

# Enhancing Health through Citizen Science

Report of an interactive workshop Citizen Science for Health at ECSA 2020

Green Paper on Citizen Science and Health 0.9

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## 1. Introduction

Citizen science as represented in the international citizen science community includes many work fields, in particular ecology, environment and geography. Health is relatively underrepresented, despite the fact that it is a diverse and promising domain with lots of potential for citizen science to contribute to innovative health research as well as to society. Looking at citizen science from different levels of participation and different types of health research is helpful to understand the variety of research projects.

Traditionally, patients are often included in health research programming; however, they are hardly or not at all engaged in decision making on specific research questions, in methodology development, data collection, analysis and the development of conclusions and recommendations, nor in new role definitions. In public health research, citizens are sometimes included in participatory action research, leading to responsive policies and interventions as well as to citizen empowerment. However, such research is seldom framed as citizen science and within public health research such (mainly qualitative) methods have less status and influence as compared to expert-based epidemiological approaches.

Another strand of citizen science health research lies in environmental health where citizens are mainly engaged as data collectors, e.g. in air pollution measurements. Finally, an important development is the emerging amount of work being done by patients themselves using a diversity of methods to answer personal questions. These include homebased 'kitchen table' food and lifestyle experiments, story writing and many others. Within this diversity, the field called personal science has methodological similarities with clinical  $n=1$  research and gained attention in the last decade through the Quantified Self community. Their output is meaningful and valuable at individual level. However, the integration of their efforts and results in the formal body of knowledge that informs health practice, is a big challenge. In sum, we recognize a great diversity of citizen engagement in health research, with different challenges and potentials for society.

With this in mind, at the 2020 ECSA international conference a special workshop 'Enhancing Health through Citizen Science' was hosted to explore this diversity and to sense into the need to strengthen collaboration among the actors engaged in any form of Citizen Science in the Health domain. The workshop was held on Tuesday 8 September 2020.

The convenors of the workshop represent the different strands of implementing Citizen Science in the Health domain.

This Green Paper brings together the results of the workshop.

The paper is divided into three sections:

- 1) Methodology
- 2) Outcomes
- 3) Conclusive remarks and steps forward.

## 2. Methodology

The interactive workshop was prepared by the authors of this Green paper. Based on their experiences with Citizen Science and Health in The Netherlands and abroad, they drafted a questionnaire covering three areas:

- A. Identification of respondents;
- B. Needs assessment of CS4H;
- C. (European) collaboration interests.

The questionnaire was implemented through Mentimeter, an interactive tool that makes live representation of the results possible. The questionnaire included closed and open ended questions. Projects on citizen science in the health domain were collected through an google doc, that was filled in by attendants of the workshop and conference.

## 3. Outcomes

### 3.1 Identification of the respondents

The workshop was visited at its peak by 39 participants, audience remained stable around 30. About two-thirds (64%) of the attendees worked in the health domain, one-third (36%) did not, but instead was curious to know what is happening in this domain. They represented a wide variety of countries:

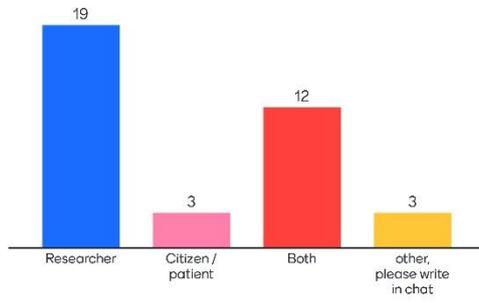


Figure 1 Answers to the mentimeter question "What country do you work in?"

