialogue processes like ASSET should be arranged in the future. There is no significant difference between age-groups, country of origin or gender in this theme.

The citizen consultations on ASSET were much more than a survey, it allowed for information, debate and deliberation time before deciding how to cast the vote. This is expressed by 96% of the citizens agreeing that the briefing materials and videos were balanced and informative, and more than 9-out-of-10 agreed that different and opposing views were presented and discussed at each table.

**Figure 13. Should public health authorities devote more resources to collect information (questions, opinions, worries, etc.) from citizens during pandemics threats? n. 425**



**Figure 14. Should dialogue processes like ASSET be arranged in the future work with pandemic and epidemics response and preparedness? n. 424**



### Assessments

Epidemic preparedness and response has been perceived as a highly technical issue, confined to experts, special interest groups and policy-makers. ASSET has proved this does not need to be so. Citizens want to contribute to policies on epidemic preparedness and response.

The strong support for arranging deliberative processes like the ASSET citizen consultation in the future and the belief that it has a meaningful role to play in the political decision-making process

#### Citizens' voices

"Trust people with the facts. Allow questions and don't be evasive. Admit where there is uncertainty. Get public consultations into the policy processes."

Irish Citizen

clearly indicates that citizens want to take part in deciding what policies should be put in place to address public health. They want their views to be heard and see themselves as participants in the decision-making process, rather than subjects of decisions made by others. This is consistent with analysis from the final session, where citizens themselves wrote recommendations to national and European policy-makers.

## European Results

The percentages given here and on the results page at <http://citizenconsultation.asset-scienceinsociety.eu/en-gb/results> are calculated in the following way: the votes from each country, regardless of the number of participants, are given equal weight when calculating the average percentages in the total. At the online results page, comparisons can be made between different countries, Europe as whole and other categories such as gender and age. The total number of votes is listed for each answering option. In total, there were 425 participants (234 females, 187 males and 4 anonymous).

We have rounded the percentages to the nearest integer, so the percentages may not always add up to 100%. We have published all the data, so everyone can download the results and make a further analysis on their own.

### 1. Personal freedom and public health safety

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



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



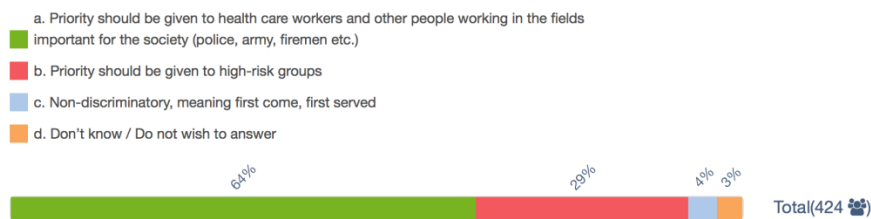
Is it ok to close public services (e.g. kindergartens, offices and schools) during a pandemic/epidemic outbreak?



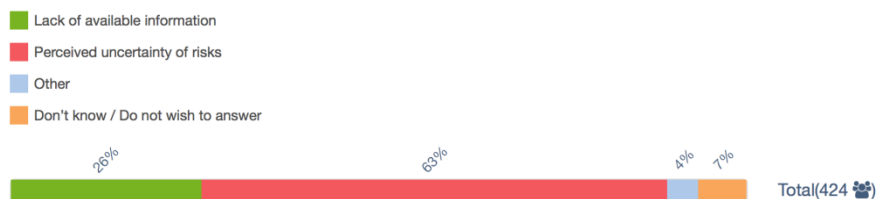
Should authorities cancel large international events, like the Olympics, during an outbreak of an epidemic or a pandemic?



What should be the principle of distribution of scarce resources (e.g. medicine) during an epidemic/pandemic outbreak?



What do you think is the main reason that vaccine covers of pregnant women tend to lag behind the general population?

