

# **Citizen Science in Health Research**

Perspectives, challenges and opportunities

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**Michiel LAMMENS**

Promotor: dr. Luk BRUYNEEL  
Copromotor: dr. Annelies DUERINCKX  
Werkbegeleider: dhr. Jef VAN LAER

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## Abstract

Citizen science, a participatory research method that engages non-professional individuals as co-researchers, has gained significant attention in various scientific domains. It remains however underexplored in health research. This study explores to what extent citizen science is used in health research, which methodologies are utilized, and what the stakeholders' perspectives are on the opportunities and challenges of citizen science in health. A scoping review of Pubmed found 689 articles of which only 108 were included. Many articles were out of scope as they revolved around environmental health and ecology, or did not apply a citizen science approach according to a predefined definition. The Pubmed and grey literature search identified 75 citizen science health projects, mostly within the biomedical research domain. Citizens were most often involved in data collection and analysis within biomedical research, and co-creation and design within health services research. The number of publications has risen over the last decade. Interviews with ten citizen science and/or health experts revealed positive attitudes towards citizen science in health, citing benefits such as increased research relevance, enhanced health literacy among citizens, and improved public trust in science. Challenges encompassed vagueness in defining citizen science in health, lack of good practices, time and cost considerations, and ethical implications. To encourage its adoption, stakeholders highlighted the importance of raising awareness with both the public and researchers, facilitating dialogue, and providing financial and non-financial incentives for researchers.

# ACKNOWLEDGES

Citizen science, it is a concept I will never forget. Throughout the year, I learned a lot around the idea of participatory research and the importance of participation in health. We, as researchers, should listen more often to the people and to the patients. We should aim at bringing science and solutions to the people.

I would generously want to thank Annelies Duerinckx and Jef Van Laer for their continuous support during the year. I admire their spirit and their passion for citizen science. By extension, I want to show gratitude to Scivil for this interesting opportunity.

I want to thank my promotor Luk Bruyneel for his willingness to support my research. Thank you for the valuable insights you have given which made the thesis more academic.

Lastly, my peers. We were all in it together and we made it together. The frustrations and finally the relief we shared were a real support.

# 1. Background

Citizen science is a growing scientific method that involves members of the public in research. It is a term used to describe the voluntary participation of non-professional researchers (i.e. citizens, lay public) in scientific activities (1–4). Citizen scientists (i.e. non-professional researchers engaged in a citizen science project) often collaborate with professional scientists to perform scientific tasks, but can also act as project leaders. They can engage in a diverse range of tasks, spanning from data collection and data analysis to co-creation of research questions, hypothesis, and design (1–3). Over the years, the number of scientific citizen science publications has experienced a sharp rise, signifying the increasing relevance of citizen participation in research (5). A possible contributing factor for this growth could be the technological and digital advances that made citizen science more accessible (e.g. use of smartphone applications) and thus made it more efficient to engage citizens. While citizen science projects have predominantly flourished in the fields of ecology, history, and astronomy, their presence in healthcare research remains relatively limited (3,5,6). Ethical considerations may contribute to this, as healthcare research often involves the collection of personal health data (1). Nonetheless, the potential of citizen science in healthcare studies to enhance research quality and place the patient at the center of investigations should not be underestimated. By involving patients and the broader public as active contributors, citizen science in healthcare has the capacity to foster patient-centric research approaches and generate more meaningful and applicable outcomes (7,8). As the world continues to embrace the benefits of citizen science, it is imperative for the healthcare community to explore and harness its potential to unlock new insights and address pressing healthcare challenges. This study investigates the place of citizen science within the current healthcare research practices.

## 2. Objectives

The objective of this research is twofold and will be carried out sequentially. First, this study will identify to what extent citizen science in healthcare research is already used, and which approaches are applied in this context. In addition, the potential of citizen science in healthcare research will be identified and the attitudes of relevant stakeholders towards it will be detected. Potential facilitators and barriers in the implementation of citizen science in health will be deduced. The findings of this study can be used to design tailored information for researchers, citizen science stakeholders and policy makers in the healthcare domain. This information could include a description of existing good practices, the potential of citizen science in healthcare research, as well as specific recommendations and/or manuals.

### 3. Methods

Two sequential methods were used to answer the research questions. A scoping review allowed the research team to familiarize themselves with the concepts of citizen science in healthcare. Semi-structured interviews were conducted to gain in-depth qualitative information of experts. This study revolved around the use of citizen science within the healthcare sphere with a focus on biomedical research (i.e. activities conducted to find means of detecting, preventing or treating disease) (9) and health services research (i.e. activities that study how social factors, financing systems, organisational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care) (10). Environmental health research (i.e. research investigating aspects of human health and disease that are determined by factors in the environment) (11) and ecology were out of scope as the research team concluded that these are already well explored within citizen science.

