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Citizen Science for Health in all Policies

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2017

document version

Publisher's PDF, also known as Version of record

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citation for published version (APA)

den Broeder, J. M. (2017). *Citizen Science for Health in all Policies: Engaging communities in knowledge development*.

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SUMMARY

Health in All Policies (HiAP), a horizontal strategy connecting all relevant policy sectors, is internationally recognised as a core policy approach to improve the population's health. For HiAP to be effective, it is recommended that both a Whole of Government and a Whole of Society approach is applied. In the Netherlands, HiAP has been in place since the late eighties of last century. Initially the focus has been on the Whole of Government approach; more recently this is amended by a national Whole of Society program. This thesis addresses the possible role of *Citizen Science* as a possible contribution to the knowledge base underpinning HiAP and a Whole of Society approach. Citizen Science, as the active contribution of citizens in research, links up with asset-based approaches and community participation that are key elements in modern health promotion.

Key questions of the thesis were:

“What are possible methods to engage citizens in developing the knowledge base for Health in All Policies (HiAP), and what are challenges and benefits of such engagement?”

This thesis draws, firstly, on a theoretical exploration in which the application of Citizen Science in public health is explored. Secondly, two case studies on the application of Citizen Science in the Netherlands were performed. Thirdly, two scoping reviews were performed. Finally, one case study was carried out focusing on perceptions of health professionals in a Dutch city district.

Chapter 1 presents the backgrounds of HiAP as a way to promote health and address ‘wicked problems’. Such problems, for example the obesity epidemic and the persisting health gap between groups with different socioeconomic position, can only be resolved by cooperation and coordination between different work fields. HiAP requires a ‘Whole of Government’ approach: policy actors join forces to address societal challenges. In addition, a ‘Whole of Society’ approach is needed in which societal stakeholders, including citizens and communities are engaged.

Participation of citizens and communities is a key strand of action in health promotion. As health promotion is starting to becoming more inclusive towards communities and asset-based, researchers and health promoters have also started to consider how the evidence base for health promotion can be adapted to this paradigm. The inclusion of citizens and communities in knowledge production for HiAP may provide essential

contextual and lay knowledge to underpin HiAP. Moreover, it links up to notions about knowledge democracy.

The chapter ends by presenting the research question addressed by the thesis:

“What are possible methods to engage citizens in developing the knowledge base for Health in All Policies (HiAP), and what are challenges and benefits of such engagement?”

Outline of the thesis

The thesis contains six chapters based on the six studies exploring methods, benefits and challenges of Citizen Science for public health in different ways. Table 1 provides an overview, per chapter, of these studies. A theoretical exploration of possible application of Citizen Science in public health was carried out to provide a general overview of types of Citizen Science projects and possible benefits for public health (Chapter 2). Two case studies were carried out in which Citizen Science activities were evaluated (Chapter 3 and 5). Two scoping reviews were performed to explore the literature about two specific types of Citizen Science application: Health Impact Assessment (Chapter 4) and neighbourhood auditing (Chapter 6). One case study concerned the perceptions of health promotion professionals, in a low-SES neighbourhood, on how they perceive local health assets for residents (Chapter 7). The general discussion combines all findings to provide answers to the study question and presents implications for practice, research, and policy (Chapter 8).

Chapter 2 presents the backgrounds of Citizen Science and explores possible ways to apply it in public health. Citizen Science first developed in the natural sciences; nowadays there are applications in other work fields, for example in historical and social sciences and in technology development. Examples of Citizen Science projects are the ‘Galaxy Zoo’ project where lay people classify images of galaxies, and the Dutch ‘Gekaapte brieven’ (Stolen letters) project where volunteers decipher 16th and 17th century letters.

Citizen Science projects can be carried out on a local or ‘mass’ scale. They range from approaches where citizens function as ‘sensors’ to ‘extreme Citizen Science’ where the citizens are in the lead of the process. The aim may vary from ‘pure’ science to educational or societal goals. The potential benefits of Citizen Science, as presented by the literature in this field, are threefold. Firstly, research capacity is increased by using the help of volunteers. Secondly, Citizen Science may yield better knowledge by providing additional information, developing new research methods or protocols and creating

‘socially robust knowledge’. Thirdly, Citizen Science may yield benefits for the citizen scientists. It may promote scientific literacy, community development, empowerment, change of attitudes, values and norms, action to improve the environment, and engagement in policy making. The chapter presents a model of similar possible Citizen Science benefits, translated to the field of public health, as a basis for studying, comparing and exploring the opportunities and limitations of public health Citizen Science (Figure 1).

