

# Public health citizen science

perceived impacts on citizen scientists: a case study in a low-income neighbourhood in the Netherlands

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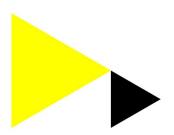
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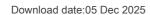


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# **RESEARCH PAPER**

# Public Health Citizen Science; Perceived Impacts on Citizen Scientists: A Case Study in a Low-Income Neighbourhood in the Netherlands

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Citizen science - the active participation of lay people in research - may yield crucial local knowledge and increase research capacity. Recently, there is growing interest to understand benefits for citizen scientists themselves. We studied the perceived impacts of participation in a public health citizen science project on citizen scientists in a disadvantaged neighbourhood in the Netherlands. Local citizen scientists, characterised by low income and low educational level - many of whom were of migrant origin - were trained to interview fellow residents about health-enhancing and health-damaging neighbourhood features. Experiences of these citizen scientists were collected through focus groups and interviews and analysed using a theoretical model of potential citizen science benefits. The results show that the citizen scientists perceived participation in the project as a positive experience. They acquired a broader understanding of health and its determinants and knowledge about healthy lifestyles, and took action to change their own health behaviour. They reported improved self confidence and social skills, and expanded their network across cultural boundaries. Health was perceived as a topic that helped people with different backgrounds to relate to one another. The project also induced joint action to improve the neighbourhood's health. We conclude that citizen science benefits participants with low educational or literacy level. Moreover, it seems to be a promising approach that can help promote health in underprivileged communities by strengthening personal skills and social capital. However, embedding projects in broader health promotion strategies and long-term engagement of citizen scientists should be pursued to accomplish this.

**Keywords:** public health; community; disadvantaged groups; residents; citizen science experiences; neighbourhood

# Introduction

Citizen science – the active participation of lay people in scientific research in ways other than as serving as research objects or respondents – has important advantages for science. It adds knowledge and insights that may help solve complex problems (Fischer 2000) and it may reduce the work load for researchers in

labour-intensive projects, for example, by gathering large amounts of data or collecting data that are otherwise difficult to obtain owing to factors such as geographic spread or hard-to-reach populations (Gommerman and Monroe 2012). The citizen science approach also yields benefits for its participants, for example, by enhancing scientific literacy or public knowledge about specific topics (Bonney et al. 2009, Brossard et al. 2005, Cronje et al. 2011, Den Broeder et al. 2016).

One of the fields in which the impacts of citizen science could be particularly important is public health and the promotion of health research. Community participation is strongly advocated in health promotion, for example, the Ottawa Charter on health promotion emphasises "strengthening community action" as one of its core strands of action (World Health Organization 1986). Partnerships among researchers and community members are considered to be important opportunities for

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empowering communities to take action for better health (Minkler 2000, Israel et al. 1998, Brown 1997, South and Phillips 2014, Wagemakers et al. 2008, Wagemakers et al. 2010, Horowitz et al. 2009).

In practice, the knowledge base for health promotion strategies is often limited to expert-driven knowledge and an epidemiological paradigm (Vaandrager et al. 2011, Minkler et al. 2003). In Amsterdam, the Netherlands, local policy makers aimed to change that by setting up a citizen science project to develop a "bottom-up" health policy for a disadvantaged neighbourhood. The project's main goal was to yield important grassroots information on views, needs, and concerns of the community that could assist in designing a more inclusive policy for this so-called "priority" neighbourhood. Through this project, community members served as peer interviewers of their fellow residents providing important contextual and "insider" information helpful in analysing project data. The project may therefore be classified as a *collaborative* project in the classification of Shirk et al. (2012). In the process, the project team ensured that the project also benefited the participating citizen scientists by enhancing their understanding of the broader determinants of health and their personal competencies. Because the project was intended to provide new opportunities and possibilities for residents to become actively engaged in improving the community's health, assessing project impacts on its citizen scientist participants was a core element of the project's design.

This paper aims to contribute to knowledge about the impacts of participation on citizen scientists in the field of public health, with a focus on disadvantaged groups. Our main research question was: What impacts were experienced by citizen scientists participating in a public health research project?

# Methods

# Project setting

The project took place in 2014–2015 in Slotermeer, a disadvantaged neighbourhood in Amsterdam, the Netherlands. A project team led by "Eigenwijks," a local community work organisation that represents, supports, and activates Slotermeer residents, was formed to set up the project. The evaluation of project impacts on its citizen scientist participants was carried out by researchers who served on the project team.

Slotermeer faces many health and community issues including obesity, mental health, loneliness, poverty, and a poor liveability. More than 60% of the population is of non-western migrant origin (Gemeente Amsterdam 2015a). Residents are considered as "hard to reach" for local public health policy makers, and this project was initiated by the local District Council. Although originally planned for 2014 it was extended to 2015 owing to the enthusiasm of the District Council about its results. Therefore, one group of citizen scientists was enrolled in 2014 and a second group in 2015.

The project objective was to gather information about resident views concerning potential neighbourhood health assets as a basis for determining local policy. Participants

in the project were named "Health Ambassadors," but we will refer to them here as "citizen scientists." The stages of the project were training of citizen scientists, data collection by citizen scientists, and reporting and analysis of results.

## Citizen scientist training

Participants were trained in groups of five to eight through an "experiential learning" approach with a focus on learning processes rather than on attaining fixed end points (Kolb 1984). The citizen scientists were stimulated to link their personal day-to-day experiences to the training content, thus creating new knowledge that combines both. Training was developed and carried out incrementally (MS, WS) with support and input from the project group (SU, KK, SKK, MS, LDB) as well as from the participants. For example, the participants asked for extra help to organise interviews. Therefore, an additional meeting was organised as a kick-off to the interview stage, and a printed guideline about how to organise interviews was developed and provided.

Training addressed three main topics. First, the perspective on health as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" (Huber et al. 2011) was explained. Second, techniques to recruit interviewees and to carry out group interviews based on "motivational interviewing" (Miller and Rollnick 2007) were described. Third, to enhance the citizen scientists' understanding of the broadness of factors that may impact community health, a Dutch translation of the model of sustainable neighbourhoods developed by Egan (2004) was explained and discussed.

Training took place over three half-day sessions within a six-week time span. The training sessions were evaluated by a questionnaire focusing on satisfaction level of the citizen scientists with the training in general, both as a preparation for the research work and as a process. It also contained open-ended questions asking about further needs. The overall satisfaction level with the training was 8.2 on a 10-point scale for 2014 and 8.0 for 2015. Several citizen scientists from the 2014 group suggested better matching of participants with different educational or language levels in different groups. This was implemented in 2015; citizen scientists then rated the training level as well-matched to their needs and knowledge level.