About half of the attendees identified with a role as researcher (19 out of 37), a minority with a role as citizen or patient (3/37), about a third (12 out of 37) identified with both roles, and 3 had other roles. See figure 2

### A3. PERSPECTIVE: with what role do you identify most?

Mentimeter



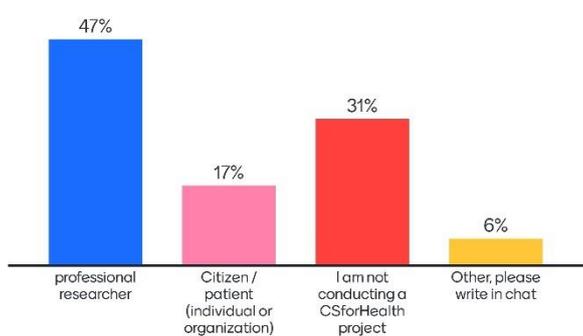
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Figure 2 Answers to the mentimeter question: "with what role do you identify most?"

When asked about the principal actor driving the project attendees worked in, the picture emerged as in figure 3.

### B5. In your CSforHealth project, who is the PRINCIPAL ACTOR driving it?

Mentimeter



36

Figure 3 Answers to the mentimeter question "Who is the principal actor driving your CSforHealth project?"

About a third of the respondents were not conducting a citizen science project in the health domain. Of the remainder 70%, professional researchers were the main drivers in about two-thirds of the group (47 out of 70%), versus a quarter of the projects being driven by citizens/patients (16/70), and about a tenth (8/70) had other drivers (unspecified).

### 3.2 Needs assessment of Citizen Science for Health

This section covered the main part of the workshop, and was designed to dive deeper into the specific nature and challenges of Citizen Science in the health domain.

#### Specificities of Citizen Science in the Health domain

Attendees were asked if they perceived a marked difference between Citizen Science in the Health domain as compared to other domains.

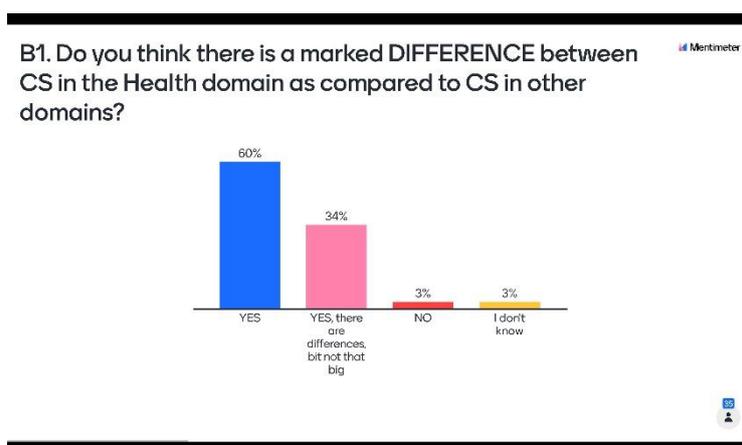


Figure 4 Answers to the mentimeter question "Do you think there is a marked difference between CS in the Health domain as compared to CS in other domains?"

The results show that a large majority feels that Citizen Science in the health domain has distinct features. About two-third believes these differences are marked, about one-third believes there are differences but not that big.

A number of issues were highlighted in which these difference reside.

Table 1. Answers to the mentimeter question "If you think there are differences, in what issues do these differences reside?"

Issue	Score
In the health domain, citizens as co-researchers can also be research subjects	26%
The quality of data in health is under more scrutiny than in other domains	17%
Ethical requirements and consent mechanism are of a different nature	34%
The range of approaches and projects is very large	15%
Dynamics of stakeholder engagement is more complex	1%
Other	7%

If we pull together the responses on the pre-given answers and the numerous open-ended answers in the category 'other', the following issues emerge as most important.

### **Roles and responsibilities of researchers and citizens**

In CS-health projects, the role of citizens as co-researchers can overlap with their role research object, in the sense that they may investigate themselves. This is much unlike CS projects in e.g. ecology or astronomy, in which citizens as researchers never investigate themselves.

At the same time, even when citizens do not investigate their own bodies or mind, as the attendees felt there is a greater responsibility and duty of care towards CS volunteers. Especially when they are patients, they can be very personally invested and sometimes vulnerable.