#### 3.1. Scoping review

A scoping review was conducted to allow the researcher to have a holistic view on citizen science within health research and to conduct a mapping of the available articles and projects (12). The scoping review used two separate information channels to provide sufficient information. First a search in Pubmed was conducted with following search string and filters:

**Search string:** (("citizen science"[MeSH Terms] OR ("citizen"[All Fields] AND "science"[All Fields]) OR "citizen science"[All Fields]) AND (("health"[MeSH Terms] OR "health"[All Fields]) AND ("researcher"[All Fields] OR "researchers"[All Fields] OR "research"[MeSH Terms] OR "research"[All Fields] OR "researched"[All Fields] OR "researches"[All Fields] OR "researching"[All Fields]))) NOT "air pollution"[MeSH Terms]

**Filters:** from 2013/1/1 - 2023/2/3; English, Dutch

The Pubmed articles around environmental health as defined by the World Health Organisation (13) or ecological non-human health were excluded. Furthermore, the articles were only included if it matched the predetermined definition of citizen science in healthcare used by the research team. The following definition was used: "*Citizen Science is scientific work carried out by the general public, often in collaboration with or under the supervision of professional scientists and scientific institutions. Citizens perform actions that in traditional research are typically completed by a professional researcher*". The articles were classified according to the research domain when possible. Articles revolving around citizen science in health but without

an actual citizen science study, were included as 'general' articles. Lastly, also the number of publications per year was analysed.

Secondly, grey literature was analysed. A list of websites potentially publishing or referencing to citizen science projects in health research was made by the research team. The websites were screened thoroughly on relevant projects. If references were made to other relevant websites containing projects, these websites were also explored. The abovementioned criteria for inclusion were also applicable in the grey literature search.

### 3.2. Semi-structured interviews

Semi-structured interviews were conducted with health researchers and citizen science experts across Flanders (Belgium) to obtain a broad view on citizen science, and its hurdles and opportunities within the health research domain. Participants were qualified if they had knowledge of the Belgian healthcare system and health care research and/or if they had extensive knowledge of citizen science. Active experience with a citizen science project was not a prerequisite. Participants were recruited from various healthcare organisations, research institutes and universities in Belgium. The research team first composed a list of possible participants. Afterwards, relevant experts were invited to participate in the interview. The contact details were obtained via the network of the research team. In case no specific person was identified within an organisation, an email providing information on the study aims and design was sent to a known employee of the organisation to ask for a referral. Interviewees were recruited until data saturation was reached. Data saturation was defined as the moment no new information arises from additional interviews (14). The interview topic guide was made based on the first findings of the scoping review and included questions around the definition, methods and their experiences of citizen science in healthcare research. The research team revised and adjusted the topic guide to allow qualitative interviews. A pilot interview was conducted with an employee of the Flemish Citizen Science centre, Scivil. The findings of the pilot interview were used in the analysis. The interviews were conducted between March and May 2023. They were held online via Microsoft Teams®. The used language was Dutch as this is the native language of the research team members and the interviewees. All interviewees had to sign an informed consent form prior to the start of the interview. The interviews were audio-recorded, with permission of the participants, to allow qualitative analysis and transcription. The audio-recording of the interview was transcribed into text. The transcripts were then coded according to the thematic analysis method of Lacey and Luff (15). NVivo® software was used as a tool to code and analyse the data.





## 4. Results

### 4.1. Scoping review

The search string on Pubmed resulted in 698 articles. From these articles, 108 matched the criteria and were included. The excluded articles and the reasons for exclusion can be found in Figure 1. The grey literature was scoped by browsing 14 websites and platforms for citizen science projects. The platforms resulted in 40 unique citizen science health projects which matched the inclusion criteria.

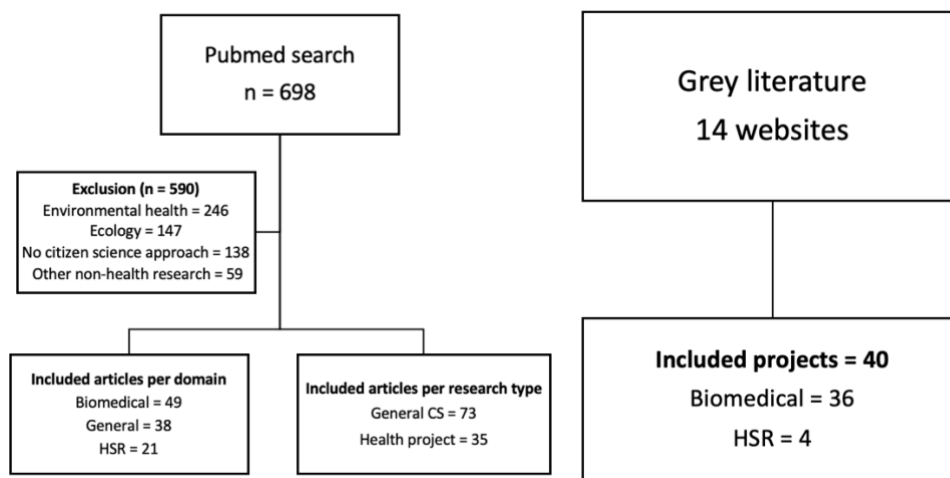


Figure 1: Included articles from the Pubmed and grey literature search. HSR = Health Services Research. CS = Citizen Science.

