

Survey Citizen Science for Health

Introduction to the survey

What is Citizen Science for health?

Citizen Science has great potential to contribute to society and to innovative research. It has come to be understood as an approach that involves citizens in knowledge production, valuing their multiple capacities to document, reflect and act upon pressing societal issues, and to generate outcomes and impacts that are well suited to specific local conditions.

Even though citizen and patient engagement in health research has a long tradition, citizen science is a relatively underdeveloped branch in the health domain. Traditionally, patients are often included in health research programming. However, their involvement is much less developed in domains like decision-making on specific research questions, in methodology development, data collection, analysis and the development of conclusions and recommendations, or in new role definitions. Yet, in recent years, a new generation of citizen and patient involvement in health research is growing. Sometimes their involvement is an implicit part of established programmes. At the same time a substantial amount of citizen engagement with health research occurs off the beaten institutional track.

As a testimony of the diversity of citizen engagement in health research, we witness, for example, citizens playing a part in research on public health issues, community health, fundamental health research, Quantified Self and Personal Health Science.

Purpose of this survey

This survey aims to make the (inter)national diversity of Citizen Science in the Health domain more visible and identify possible avenues to strengthen their significance. More specifically, the purpose of this survey is to get a better view on:

- a) the diversity of stakeholders involved
- b) the diversity of projects that identify themselves Citizen Science for Health
- c) the conditions that hamper or facilitate their impact for science and society
- d) their needs for support.

This survey is organized by the Working Group Citizen Science for Health, which is part of the European Citizen Science Association. For more information on the survey and the Working Group: see our website. <https://peer-produced.science/cs4h/>

The privacy of your responses to this survey will be addressed in the first question of this survey. You can read the full privacy statement here. <https://peer-produced.science/cs4h/>

You are about to start the survey. The Survey contains 5 parts, and should take you between 10 to 20 minutes.

About yourself

1. We guarantee the confidential handling of the data you provide us with in this survey. This survey conforms to GDPR and has been approved by the ethical review board of the University of Twente (ethical approval #210928). Please check the 'I agree' box after reading the full statement on our website. If you do not agree with the statement, please do not fill in this survey. Read our privacy statement here: <https://peer-produced.science/cs4h/>
 - I agree
2. How old are you?
 - 18 - 25
 - 26 - 35
 - 36 - 45
 - 46 - 55
 - 56 - 65
 - 66 - 75
 - 76 or older
3. Which gender do you identify with?
 - Woman
 - Man
 - Non-binary
 - Other
4. What is your highest level of education?
 - Primary school
 - Secondary school
 - Higher education

5. What country do you live in?

- Austria
- Australia
- Belgium
- Bulgaria
- Croatia
- Republic of Cyprus
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- India
- Ireland
- Italy
- Latvia
- Lithuania
- Luxembourg
- Malta
- Netherlands
- Poland
- Portugal
- Romania
- Slovakia
- Slovenia
- Spain
- Sweden
- Switzerland
- United Kingdom
- United States of America
- Other

6. Is this also the country you work in? (either paid or volunteer work)

- Yes
- No

7. What country do you work in?

- Austria
- Australia
- Belgium
- Bulgaria
- Croatia
- Republic of Cyprus
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- India
- Ireland
- Italy
- Latvia
- Lithuania
- Luxembourg
- Malta
- Netherlands
- Poland
- Portugal
- Romania
- Slovakia
- Slovenia
- Spain
- Sweden
- Switzerland
- United Kingdom
- United States of America
- Other

Citizen science and you

Citizen Science has great potential to contribute to society and to innovative research. It has come to be understood as an approach that involves citizens in knowledge production, valuing their multiple capacities to document, reflect and act upon pressing societal issues, and to generate outcomes and impacts that are well suited to specific local conditions.

8. Were you familiar with the term citizen science before reading this description?
 - Yes
 - Yes, but I know it under a different name (please specify in the following question)
 - No
 - No, but I know the concept under a different name (please specify in the following question)
9. How would you label what we described as 'citizen science'?
10. Are you or have you been involved in citizen science?
 - Yes
 - No
11. Which of these descriptions fit your perspective best? Checkmark all the descriptions that apply to you.
 - I am a person with a health condition
 - I am a person without a health condition
 - I am a carer for or a family member of someone with a health condition
 - I am a patient advocate, representative or volunteer
 - I am a health professional
 - I am a researcher
 - I am a project manager for a citizen science project
 - I am a policymaker
 - I am an entrepreneur
 - Other
12. Are you professionally affiliated with a company, civil society organisation, hospital or research institution?
 - A civil society organisation
 - University or other research institution
 - Hospital
 - Industry
 - Government
 - I am not affiliated, I am an independent researcher
 - Other

Citizen science for health

13. Citizen science (CS) is characterized by many definitions, and is applied in many domains. There could potentially be some differences between citizen science in health compared to citizen science in other fields/areas. If you think there are differences, what do you think these are?

Please tick as many of the statements below as you think apply. You can choose more than one option.

- In health, citizens are more likely to be the subject of research than in other areas of CS.
- The quality of data in health is under more scrutiny than in other domains.
- The ethical requirements and consent mechanisms are of a different nature.
- The range of approaches and projects is larger than in other domains.
- The dynamics between stakeholders (e.g. patients, doctors, researchers) are more complex.
- Health institutions are more reluctant to embrace CS approaches compared to institutions in other fields.
- There is no marked difference between CS within and outside the health domain.
- I don't know
- Other

14. There is great variety in citizen science for health projects and it is helpful to map this diversity. Considering the CS projects you know of, what are the major aspects that most clearly differentiate citizen science for health projects from other citizen science projects? Please tick the two most important aspects.