A schematic overview of the training is provided in **Table 1**.

# Data collection by citizen scientists

Citizen scientists collected data during a six-week period launched by a kick-off dinner that celebrated the finalisation of the training and provided instructions and printed guideline to help participants set up interviews. Interview topics included what aspects of the neighbourhood residents viewed as health enhancing (health assets) and what aspects needed to be improved (barriers for health). The citizen scientists also asked residents which actions the residents themselves could develop to improve the community's health. The citizen scientists were trained to carry out group interviews but were invited to also use

Table 1: Training overview.

Session	Topics	Methods	Materials	
Training day 1	Introduction of group members and trainers to one another	Group discussion, storytelling, mini lectures	Flip chart	
	Introduction to the project			
	Health definitions (including "Positive Health")			
Training day 2	Interview techniques and attitudes	Group discussion, small group assignments, video, mini lectures	Powerpoint slides, video examples of interview techniques, flip chart, fill-in forms to reflect on video	
Training day 3	Interview techniques and attitudes	Group discussion, video, mini	Powerpoint slides, video examples of interview techniques, flip chart	
	Health determinants (including Egan model)	lectures		
	Next steps in project			
Kick-off meeting	Recruitment of interviewees	Joint dinner, group instruction	Handout with tips for planning of interviews	
	Reporting			
	Next steps		Reporting form "My Group's Story"	

other methods, such as one-on-one interviews, if they preferred. Indeed, the citizen scientists used a large variety of interview methods, in varied settings, and with many types of interviewees. Interviews took place in homes, schools, shops, community meeting places, and in the street. Some citizen scientists interviewed family and friends, others interviewed random people, and others purposefully searched for different "voices," for example, by interviewing youngsters or older people. According to the citizen scientists, these groups were often not listened to by neighbourhood health professionals. Citizen scientists received practical support from neighbourhood community workers assisted by students from the Amsterdam University of Applied Sciences (SU, KK, JW, and SKK). Support included developing personal strategies to engage residents in interviews. The citizen scientists recorded the results of their interviews on easyto-fill out forms and interviewed a total of 316 fellow residents; one trained citizen scientist did not manage to carry out interviews owing to personal circumstances but remained a group member in all other project stages.

#### Data reporting and analysis by citizen scientists

The third project stage, reporting of results and analysis, consisted of discussion of the interview results in focus groups and jointly interpreting and explaining the data collected, after which these data were further analysed (LdB) yielding an overview of health enhancing neighbourhood features as well as barriers brought forward by the residents interviewed (**Table 2**). Results were presented back to the citizen scientists, to the community, and to the District Council in a report and two brochures (den Broeder et al. 2015, RIVM 2015, RIVM 2016). Moreover, a meeting with all citizen scientists was organised in which these end results were discussed, with the aim of developing recommendations for action, to be taken either by the District Council, by professionals in the neighbourhood, or by residents themselves.

After their interview activities, both the 2014 and 2015 citizen scientist groups organised a neighbourhood

health festival in the community centre, supported by community workers (KK, SU, and JW). At the festival each citizen scientist received a "Health Ambassador" certificate confirming their participation in the project. Project results were used as input for the District Council's District Development Strategy. For example, citizen scientists have become actively engaged in the development of a new programme to combat loneliness in the neighbourhood, one of the topics they discussed during the analysis stage. Moreover, the citizen scientists are explicitly mentioned in the District Development Plans for 2016 and 2017, and the intention is that a larger network of "ambassadors for health" will be developed for the other neighbourhoods in the larger Nieuw-West area (Gemeente Amsterdam 2015b, Gemeente Amsterdam 2016).

#### Research study design

To study the project impacts on the citizen science participants we applied an action research approach; activities with and by citizen scientists were closely linked to research activities carried out to evaluate the perceived impacts of the project. For example, focus groups with the citizen scientists were organised to collect data about how they perceived impacts of the project, but also for them to share and discuss the results of their interviews with each other. Mixed methods were applied as a concurrent triangulation strategy (Creswell 2009). An overview of the project after the initial recruitment, for the citizen scientists enrolled in both 2014 and 2015, is provided in **Figure 1**.

# Selection of citizen scientists to study

All citizen scientists who remained engaged throughout the project were included in this study. They had been selected by the local community work organization, using its resident network in the neighbourhood. They were invited in an informal way, by phone, in person, or in groups gathered at the community center (SU, KK). Several additional persons, having heard about the project from friends in the neighbourhood, came forward without

services

**Table 2:** Neighbourhood features brought forward by residents (N = 316) in the interviews carried out by the citizen scientists.

## Health enhancing neighbourhood features

Attractive and abundant public greenery, in particular the Sloterplas lake

Further enhancement options: Public toilets, more and safer; well-kept children's playgrounds; free or inexpensive public sports facilities for adults

Transport and connectivity is rated good. Public transport is rated as excellent

Further enhancement option: Improve traffic safety around schools

Social and health facilities are abundant and good quality Further enhancement option: Better communication to provide residents with information about the availability of these

# Barriers for health in the neighbourhood

Insufficient information about healthy lifestyles, insufficient health promotion activities

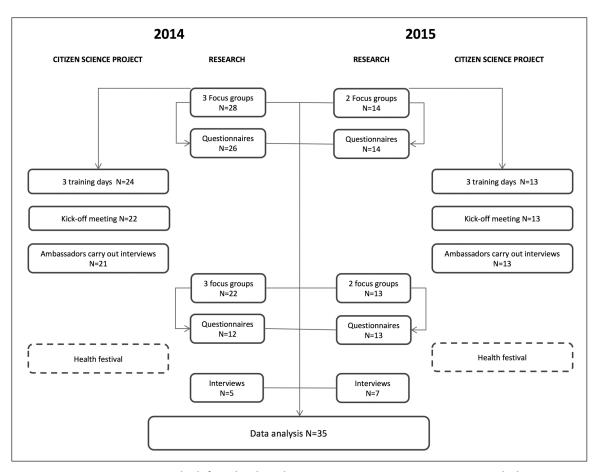
One-sided local economy with a small variety of shops; abundance of unhealthy food choices and junk food stores Unhealthy behaviour of people in the streets, in particular junk

food and soft drink consumption Poverty as such is a health threat; moreover it is a barrier for people to adopt healthy life styles

Poor social cohesion and lack of intercultural exchange, loneliness and a sense of unsafety; lack of meeting places for social contact

Litter in public space, lack of litter disposal facilities and resulting pests inadequate environmental behaviour of residents

Poor quality housing, unhealthy indoor environment and dwellings that are too small for the size of families living there



**Figure 1:** Project overview. Items in the left and right columns are citizen scientists' activities including training; items in the middle column are research activities to study the impacts of their participation as citizen scientists.

being invited. In 2014, those that came forward after the start of the training were placed on a waiting list for the 2015 group. Selection criteria were being a resident of Slotermeer; being engaged in social activities in the neighbourhood; having an interest in community health issues; and being able to speak and understand Dutch on a basic level. Persons who were not selected were invited

to participate in other community centre activities such as courses or social groups.