This brings with it the need to manage expectations well, and maybe better than in other domains. This regards the outcomes of the research, and also the support that can be given during the research process.

### **Nature and degree of participation**

There is a wide range of empowerment scenarios available with the health domain. 'Patient participation' and 'patient engagement' is a long standing theme with the health domain. Citizen Science brings a new angle to the table, in the sense that an ever more active role is being delineated for patients in their role as active researchers.

As health is an issue 'close to home', the motivation of participants can be very strong. For the same reason, attendees reckoned that mass involvement of the public in research can be far greater than in other domains.

### **Data quality and data sensitivity**

In the health domain, privacy of health data is under much more scrutiny than in other sectors. The integration of so-called Real World Data provided by health-apps, Facebook notes, health trackers etcetera, with clinical data, poses massive challenges as regards the quality, handling and governance of the data.

### **Ethics**

Citizen Science in Health is considered to pose challenges as regards research ethics. This is an issues that has been raised in a number of scientific papers already (Vayena, et al, 2016). The health sector is, on the one hand, characterized by innumerable procedures in order to protect citizens from maltreatment and abuse. On the other hand, the same procedures provide little autonomy to the individual citizens if he or she want to conduct research on him or herself. This means, people have the freedom to do what they want, but it will not be publishable research, as it will not pass medical ethical review boards. Even when patients align

with academics, such as is the case in the award winning Dutch proposal MyOwnResearch (2.6 Million Euro), ethical considerations of the review board eventually led to an abortion of the project. Parkinson patient Sara Riggare from Sweden could not defend her PhD on research conducted on herself, as it did not comply with the ethical requirements of the Karolinska Institute.

### **Stakeholder complexity and cultural and basic attitude of the medical sector**

Many observations of the attendees considered the hierarchical and paternalistic organization of the health sector. Especially in the domain of n-of-1 research, the sector is perceived to be less prone to engaging in new types of relationships and dynamics than in other domains. Even though there is ample discourse in the health sector about patient involvement in research, there is as of yet hardly any scope for patients to claim leading roles.

This basic attitude also transpires in the difficulty of acquiring funding for Citizen Science projects, especially when they challenge existing role definitions.

At the same time, the health sector is inherently complex, and can be recognized in the wide variety of stakeholders: medical doctors, medical researchers, legislative and ethical bodies, politics, commercial parties, health insurers, government, patient organisations, food industry, etc. This complexity is both an advantage (as in many ways to collaborate) and a challenge (as in lots of interdependencies that hamper progress).

#### Characterizing the diversity of Citizen Science project in Health

Mapping the diversity of CS projects in health is an issue under debate. Should it be done according to the degree of involvement of the volunteers / participants? Or the domain in which the project operates (care, cure, public health etc)? The questionnaire asked attendees to rank the following number of issues as to their potential to map the diversity best:

- *Levels of participation*: ranging from little demanding roles such as data monitoring to full control and leadership;
- *Content*: the domain within the health sector, like care, cure, prevention, public health etc);
- *Purpose*: the goal of the project;
- *Agency*: the driver of the project;
- *Domain of impact*: education, knowledge, social change, empowerment;
- *Research phase*: engagement depending on the phase of the research;
- *Other*

The results are given in figure 5.

Agency and Purpose emerged as the two most powerful issues to map the diversity of Citizen Science in Health, closely followed by Domain of Impact.