#### Excluded Pubmed articles

Despite environmental health and ecology being out of scope and thus excluded from this review, 393 articles around these themes were found in the search results on Pubmed. These articles mainly revolved around animal vector surveillance (e.g. mosquitos); air, soil and water quality control; and the counting of species. Many environmental projects do however acknowledge the effect of environmental factors on human health. Other non-health research (n = 59) included articles without specific citizen science – health reference or social research projects, amongst other things.

A total of 137 articles were excluded because they did not contain a citizen science methodology in accordance with the predefined definition. In many articles, the term crowdsourcing was used as a synonym for citizen science, but the methodology often lacked active participation of citizens. In the last sentence in the predefined definition (citizens performing tasks which in traditional research are typically done by professional researchers), was often not applicable to the excluded research activities. Repeatedly, the methodology was a widely distributed questionnaire, often via smartphone application, which citizens had to

complete without other involvement. Other projects that were excluded were: (I) activities in which citizens participated in focus groups or interviews without any further involvement in the research process, and (II) school-based projects where pupils had to study substances to improve health literacy but where no new scientific knowledge was generated.

### Research domain and tasks of the identified projects

Most of the included projects found in Pubmed and grey literature fall within the biomedical sphere. A total of 60 biomedical citizen projects were identified, in contrast with only 15 health services research projects. Various methods were used to engage citizen scientists in these projects. The number of times a citizen science method was used can be found in *Table 1*. Within biomedical research, citizens were most often involved in data collection and analysis. In these projects, citizens could be tasked by screening research articles or trials based on predefined rules, or had to annotate images of cell structures or tissue samples. A short tutorial and training session was given prior to the classification of the images. These annotations were then frequently used to train artificial intelligence machines (e.g. Eye for Diabetes (16)). Data collection was often used in the context of biological samples which citizens had to collect on themselves (e.g. Isala project conducting research on vaginal microbiome (17)). Another interesting way of engaging citizens in biomedical research is through the means of gamification. In these games (e.g. Genigma (18)), researchers develop puzzles for citizens to indirectly aid advancing research by playing. Health services research projects often engaged participants to collect health information within their neighbourhood (community research). Citizen scientists received a training on how to conduct qualitative research and how to survey. Another design used in both types of research is co-creation and design. In this type, motivated citizens and/or patients can prioritize research questions, pose hypotheses or co-create the research design (e.g. determine the type of outcomes). One example of co-creation in Flanders is “*De Slimme Diabetesassistent*” (Smart Diabetes assistant) (19). Based on the preference of citizens and their input in a later design phase, a smart device monitoring glucose levels was developed.

*Table 1: Number of times a citizen science method was used.*

<b>Methods used in identified health projects</b>	<b>Biomedical research</b>	<b>Health services research</b>	<b>Total</b>
Co-creation and design	9	7	16
Community researchers		5	5
Data analysis	20	2	22
Data collection	18	1	19

Gamification	13		13
<b>Total</b>	<b>60</b>	<b>15</b>	<b>75</b>

### Evolution of citizen science Pubmed publications

Figure 1 shows the evolution of Pubmed publications in the last decade. The number of publications has clearly risen throughout the last decade starting from 2016. A maximum was reached in 2019 with a total of 31 publications. A decline of publication can be seen in 2020 but has been steady in 2021 and 2022 with both counting for 19 publications. As the scoping review has been conducted on the 2<sup>nd</sup> of February 2023, the last year only accounts for two months. If extrapolated for one year, a total of 18 publications can be expected, approximately the same as the previous two years.