Initially, 42 citizen scientists were recruited. In 2014, six persons dropped out. Four of these decided not to participate immediately after the initial focus groups, which they had attended out of personal interest but not with the aim of participating in the project. Two other citizen scientists dropped out later due to personal

circumstances. In 2015, one person dropped out for personal reasons, thus 35 citizen scientists remained engaged throughout the project. All were informed, beforehand, that they would receive a financial incentive of €150.00 for their citizen science work after completion of the second round of focus groups.

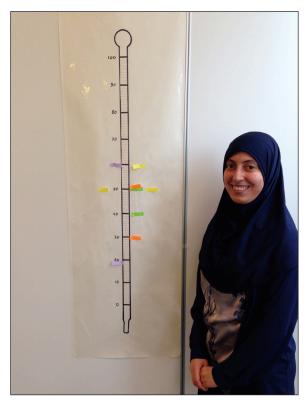
#### Data collection about citizen scientists

Focus groups with both groups of citizen scientists (2014, 2015) were held both before their citizen scientist training and after they had carried out their citizen science task (LDB, MS, WS, KK, AEB). The 45-minute focus groups were held in the community centre, and a focus group protocol was applied. In total 10 focus group with 4–8 persons were conducted. All focus groups were videorecorded and transcribed verbatim.

The main topic in the focus groups held before the project activities began was how the citizen scientists perceived the health of the neighbourhood. Focus groups were started off by filling out a "thermometer" for the health of the neighbourhood; these scores were then placed on a large wall poster (Figure 2). After this, a discussion took place about health in general and the health of the neighbourhood. The focus groups also served to facilitate the citizen scientists in getting acquainted with the project team and each other.

In the focus groups held after the citizen scientists had carried out their citizen science tasks, two topics were central: The information participants had collected and their personal experiences as citizen scientists. All citizen scientists were also invited as respondents for post-project semi-structured interviews about their experiences as citizen scientists (opportunity sampling) (AVDW, LDB). Average interview duration was 30 minutes, and interviews were recorded and transcribed verbatim. Examples of questions were: "How do you feel about the project Healthy Slotermeer?", "What is your own role in the project?", and "What has the project meant to you as a person?". After the interviews, the citizen scientists received a € 10.00 gift cheque as an acknowledgement.

At focus groups conducted both before and after project activities, the citizen scientists filled out a structured questionnaire. Items included personal data, two visual analogue scales rating personal and neighbourhood health (de Boer et al. 2004), the Chew Three-item Health Literacy (HL) scale, Dutch version (Fransen et al. 2011), and the 13 item Sense Of Coherence (SOC) scale (Dutch version) (Swan et al. 2015). The Chew HL scale measures functional literacy level needed to understand written health information by means of three five-point Likert scale questions. The SOC scale is a validated scale consisting of 13 seven-point Likert scale questions measuring the degree to which a person experiences reality as comprehensible, meaningful, and manageable; a high SOC contributes to health and health behaviour. SOC may increase over the life span, and focused interventions may support this. Therefore, SOC is a key concept in asset approaches in health promotion (Eriksson and Lindström 2005, Nilsson et al. 2010, Super et al. 2014). The SOC-13 scale has been translated and applied in different parts of the world with different groups; a worldwide



**Figure 2:** Wall poster displaying citizen scientists' rating of the neighbourhood's health. The person in this photo is a research assistant. Informed consent for use of this photo was obtained.

review looking into the validity of the scale suggests that it is interculturally stable (Eriksson and Lindström 2005) The SOC scale copyright holders granted permission for its use in this study.

#### Analysis of data about citizen scientists

Analysis of the qualitative data was carried out through descriptive and thematic coding (Tracy 2013). The codebook for descriptive coding was based on a model of benefits for citizen scientists that we presented in an earlier paper (Den Broeder et al. 2016). This model contains four clusters of potential direct impacts of participation in a public-health citizen science project on the citizen scientists (Figure 3). The first cluster refers to increase of health literacy, conceptualised as an asset: "a person's ability to access, understand, and use health information in ways that promote and maintain good health" (Nutbeam 2008: 2076). The second cluster refers to empowerment of citizen scientists to take action on a personal or collective level. The third cluster refers to community building, social capital, social learning, and trust. The fourth cluster refers to change of attitudes, norms and values. These clusters are marked 4, 5, 6 and 7 in the figure. The codebook was tested and refined by pilot coding of two interviews (LL, LdB), then applied to all data, i.e., interview and focus group transcripts (the codebook and code descriptions are presented in **Table 3**).

Two coders (LDB, LL) carried out coding using MaxQDA software, version 12. Coding outputs were compared; decisions on codes assigned were taken based on consensus. After descriptive coding, output lists per code

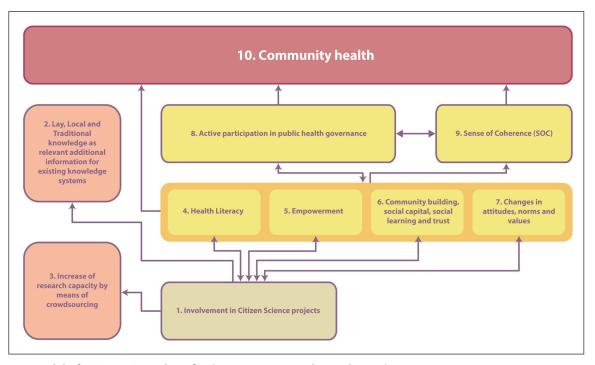


Figure 3: Model of citizen science benefits (Source: Den Broeder et al. 2016).

and per code set were analysed and recurrent themes identified for each code set (thematic analysis). Themes were then clustered across code sets into broader, more generic themes describing citizen scientists' experiences and perceptions (LDB, LL, AW, JS). Coding outputs of focus groups held before training of the citizen scientists were used solely to verify changes of perception (or lack of change) reported by citizen scientists.