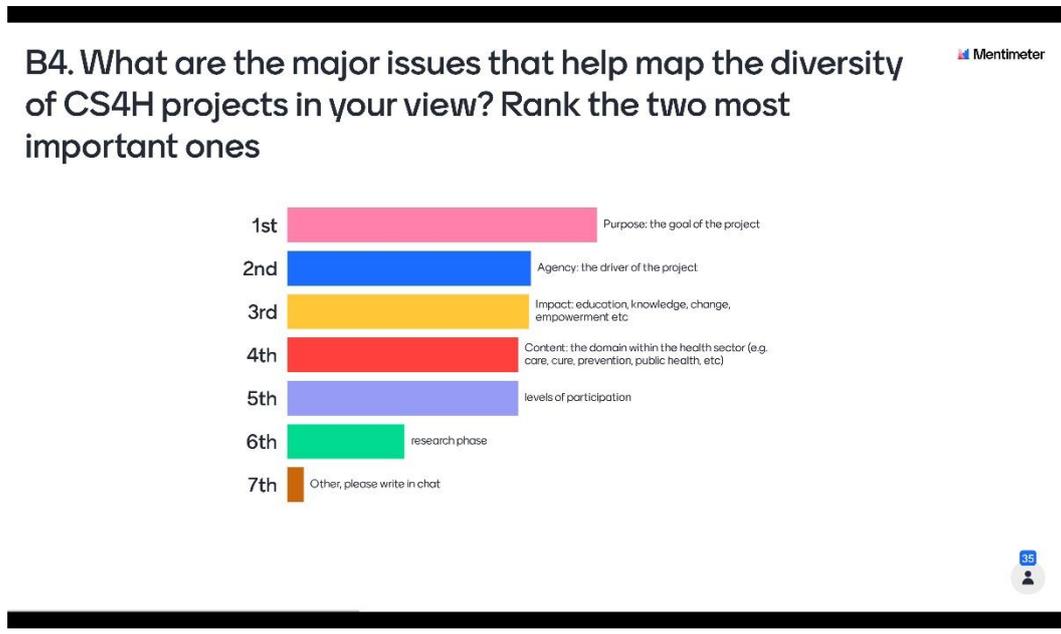


Figure 5. Answer to the mentimeter question "What are the major issues that help map the diversity of CS4H projects in your view? Rank the two most important ones."

As a follow-up question, attendees were asked to identify the projects they are involved in according to issues Agency and Purpose, providing a graph with four quadrants. The horizontal axis in the graph represents Agency, and ranges from project driven by citizens, patients or others in non-professional roles such as informal caretakers, to projects driven by researchers and/or professional experts such as policy makers. The vertical axis represents Purpose, ranging from projects exclusively serving individual purposes to those serving generic purposes. See figure 6.

## B6. Keeping in mind the graph as shown in the previous slide, where do you situate your project?

Mentimeter

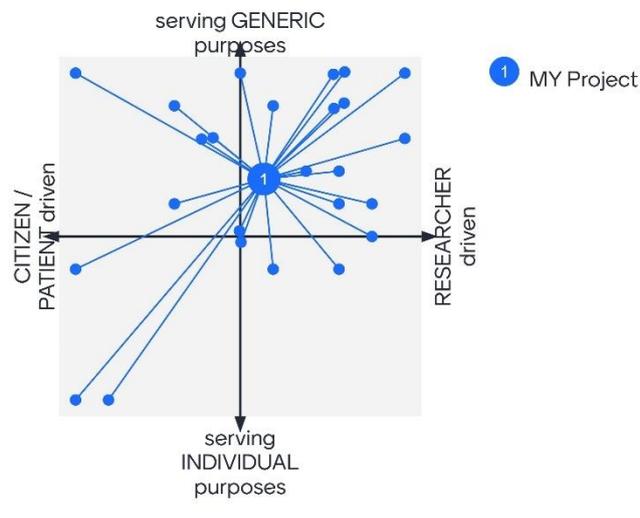


Figure 6. Response to the mentimeter question: "where do you situate your project is you need to position it along the axis of Agency and Purpose?"

The graph shows that most of the attendees projects have their point of gravity in researcher-driven project that focus primarily on serving generic purposes (think of community health projects, many mHealth projects, air pollution measurements (iSpex), Foldit etc). It is believed that especially the projects in the lower left quadrant remain under represented (think of home based patient experimentation with food and lifestyle, QS, Personal Science etc). This is inherent to the nature of these projects, as they tend to serve primarily individual purposes and are less visible. The convenors believe that one of the major challenges of Citizen Science in Health is to draft projects that attend both individual and generic purposes, ideally in a collaborative mix between researcher involvement and citizen involvement.

