ISSN: 2736-6189

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Citizen Science in the Community: Gaining Insight in Community and Participant Health

Ashfaq UI Hassan*

Department of Anatomy, SKIMS Medical College, India

Editorial

The aim of this study was to examine if citizen science contributes to gaining insight into community health and to the health of the citizen scientists themselves. Therefore, thirteen citizens in four deprived neighbourhoods were trained as citizen scientists to conduct research in their own communities. Results showed that the citizen scientists identified forty (health related) themes in their communities. The citizen scientists reported an increase in their overall self-perceived health which, however, was not significantly demonstrated in the pre-questionnaire and post-questionnaire.

It has been evident for quite some time that places and communities have multiple and various impacts on individual - level and community-level health. Research in a Canadian population shows that people who dislike aspects of their neighbourhood's physical environment are 1.5 times more likely to report chronic health conditions, while those who like their neighbourhood's physical environment are less likely to report fair/poor health Neighbourhood environment is also associated with being overweight and obese Further, perceived social cohesion in a community is linked with better health and wellbeing. In community health, addressing neighbourhood aspects (e.g., quality of housing, access to amenities, safety and social cohesion) in addition to more conventional determinants of health (e.g., low income, lifestyle behaviour) is of increasing importance to local health policy.

Especially in deprived neighbourhoods, there is growing interest among researchers and policymakers to understand the role of place and community in reducing health inequalities. Research suggests that citizen perceptions of their neighbourhood and housing problems may mediate the health effects of neighbourhood deprivation. Therefore, improving community health requires close collaboration with citizens, communities and social healthcare providers as well as other stakeholders, for example, housing associations, transport services, wellbeing initiatives. The Alma Ata declaration of the World Health Organisation endorses the importance of sectors other than the health sector, such as the 'social sector', to attain the 'highest possible level' of health. The WHO also describes the importance of the involvement of the public in their health as 'the right and duty to participate individually and collectively in the planning and implementation in their health care'.

The involvement of citizens in improving community health can occur in many different gradations. Citizen science is an example of citizen participation in which citizens or local residents are actively involved as research partners in scientific research. Citizen science uses the collective strength of communities to identify research questions, collect and analyse data, interpret results, make new discoveries and develop technologies and applications. Citizen science engages citizens to address and answer to complex environmental

*Address for Correspondence: Ashfaq UI Hassan, Department of Anatomy, SKIMS Medical College, India, E-mail: ashhassan@rediffmail.com

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Received: 06 March, 2022, Manuscript No. IJPHS-22-63231; Editor assigned: 07 March, 2022, PreQC No. P-63231; Reviewed: 11 March, 2022, QC No. Q-63231; Revised: 12 March, 2022, Manuscript No. R-63231; Published: 17 March, 2022, DOI: 10.37421/ijphs.2022.7.271

and societal issues and has the capability to generate large quantities of data. Furthermore, citizen science is an important tool for democratizing science and stimulating equitable and universal access to scientific data and information.

Although citizen science has a broad history in ecology and astronomy, the application of citizen science in public health is a relatively new field of study and is believed to be a promising strategy for creating healthier and more equitable neighbourhoods and communities stated that although citizen participation in public health has been advocated, research to date has found no evidence for its impact on community health. the interaction of the citizen scientists with the community members the positive impact of a citizen science project can diffuse to the community members-Studies also show that citizen involvement increases public engagement, encourages people to listen to a diversity of opinions and contributes to a higher degree of legitimacy of decisions Besides, citizen participation can have a positive effect on the participants themselves. When citizens in a community participate together in networks, this can contribute to life satisfaction, social cohesion and conformity in a positive way. In this study, we focus on whether citizen science contributes to gaining insight into the health of citizens living in deprived neighbourhoods as well as the health of the citizen scientists themselves.

Setting and participants

The study was conducted in four low socioeconomic neighbourhoods (Limmel, Nazareth, Wittevrouwenveld and Wyckerpoort; total n = 12,480 inhabitants) in Maastricht, the Netherlands (Centraal Bureau voor Statistiek [CBS], 2020) between June 2018 and April 2019. The four targeted neighbourhoods were also the setting of an integrated community approach (ICA) aimed at improving population health. In the ICA health and social care providers, the municipality, the primary health insurer, the Provincial State, professionals and citizens collaborate together since December 2016 to improve the health of the community. One of the main elements of the ICA is active involvement of the citizens living in the four neighbourhoods and therefore a citizen science approach was initiated. The citizens in the four neighbourhoods face health challenges and socioeconomic problems which impact their health status, such as low self-perceived health, poverty, lifestyle problems (e.g., overweight) and a feeling of loss of control over their own lives Public Health Services South Limburg, 2016. The neighbourhoods are characterised by a higher number of non-western immigrants (range: 15% in Wyckerpoort to 21% in Limmel, compared to 11% in Maastricht). Although the neighbourhoods share the same challenges, they also have some unique features. The neighbourhood Limmel has a relatively large student population (15-25 years old) compared to the rest of the Maastricht region (33% vs. 19%). Wyckerpoort has a relatively high number of single households compared to the rest of Maastricht (39% vs. 29%).