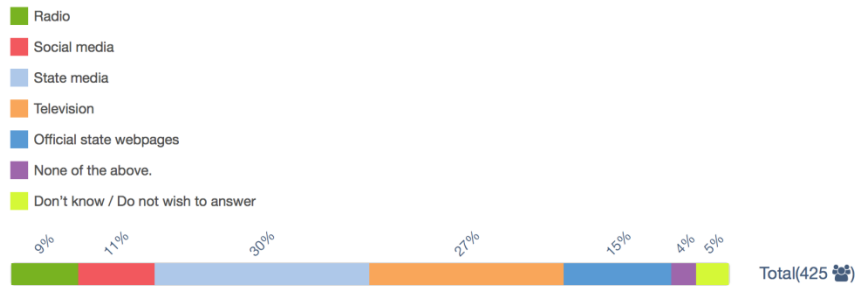


## 2. Communication between citizens and public health authorities

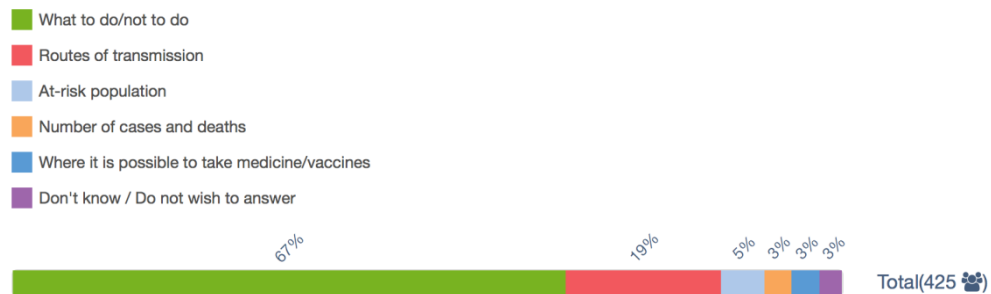
Are you satisfied with the information from public health authorities during epidemic threats like Zika?



During a pandemic or epidemic outbreak, what kind of communication channels would you prefer public authorities to use?



What is the most important information about a pandemic that you need from the public health authorities?



Should public health authorities devote more resources to collect information (questions, opinions, worries, etc.) from citizens during pandemics threats?



### 3. Transparency in public health

During a pandemic outbreak like the 2009-2010 influenza pandemic, are you comfortable with certain information not being publically available for security purposes?



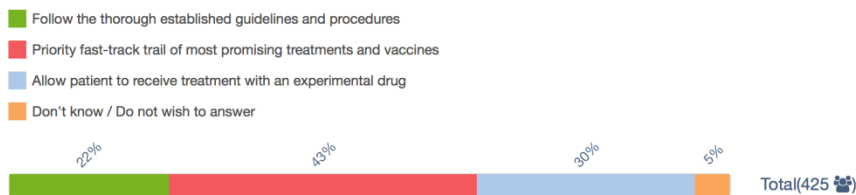
Should dialogue processes like ASSET be arranged in the future work with pandemic and epidemics response and preparedness?



Do you think that all relationship with vaccine manufacturer should be declared and publicly available?



During epidemic outbreaks like the Ebola virus disease, how should public health authorities work with new epidemic drugs and vaccines?



## 4. Access to knowledge

Do you think scientific studies in the field should be published and promoted if there is a large degree of uncertainty about the results?