The main virtue of the graph is that it provides more symmetry in the relation between actors: citizens might engage in projects driven by researchers, and vice versa, researchers might engage in project driven by citizens. The graph also highlights a specific feature of Citizen Science in the health domain. More than in other domains, the individual level emerges as a level were meaningful Citizen Science can be conducted – as was observed in the previous section. At the same time, it implicitly addresses the issue of reciprocity and value. A Citizen Science project in which participating citizens and researchers are not getting enough of it, has a potential challenge in making more tangible and explicit how and what kind of individual and collective purposes are being served.

### Success factors

Attendees were in general positive about the success of the CS projects they participated in, and rated the success almost 5 on a scale from 0 to 7.

Attendees were asked to identify the success (Table 1) and failure (Table 2) factors in their respective project.

*Table 2 Items (success factors) based on the collection of answers (specification).*

<i>Success factor</i>	<i>Specification</i>
Patient/citizen involvement/engagement	<ul style="list-style-type: none"> <li>• Long term cooperation and good relations with the citizens organisation</li> <li>• High level of active participation!</li> <li>• Diversity of involved citizen</li> <li>• Deeper connection with communities and association when planning research</li> <li>• Community involvement</li> <li>• Involvement of patients as researchers made an epistemic difference</li> <li>• Participants prioritising research question/purpose, clear agency, achievable outcomes</li> <li>• Also from pharma side it has even become necessary to get input from the patients</li> <li>• Involve citizen in different research phases</li> <li>• Listen to citizens and really want to understand what they need</li> <li>• Truly listening, if you wish patients to participate.</li> </ul>
Collaboration among wider stakeholders	<ul style="list-style-type: none"> <li>• Dedication and tenacity of stakeholders</li> <li>• Willingness from different stakeholders to jump in such an innovative project</li> <li>• Engagement/buy-in of key stakeholders/policy-practice partners</li> <li>• Closer collaboration with diff stakeholder (which takes time!!!)</li> <li>• Stakeholder engagement</li> <li>• clarity about role of research institute</li> <li>• Appreciation of qualities and input if other stakeholders</li> <li>• Teamwork</li> <li>• Transdisciplinary research team</li> <li>• Effort of project team</li> </ul>
Relevance	<ul style="list-style-type: none"> <li>• Relevance to citizens - providing them with data and information that they can use to manage risk whilst also providing research data to influence policy change</li> <li>• Participants are satisfied and want to continue</li> <li>• Including all aspect of the issue</li> <li>• Relevance to patients</li> <li>• Patients unmet need</li> <li>• Added value to all of us</li> </ul>

	<ul style="list-style-type: none"> <li>• Relevance to citizens providing data that can be used to change behaviour and reduce risk</li> <li>• High usability of results in health politics, patient care, and self-help</li> <li>• High practical relevance and empirical realism of the results</li> </ul>
Methodology	<ul style="list-style-type: none"> <li>• New type of research</li> <li>• Good research design</li> <li>• Research co-creation</li> </ul>
Marketing & communication	<ul style="list-style-type: none"> <li>• Promotions, science communication, media releases</li> <li>• Science communication is interesting, informative, and timely</li> <li>• Winning awards (which you have to apply for yourself as the CS4H practitioner)</li> <li>• Government is looking for innovations in this area</li> </ul>
The results made it successful	<ul style="list-style-type: none"> <li>• Citizen empowerment</li> <li>• Personal transformative experience for participants</li> <li>• Changes in perspective occur in the different parts</li> </ul>
COVID-19	<ul style="list-style-type: none"> <li>• Covid-19 as it showed how fast the maker community can react and produce PPE</li> </ul>

Table 3 Items (failure factors) based on the collection of answers (specification).

