Enhancing Health through Citizen Science

Debriefing of the online interactive workshop

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Abstract

This presentation will summarize the findings of an online virtual workshop that will take place at the ECSA conference on Tuesday 8 September 2020, 10-11:30 h.

If you want to join that workshop, please contact Gaston Remmers at q.remmers@mdoq.nl

Goal of the workshop is to develop the base for a joint green paper on the core dimensions and challenges for the development of Citizen Science in Health. The green paper will be shared within ECSA. It will also serve as a starting point for creating an international network on Enhancing Health through Citizen Science.

Background to the interactive ECSA workshop on September 8

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 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 concrete research questions, in methodology development, data collection, analysis and the development of conclusions and recommendations, nor in new role definitions. In public health, 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 such (mainly qualitative) research has less status and influence as compared to expert-based epidemiological approaches. Another strand of 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 conducting n=1 research, sometimes known as Quantified Self. 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.

Workshop Enhancing Health through Citizen Science

During the online, interactive workshop, participants will:

- A) Jointly explore and discuss what the dimensions and challenges are of citizen science for health, and how citizen science for health is distinct from other areas than health;
- B) Work towards a theoretical framework, based on the active input by the participants (using online polls).

We will discuss experiences and challenges around citizen science for health, and will ask you to share with us good practices of citizen science for health. The output of the workshop will serve as a base for a green paper on Enhancing Health through Citizen Science, that will be shared within ECSA. And as a starting point for creating a network on **Enhancing Health through Citizen Science**.