We carried out descriptive analysis of the questionnaire data. Responses for the HL scale were scored from 0 to 4, added, and averaged. An average score  $\geq 2$  indicates adequate HL; scores under 2 indicate inadequate HL (Fransen et al. 2011). Scores on SOC were calculated by adding up the points (1–7) marked for each item. Similar to previous research with this scale in the Netherlands, we rated SOC  $\leq$  67 as "low" and SOC  $\geq$  68 as "high" (Swan et al. 2016).

The significance of changes in scores before and after participation in the project were analysed by performing paired T-tests on scores for personal and neighbourhood health, HL, and SOC.

#### Results

#### Background of the citizen scientists

Most citizen scientists were women and most were members of cultural minority groups and/or migrants. Most had a moderate educational level; several nonwestern migrants stated that they had followed a university education in their country of origin. The income level of the citizen scientists was low to moderate – four had paid work while the others were homemakers, unemployed, pensioners, or received social benefits. One was a student. Background data of the citizen scientists is presented in **Table 4**. Except for gender composition, the citizen scientist groups resemble the neighbourhood's population, with 26% unemployment (homemakers, in

the Netherlands, are not registered as unemployed) and 28% of the households combining low income with low educational level of the head of household. In Slotermeer, more than 60% of the inhabitants are of migrant origin, in particular Turkish and Moroccan, and 37 to 41% of the inhabitants have low literacy levels (Gemeente Amsterdam 2015a).

# Focus group and interview results

All quotes hereafter are Dutch to English translations. As some citizen scientists' mastery of Dutch was basic, the original quotes were not always well formed. These were corrected at translation to improve readability of this paper.

#### Generic results

The main reason that the citizen scientists participated was that they were enthusiastic about the theme "health" and felt this was a topic worth working on. They felt the neighbourhood could be improved in that respect and they wished to contribute to that effort:

"Why I joined the project? Because I think it is something good for our neighbourhood. Health is important for us, because the dark spot in Amsterdam is this neighbourhood here, it is Slotermeer."

(interview citizen scientist 30)

Other motivations were that they were keen to meet new people and learn something new. Some citizen scientists with a migrant background saw the project as an opportunity to get in touch with people outside their own cultural group, thereby developing their language skills:

"I thought, this is a good project; I should participate, even though I don't speak Dutch very

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	Table 6. Coor Door a

Code name/description	Inclusion criteria	Exclusion criteria
HL Finding info Any remark referring to the ability to find information about health, health care, health behavior	Include when respondent refers to own abilities Include when one's own ability is compared to others, implicitly or explicitly	Exclude when referral is solely to other's abilities  Exclude when not referring to health, health care, or health behaviour
<b>HL Understanding info</b> Referring to the ability to understand information about health, health care, health behavior	Include when respondent refers to own abilities Include when one's own ability is compared to others, implicitly or explicitly	Exclude when referral is solely to other's abilities  Exclude when not referring to health, health care, or health behaviour  Exclude when referring solely to quality or accessibility of the information
HL Applying health info Referring to the ability to apply information about health, health care, health behavior to one's own situation	Include when respondent refers to own abilities Include when one's own ability is compared to others, implicitly or explicitly	Exclude when referral is solely to other's abilities  Exclude when not referring to health, health care, or health behaviour  Exclude when referring solely to the usefulness or applicability of the information
Emp Options for personal action Referring to possibilities to take action in personal life	Include when personal options for action are referred to Include when one's own options are compared to others, implicitly or explicitly	Exclude when referral is solely to other's options
Emp Options for collective action Referring to possibilities to take action with other community members	Include when community options for action are referred to Include when one's own contribution to collective action options are referred to	Exclude when referral is solely to options in other communities
<b>Comm Community building</b> Referring to contribution to greater social cohesion in or quality of the community	Include when features of the community are referred to	Exclude when solely referring to individual features of persons
Comm Social capital Referring to one's own social network and access to broader networks social networks	Include when referring to one's own networks/access to r networks	Exclude when referring solely to the networks as such Exclude when referring solely to other people's networks
<b>Comm Social learning</b> Referring to shared learning experience	Include when learning is referred to Include when shared experience is referred to	Exclude in case of referring to individual learning
<b>Comm Trust</b> Referring to experience of trust	Include when referring to trust in other group members Include when referring to trust in project team Include when referring to trust in trainers	Exclude when referring to trust in people or institutions outside project scope

(contd.)

Code name/description	Inclusion criteria	Exclusion criteria
Att Attitude change	Include when attitudes are changed	Exclude when referring solely to other people's attitudes
Referring to adoption of new attitudes, i.e., systems of	Include when existing attitudes are reinforced	
thought, opinions, tendencies	Include when existing attitudes are further developed	
Att Change of norms	Include when norms are changed	Exclude when referring solely to other people's norms
Referring to adoption of new norms, i.e., what is considered Include when existing norms are reinforced	Include when existing norms are reinforced	Exclude when referring solely to collective norms
positive/negative, appropriate/inappropriate	Include when existing norms are further developed	
Att Change of values	Include when values are changed	Exclude when referring solely to other people's values
Referring to adoption of new values, i.e., views on what are	Include when existing values are reinforced	
important aspects in life that underpin one's opinions and behaviours	Include when existing values are further developed	
OC Positive points	Include when positive points are mentioned	Exclude when referring solely to positive points as perceived by
Referring to positive points of the project as mentioned by the citizen scientist		other people
OC Negative points/points of improvement	Include when negative points or points of improvement are	Exclude when referring solely to negative points or points for
Referring to negative points or points of improvement of the project as mentioned by the citizen scientist	mentioned	improvement as perceived by other people
OC Motivation to participate	Include when reasons to participate in the project are	Exclude when referring solely to other people's reasons to
Referring to motivation of citizen scientist to participate in the project	mentioned	participate
OC Other effects of project	Include when other effects of the projects on the citizen	Exclude when referring solely to other effects experienced by other
Referring to other effects of the project as perceived by the citizen scientists, e.g., it brought them fun	scientist are experienced	people