<i>Failure factor</i>	<i>Specification</i>
Citizen commitment/engagement	<ul style="list-style-type: none"> <li>• Citizen commitment/engagement</li> <li>• Com Citizen commitment/engagement</li> <li>• Community engagement</li> <li>• Patient involvement</li> <li>• Participant response</li> <li>• How to involve citizens successfully?</li> <li>• Retention of participants</li> <li>• Difficulties engaging citizen scientists to take part in community engagement</li> <li>• Patient involvement</li> <li>• Participant response</li> <li>• How to involve citizens successfully?</li> <li>• Retention of participants</li> <li>• Difficulties engaging citizen scientists to take part</li> </ul>
Collaboration	<ul style="list-style-type: none"> <li>• Cocreation with several institutions</li> <li>• Getting public health service on board</li> <li>• Lack of true recognition of patient knowledge, lots of compliments, but not translated into real commitment</li> <li>• Long term collaboration</li> <li>• Lack of upper management understanding the limitations (time, funding, science communication, etc) and issues</li> </ul>
Ethics	<ul style="list-style-type: none"> <li>• Conflict with ethical review board</li> <li>• Issues with ethics</li> <li>• Ethic issues</li> <li>• Difficulty with ethical committee to accept the study type. It is not fitting in the regular ways of research</li> </ul>
Complexity	<ul style="list-style-type: none"> <li>• Complexity of broad health issues</li> <li>• Research questions of citizens that are relevant but difficult to answer</li> <li>• How to make sure to push research of good quality</li> <li>• Change in purpose</li> </ul>
Implementation	<ul style="list-style-type: none"> <li>• Finding a good balance between individual outcomes vs generic outcomes</li> <li>• Not enough transformation of results into concrete actions/new policies, etc.</li> <li>• Lack of upper management understanding of citizen science outcomes</li> </ul>
Funding	<ul style="list-style-type: none"> <li>• Funding</li> <li>• Funding ends when many things can still be done</li> <li>• Funding to implement project longterm funding</li> </ul>
COVID-19	<ul style="list-style-type: none"> <li>• Covid-19 access to citizens</li> <li>• Pandemic came up and derailed project</li> <li>• Covid19 prevented people from participating</li> </ul>

Most strikingly, several issues appear to be both enablers and disabler. So, much depends on the quality of the engagement of citizens and the community with the project and on the quality of the collaboration within the team and the wider stakeholder are both engagement the collaboration with stakeholders. The relevance of the project to the citizens / patients seems to be an important issue too.

#### Conditions that help prosper Citizen Science for Health

Attendees were asked to rank a number of pre-formulated issues that need to be developed in order for citizen science for health to prosper. The results are given in table 4.

*Table 4. Conditions that need to be developed to make CitizenScience for Health prosper ((The range of the rating scale is 0 (not important) to 5 (very much needed)).*

<b>Condition</b>	<b>Rating</b>
Adequate ETHICAL FRAMEWORKS and review procedures	4.7
BALANCED 'RETURN on INVESTMENT' - BOTH researcher AND citizen/patient must be satisfied with participating in the project	4.5
Provision and development of TOOLING for CITIZENS conducting research (apps, ehealth devices, adequate research procedures etc)	4.4
Development of a multistakeholder co-creative LEARNING INFRASTRUCTURE	4.4
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)	4.2
ACCESS of CITIZENS to their health records	4.2
Publication / DISSIMINATION of research and results	4.1
Development of appropriate RESEARCH METHODS including STATISTICS (including the upgrading n-of-one observations to insights at group level)	4.0
Communication and LOBBY channels vis-a-vis POLICY makers	4.0
Make the already EXISTING DIVERSITY of CS practices of citizens VISIBLE (unlocking the potential of citizens)	3.9
Familiarity with / EDUCATION of (medical) PROFESSIONALS on CS	3.8
LEGISLATIVE frameworks (e.g. regarding eHealth tools, involvement of industry, or....)	3.8
ACCESS to HEALTH LITERATURE for citizens	2.9
ACCESS to LAB FACILITIES for citizen/patients	2.9
OTHER (possibility to specify)	2.3

The result do not show a very marked difference between the issues raised. Yet, some issues can be highlighted.

