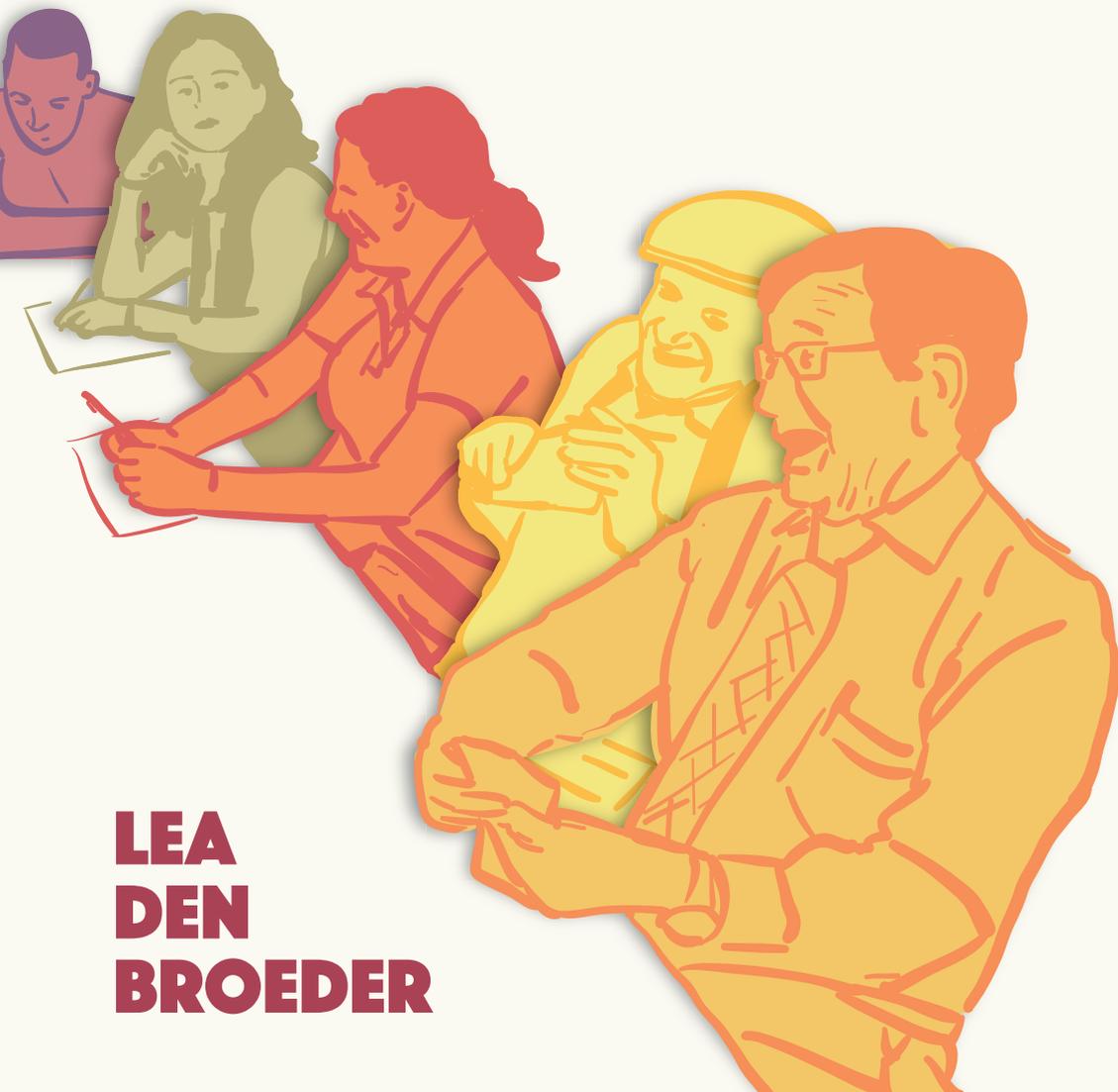


# CITIZEN SCIENCE FOR HEALTH IN ALL POLICIES

*Engaging communities in knowledge development*



**LEA  
DEN  
BROEDER**



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**Citizen Science for Health in All Policies**  
Engaging communities in knowledge development

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door

**Julia Maria den Broeder**  
geboren te Amsterdam

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**“Voici mon secret. Il est très simple: on ne voit bien qu’avec le cœur.  
L’essentiel est invisible pour les yeux”**

(“And now here is my secret, a very simple secret: It is only with the heart that one can see rightly; what is essential is invisible to the eye”)