Eligible participants in this citizen science project were citizens aged 18 years and older from the four neighbourhoods who were able to communicate in Dutch and were motivated to improve the health of their neighbourhoods. We recruited citizens through existing networks in the community (e.g., community health workers, well-known active citizens) and by using snowball sampling. Flyers with information about the project were displayed at four community centres and the two primary care centres. Additionally, one of the researchers (SG) joined an existing information market on running community initiatives in order to inform citizens in the communities about the project. Fifteen citizens were interested in participation in the citizen science project. We did not exclude participants who were overrepresented in any manner (for example the same age group), since a larger sample size had priority in our study.

Also, since empowerment of the community was a goal of the project, we did not want to exclude participants who were enthusiastic about (changing) their own health and the health of their community. They had a 1-h meeting prior to the start of the project with either the main investigator (SG) or the research assistants (IHJ, LW) to clarify any questions and to make sure the participants were motivated to start. Two participants dropped out before the data collection phase because the project was too time consuming (n=1) or because of emotional reasons (n=1). Written informed consent was obtained from the remaining thirteen citizen scientists. At the end of the citizen science project, the citizens scientists received a certificate for their participation and a voucher of \leq 50.

We used a mixed-method design to collect and analyse our data. To answer our first research question the citizen scientists used a triangulation of data collection methods. To answer our second research question we used both qualitative (focus groups) as quantitative (questionnaire) research methods. The rationale for using a mixed methods approach was to yield a complete and in depth answer to our research questions.

The thirteen citizens received two training sessions of 2.5 h each in which they were trained to become citizen scientists. The first session was provided by a certified trainer who introduced the citizens to the concept of health and how to look at health from a holistic perspective using the concept of Positive Health. Positive Health is described by Huber as 'the ability to adapt and to self-manage, in the face of social, physical and emotional challenges'. We used Positive Health as a framework since it looks at health from a broad perspective and is the common vision on health in the ICA to improve community health. One of the exercises was about how to use the six domains of the Spiderweb diagram of Positive Health to visualise the citizen's individual state of health. The certified trainer was purposefully chosen by the authors based on her ability to connect a diverse group of people and to create a positive atmosphere during the training sessions.

The second training session focused on research skills and was given by the main investigator and the research assistants. Citizens were taught the basic skills of research and data collection (e.g., ethics, participant selection, data collection methods, reporting). One of the exercises involved using the six domains of the Spiderweb diagram of Positive Health as guidance to interview their fellow project members. Further, the participants each made an individual plan for the data collection phase, including methods of data collection. Participants received instructions on paper in the form of a syllabus as a guide for the data collection phase.

The training was designed to incorporate mechanisms of change of the explanatory theoretical model of change for an experience-based codesign approach. During the training, it was important to help shift citizen's thinking from 'I' to understanding that being part of a group of citizen scientists can change the health of citizens living in the deprived neighbourhoods (by influencing policy). The citizens created a sense of working together (cooperation) and build shared commitment and responsibility for change (accountability), which motivated them to start the data collection in the neighbourhoods (mobilisation). During the second training, the citizens jointly decided to change their group name to 'Health Ambassadors' as they found 'citizen scientists' difficult to pronounce and too abstract. In this paper, we use the term 'citizen scientist'.

Data collection by the citizen scientists

After the two training sessions, the citizen scientists collected data in their own neighbourhoods for eight weeks. The research questions they focused on were: (1) what does health means to me and for my own community according to the six dimensions of Positive Health? and (2) What can I/we do to enhance my/our health and the health of the community? The citizen scientists were

free to choose their research participants as well as the number of research participants they wished to include.

They used self-developed registration forms based on the Spiderweb of Positive Health and made notes on a notepad to document observations and statements from interviews, while some used their mobile phones for audiotaping of interviews. The citizen scientists were stimulated to use the data collection tool which best suited them (e.g., interviews, photos, observations etc.). During the eight weeks of data collection, there was frequent contact between the citizen scientists and the researchers by means of a WhatsApp group which linked all thirteen citizens and three smaller subgroups to the researcher for individual support, if needed. The main investigator and the two research assistants were each available to a subgroup of citizen scientists to check on progress and offer advice or practical assistance during data collection. Also, the citizen scientists themselves shared information that could be helpful for the others. For example, some of the citizen scientists shared their intention to interview people at a local Christmas market.

Focus groups

Each citizen scientist was invited to share and discuss the results of the data collection phase with the other citizen scientists and the researchers. The citizen scientists were divided into three groups, and a focus group was conducted with each group and lasted on average 1.5 h. Because one of the citizen scientists could not join the focus group due to the flu, a semi-structured interview was held to collect the data and discuss the findings of this citizen scientist. The topic list for the interview contained the same questions as the topic list for the focus groups. The focus groups and the interview were audio recorded and transcribed verbatim by the primary researcher (SG).

During the focus groups, citizen scientists were encouraged to share their findings by explaining what information they gathered from whom and which data collection method they used. We frequently asked the citizen scientists during the focus groups if the mentioned items were their own opinions or something that was mentioned in an interview or seen in an observation. In addition, the citizen scientists were asked to elaborate on how their involvement as a citizen scientist affected their own health and/or their perception on health. The principal investigator wrote down the main results on coloured post-it notes and arranged the notes with input from the citizen scientists on a flapover to display common themes [1-5].

Conflict of Interest

None.

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How to cite this article: Hassan, Ashfaq UI. "Citizen Science in the Community: Gaining Insight in Community and Participant Health." Int J Pub Health Safety 7 (2022): 271.