On top of the list we find ethics, which is currently seen as a major impediment to the flourishing of Citizen Science in Health. Next to that, creating a level of benefits that is satisfactory for both researchers and citizens is deemed crucial. This aspect relates immediately to the success factor 'relevance', as raised in the previous section: the perceived relevance or value for the participant is key. Next, there are a number of technical issues regarding data and data infrastructure that need to be sorted out. This includes the provision of tools to citizens and patients to be able to actively monitor and engage in data sampling and analysis. Although access to lab facilities is ranked lower, we would understand that this could be part of the tooling too. Adequate research methods and statistics also was ranked high.

Clearly, given the complexity and the challenges, attendees valued very much the establishment of a learning infrastructure or community. Given the observations under 'other', education of students and professionals on CS4H was considered part of it. In the same 'other' section, *governance* showed up as an important aspect, especially as regards the involvement of patients / citizens in the design phases of the research. One respondent summarized it as 'citizens in the driver seat'. *Political support*, expressed as 'sustained support from funders', 'recognition by the research institutes that CS as a credible research option and way forward' or 'embedding CS in the core of the research institutions and regulatory health organisations' is deemed important.

### 3.3. Collaboration interests

The attendees were asked to estimate the number of professionals and citizens engaged in or developing any type of citizen science for health project in their respective countries. See results below.



Figure 7. Answers to the mentimeter questions "Do you have an idea how many professionals and citizens are engaged in CS4Health projects in your country?"

A majority (about 60%) admitted they did not have a clue. This underlines the fact that citizen science in the health domain is a largely underdeveloped area of research.

The questionnaire showed an overwhelming YES to the question whether there was an interest to connect more with other CS4H projects in Europe (29 out of 30).

Some 93 % of the attendees would be interested in a Special Interest Group On Health within ECSA. See figure 8.

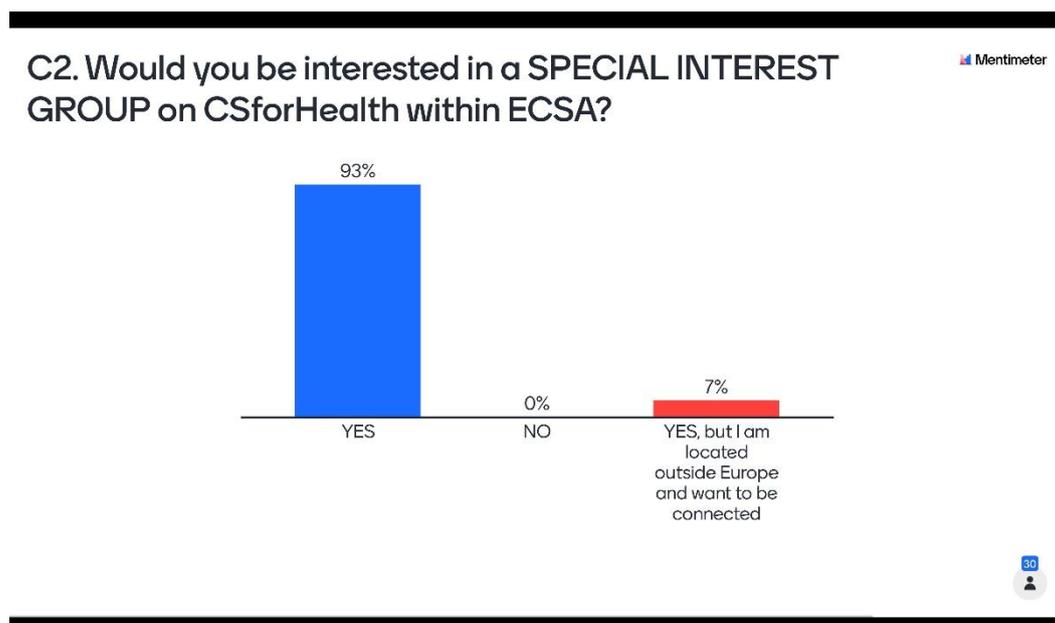


Figure 8. Answers to the mentimeter question "Would you be interested in a special interest group on CS for Health within ECSA?"