*From: Antoine de Saint-Exupéry (1943) Le petit prince*



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# CHAPTER 01



# General introduction





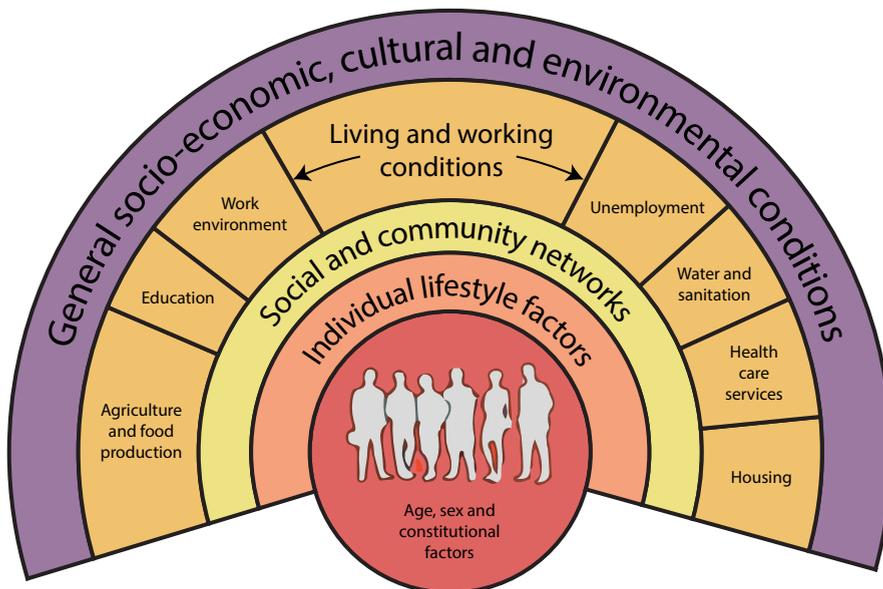
## 1.1 BACKGROUND

### 1.1.1 Health challenges as wicked problems

Health is a fundamental right for all human beings (1). A healthy population is also important for social and economic prosperity and for the wellbeing of all; for example, (chronic) diseases have major labour market impacts (2). Therefore, policy makers, health professionals and society at large have a stake at attaining the best possible state of health for all.

One way to attain good population health is delivery of adequate cure and care services for those in need. In addition, it is also necessary to prevent the development of health problems and to improve and promote health. The Ottawa Charter on Health Promotion defines health promotion as: ‘the process of enabling individuals and communities to increase control over, and to improve their health’ (3).

The promotion of health is challenging because many factors outside the realm of the health sector itself have considerable health impacts. The model of Dahlgren and Whitehead (4) is one of the most frequently used models showing how individual health is affected by people’s lifestyle factors and the social and community networks, living and working conditions and broader societal circumstances and developments.



**Figure 1.** Model of health and its determinants. Source: Dahlgren and Whitehead, 1991

Because of the interconnectedness of health and other policy fields, many health challenges are ‘wicked problems’. Rittel and Webber (1973) introduced the term wicked problems. Such problems are linked, in complex ways, to many other, related, problems, as well as to different interests or goals of a variety of stakeholders. Wicked problems are hard to define without, at the same time, considering possible directions to resolve them, but a ready-made solution is not available. They can only be properly addressed when there is an understanding of the complexities of their broader context. Resolution of wicked problems goes step-by-step in a trial-and error mode and it is impossible to define exactly when the resolution is ‘good enough’ (5).

An example of a wicked problem is obesity. Although the increase of obesity rates of the past years seems to be slowing down, the rates are still a cause of concern. In 2014, 16% of adults in EU member states were obese, i.e. had a BMI of 30 or more; this was the case for 11% in 2000. In the Netherlands, in 2015, 13.7% was obese. Of youth under 20, 2.8% was obese (6).

Another wicked problem is the persisting health gap between groups with a higher and a lower socioeconomic status. In the Netherlands, of the group with lowest educational level 47% rated their health as good, while 86% of those with high education rate their health as good (volksgezondheidenzorg.info - monitor data 2012). In Europe, of the quintile of the population in the highest income group, 80% reports being in good health, while for the quintile in the lowest income group this is the case for 60%. There are also differences in important health determinants. For example, smoking is more common in low-income groups: in Europe 14% of people with high income smoke, and 20% of those with low income (OECD Health at a glance Europe 2016).

Because of the complexity of these wicked problems, single interventions are not sufficient to reduce the obesity epidemic and socioeconomic health inequalities. They cannot be addressed by a one-stop solution. So although in health promotion the focus is often on (individual or community focused) behavioural interventions, it is important to complement these with upstream policies, i.e. policies that shape living circumstances that affect health or health behaviour, like education policies, the production of foods and transport, health care, social support, employment, housing, economic and environmental policies (7-9).

### 1.1.2 Health in All Policies and Whole of Government approaches for health promotion

The coordinated policy approach of all different sectors to promote the health of populations or population groups is often referred to as Health in All Policies (HiAP). Sihto et al. (2006) define this as 'a horizontal, complementary policy-related strategy contributing to improved population health. The core of HiAP is to identify and address determinants of health that can be altered to improve health but are mainly controlled by the policies of sectors other than health' (10). The approach explicitly emphasises that the promotion of health is a (joint) responsibility of all relevant sectors (11). It thus exceeds the related concept 'Healthy Public Policy' (HPP) that was developed in 1988 (12). HPP means that there is a concern for health issues in policy development, but not necessarily that there is a coordinated strategy underlying this (13, 14). In 2010, sixteen countries and regions worldwide had applied HiAP (15). HiAP is a prominent element in the Health 2020 policy framework and strategy of the WHO Regional Committee for Europe (16) and in the WHO Healthy Cities network in Europe (17). The Dutch government, since the late eighties of last century, considers HiAP as an important way to address complex health issues (13). In 2011, the policy document 'Gezondheid Dichtbij' (Health Close By) (18) was published, which currently still constitutes the basis for the government's public health policy, focusing on reducing chronic diseases and on closing the health gap between groups with higher or lower socioeconomic position (19).