Table 1. Overview of studies underlying this thesis

| Chapter | Study question | Methods applied |
|--|--|--|
| 2. Citizen Science for Public Health | What is the value of Citizen Science in public health? | Exploration of the literature about Citizen Science in other work fields and application of insights gathered on the field of public health. |
| 3. Public health Citizen Science; perceived impacts on citizen scientists. A case study in a low income neighbourhood in the Netherlands | What impacts were experienced by citizen scientists participating in a public health research project? | Participatory action research contributing to setup of Citizen Science project (concepts, methods and materials). Focus groups, interviews, questionnaire. |
| 4. Community participation in Health Impact Assessment. A scoping review of the literature | How is community participation in HIA currently perceived and how is it put to practice? | Scoping review in scientific literature and member checking by experts. |
| 5. We are all experts! Does stakeholder engagement in Health Impact Scoping lead to consensus? A Dutch case study | Did stakeholder and resident engagement in Health Impact scoping lead to consensus? | Participatory Action Research contributing to setup of scoping workshops (methods and concepts). Questionnaires, observation, interviews. |
| 6. Resident participation in neighbourhood audit tools - a scoping review | Which participative systematic neighbourhood auditing tools exist and how can these tools be characterized? | Scoping review in scientific and grey literature. |
| 7. Neighbourhood health assets: perceptions of local professionals in a Dutch low-SES neighbourhood. A qualitative study | What are perceptions of professionals, based in a ‘priority district’, on health, neighbourhood assets and residents’ capacities to create and maintain good health? | Interviews, Nominal Group Technique. |

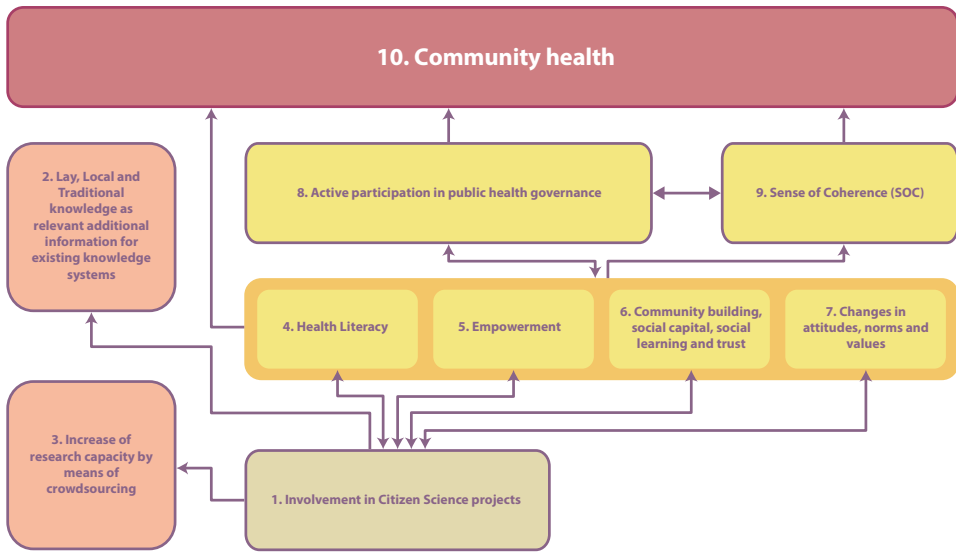


Figure 1. Effects of Citizen Science on health, health governance and knowledge system

Related approaches in public health and health promotion like Participatory Action Research provide examples that can benefit Citizen Science development in public health. However, there are also challenges. An important issue is the motivation and selection of participants and the need for appropriate representation of a target group. There are questions regarding the quality of research carried out by lay people. Finally, it can be disputed whether Citizen Science in public health will lead to better, more inclusive policies and better health. These questions deserve thorough consideration and practice testing in the further development of public health Citizen Science.