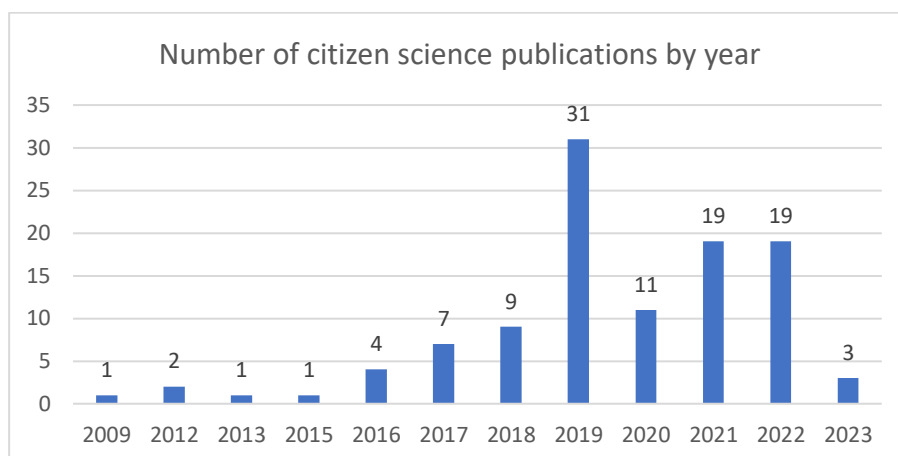


Figure 1: Number of Pubmed publications per year.

## 4.2. Semi structured interviews

Eighteen experts or organisations were invited to participate in semi-structured interviews by mail. Of the 18, ten responded positively and participated in an interview (response rate of 56%). Half of the participants had experience with conducting citizen science projects, others provided a valuable perspective on the current conduct of health research or healthcare organisation. The relevant details of the participants are reported in Table 2.

Table 2: Details of the participated interviewees

Invited experts / organisations	18
Interviewees	10

Organisation	Health care organisation (3) Research institute or university (5) Research supporting organisation* (2)
Citizen science research experience	5

\* Research supporting organisations are organisations not actively conducting research but involved with communicating about or advocating for citizen science research.

### Advantages of citizen science in health

All interviewees had a positive attitude towards citizen science in health research and would like to see more participation of non-professional researchers. The most prominent advantage of citizen science that was stated by all interviewees is the increased relevance of the conducted research. Through participation of citizens and close collaboration with researchers, it is more likely to design and tailor research to the needs of the public and patients. As stated, this could in turn lead to more patient centered policy measures and services that are more appreciated by the public (e.g. services within the supplementary health insurance package). Furthermore, some interviewees also mentioned that citizen science can make research teams more inclusive and diverse thus leading to more relevant results for a broader set of people. However, this statement should also be used carefully according to interviewees as citizen scientist are likely to be more wealthy and higher educated people.

The higher relevance of the conducted research could also increase the efficiency of the research process according to the interviewees. When engaging citizens, societal and patient centered research parameters (e.g. questions, outcomes) can already be appraised prior the design phase. *Interviewee 2: "Citizen science could make research more patient centered and more relevant to the target population. You can pose relevant research questions early on."* Another efficiency gain stated by most of the interviewees revolved around the data collection. Citizen participation in the data collection (e.g. sampling own tissue, labeling anatomic pictures) could help researchers with repetitive tasks which require considerable amounts of data or manpower. By harnessing the work capacity of motivated people through citizen science, research can be sped up and potentially reduce costs.

Another important advantage is enhancing the health and scientific literacy of the involved citizens. *Interviewee 4: "If a citizen is engaged in a citizen science project, you will see that the skills and knowledge will be transferred to these citizens"*. As said, not only do they learn about the scientific process within studies, but in the case of patients, they can also learn more about their own disease which can be a positive stimulus to their well-being. However, it was also stated that this is only a side-effect of citizen science and may not be the only motive to engage citizens in research.

Lastly, it was also stated by most of interviewees that citizen science can help closing the gap between public and research. The collaboration between professionals and citizens can generate trust and result in more appreciation for research by the public. The feeling of mutual ownership could create a sense of appreciation and motivation with the citizens.

#### Definition vagueness of citizen science in health research

One major issue of citizen science according to the interviewees is the vagueness of its definition. When asked for the definition of citizen science, most of them stated that it was science where the public acted as co-researchers together with professionals. Following their answer, they often stated that the definition of citizen science in health is not conclusive. As a result, it is not always clear for the experts which studies could be labeled as citizen science or not. One factor mentioned that contributes to this confusion was the long-standing tradition in health research of involving citizens as research subjects rather than research partners. This tradition blurs the line between research subjects and co-researchers, sometimes resulting in falsely acclaimed citizen science studies.

To cover this, interviewees stated criteria which must be met to speak of citizen science. Firstly, it is mentioned that the research conducted by professionals and citizens, must add new knowledge to the health domain. Furthermore, the research must be (co)-conducted by and for the citizens, aiming at the active involvement of citizens within the research team and the societal relevance of the study. All interviewees agreed to the predefined statement that *“Citizens perform actions that in traditional research are typically completed by a professional”*. However some interviewees nuanced this by mentioning that citizen science can create an opportunity to perform tasks which in normal situations could not be done by professionals (e.g. collecting ticks in a wide geographical area). Interviewees mentioned that citizens can conduct various tasks ranging from study design to data-collection and analysis. Intrinsic motivation of the citizens – as opposed to motivation driven by remuneration as in clinical studies – was also mentioned by some interviewees. Lastly, it was also mentioned that citizen science projects should also establish a community of researchers and citizens with mutual trust and respect. Visible and clear two-way communication about the project in different phases between professionals and citizens was stated in this respect.