### Topics for collaboration

Topics for collaboration were asked for in an open ended structure. In general, the working group is seen as a 'point of reference to engage with each other as CS-practitioners, to learn from each other's approaches, and to join forces to influence policy makers and research institutes'. It is seen as a relevant node for networking, to speed up learning, to develop common CS4H projects and to showcase the potentials and pitfalls of CS. See below for the list of issues for collaboration and exchange.

As topics for collaboration, the following list emerged.

Table 5. Potential topics for collaboration

<i>Issues</i>	<i>Specifications</i>
Methodology development	<ul style="list-style-type: none"> <li>• Citizen science research methods and outcomes</li> <li>• Different methods, validation of CS, and more general what people are doing.</li> <li>• Common methodologies to follow / common tools that can be shared</li> <li>• How to apply citizen science in health contexts,</li> <li>• How to deal with citizen's data</li> <li>• How to work together with different disciplines and how to reach the public</li> </ul>
Positioning of CS4HEALTH	<ul style="list-style-type: none"> <li>• Visibility of the diversity and complementarity of CS4Health approaches</li> <li>• Exchange of success stories (what works and how can we make use of that in other projects)</li> <li>• Framing the borders of what is (and isn't) CS in the health context.</li> <li>• Location to share best practice</li> <li>• Collaboration for funding opportunities</li> <li>• Collaboration to develop joint projects</li> <li>• Activism and CS</li> <li>• Transformation of results into new policies</li> </ul>
Ethics and legal issues	<ul style="list-style-type: none"> <li>• Ethical issues</li> <li>• Ethical regulations</li> <li>• Legal issues</li> <li>• Health-related legislation</li> </ul>
Specific topics for collaboration	<ul style="list-style-type: none"> <li>• Covid-19</li> <li>• Multiple health problems</li> <li>• Air quality and health</li> <li>• Health promotion, linking to nature-based solutions, healthy living style, etc.</li> <li>• Social relation vs care relation with families, friend groups</li> <li>• Mental issues</li> <li>• I would like to see collaboration happen across a broad range of medical and scientific fields (not just epidemiology, entomology but cancer etc)</li> <li>• High school pupils CS projects</li> <li>• Community health in different cities</li> </ul>

#### 4. Conclusive remarks and steps forward

The health domain presents distinctive features as compared to other domains when engaging in Citizen Science. More than in other domains, the individual level and attached roles and responsibilities, emerge as a meaningful area for Citizen Science. This might explain why Agency and Purpose came out as useful angles to differentiate among Citizen Science projects in Health.

As convenors, we would argue that some of the conditions needed to help CS prosper, would differ according to the combination of Agency and Purpose of a specific project. For example, the ethical challenges in Personal Science projects (lower left quadrant) are different from the ethical challenges in community health initiatives (upper right quadrant).

The conditions that need further development in order to progress CS in health are diverse and pertinent, and are interdependent.

The survey highlighted the interest among participants to join forces. We conclude that there is enough reason to explore further the establishment of a special working group on Health within ECSA.

We believe there are a few options to explore:

- Extend the survey among a broader network in Europe;
- Produce a paper on the distinctiveness of CS in health;
- Propose an ECSA working group at the General Assembly of 27 November 2020;
- Characteristics of the Working Group:
  - 'Light' management (any volunteers?);
  - Following principles of a Community of Practice, notably:
  - Those who wish to bring an issue further, convene and prepare a session through the working group;
  - The Working Group management establishes a simple rhythm of online meetings