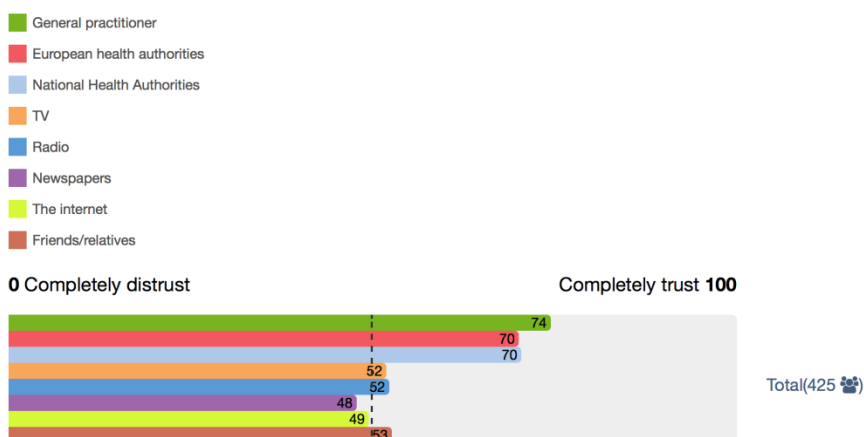




### When you are ill who do you consult first?



### How much do you trust each of the following sources of information regarding the recent Zika epidemic?

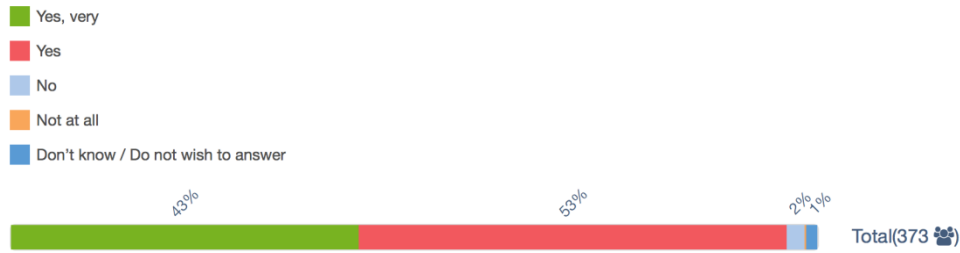


### What is the best way to provide information in times of pandemics/epidemics?



## Evaluation

Were the briefing materials and videos balanced and informative?



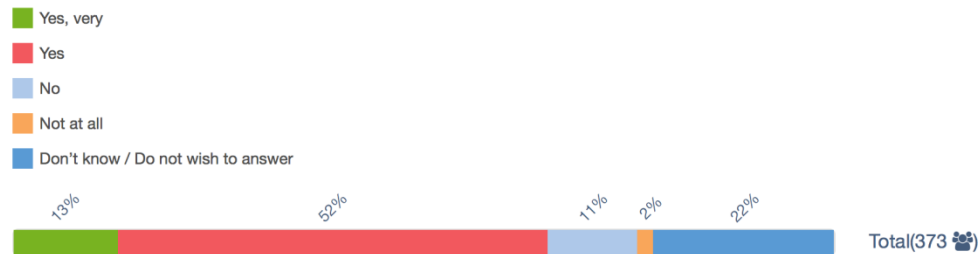
Were different and opposing views presented and discussed at your table?



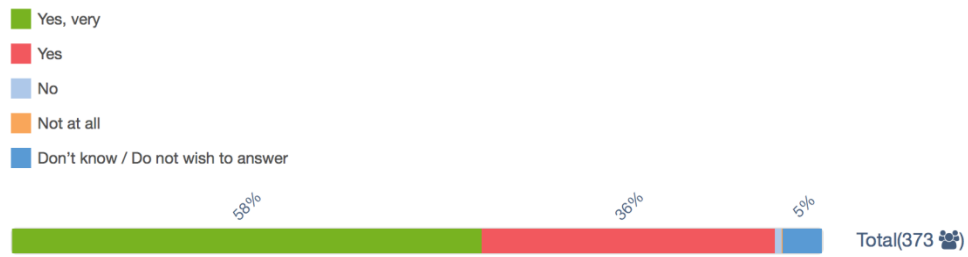
Are you generally satisfied with the organisation of the ASSET Citizen Consultation in your country?



Do you believe that the ASSET results will be used in a meaningful way for political decision making?



Should global dialogue processes like ASSET be arranged in the future on different and/or similar issues?



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## Back page

- Trust in information
  - The GPs should be trained to adapt to the changing society, and decision-makers should be urged to be visible and present at the internet, as the use of the internet is increasing
- Risk Communication
  - Build a transparent and clear risk communication to restore trust towards society
- Pregnancy and vaccination
  - Update, clarify and standardize influenza vaccination advice materials for pregnant women
- Ethics
  - In an emergency situation, public health interests should infringe upon the individual freedom
- Citizens' voices
  - The citizens believe that honesty and transparency can increase the public trust (no matter how bad the situation is), and that it is their right to know and understand the accurate situation
- Lessons learned and Citizen Participation
  - Public health authorities should devote more resources to collect citizen's input to policies on epidemic preparedness and response



### ASSET

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



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