Chapter 3 describes and discusses the self-perceived effects on 35 citizen scientists of participating in a local public health Citizen Science project in a disadvantaged neighbourhood in the Netherlands. The aim of the project was to gather information about resident views concerning potential neighbourhood health assets. Moreover, the project aimed at stimulating these citizen scientists to become engaged with and contribute to a healthy neighbourhood. The citizen scientists were trained after which they interviewed fellow residents. The evaluation of this project was carried out as Participatory Action Research; methods included focus groups, interviews and questionnaire rating personal and neighbourhood health, health literacy (HL) and Sense Of Coherence (SOC).

The results showed a number of closely related effects of the project on the citizen scientists. Firstly, the citizen scientists acquired an understanding of the broader determinants of health. Secondly, they acquired new knowledge about healthy life styles and reflected on these in relation to their personal habits. Thirdly, they made health enhancing changes in their personal life. Fourthly, the citizen scientists reported having developed new social competences and an increase in self-confidence. Fifthly, the citizen scientists expanded their social networks, surpassing cultural boundaries. The sixth impact reported was that the project had functioned as a trigger to take joint action for a healthier neighbourhood. Although there were no significant changes in the citizen scientists' rating of their personal or neighbourhood health or in SOC scores, HL scores had increased significantly. These outcomes suggest that the project has functioned as a health promotion intervention. Moreover, the approach seems to benefit citizen scientists with low educational levels. However, for these benefits to materialise, sustained engagement would be crucial.

Chapter 4 describes a study concerning Health Impact Assessment (HIA), a key instrument for HiAP. HIA is 'a combination of procedures, methods and tools by which a policy, program or project may be judged as to its potential effects on the health of a population, and the distribution of those effects within the population'. A scoping review design was followed to take stock of views, methods and experiences regarding community participation in HIA.

A combined Scopus and Medline search, followed by title screening and abstract screening yielded 43 papers, including case studies, evaluation studies, reviews, and opinion papers in scientific journals. Data charting was carried out as an iterative process, providing space for the researchers to adapt the data chart and criteria during the charting stage. Thematic analysis produced preliminary results, which were checked by consultation of four experts and by additional grey literature analysis.

The review showed that community participation is generally considered a core element in HIA. Main reasons presented are, firstly, the opportunity to gather new or additional (local) knowledge, secondly, the adherence to or application of democratic values and, thirdly, empowerment of communities. The results further showed high variation in the methods applied as well as various combinations of methods. The theoretical or practical underpinning of the choice for specific methods and their appropriateness for application in a given HIA is mostly absent. Experiences with community participation in HIA are mostly described in positive terms, emphasising the value of the knowledge brought into the HIA process by communities, the cooperation between communities

and other local actors and the empowerment of the community. It is often unclear how the effects on communities and policies reported in case studies are measured.

The chapter ends by recommending that community based HIA, in order to attain the effects aimed for in terms of community empowerment, should link up more closely to existing health promotion programmes or strategies. Moreover, theory-informed and explicit decisions should be made on methods and approaches concerning the inclusion of communities in HIA and work should be undertaken to establish more robust evaluation of the possible effects of community participation in HIA on knowledge, communities and policies.

Chapter 5 describes a case evaluation of stakeholder engagement in Health Impact Scoping in a small town in the Netherlands. The case consisted in two health impact scoping workshops, looking into possible health impacts of a major rail and road infrastructure development, substantially increasing passenger and cargo transport through the town center. The case evaluation focused on consensus-building as a possible impact of the workshops.

A Participatory Action Research approach was adopted. Methods included observation, semi-structured questionnaires and semi-structured interviews. The data were analysed using a codebook. Participants reported a broadening of perspectives on health in relation to the environment and attainment of shared perspectives. Still, meaningful differences remained, indicating that joint learning experiences, trust and mutual respect created a 'sense of consensus' rather than a joint view on the issues at stake. The interviewees reported that smooth organisation of the workshops, space for all participants to express and exchange views and interests and a high level of trust among participating stakeholders promoted consensus-building. Moreover, the topics health and healthy environment were considered as non-threatening topics that everyone can connect to. Perceived barriers for consensus-building included hidden interests and poor communication by national stakeholders, and different mental models, or ways of thinking, related to the different positions of various stakeholders and the roles they have to play. However, these factors apparently did not block the process of reaching (perceived) agreement between all stakeholders.

