

FAIR Health

Results of Open Survey on Boosting Citizen Science in EU Health Research

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Document Information

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1. Introduction

As part of the FAIR4Health project (www.fair4health.eu), there is a need to perform a comprehensive analysis of current barriers, facilitators and potential overcoming mechanisms in EU for the implementation of a FAIR data policy in health research institutions. Information from all the different domains involved (technical, ethical, security, legal, cultural, behavioural and economic) is being gathered in order to inform a guideline directed towards providing the optimal strategy for implementing this FAIR open data policy in EU health research institutions.

In this context, the task T2.7. “Boosting citizen science for FAIR data generation in health research” addresses the perceived suitability of public engagement mechanisms and strategies that may leverage citizen participation in health research based on the report “Innovative Public Engagement: A Conceptual Model of Public Engagement in Dynamic and Responsible Governance of Research and Innovation” from the PE2020 project. The Open Survey on boosting citizen science in EU health research was released in April 2019 and disseminated among all stakeholders involved in the health data workflow, ranging from citizen/patients to medical doctors and researchers.

The survey was released in 9 languages: English, Spanish, French, Italian, Portuguese, German, Dutch, Serbian and Turkish. All questions were designed on a voluntary basis. This means that it was possible to complete the survey without filling out all the questions.

At the end of this report you can find an Annex including the Open Survey on boosting citizen science in EU health research. The full survey in English is also available in PDF format in the following link: <https://osf.io/czbmj/>

In order to facilitate its dissemination and collecting of responses, the survey was adapted to an online format making use of the Google Forms® tool. It is also available at: <http://bit.ly/FAIR4Health-Citizen-Science>

2. 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, jointly with other reports, to inform a discussion in a focus group between key experts in the field and will be included in the deliverable D2.3. “Guidelines for implementing FAIR open data policy in health research” as part of the work developed within the FAIR4Health project and will be released later this year (2019).

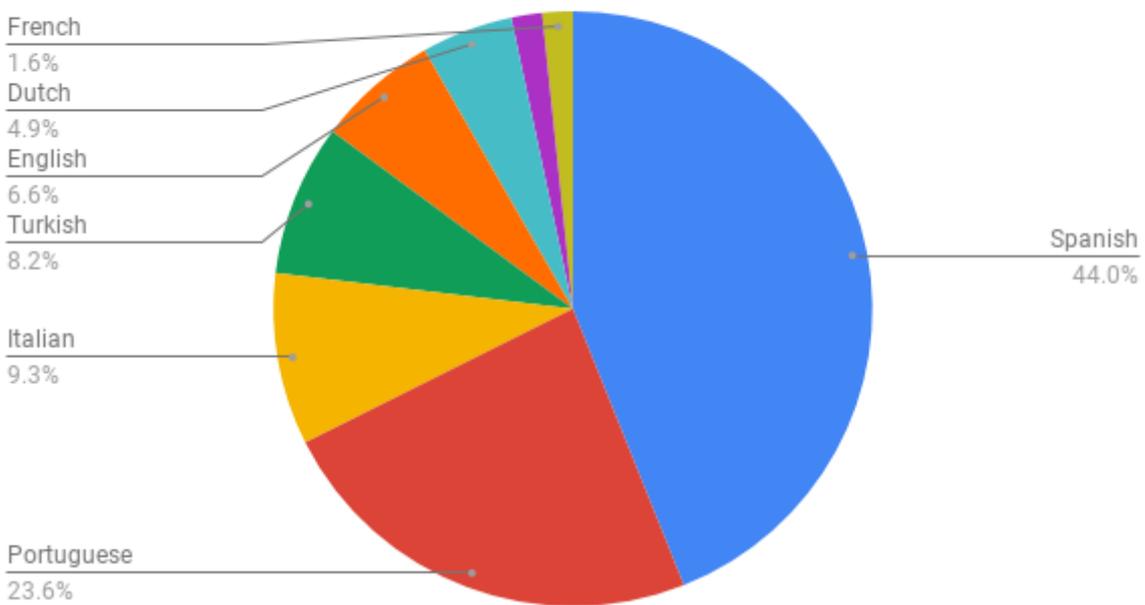
3. Final results

In total, 182 respondents submitted the survey.