**Table 4:** Background of citizen scientists.

#### Personal characteristics (N = 35)

Gender	N	Age	N	Country of birth	N
Female	32	21–30	3	Morocco	17
Male	3	31–40	10	Netherlands	6
		41–50	15	Turkey	3
		51–60	1	Egypt	2
		>60	4	Surinam	2
		Unknown	2	Other non-western	2
				Missing	3

#### Socioeconomic characteristics (N = 35)

Education	N	Employment	N	Monthly income	N
None	1	Homemaker	17	<1.000	6
Elementary	3	Unemployed	4	1.000-1.350	10
Secondary/vocational	17	Social assistance	1	1.350-1.800	6
Higher	5	Work (part time)	3	1.800-3.150	3
Academic	6	Work (full time)	1	Won't tell	3
Unknown	3	Pensioner	3	Don't know	3
		Student	1	Missing	4
		Other	3		
		Unknown	2		

well. But I understand you (the interviewer) for example, and I try to improve my language by this interview, by the communication in Dutch. That is why this contact with others is so important: Otherwise we remain like this forever ... I feel that I need to do something for myself, for my life; not just getting up, watching TV and looking after the children."

(interview citizen scientist 30)

Several citizen scientists mentioned that the financial incentive motivated them. Some also stated that they appreciated being personally acknowledged for contributing to the project. One citizen scientist said she was "sick and tired" of Slotermeer's negative reputation; she was motivated by the opportunity to prove that it was a much better neighbourhood than "outsiders" thought.

Participating in the project was a positive experience for all citizen scientists. They had enjoyed group work during training and felt that learning as a group was more effective than it would have been as an individual. Carrying out interviews was perceived as a new and challenging assignment; they valued this as something very special. They reflected on the project as a new and promising approach to improve the neighbourhood's health:

"I think it is a beautiful way to collect people's ideas and to use that information to do something good for them. At first I thought, 'Healthy Slotermeer,' what's that? It is useless! But after I had joined the project I saw how effective this can be." (interview citizen scientist 22)

A few citizen scientists said that although they liked the project, the practical organisation had not been flawless, in particular regarding timeliness of information about meeting times and places.

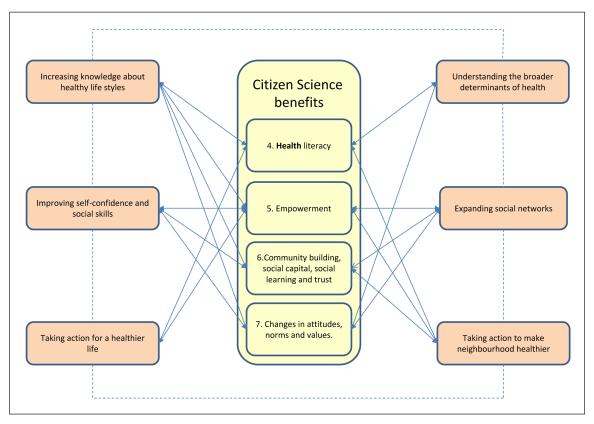
Main personal impacts as experienced by citizen scientists. Through our thematic analysis of the coded interview and focus group data, we identified an average of 16 themes per code set, with each set relating to one of the dimensions of the model of Citizen Science benefits. These themes were strongly interrelated and a multitude of overlapping aspects could be observed. Clustering the themes across code sets, we could observe six main personal impacts of the project experienced by the citizen scientists (**Figure 4**).

#### Understanding the broader determinants of health

The citizen scientists reported to have developed a new perception of health as encompassing many other aspects of life, while their initial idea about health was more narrowly focused:

"I had this idea about healthy food, exercise, mental wellbeing. But for many people things like police officers in the streets play a role for health. In that sense I have started to look at health differently, wondering what really makes people healthier. I want to know whether people know what is good for them or what would help them. I don't know that and I am rather curious about it." (interview citizen scientist 7)

The perceptions of health as expressed during the focus groups conducted before their training confirm that



**Figure 4:** Impacts of the project and citizen science benefits. The numbers relate to the numbers in the model of potential citizen science benefits shown in Figure 3.

a change had occurred. In particular, at that time the citizen scientists had a focus on health as a personal, not collective, issue that depends on one's own behaviour. Several citizen scientists defined health as equal to healthy behaviour: "Today I am healthy because I took a bicycle ride."

The citizen scientists had also adopted a more positive definition of health, instead of focusing on the absence of health problems: "Health is good when it is good, not just when there is nothing wrong."

In addition, during the project, the citizen scientists seem to have developed an understanding of the social determinants of health, perceiving the neighbourhood as an important factor shaping people's health and perceiving their neighbourhood through a "health lens." They have become interested to hear what residents think about the neighbourhood as a healthy or unhealthy place. The citizen scientists report that this gave them new insights about what makes a neighbourhood a healthy place. The importance of living circumstances in the neighbourhood was confirmed to them during the interviews they conducted, sometimes to their own surprise:

"Yeah, they [the residents interviewed, LdB] live here and they had quite some comments about the neighbourhood. For example, they said there is a lot of traffic there. I had never thought about that. You just go to talk to them with a certain vision in mind, with a thought and an expectation. I heard totally different things. That was some kind of special experience." (focus group 3)

#### Increasing knowledge about healthy life styles

Most important was the development of health knowledge. The citizen scientists claimed that they learned a lot about health and in particular about healthy life styles. The citizen scientists had developed "health consciousness" through this knowledge, and had started reflecting on their own (and other people's) health habits:

"I was never very much occupied with what I ate. I never thought about anything that I did in terms of how healthy or unhealthy that was. But since the project I am constantly thinking about it. I did that quiz at the health festival and scored terrible results. Then I said to myself: How can you be a Health Ambassador and not know anything about what you eat or drink!". (interview citizen scientist 22)

The citizen scientists said that this learning process was continuing at the time of the interviews/focus groups; they reported the intention to gather more extensive knowledge, either by searching for it by themselves or by subscribing to other courses at the community centre. One example of the latter was a citizen scientist who had enrolled in a course about "healthy development in puberty."

#### Taking action for a healthier life

The project seems to have activated citizen scientists to make changes in their personal life. Healthier food patterns were most frequently mentioned, as well as taking more physical exercise. Almost all citizen scientists talked about this during interviews and focus groups. They linked this to the information they received during the training, but also to a more generic sense of stronger "health consciousness." They also applied this improved life style to their family and friends:

"I really like it. I myself have changed, because I was not like that before. I take a lot of exercise; my children have all joined sports clubs now. I always cook a healthy dinner. A great many things have changed in my life."

