

Boosting Citizen Science in EU Health Research

March 2019

Objectives:

The purpose of this survey is to gather feedback from citizens about the suitability of several Public Engagement (PE) strategies to be applied for boosting citizen science in EU health research.

The results of this survey will be used as input for further discussion in a focus group between key experts in the field and will also be included in the report "Guidelines for implementing FAIR open data policy in health research" as part of the work developed within the FAIR4Health project.

You could find further information about FAIR4Health in this link: <https://www.fair4health.eu>

In case you have further questions, we encourage you to contact the FAIR4Health coordination team making use of the form embedded in this link: <https://www.fair4health.eu/en/contact>

References:

[1] European Commission/EACEA/Eurydice, 2018. *The Structure of the European Education Systems 2018/19: Schematic Diagrams*. Eurydice Facts and Figures. Luxembourg: Publications Office of the European Union. doi:10.2797/302115

[2] Mikko Rask, Saulé Maciukaitė-Zvinienė, Loreta Tauginienė, Vytautas Dikcius, Kaisa Matschoss, Timo Aarrevaara, Luciano D'Andrea. 2016. *Innovative Public Engagement: A Conceptual Model of Public Engagement in Dynamic and Responsible Governance of Research and Innovation*. Deliverable D2.2 of the PE2020 project. Available at: <https://pe2020.eu/wp-content/uploads/2016/05/Innovative-Public-Engagement-FINAL-1.pdf>

Just a bit about you:

Are you a citizen of the European Union?

- Yes
- No

Please, indicate your educational level¹:

- I don't want to disclose it
- ISCED 1: Primary education (up to 10-13 years old)
- ISCED 2: Lower secondary education (up to 14-16 years old)
- ISCED 3: Upper secondary education (up to 18 years old)
- ISCED 4: Post-secondary non-tertiary education
- ISCED 5: Short-cycle tertiary education
- ISCED 6: Bachelors' or equivalent level
- ISCED 7: Masters' or equivalent level

Please, indicate which of the following roles better defines you (choose all that apply):

- General Audience (Patient/Citizen)
- Healthcare professional
- Health Informatics professional
- Member of Ethics Committee
- Scientific researcher
- Decision-maker in public or private companies
- European Commission Representative
- Public Health Representative
- Other: _____

¹ According to the International Standard Classification of Education (ISCED 2011). More info at: <http://bit.ly/ISCED2011>

Public engagement mechanisms:

Please rate from 1 (very low) to 5 (very high) the suitability of the following PE mechanisms for boosting citizen science in EU health research:

Public communication: The aim is to inform and/or educate citizens. The flow of information constitutes one-way communication from sponsors to public representatives, and no specific mechanisms exist to handle public feedback (examples include public hearings, public meetings and awareness raising activities).

Suitability of public communication	1	2	3	4	5
-------------------------------------	---	---	---	---	---

Public consultation: The aim is to inform decision-makers of public opinions on certain topics. These opinions are sought from the sponsors of the PE initiative and no prescribed dialogue is implemented. Thus, in this case, the one-way communication is conveyed from citizens to sponsors (examples include citizens’ panels, planning for real and focus groups).

Suitability of public consultation	1	2	3	4	5
------------------------------------	---	---	---	---	---

Public deliberation: The aim is to facilitate group deliberation on policy issues of where the outcome may have an impact on decision-making. Information is exchanged between sponsors and public representatives and a certain degree of dialogue is facilitated. The flow of information constitutes two-way communication (examples include ‘mini publics’ such as consensus conferences, citizen juries, deliberative opinion polling).

Suitability of public deliberation	1	2	3	4	5
------------------------------------	---	---	---	---	---

Public participation: The aim is to assign part or full decision-making-power to citizens on policy issues. Information is exchanged between sponsors and public representatives and a certain degree of dialogue is facilitated. The flow of information constitutes two-way communication (examples include co-governance and direct democracy mechanisms such as participatory budgeting, youth councils and binding referendums).

Suitability of public participation	1	2	3	4	5
-------------------------------------	---	---	---	---	---

Public activism: The aim is to inform decision-makers and create awareness in order to influence decision-making processes. The information flow is conveyed in one-way

communication from citizens to sponsors but not on the initiative of the sponsors as characterises the 'public consultation' category. (Examples include demonstrations and protests).

Suitability of public activism	1	2	3	4	5
--------------------------------	---	---	---	---	---

THANKS FOR BOOSTING THIS RESEARCH!