#### Hurdles and challenges of citizen science in health

Most interviewees found that the lack of good practices or examples were the biggest holdback to more citizen science projects in health. For many, it was difficult to name projects. Moreover, not all interviewees were aware of the different methods that could be used within health

research. According to them, the lack of knowledge of citizen science could be one of the reasons why its usage in health research is lagging and why many researchers are hesitant on the idea of using citizen science methods in their studies.

Moreover, to some interviewees and depending on the methods used to engage citizens, citizen science can be time consuming and costly. *Interviewee 6: "We had to invest a lot in our projects to create training modules to allow that citizens to help. Those modules have gone through a lot of iterations before they were able to provide good results"*. The added time and cost can create a disincentive to use citizen science. Some also expressed the lack of specific funding for citizen science and the more difficult ethical approval due to questions around quality as hurdles for using citizen science in health.

Communication was also often stated as a complicating factor since scientific communication expertise is often not present in a research team. Moreover, this communication creates an extra cost and requires additional manpower, adding to the hurdle to use citizen science. Experts however do acknowledge the importance of communication in creating a lasting motivation with the citizens possibly resulting in better quality and more widespread participation.

Some interviewees also mentioned the ethical issues around health research and the participation of citizens. Ethical implications including privacy should be carefully considered when working with large scale citizen science projects.

#### Opportunities of citizen science in health

Many interviewees expressed that raising awareness of the concept of citizen science is needed to increase the usage within health research. Awareness can be created by investing in good scientific communication and using broad media to enhance public knowledge and making citizen science more visible and attractive. Good practices and examples of successful citizen science projects and methods in health should be collected and made public to trigger researchers. According to the interviewees, researchers with and without experience should be able to communicate with each other to discuss experiences and questions about the potential advantages and pitfalls of citizen science. According to many interviewees, exchanging experiences and good practices, could make citizen science more efficient as everyone can build on previous ideas and try tackling the encountered challenges. Platforms where discussion is possible are mentioned to address this issue. Furthermore, tools or trainings should be available for researchers to learn how to communicate with citizen scientists.

On a more practical note, several interviewees would like to see the incentives to help finance large citizen science projects with funding. They state that engaging citizens creates societal value due to the previously mentioned advantages (higher research relevance, generating trust, improving health literacy) and thus can be rewarded financially. However, not only financial incentives are stated. Some also mentioned stimuli for researchers in terms of time, for example a priority treatment for ethical or journal approval to reward the added value of involving citizens.

## 5. Discussion

The findings of this study shed light on the use of citizen science in health research and provide valuable insights into its importance and relevance. The results indicate that citizen science has gained attention in health with a growing number of publications. Many articles and projects within health are however related to environmental monitoring. The definition of citizen science remains unclear, as can be seen in the scoping review and the semi-structured interviews. The potential advantages of citizen science are numerous and include: increased relevance, higher study efficiency, greater health and research literacy and more trust between the public and the research community. The lack of good practices and scientific communication skills, together with the vagueness in its definition challenges the implementation of citizen science in the health domain. Nonetheless, increased awareness, financial and non-financial support can motivate researchers to enforce citizen science in health research.

Despite citizen science increasingly being used within health and the number of publications on the rise, it still is more present in other research domains (3,6,20). Ethical considerations, issues around reliability of data and challenges around patient security make citizen science less suitable for health research (1,21). Furthermore, the longstanding passive involvement of citizens in clinical trials and strong patient dependence on care facilities, professionals and industry kept citizens relatively unempowered (22). Technological and digital advances, together with an increased interest in own health (e.g. via smartwatches) has helped citizen science find its ground in health (22). However, not every research can or should include a citizen science method, but as stated in the interview: researchers should always start their study by considering if engaging citizens is possible and useful to reach their objectives.

Many articles in the scoping review did not meet the definition of citizen science, highlighting the importance of maintaining clear criteria for citizen science in health research. The vagueness surrounding the definition creates confusion and can frustrate researchers who genuinely place the citizen in the middle of their research, according to interviewees. A criteria-based definition like the ECSA's 10 principles of citizen science can be the basis of evaluating which projects can be classified as such (23). Key aspects should include emphasizing the addition of new knowledge to the health domain, active citizen involvement, and mutual trust and respect between researchers and citizens. However careful consideration is needed as a stricter definition can limit the natural evolution of citizen science and can undermine the ideas of the vivid citizen science community that has been built (24).