- Agency: the driver of the project
- Purpose: the goal of the project
- Content: the domain within the health sector (e.g. care, cure, prevention, public health, etc)
- Impact: education, knowledge, change, empowerment etc
- Research phase: ideation, design, execution, analysis, documentation, dissemination
- Levels of participation: ranging from being informed, to being in the drivers' seat
- I have no idea
- Other

15. Considering the CS projects you know of, who are usually the principal actors driving the projects?

- Professional researchers
- Citizens
- I don't know
- Other

16. Are you or have you been involved in a health related citizen science project?

- Yes
- No

Citizen science for health: projects and practices

17. How many health related citizen science projects have you been involved in?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- Other

18. Which health related citizen science project(s) have you been involved in?

Please add titles of your most important projects, hyperlinks to websites etc. No lengthy descriptions needed.

19. Please name the one citizen science for health project you have been most involved with.
The following questions will relate to the project you enter here.

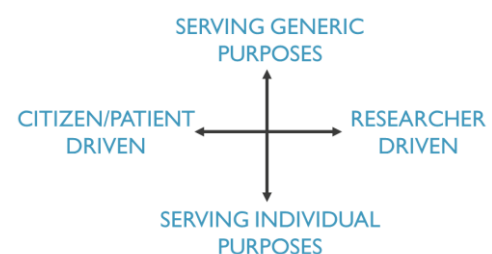
20. Are there any health related citizen science projects, that you yourself are NOT involved in, that should be highlighted for their exemplary value?

Please add titles of the most important projects, hyperlinks to websites etc. No lengthy descriptions needed.

21. In the citizen science for health project you have been most involved in, who are the principal actors driving it?

- Professional researchers
- Citizens
- Other

22. Agency and Purpose are important characteristics that can distinguish between citizen science projects. Looking at the graph shown here, where would you situate the citizen science for health project you have been most involved in?



- Upper right corner (researcher driven, oriented towards public goals)
- Upper left corner (citizen driven, oriented towards public goals)
- Lower left corner (citizen driven, oriented towards individual goals)
- Lower right corner (researcher driven, oriented towards individual goals)
- Other

23. Do you consider the project you have been most involved in to be successful or not?

- Successful
- Unsuccessful
- Not sure

24. What were the most successful aspects of the project? (max 3)

Please explain

25. What were the most unsuccessful aspects of the project? (max 3)

Please explain

26. Based on your experiences of the citizen science for health project you described above, what are the major conditions that you think need to be developed in order for health related citizen science projects to prosper?

Please scale each item from "not important at all" to "very important".

- DATA INFRASTRUCTURE to appropriately connect data of different sources (e.g. Real World Data, clinical data, etc), including issues such data quality, ownership, security, interoperability)
- adequate ETHICAL FRAMEWORKS and review procedures
- familiarity with / EDUCATION of (medical) PROFESSIONALS on CS
- Make the already EXISTING DIVERSITY of CS practices of citizens VISIBLE (unlocking the potential of citizens)
- ACCESS to HEALTH LITERATURE for citizens
- ACCESS of CITIZENS to their health records
- provision and development of TOOLING for CITIZENS conducting research (apps, ehealth devices, adequate research procedures etc)
- ACCESS to LAB FACILITIES for citizen/patients
- BALANCED 'RETURN on INVESTMENT' - BOTH researcher AND citizen/patient must be satisfied with participating in the project
- Publication / DISSEMINATION of research and results
- communication and LOBBY channels vis-a-vis POLICY makers
- development of a multistakeholder co-creative LEARNING INFRASTRUCTURE
- LEGISLATIVE frameworks (e.g. regarding eHealth tools, involvement of industry, or....)

27. Please write down any other condition you deem important in order for citizen science for health to prosper that is not in the list above.

28. In the future, which actors and/or organisations should be more involved in citizen science for health initiatives?

(tick the two most important actors. If you wish, you can specify or comment in more detail in the next question)

- Societal partners (Patient organisations, NGO's,...)
- Research institutions (universities,...)
- Companies (pharmacies, industry,...)
- Governmental bodies (government agencies, local, regional or (inter)national governments)
- Other

29. Please feel free to specify or elaborate on the selection you made in the previous question

Citizen science and COVID-19

30. Do you think that citizen science has played a role in tackling the COVID19 crisis?

- Yes
- No
- I don't know

31. In what ways did CS play a role in the COVID-19 crisis?

- Self testing of citizens on immunology markers.
- Unlock knowlegde of citizens on COVID-19.
- Self-tracking of early symptoms.
- I don't know.
- Other

32. In what ways did CS not play a role in the COVID-19 crisis, that it could have done?

- Self testing of citizens on immunology markers.
- Unlock knowlegde of citizens on COVID-19.
- Self-tracking of early symptoms.
- I don't know.
- Other

33. Which long-term opportunities do you see for citizen science to tackle treatment or prevention of pandemics like COVID-19 in the future?

34. Which citizen science projects do you know of that have played a role in tackling the COVID-19 crisis? Please add titles of your most important projects, hyperlinks to websites etc. No lengthy descriptions needed