Language chosen: Total responses: 182

	N	%
Spanish	80	43.96%
Portuguese	43	23.63%
Italian	17	9.34%
Turkish	15	8.24%
English	12	6.59%
Dutch	9	4.95%
German	3	1.65%
French	3	1.65%
Serbian	0	0.00%

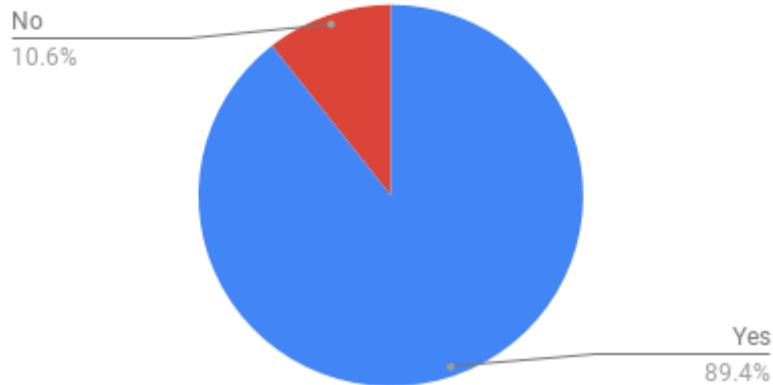
Language chosen



Are you a citizen of the EU? Total responses: 179

	N	%
Yes	160	89.39%
No	19	10.61%

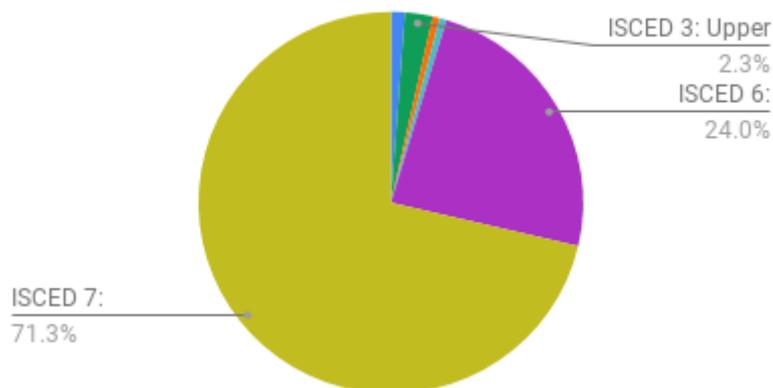
EU citizen?



What is your educational level? Total responses: 171

	N	%
I don't want to disclose it	2	1.17%
ISCED 1: Primary education (up to 10-13 years old)	0	0.00%
ISCED 2: Lower secondary education (up to 14-16 years old)	0	0.00%
ISCED 3: Upper secondary education (up to 18 years old)	4	2.34%
ISCED 4: Post-secondary non-tertiary education	1	0.58%
ISCED 5: Short-cycle tertiary education	1	0.58%
ISCED 6: Bachelors' or equivalent level	41	23.98%
ISCED 7: Masters' or equivalent level	122	71.35%