The positive attitude towards citizen science expressed by all interviewees underscores its benefits. Increased research relevance emerges as a prominent advantage, as citizens' active participation and collaboration with researchers enable the design and adaptation of research to address public needs and concerns (3). Citizen science generates valuable data that cannot be obtained or are hard to reach by other scientific methods, and on top creates more diverse insights than a professional research team can compose (25).

Furthermore, the findings highlight that citizen science can contribute to increased efficiency. Involving citizens in data collection and analysis can make a study more cost-effective by helping researchers perform repetitive tasks and gather larger datasets, thereby accelerating the research and potentially reducing costs (3). However, the initial investment, both financially and in terms of time, required to create training modules and/or resources for citizen participation can be a significant deterrent (25). Specific funding that reflects the added societal value of citizen science (health literacy, increased public trust, patient centered) can motivate researchers to make the investment.

As with participatory health research (26), citizen science can empower individuals, particularly patients, to better understand research processes and their own health conditions, leading to potential positive impacts on well-being. Higher health literacy results in empowered citizens which can address health issues, reduce inequalities, and improve the public health (27). Additionally, citizen science can bridge the gap between the public and research communities. Collaborative efforts between professionals and citizens can foster mutual trust and appreciation, generating greater public support and interest in scientific endeavors (3).

There is a need to raise awareness and create acceptance around citizen science by showcasing successful citizen science projects and methodologies (25). Both researchers and public need to understand what citizen science is and what the advantages and impact are when used within health research (25). Displaying good practices and examples can help make citizen science more known and efficient by building on previous experiences.

The results of this study do however have some limitations. The scoping review was only conducted by one researcher. The interview data can contain bias as people who have a positive interest in citizen science are more likely to participate thus resulting in an overall optimistic attitude. Only three interviewees worked for a health care organisation, possibly an under presentation to collect all possible views.

The challenges and opportunities described in this study can be used to further develop guidelines on how to conduct proper citizen science in health research. It can help motivate researchers and citizens alike to organise or participate in a citizen science project. Policy makers and management of research institutes can guide researchers to use citizen science in health research. Future studies can aim at producing evidence that measure the impact and differences of using citizen science compared to a traditional method. Furthermore, a future study could explore the perspective of citizen scientists on the use of citizen science in health research.

## **6. Conclusion**

To conclude, this study emphasizes the growing importance of citizen science in health research. Citizen science in health is still in its growing phase and many good examples on how to engage citizens are already described in literature. The positive attitude of stakeholders, together with the identified advantages, highlights the value of citizen involvement in health studies. By addressing the challenges such as the unclear definition, little public awareness and good practices, and the practical hurdles of time and finances, citizen science can reach its full potential to advance health research. Embracing citizen science as a valuable and complementary approach can lead to more relevant, efficient, and inclusive research outcomes, ultimately benefiting both researchers and the public.

# References

1. Wiggins A, Wilbanks J, Bionetworks S. The Rise of Citizen Science in Health and Biomedical Research. *The American Journal of Bioethics* [Internet]. 2019;19:3–14. Available from: <https://www.tandfonline.com/action/journalInformation?journalCode=uajb20>
2. Wat is citizen science? | Scivil [Internet]. [cited 2022 Nov 12]. Available from: <https://www.scivil.be/book/wat-citizen-science>
3. Veeckman C, Keersmaekers F, Verbrugge K, Livémont E. The citizen science starter kit. Getting started with citizen science. [Internet]. Thomas T’joen; 2022 [cited 2022 Nov 12]. Available from: <https://eutopia-university.eu/english-version/resources/zenodo/a-eutopia-citizen-science-starter-kit-1>
4. ECSA’S characteristics of citizen science. [Internet]. 2020 [cited 2022 Nov 12]. Available from: [https://ecsa.citizen-science.net/wp-content/uploads/2020/05/ecsa\\_characteristics\\_of\\_citizen\\_science\\_-\\_v1\\_final.pdf](https://ecsa.citizen-science.net/wp-content/uploads/2020/05/ecsa_characteristics_of_citizen_science_-_v1_final.pdf)
5. Pelacho M, Ruiz G, Sanz F, Tarancón A, Clemente-Gallardo J. Analysis of the evolution and collaboration networks of citizen science scientific publications. *Scientometrics*. 2021 Jan 1;126(1):225–57.
6. Follett R, Strezov V. An analysis of citizen science based research: Usage and publication patterns. *PLoS One*. 2015 Nov 1;10(11).
7. Harrington RL, Hanna ML, Oehrlein EM, Camp R, Wheeler R, Cooblall C, et al. Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group. *Value Health* [Internet]. 2020 Jun 1 [cited 2023 Jul 26];23(6):677–88. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/32540224>
8. Marks L, Laird Y, Trevena H, Smith BJ, Rowbotham S. A Scoping Review of Citizen Science Approaches in Chronic Disease Prevention. Vol. 10, *Frontiers in Public Health*. Frontiers Media S.A.; 2022.
9. Scientific Working Group on Quality Practices in Basic Biomedical Research, UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases. *HANDBOOK : QUALITY PRACTICES IN BASIC BIOMEDICAL RESEARCH*. 2006.
10. Agency for Healthcare Research and Quality. Last reviewed 2014. *An Organizational Guide to Building Health Services Research Capacity*.
11. European Environment Agency. *Environmental Health* [Internet]. [cited 2023 Aug 4]. Available from: <https://www.eea.europa.eu/help/glossary/eea-glossary/environmental-health>
12. Arksey H, O’Malley L. Scoping studies: towards a methodological framework. <https://doi.org/10.1080/1364557032000119616> [Internet]. 2007 Feb [cited 2022 Nov 24];8(1):19–32. Available from: <https://www.tandfonline.com/doi/abs/10.1080/1364557032000119616>
13. World Health Organisation. *Environmental Health*.
14. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med*. 2022 Jan 1;292:114523.