(intervious sitings existing assistation of the content of the

(interview citizen scientist 35)

Other actions mentioned were making their own house healthier, for example by improving the indoor environmental quality, keeping their direct living environment clean by picking up rubbish in the street, investing more in social contacts with neighbours, or taking up new education or training.

# Improving self-confidence and social skills

The citizen scientists stated that they had acquired new social competences. They said that, at first, they were insecure when initiating an interview, but were then surprised to experience how easy it was to approach fellow residents, even though some topics were easier to discuss than others. Their self-confidence had grown and they felt that this was due to the project, as they had received training in addressing people and in interview skills. Some reported having gained better mastery of the Dutch language, which made it easier for them to communicate with other people. The citizen scientists felt proud of their work; moreover, they stated that being a "Health Ambassador" provided a certain social status to them:

"Well, maybe it gives me a good feeling, too. It is now acceptable for me to speak out in the street: 'Can I talk to you about health?' Even without saying that I am a Health Ambassador. I call it 'ambassador of health issues.' Well, that creates some authority on the spot!". (interview citizen scientist 14)

Several citizen scientists stated that the project gave their personal development a boost; some reported that participation changed their self-image. One citizen scientist held a public presentation about the results of her interviews at the health festival, in the presence of District Council officials, which she experienced as a big step forward:

"I was really someone that could never speak for a group of people. I had been very scared, I had black-outs. But standing there, at that moment, made me think: Hey, I am really proud of myself! After all, I am able to do this!". (interview citizen scientist 40)

#### Expanding social networks across cultural boundaries

The citizen scientists reported that by participating in the project they extended their personal social networks. They met new people in the group of citizen scientists, and several reported having become friends or keeping connected to the other group members after the project ended, for example, in a WhatsApp group. Several reported that they helped each other in organising health activities in the neighbourhood. The "health festival" was an example about which all spoke with enthusiasm.

Meeting new people in the neighbourhood in general was another effect of the project confirmed by all citizen scientists. In particular, citizen scientists reported that they managed to establish contacts with residents across cultures. This issue was considered of great importance, as they felt that different cultural groups in the neighbourhood do not mix easily; this was one of the most serious problems in Slotermeer, according to the citizen scientists. They had the impression that cultural differences cause a lack of trust between the different groups, and that social cohesion is poor:

"I find it striking, and important, although it is no real news, that everyone here [in Slotermeer, LdB] wants more contact with one another ... Somehow it doesn't work out well, while everyone wants it! All the people I interviewed said the same: They want more contact. If everyone wants it, then why doesn't it happen?".

(focus group 3)

The citizen scientists expressed the wish that the Slotermeer residents would learn to understand, respect, and value each other's culture so that the social quality of the neighbourhood could be improved. They hoped the project could contribute to that; although it could only be a small contribution it might set off a larger movement. The fact that, as citizen scientists, they managed to establish cross-cultural contacts in the course of the project was important to them. They identified two important factors that helped them to accomplish this. First, the citizen scientists mention learning experiences during training sessions that were helpful: They had learned to listen to others without judging and to respect other people's opinions and views. They also experienced a feeling of being respected themselves:

"And you are being listened to. You give each other space to talk. That is what I experienced. Like citizen scientist X said: At first, she did not dare to speak, out of fear to make mistakes in the Dutch language, but now she knows she won't be laughed at" [citizen scientist's name removed for privacy, LdB].

(focus group 5)

This was experienced both within the citizen scientists' group and when interviewing fellow residents. Citizen scientists reported having developed a better understanding and appreciation for people with different

cultural backgrounds. They often felt surprised by what they saw and heard. One citizen scientist of Dutch origin, for example, reported how her view changed regarding the group members with a Moroccan background:

"I did notice how strong those Ambassadors really are. They are truly powerful women; I was surprised! I find this very positive." (interview citizen scientist 11)

The second factor that the citizen scientists considered important for their successful cross-cultural contacts was the usefulness of "health" as an inspiring topic for conversation. According to the citizen scientists, "health" was perceived as something everyone can relate to, that no one opposes, and that is relevant for all residents in the neighbourhood. The citizen scientists reported that everyone was eager to discuss health, and that they had surprising and interesting conversations about the topic. Discussing health provided the citizen scientists with a sense of recognition, because the residents they interviewed came up with concerns and views that resembled their own.

Talking about health seems to have created a common interest and thus a reason for people to relate to one another:

"I think choosing health as a topic is great. It is a joint issue. You can look at health from an Islamic or Turkish perspective. But the core of health is that it is human. It is always positive to work on an issue like that; something that just everyone experiences."

(interview citizen scientist 22)

#### Taking action to make the neighbourhood healthier

The citizen scientists report they have taken action or plan to do so, to enhance the neighbourhood's health. They base their actions on what they learnt during the training, but also on information gathered when interviewing fellow residents. They discovered, for example, that many residents do not know how to access information about health care and about opportunities for financial support. They report having taken action to improve accessibility of this information.

Several citizen scientists were triggered by resident accounts of the poor state of housing in the neighbourhood, in particular regarding indoor environments. One citizen scientist collected photos to illustrate this, showing mould on walls and ceilings:

"I would like to talk about the neighbourhood's houses, because I saw photos that are just shocking. I thought my own house was bad, but then the neighbours sent all those photos. I was interested: "how do you live?" Because people sometimes say they live in a dirty place, and some exaggerate the problems. But when I saw those photos I thought: 'this is terrible, how can your children sleep in there?' You just hear that 50% of those children have asthma!".

(focus group 4)

Their response was attempting to make an inventory of the problems, and pass this information to the housing corporation or the municipality. Several citizen scientists also helped individual families to get the housing corporation to improve the state of their dwelling, for example by making phone calls on behalf of those families.

