

Towards a framework for the monitoring and evaluation of citizen science for health

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Monitoring and evaluating projects is important to ensure that the project proceeds smoothly and desired goals and deliverables are met. Several monitoring and evaluation frameworks have been developed to evaluate citizen science projects. Citizen science for health is an upcoming domain within citizen science; however, citizen science for health differs from other domains, such as biodiversity or geo-science, with regards to ethics and privacy of health data. Therefore, it is imperative that a framework be developed that can appropriately monitor and evaluate citizen science for health projects. Based upon one of the existing monitoring and evaluation frameworks, a first outline of such a framework has been developed. A roundtable session at the Engaging Citizen Science Conference 2022 was used to elicit possible topics for the ways in which citizen science for health distinguishes itself from other domains of citizen science. The topics mentioned by the participants were, amongst others: ethics, reciprocity, data privacy, transdisciplinary cooperation, personal and societal health outcomes, education of different stakeholders, and working towards sustainability and taking steps to create an impact with the outcomes of citizen science research. The roundtable discussions provided relevant input on areas where the current outline might be adapted when working towards a framework for the monitoring and evaluation of citizen science for health and wellbeing. Focus groups are foreseen to co-create a framework 1.0 for monitoring and evaluating citizen science for health projects.

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1. Introduction

Many citizen science projects have a longitudinal approach. This means that there is a long-term cooperation between different partners in a project. For such projects, it is important to monitor the progress of the project and to evaluate the project at the end of the project. Monitoring and evaluation can help to structure a project and to make sure that all parties involved are content with the progress made and the goals that the project is working towards.

There are already several frameworks for evaluating citizen science projects. One of these frameworks is the citizen science monitoring and evaluation framework that is constructed by Kieslinger et al. [1] This framework is created for use in the field of socio-ecology and has been adapted to be used in the field of citizen social science. The framework is organic in the sense that it is adapted and improved, based on new insights. The framework evaluates projects both on process, outcomes and impact. Moreover, these aspects are evaluated on the dimensions of 1) science, 2) participants, and 3) socio-ecology and economy.

Although this framework is well-established, citizen science for health is inherently different from other domains. The use of citizen science approaches in the field of health and wellbeing is relatively new and upcoming. Citizen science for health refers to citizen science projects that focus on better understanding of and/or improving health, which can range from public health to individual or personal health. [2,3] The health domain inherently differs from other fields of research. For example, research potentially directly affects the health and life of the citizen scientist, since citizen scientists in the domain of health can both be co-researcher as well as participant. Furthermore, health-related research involves sensitive data.

Therefore, citizen science for health requires additional topics for monitoring and evaluation, and some topics may require a stronger emphasis in the monitoring and evaluation process. As citizen science for health is an upcoming field of research, there is not yet a complete overview of what makes this domain unique and what topics should be emphasized and included in a monitoring and evaluation framework. The development of citizen science for health as a field of research runs in parallel with the development of the suggested framework.

This paper focuses on the steps to be taken to adapt the existing framework for the evaluation of citizen science to be effective in the domain of citizen science for health. The first step is to create a common understanding of the additional emphasis and attention for a specific framework for citizen science for health projects that is of interest for both project managers and (citizen) scientists working in this domain.

2. Method

Expert elicitations were used to collect areas for monitoring and evaluation that are important in citizen science for health and underrepresented in the current citizen science evaluation framework. The expert elicitations consisted of two 20-minutes discussions with each group containing 4-6 participants. All participants were visitors at the Engaging Citizen Science

Conference 2022. The discussions began with a short introduction to the topic. Preliminary suggestions were provided by the authors of the current framework and the authors of this paper. Thereafter, all participants were asked to provide additional areas and feedback on the suggested ones. All additional areas for monitoring and evaluation for citizen science for health were written down by the presenter (SW). After the roundtable discussions, concrete areas for expansion of the current framework were formulated based on the written notes.

3. Results

During the roundtable discussions several topics/areas were mentioned that would require specific attention in a framework for the monitoring and evaluation of citizen science for health. These include:

- Ethics—health research often concerns human subjects. In citizen science, research could include people that are both (co-)researcher and participant. In the case of interventional studies, people might be asked to undergo a behavioral change or submit to a medical procedure. This would require strong attention to ethics.
- Reciprocity—in the field of health, patients can be the expert on certain topics regarding health & wellbeing. However, the patient-scientist relationship can be a paternalistic one and can be researcher-driven. How can we establish a more equal relationship in which there is space for reciprocity? It is important that all participants are appreciated for their specific knowledge and contribution to the project and all participants are treated as equal.
- Data privacy—collected data is often related to someone's health, making the data sensitive. Correct handling of the data is therefore important and necessary, especially in the case of open and FAIR (findable, accessible, interoperable and reusable) data.
- Transdisciplinary cooperation—health research projects often take a participatory approach. Different stakeholders may be involved in the project, including citizens, researchers, organizations, the government, and companies. It is important to monitor and evaluate the cooperation between all parties.
- Personal and societal health outcomes—one of the principles of citizen science according to ECSA [4] is that all participants should benefit. Therefore, it is important that participants gain insight into or improve upon their health or wellbeing, or that public health be improved. These outcomes should be evaluated.
- Education of different stakeholders—in order to participate in citizen science for health projects, and to be able to work together towards a common goal, there may be a need for providing education to one or more of the stakeholders. This should be monitored and evaluated.
- Working towards sustainability and taking steps to create impact with the outcomes—citizen science aims to gain scientific knowledge. However, inherent to citizen science is also the goal of performing research that is relevant to society. In the domain of health this often requires taking steps after the process of knowledge creation through social action or implementation of scientific results.

4. Conclusion and future work

The Roundtable discussions provided relevant input on areas where the current outline might be adapted when working towards a framework for the monitoring and evaluation of citizen science for health and wellbeing. Most of the additions are related to ethics and the cooperation between the different parties in the project. Ethics is an important area of attention in health-related research in general. Therefore, it is not surprising that citizen science for health also needs to be mindful of ethical issues. Additionally, the possibility of being involved in setting up and executing research related to a person's own health makes it even more imperative that ethical issues are considered carefully. The possibility of personal stakes in the project demands that there is close attention to the collaboration between the stakeholders.

The outcomes of the roundtable discussions will be followed-up by expert elicitations from members of TOPFIT Citizenlab, a fieldlab for citizen science for health and wellbeing in the Netherlands, and members of the ECSA working group Citizen Science for Health. All expert elicitations will then inform an adapted and co-created framework for use in the field of citizen science for health.

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