15. Lacey A, Luff D. Qualitative Data Analysis [Internet]. 2007 [cited 2022 Nov 15]. Available from: [www.rds-yh.nihr.ac.uk](http://www.rds-yh.nihr.ac.uk)
16. Oog voor diabetes [Internet]. [cited 2023 Jul 29]. Available from: <https://www.oogvoordiabetes.be>
17. Universiteit Antwerpen. Isala [Internet]. [cited 2023 Jul 29]. Available from: <https://isala.be>
18. EU-CITIZEN.SCIENCE. Genigma [Internet]. [cited 2023 Jul 30]. Available from: <https://eu-citizen.science/project/236>
19. De Slimme Diabetesassistent [Internet]. [cited 2023 Jul 30]. Available from: <https://www.deslimmediabetesassistent.be>
20. Bautista-Puig N, De Filippo D, Mauleón E, Sanz-Casado E. Scientific landscape of citizen science publications: Dynamics, content and presence in social media. *Publications*. 2019;7(1).
21. Kullenberg C, Kasperowski D. What Is Citizen Science?-A Scientometric Meta-Analysis. *PLoS One* [Internet]. 2016;11(1):147152. Available from: <https://www.wallenberg.com/mmw/projektanslag-2013>
22. Walls TA, Coria A 1, Sr F. Citizen Health Science: Foundations of a New Data Science Arena. *International Journal of Population Data Science Journal Website: www.ijpds.org* [Internet]. 2019;4. Available from: <https://doi.org/10.23889/ijpds.v4i1.1074>
23. ECSA 10 Principles of Citizen Science [Internet]. 2021 [cited 2023 Feb 10]. Available from: <https://eu-citizen.science/resource/88>
24. Muki M(, Haklay ), Dörler D, Heigl F, Manzoni M, Hecker S, et al. What Is Citizen Science? The Challenges of Definition. *The Science of Citizen Science* [Internet]. 2021 [cited 2022 Nov 12];13–33. Available from: [https://link.springer.com/chapter/10.1007/978-3-030-58278-4\\_2](https://link.springer.com/chapter/10.1007/978-3-030-58278-4_2)
25. Marks L, Smith BJ, Mitchell J, Laird Y, Rowbotham S. The case for citizen science in public health policy and practice: a mixed methods study of policymaker and practitioner perspectives and experiences. Available from: <http://creativecommons.org/licenses/by/4.0/.TheCreativeCommonsPublicDomainDedicationwaiver>
26. Ay AUL. Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice. Vol. 90, *The Milbank Quarterly*. 2012.
27. World Health Organisation. Health literacy [Internet]. [cited 2023 Aug 1]. Available from: <https://www.who.int/teams/health-promotion/enhanced-wellbeing/ninth-global-conference/health-literacy>

# Annex

## Topic guide semi-structured interviews

### INLEIDENDE VRAGEN

- Kunt u zich alstublieft kort voorstellen?
- Wat kan u ons vertellen over uw ervaring met gezondheidszorg onderzoek en het betrekken van burgers?
- In welke mate was je bekend met citizen science?

### VRAGEN MET BETREKKING TOT CITIZEN SCIENCE

#### Betrokkenheid van burgers in gezondheidsonderzoek

*Met dit eerste luik willen we ingaan op het algemeen belang van het betrekken van burgers in gezondheidszorg onderzoek. Dit hoeft niet speciaal gefocust te worden op citizen science maar kan ook passieve betrokkenheid omvatten.*

- Op welke manieren worden burgers op dit moment meestal betrokken bij gezondheidszorgonderzoek?
- In welke mate is het belangrijk dat burgers betrokken worden bij gezondheidszorgonderzoek?
  - Welke voordelen zit u in deze betrokkenheid voor de burgers?
  - Welke andere stakeholders zouden voordelen kunnen ondervinden van deze betrokkenheid en waarom?
  - Wat zijn de risico's of nadelen?
- Welke evolutie zou u graag zien in deze betrokkenheid en waarom?
  - Indien een positieve evolutie:
    - Welke aanbevelingen zou je doen om de betrokkenheid te verhogen?
    - Welke tools, richtlijnen, ... ontbreken nog om op een degelijke manier betrokkenheid van burgers te verhogen?