In conclusion, the approach applied in this setting seems to be first step towards more meaningful participation in spatial planning. Health appears to be a topic that has the potential to connect different stakeholders, including residents, and promote their engagement in policy development. Joint learning posed an opportunity to deal with differences in stakeholder roles, frames of mind and personal preferences. However,

explicitly addressing these differences, right from the start, would have made sense from the participants' point of view. The chapter ends by recommending to include explicit acknowledgment and acceptance of disagreements as a ground rule in future stakeholder engagement processes.

Chapter 6 describes a scoping review looking into resident participation in neighbourhood audit tools. Neighbourhood auditing is aimed at obtaining insight into the characteristics of neighborhoods by systematically visiting and observing them. The study objectives were to identify participative audit tools, to describe the different levels of resident participation in these audit tools, to provide an inventory of what these tools measure; and finally, to describe the methods applied in the tools. A systematic search for scientific literature was carried out in Scopus, and grey literature was identified by Google search. Data were charted and analysed.

The search yielded 13 instruments that involved residents. Results showed that in half of the cases ($n = 6$), residents were involved by carrying out data collection. In only 2 cases, residents were involved in problem definition, data collection, and analysis and interpretation of the data that were collected. However, the papers did not extensively describe exactly how residents were involved. Within the 13 instruments that involved residents, we identified 22 different domains and more than 150 sub domains, focusing mostly on the physical characteristics of the neighborhood. This implies an important pitfall: these characteristic may not be appropriate proxies to capture the behavior of the residents that actually live in the neighborhood/community or street that is audited, nor the social quality of the area. Most of the 13 instruments were paper forms, usually containing close-ended questions or scales. There were two digital tools available, one for tablets and one for hand-held computers. The chapter ends by recommending, firstly, in-depth examination of resident involvement in practice settings. Secondly, to enable assessment behaviour and social neighbourhood characteristics, new methodologies could be explored, in particular combinations of momentary measurements of targeted areas within a neighborhood, with the measurement of more general physical features. Thirdly, the use of technologies, like mobile applications, that could potentially support broader resident engagement and more extensive participatory data collection, should be explored. Finally, any new approach which is intended for neighborhood auditing with residents should carefully consider how to deal with the dilemma that scientific auditing seems hardly participatory, and community-based auditing seems insufficiently robust and systematic for scientifically sound analysis and results.

Chapter 7 describes a study in which health and welfare professionals in a Dutch 'priority neighbourhood' were interviewed about their perceptions on health and local

health assets. A priority neighbourhood is a neighbourhood with a multitude of social (including health) and economic challenges.

A varied group of 21 professional health and care workers was interviewed, in order to obtain a broad range of different visions and approaches. The interviews were conducted using a semi-structured interview protocol. To illustrate what 'assets' are and to challenge the professionals to think about a broad range of neighbourhood assets we used the 'Egan wheel' which contains seven neighbourhood dimensions. Seven of the professionals who participated in the interviews subsequently participated in a Nominal Group Technique (NGT) session, which functioned as a member check.

The study showed that the professionals interpreted health broadly and that they emphasised the social aspects of both health and healthy behaviour, for example giving support to, or being supported by, others. However, the professionals considered the residents and their behaviour as unhealthy. The professionals regarded several aspects of the physical infrastructure, like greenery, as health assets, but frequently mentioned some other physical aspects, like poor housing and litter in the streets, as health barriers. The professionals also considered the services provided in the neighbourhood, including their own services, as important health assets, although there were some doubts about the effectiveness and accessibility of the latter. However, in their opinion the social quality of the neighbourhood was insufficient and should be improved as a matter of urgency. The professionals emphasised inabilities and lack of knowledge of residents and provided many examples of this. They saw poverty, unemployment and lack of education as barriers for healthy behaviour and a healthy utilisation of available neighbourhood assets. Instead of targeting individual residents, the professionals proposed action to enhance collective capabilities like group health promotion or (support for) self-organisation of residents.

Chapter 8 summarises and combines the results of the preceding chapters and proposes ways forward in the utilization of Citizen Science for HiAP. Because citizen engagement in knowledge production for HiAP is still new, standard methodologies on how to ensure and manage citizen participation in these approaches are not readily available. Moreover, there is a large variety in Citizen Science applications in terms of type, aim and level of the citizen engagement. These aspects influence the methods applied. Moreover, the way communities and citizens are involved in knowledge development may vary according to the topic covered by the Citizen Science research. Citizen Science for HiAP, therefore, possibly requires specific methods and procedures fit for this work field.