They also wish to promote healthy lifestyles for their fellow residents. This was one of the reasons to develop and carry out a health festival. However, several said that more was needed. They asked for more training to become lay health extension workers and to run workshops about healthy living. While citizen scientists saw a clear role for themselves, they also called for collective action as a requirement for a healthier neighbourhood. They perceived small, temporary projects as ineffective; arguing that a broader and continuing movement is needed. Although some of them felt that they had already contributed sufficiently by participating in the project, most citizen scientists suggested that they could play a role in setting this up:

"It should not be like this: 'I have a nice little initiative for 10 people.' Then it all stops again. No, it should be broader and it should be linked to those places we call our community centres, to make it easier. But yeah, you would also need a core group of active and engaged residents." (focus group 3)

Their expectations regarding their ability to improve the neighbourhood's health was not fully optimistic. The citizen scientists reported that residents have lost confidence in local policies or local professionals because of unkept promises. They also reported that many residents had asked them what would happen next, and that they had felt they could not provide an appropriate answer:

"When you talk to those people ... I felt, like, let me say it like this, like my hands were just tied. Because you can't do anything, you really can't do anything at all. If we had been able to do something, we would have. But we weren't."

(focus group 4)

Like their fellow residents, they expressed a sense of powerlessness to accomplish real change. Some reported having developed a less positive vision of their neighbourhood than before the project due to these experiences. One example is the local food environment, which was considered very unhealthy, with an overwhelming supply of fast food and soft drinks. The citizen scientists felt that this problem was something they could not help solve.

# Questionnaire results

Not all citizen scientists completed both questionnaires due to printing problems at the second round of focus groups with the citizen scientists enrolled in 2014. Moreover, many citizen scientists encountered difficulties in filling out the questionnaires, in particular for the SOC-13 items. They experienced the questions as

complicated and difficult to interpret. However, for those citizen scientists who filled out both questionnaires or parts of them, we compared scores before and after the project. An overview of scores and of the comparisons is shown in **Table 5**.

At the start of their participation in the project, the citizen scientists rated their own health and the health of the neighbourhood by an average of, respectively, 6.77 and 5.20 on a 10-point scale. At the second measurement, after their participation in the project, these averages were 6.19 and 5.28. A paired comparison of scores before and after the project, i.e., comparing scores at first and second measurement per citizen scientist, showed that the changes were not statistically significant.

The calculated HL score at the start of their participation was "inadequate" for 8 out of 30 citizen scientists. These persons were all migrants with a non-western country of origin, although all but one had been living in the Netherlands for 10 years or longer. After participation, scores were inadequate for 2 out of 20 citizen scientists. Comparing scores per citizen scientist showed an average increase of HL scores by 0.5. This increase is statistically significant; paired one-tailed T-test yielded a P-value of 0.0045.

The SOC at the start of participation was "high" for 11 citizen scientists who filled out the SOC scale and "low" for 13 citizen scientists. After participation, of those who filled out the SOC scale, 7 citizen scientists scored "high" and 14 "low." Paired comparison of the calculated SOC

scores showed that the changes were not statistically significant.

# Discussion and conclusions

The aims of the Slotermeer project were twofold: To develop knowledge that could serve as input for local policy development, and to enhance the citizen scientists' personal resources to actively engage in improving the community's health. This paper focused on describing the impacts of the project on the citizen scientists.

#### Discussion of main results

Our analysis of the qualitative data showed a number of distinct, but closely related, effects of the project on the citizen scientists as shown in **Figure 4**. First, the citizen scientists changed their views on health and acquired an *understanding of the broader determinants of health*. Second, they *increased knowledge about healthy lifestyles* and reflected on these in relation to their personal habits. This materialised in the third impact: *Taking action for a healthier life*. Fourth, the citizen scientists reported having developed new social competences; related to this, they reported *improved self-confidence and social skills*. Fifth, the citizen scientists *expanded their social networks across cultural boundaries*. The sixth reported impact was that the project had functioned as a trigger to *take action for a healthier neighbourhood*.

The quantitative data confirmed these findings. We found no significant changes in how citizen scientists

**Table 5:** Scores for personal/neighbourhood health, Health Literacy, and Sense of Coherence. Paired comparisons, i.e., measurements on the same person before and after the project, have been made for those citizen scientists who filled out complete (sub)scales in both questionnaire rounds.

Rating of personal health (scale 0-10)		Av.		Av.
Average personal health rating before $(N = 30)$ and after project $(N = 23)$	Before	6.77	After	6.19
Paired comparison average personal health rating before and after project ( $N = 20$ )	Before	6.67	After	6.24(P = 0.2161)
Rating of neighbourhood health (scale 0-10)		Av.		Av.
Average neighbourhood health rating before project $(N = 30)$ and after project $(N = 23)$	Before	5.20	After	5.28
Paired comparison average neighbourhood health rating before and after project ( $N = 17$ )	Before	5.29	After	5.35(P = 0.4270)
Adequate/inadequate HL (score range 0–4; $\geq$ 2 adequate	te)	N		N
HL (in)adequacy before project $(N = 30)$	Adequate	22	Inadequate	8
HL (in)adequacy after project ( $N = 20$ )	Adequate	18	Inadequate	2
Paired comparison HL scores (in)adequacy ( $N = 17$ )		N		N
HL (in)adequacy before project	Adequate	14	Inadequate	3
HL (in)adequacy after project	Adequate	17	Inadequate	0
		Av.		Av.
Paired comparison average HL scores ( $N = 17$ )	Before	2.63	After	3.14(P = 0.0045)
SOC scores (range 13-91, ≥68 "high", ≤67 "low")		N		N
SOC before project (N = 24)	High	11	Low	13
SOC after project (N = 21)	High	7	Low	14
Paired comparison high/low SOC before – after $(N = 15)$		N		N
SOC before project	High	7	low	8
SOC after project	High	5	Low	10
		Av.		Av.
Paired comparison SOC scores before – after ( $N = 15$ )	Before	63.21	After	63.28(P = 0.4884)

rated personal health; this would have been surprising as participation did not last very long and health status, including self-reported health, does not change overnight. The lack of change in the citizen scientists' rating of neighbourhood health before and after their participation in the project was equally unsurprising. The qualitative data show that, on one hand, the citizen scientists came across problems such as poor housing and loneliness, while on the other hand they identified unexpected positive neighbourhood aspects such as attractive greenery and effective public transport. We suppose that these have balanced each other out.

An interesting finding was that the increase in knowledge about and understanding of health issues was reflected in increase of (measured) HL. This also links up to the observation of some citizen scientists that the project helped to improve their level of understanding of the Dutch language.

SOC scores appear to be in line with data collected with this scale in a study of 781 Dutch persons of 18 years and older, which showed high SOC for 386 persons and low SOC for 395 persons (Swan et al. 2016). No significant change of SOC scores occurred. Although other studies have demonstrated that an increase of SOC scores is possible, this requires intensive interventions focused on empowerment and development of reflection capabilities (Super et al. 2015, Kähönen et al. 2012, Vastamäki et al. 2009). The "Healthy Slotermeer" project probably lacked that high degree of intensiveness.