Educational level

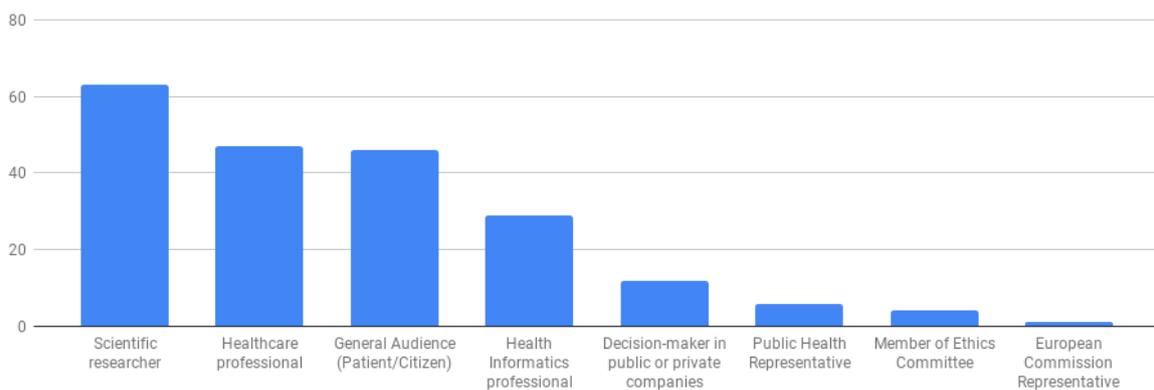


Please, indicate which of the following roles best defines you (choose all that apply).

Total responses: 182

	N	%
Scientific researcher	63	34.62%
Healthcare professional	47	25.82%
General Audience (Patient/Citizen)	46	25.27%
Health Informatics professional	29	15.93%
Decision-maker in public or private companies	12	6.59%
Public Health Representative	6	3.30%
Member of Ethics Committee	4	2.20%
European Commission Representative	1	0.55%

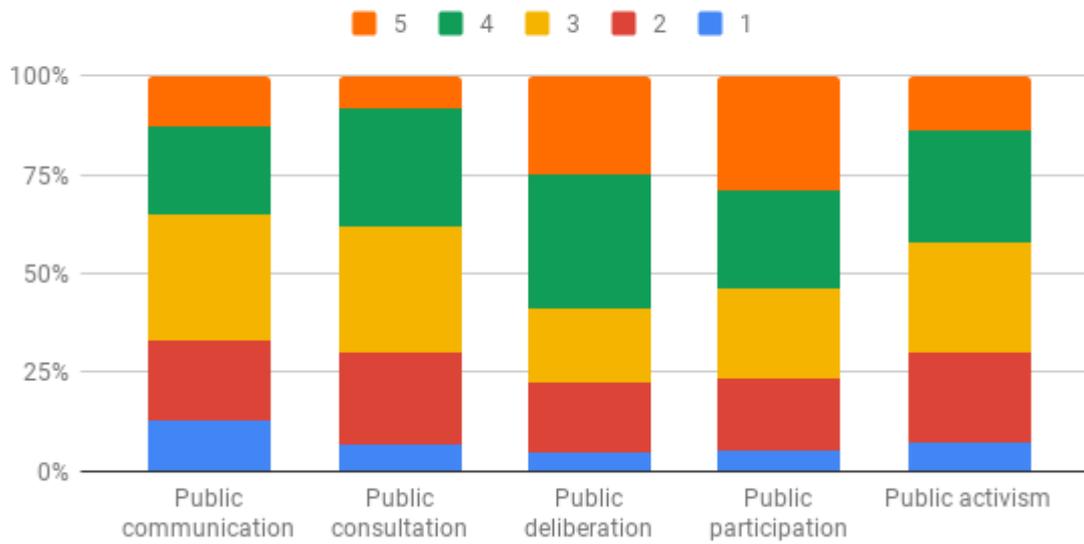
Respondents' profile



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

	1	2	3	4	5	Avg	Std	N
Public communication	22	34	54	38	22	3.024	1.457	170
Public consultation	12	42	57	53	15	3.095	1.231	179
Public deliberation	8	32	34	61	45	3.572	1.375	180
Public participation	9	33	41	45	52	3.544	1.415	180
Public activism	13	40	50	50	25	3.191	1.317	178

Suitability of PE mechanisms



According to the results of this open survey, the most suitable PE mechanisms for boosting citizen science in health research is **Public Deliberation** (3.572 ± 1.375) closely followed by **Public Participation** (3.544 ± 1.415), while the least suitable one is Public Consultation (3.024 ± 1.457).

Annex: Open Survey on Boosting Citizen Science in EU Health Research

Open Survey on 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:

1. Are you a citizen of the European Union?

- Yes
- No

2. Please, indicate your educational level:

- 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

3. 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: _____

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:

4. 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
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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
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6. 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
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7. 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
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8. 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
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THANKS FOR BOOSTING THIS RESEARCH!