Methods and approaches for Citizen Science

Overlooking the citizen engagement case studies, the study under Slotermeer professionals and the scoping reviews carried out for this thesis, two key issues come forward, relating to methodological aspects in Citizen Science for HiAP.

Firstly, it becomes clear that learning is an important ingredient of HiAP Citizen Science. Increased skills and knowledge and increased 'scientific literacy' is one of the impacts, and often an explicit aim of Citizen Science in general. In Citizen Science projects, learning is 'experiential', i.e. action oriented and stimulated by the confrontation between the knowledge transferred, including abstract concepts or models, and the concrete experiences of the participants. In the framework of HiAP, researchers and other stakeholders, in particular local professionals for whom asset-based approaches are still difficult to implement, may need to be engaged in this joint learning process as well.

Secondly, group based approaches are meaningful, bringing people together in networks or communities of 'lay researchers' that help build community capacity and empower individuals within that community. This group-based aspect of Citizen Science links up to the theory and practice of health promotion. On a more generic level, the groups and networks built up through Citizen Science projects may provide a mechanism that enables residents to act as partners in cooperation for HiAP.

Benefits and challenges of Citizen Science approaches

This thesis shows that Citizen Science for HiAP, in addition to –possibly- increasing research capacity, benefits knowledge development by yielding contextual information and insider knowledge to help develop for HiAP strategies. Moreover, Citizen Science has the potential to yield socially robust knowledge, i.e. shared knowledge that is developed in an iterative process between scientists, society and citizens. This knowledge can underpin ways forward to address wicked (health) problems. The case studies and scoping reviews also reveal important challenges regarding the participation of communities. Firstly, an issue that comes up frequently is, which community members to engage. In any given case of citizen engagement in knowledge development for HiAP it will be necessary to prevent tokenism and consider whether participants have a specific mandate to speak on behalf of their community or specific community groups, and how to guarantee that all voices are heard. Secondly, challenges arise in engaging these persons or groups and securing their participation in the longer run. Specific expertise in reaching out to underprivileged or marginalized groups and engaging them is essential. One promising way is also to engage local professionals

or (trained) community key persons. Moreover, there needs to be an ongoing dialogue about shared –or disputed- knowledge between researchers and citizen scientists and an action perspective should be included.

The third challenge is how to value the quality of the knowledge developed. As Citizen Science for HiAP has a societal goal, namely to inform HiAP strategies including a variety of societal stakeholders, research quality does not only mean scientific value, but also societal value. This means that this research should have value for the communities participating, but also for a broader group of stakeholders that are engaged in Whole of Society approaches to address (wicked) health challenges. New evaluative frameworks could be developed for Citizen Science projects, including both the scientific quality as well as the spin-off of the projects in terms of creating community or citizen networks that contribute to Whole of Society strategies to address wicked health problems.

Ways forward

Overlooking the different chapters in this thesis, the conclusion seems justified that Citizen Science has important potential to contribute to HiAP, but that it should not be equalled to ‘cheap data collection’ or ‘easy science’. To realise the promise of Citizen Science for HiAP, work needs to be done to further develop the approach. The thesis recommends four strategic directions:

- 1) Methodological innovation, by improving the balance between qualitative and quantitative methods and by exploring technological possibilities like ‘quantified self’ approaches and app technology as ways, for citizens, to conduct their own research or to participate in broader research projects.
- 2) Investing in citizen scientists to ensure that the approach yields the potential benefits described in this thesis.
- 3) Connecting Citizen Science approaches with broader HiAP strategies to ensure contribution to these strategies.
- 4) Evaluation of Citizen Science approaches for HiAP, which is multiperspective, multidimensional and multilevel.

In conclusion

It seems that the application of Citizen Science may contribute to socially robust knowledge to underpin HiAP. It may also help build Whole-of-Society networks of citizens, communities and other stakeholders, that are important for effective HiAP. And, finally, Citizen Science may be applied as a health promotion intervention, empowering and supporting communities to address their health needs. However, Citizen Science is new for the field of public health, although it has links to and sometimes resemblance with, existing participatory action research approaches. There are challenges regarding the selection of participants and methods applied. Moreover, the scientific and societal value of the results of HiAP Citizen Science projects needs a critical examination. Therefore, the approach needs to be not only further developed, but, more importantly, experimented and evaluated.