Of course, SOC scores of the citizen scientists must be interpreted with caution as they experienced the questions in the SOC scale as complicated and therefore may have misunderstood some questions. Other Dutch researchers came across similar problems in measuring SOC of people with a low educational level (Herens 2016), but at present there are no validated alternatives that are better suited to similar target groups.

## Citizen science and health promotion

Two things in particular stand out from the results: The contribution of this project to intercultural exchange between the citizen scientists and other residents and the activation of the citizen scientists for their own and the neighbourhood's health. The intercultural exchange, substantiated in the citizen scientists' observation that "health" is a theme that has the potential to join people with different backgrounds, is highly relevant in relation to the setting of the project: A neighbourhood that is strongly divided and where cultural groups do not mix. The citizen scientists' curiosity, and their willingness to listen to different points of view, may very well have played a role in bringing about intercultural contacts. Citizen science has been reported to increase social capital and social cohesion in environmental monitoring (Conrad and Hilchey 2011, Jones et al. 2006, Whitelaw et al. 2003). Our case shows that this might be true not only for monitoring focused on health-relevant environmental factors but also for other types of public health citizen science.

The empowerment and activation of the citizen scientists was part of the project's focus from the beginning. They made their own decisions on how, where, and whom they

would interview. Moreover, they presented findings to the community and the District Council and took action to help address problems identified through their research work. The fact that the project was led by community workers, instead of by the researchers, has been meaningful to support the self-organisation of residents in the framework of this project and afterwards.

As described above, learning occurred throughout the project and the citizen scientists reported that they changed lifestyle behaviours or intended to do so. Moreover, they took action to make their neighbourhood a healthier place. As such, it seems that the project has functioned as a health promotion intervention. Indeed, there are linkages between empowerment, social capital, and community health (Wagemakers et al. 2010). Participatory or community approaches are a key element of health promotion, and the reasons why the citizen scientists liked to be part of the project resemble four important motivations for participation identified in effective community health promotion projects: Action that serves a tangible purpose; opportunities for selfdevelopment; recognition and status as a role model; and meaningful relationships (Fienieg et al. 2012). The freedom of the citizen scientists to decide how exactly they would carry out their research work instead of following prescribed procedures - although some might considered it a "threat" to the scientific quality of the data collected – may have enhanced their feeling of ownership of the project.

The project also demonstrates that public health citizen science can very well be put to practice with citizen scientists who do not have high educational levels or good reading and writing skills. As such, this project links up with similar experiences in other work fields (e.g., Bonney et al. 2014, Braschler 2009).

#### Strengths and weaknesses of this study

The impacts of the Healthy Slotermeer project were studied on the citizen scientists using the "benefits of citizen science" model. This was a strong point of the project, as the model proved useful to analyse the data collected and identify specific impacts of participation. Moreover, the model helped to provide an overview of the interrelatedness of different aspects. For example, using new knowledge about health to change one's lifestyles can be considered an increase in **health literacy**, but also as **empowerment** while increasing options for **effective action** to improve one's own life. Similarly, improved **social capital** became apparent in the **joint actions** of the citizen scientists, some of which can further support **social cohesion**. An example of this was the organisation of the Health Festival by the citizen scientists.

Another strong point is the combination of different qualitative and quantitative methods to evaluate the impacts of participation on the citizen scientists. This combination made it possible to obtain a richer and more in-depth image of these impacts.

A weakness of this study is that it relies mostly on selfreported impacts: Citizen scientists may have provided socially desirable answers. Other possibilities to study impacts of this project could have been to interview local professionals or to count the number of actions taken by citizen scientists. However, listening to the voices of residents that are seldom heard was core to this project. Therefore, we believe that it was appropriate to take their personal experiences as a starting point when evaluating the project's impacts. The use of different techniques to tap these experiences combining focus groups, interviews, and questionnaires provided us with the opportunity to gain deeper insight into these experiences.

#### Lessons learnt and further steps

We have shown that public health citizen science may not only help to collect local information, but also can be a good strategy for community based health promotion. The development of residents' skills and the engagement of the community in the development of local strategies to create a social and physical environment that supports health and healthy behaviour are essential elements of the Ottawa Charter's strategies for health promotion. Moreover, the approach seems to benefit citizen scientists with low educational levels. The methods applied, including the training and support of citizen scientists, need to be further developed and evaluated with similar groups and in similar places, adding to the body of knowledge about impacts on citizen scientists.

In this project, first steps were taken to build a partnership between the citizen scientists and the researchers. However, although the citizen scientists did make some decisions regarding their research activities autonomously, much more could be done, for example by means of co-creation in the early design of future research projects. A more equal partnership, with space to discuss and, occasionally, disagree, may enhance beneficial effects both on the research as well as on those participating, both for researchers and citizen scientists (Jagosh et al. 2012, Horowitz et al. 2009).

Moreover, the health promoting potential of public health citizen science projects, like all health promotion, can be meaningful only if embedded in broader, longer lasting strategies (Jackson et al. 2006). Indeed, shortlived projects without follow-up or implementation of their recommendations may have the adverse effects of disappointing and discouraging the groups engaged.

The citizen scientists in this project showed a concern precisely about such a possible lack of follow-up. We recommend therefore that public health citizen science should not be restricted to projects with short duration, but rather should pursue long-term engagement, including activities explicitly addressing citizen scientists' needs for strengthened advocacy skills. In the case described in this paper, for example, we would recommend that the project be linked with the District Development Strategy, which is adapted every four years and provides the background for the annual District Plans. In this way the beneficial impacts of public health citizen science projects on disadvantaged communities could be sustained and enhanced.

# Ethics and consent

All persons included in this study were informed about the aims of the study. Informed consent was obtained for each focus group (all participants), each questionnaire, and each interview. Consent was given orally and was recorded for reasons of varying literacy levels of the participants. Ethics Committee approval was not applicable for this study. The code of conduct for scientific research of the National Institute for Public Health and the Environment, which is based on the Netherlands Code of Conduct for Academic Practice, was adhered to. See: http://www.vsnu.nl/files/documenten/Domeinen/Onderzoek/The%20 Netherlands%20Code%20of%20Conduct%20for%20 Academic%20Practice%202004%20%28version%20 2014%29.pdf.

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# **Competing Interests**

The authors have no competing interests to declare.

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