#### Citizen science in het gezondheidsonderzoek

*We gaan nu wat concreter in op citizen science in het gezondheidszorgonderzoek.*

- Wat is volgens u een definitie die citizen science omschrijft?

*De definitie die wij hanteren in dit onderzoek om citizen science te beschrijven is als volgt: "Citizen Science is wetenschappelijk werk dat door het brede publiek wordt uitgevoerd, vaak in samenwerking met of onder leiding van professionele wetenschappers en wetenschappelijke instellingen. Burgers voeren acties uit die in traditioneel onderzoek vaak door professionals gedaan worden." Dit gaat dus over actieve betrokkenheid van burgers.*
- Bij het overlopen van deze **definitie**, welke voorbeelden van gezondheidszorg projecten kan u dan voor de geest halen?
  - U heeft daarstraks ook concrete voorbeelden aangehaald over algemene burger betrokkenheid, in welke mate passen deze onder deze definitie?
  - Waarom passen deze er wel/niet onder?

- Welke elementen zou u toevoegen in deze definitie om specifiek de vertaling te maken naar het gezondheidszorgonderzoek?
- In welke mate bent u het ermee akkoord dat participatie van studie-deelnemers in traditioneel gezondheidszorg onderzoek ook onder deze definitie valt?
  - Welke kenmerken dienen in traditioneel onderzoek zeker aanwezig te kunnen zijn om van citizen science te spreken?

*Volgens de algemene definitie, welke niet specifiek is voor gezondheidszorg onderzoek, kunnen burgers heel wat diverse taken uitvoeren. Deze gaan van het verzamelen van data, tot data-analyse en co-creatie van de onderzoeksvragen en opstellen van onderzoeksprotocol.*

- Op welke manieren kunnen burgers actief betrokken worden bij gezondheidszorg onderzoek?
  - Welke mogelijkheden ziet u in het gezondheidszorgonderzoek?
  - In welke mate mogen participerende burgers beslissingen maken in het onderzoek?
  - *Tijdens mijn voorafgaande scoping review omtrent citizen science werd het uitsturen van enquête of beschikbaar maken van een mobiele applicatie en deze heel breed verspreiden naar burgers, ook gezien als citizen science. In welke mate past dit onder de noemer van citizen science?*
- *[Indien het vaak over patiënt als burger gaat]:* U sprak al enkele malen over patiënten. In welke mate kunnen niet-patiënten bijdragen tot gezondheidszorgonderzoek?
  - Op welke manier kunnen ze dit doen?
- Voor zover u ze nog niet benoemd hebt tijdens dit interview, welke opportuniteiten ziet u in het gebruik van citizen science in gezondheidszorgonderzoek?
  - Voor burger zelf?
  - Voor onderzoekers?
  - Zijn er nog andere doelgroepen waarvoor het voordelen kan hebben? En welke voordelen?
- Zijn er ook nadelen van deze actieve participatie van burgers?
- Welke uitdagingen zijn er om meer citizen science methode toe te passen in gezondheidszorgonderzoek?
  - Welke aanbevelingen zou u doen?
- In bijvoorbeeld het ecologische domein is citizen science al heel bekend.
  - Waarom denkt u dat er daar meer aan citizen science gedaan wordt?
  - Zijn er participatieve werkvormen in het gezondheidszorgonderzoek die wel sterk gelijken op citizen science?
  - Wat zijn de termen die hier gebruikt worden?
- Welke evolutie zou u graag zien met betrekking tot citizen science in gezondheidszorgonderzoek?

#### [Indien actieve ervaring] Citizen science onderzoek

- Hoe werden burgers betrokken in het onderzoek?
- Welke positieve ervaringen hebt u?
- Welke zaken zou u de volgende keer anders aanpakken?
- In welke mate zou u opnieuw een citizen science benadering gebruiken om uw onderzoek uit te voeren?

## AFSLUITENDE VRAGEN

- Wat is voor jou het belangrijkste dat je meeneemt uit dit interview?
- Wilt u nog iets toevoegen over dit onderwerp? Is er een bepaald punt dat we niet besproken hebben en dat u graag nog zou toevoegen?
- Welke aanbevelingen heb je voor ons met betrekking tot dit onderzoek?
- Heb je nog vragen voor mij?