HiAP typically requires a 'Whole of Government' approach (20). The 'Whole of Government' approach was developed to overcome the barriers to effective problem-solving posed by 'pillarised' policymaking. It means that public agencies develop cross-border activities, without removing the borders themselves, in order to address wicked (health and other) problems that require coordinated governmental action (21, 22).

A key tool for HiAP and the Whole of Government approach is Health Impact Assessment (HIA), a systematic way to prospectively estimate expected and unexpected –positive and negative- impacts of policies and programs on health (determinants) and their distribution across populations. HIA thus provides policy makers with information they can utilize to create healthier policies, programmes or projects (23-29). The engagement of affected population groups, for example residents living close to planned spatial developments, is advocated in HIA guidelines for reasons of democracy and transparency in decision-making (28, 30).

### **1.1.3 Whole of society approach for health promotion**

Although coordinated governmental action is a key element for HiAP, resolving wicked problems requires more than such policy-based action. Many actors in civil society can contribute to promotion of population health, including, for example, (health promotion and other) professionals, schools, employers and entrepreneurs as well as the general public. Therefore, the Whole of Government approach by itself is insufficient; it needs to be complemented by a 'Whole of Society' approach that involves all relevant actors in civil society. Kickbusch and Gleicher (20) define Whole of Society approaches as 'a form of collaborative governance that emphasizes coordination through normative values and building trust among various actors in society. The approaches usually imply steering instruments that are less prescriptive, less committed to a uniform approach and less centralized and hierarchical' (20 p34). Thus, the Whole of Society approach moves away from a one-dimensional 'technocratic' approach in health promotion to an approach where different actors explore how shared goals, like 'reducing the obesity epidemic' or 'closing the health gap' should be attained. These actors can be any person or group committed to contribute to finding solutions for a problem, and their action is primarily based on this intrinsic motivation, instead of on predefined policy decisions. The Dutch National Program 'Alles is Gezondheid' (Everything is Health) (31), which is part of the national prevention policy mentioned before, is a typical example of a Whole of Society approach. This program, in place since 2014, aims at stimulating societal partners from different work fields to develop and connect activities to improve the health of the population or of specific population groups. One of the mechanisms applied in the program is the 'pledge' in which societal partners present the activities they will develop to this aim. The pledges show a large variety in topics, activities, and stakeholders. Other mechanisms include a range of communicative activities, conferences and meetings, and 'challenges' where societal partners can link up to a specific theme during a short time interval.

## **1.2 A NEW ROLE FOR COMMUNITIES IN HEALTH PROMOTION**

Communities are considered as important allies in health promotion strategies, contributing to the Whole of Society approach. A community is "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings" (31 p1936). By partnering with communities, it becomes possible to develop tailored interventions. Moreover, engaging citizens and communities is considered as an expression of democratic values. One of the five core strategies of the Ottawa Charter for Health Promotion (3), therefore,

is to strengthen community action. In the next sections, the focus will be on community action and on new ways communities can contribute to Whole of Society processes.

**Table 1.** Terms relating to HiAP (10, 12, 20, 21, 28)

Health in All Policies	A horizontal, complementary policy-related strategy contributing to improved population health
Healthy Public Policy	An explicit concern for health and equity in all areas of policy and an accountability for health impact.
Whole of Government	Whole-of-government denotes public services agencies working across portfolio boundaries to achieve a shared goal and an integrated government response to particular issues
Whole of Society	A form of collaborative governance that emphasizes coordination through normative values and building trust among various actors in society
Health Impact Assessment	A combination of procedures, methods and tools that systematically judges the potential, and sometimes unintended, effects of a policy, plan, programme or project on the health of a population and the distribution of those effects within the population

### 1.2.1 Asset based approaches as a basis for community engagement

For a long time, the focus in health promotion has been on those problems that professionals identify and define. However, over the past years, new approaches were developed that were more inclusive to citizens and communities. For example, the ‘intervention mapping’ methodology, a systematic procedure to analyse a problem in order to develop or apply effective interventions, nowadays includes dialogue with the target community as part of a needs assessment. In addition, it recommends that the community remains engaged throughout the whole process (33). Inclusiveness in intervention mapping is an example of an ‘asset-based approach’. Morgan and Ziglio (2007) introduced this term. The asset-based approach “aims to redress the balance between evidence derived from the identification of problems to one which accentuates positive capability to jointly identify problems and activate solutions, which promotes the self-esteem of individuals and communities leading to less dependency on professional services” (34 p18). This does not mean that health problems or challenges are overlooked: Morgan and Ziglio present the asset-based approach as a complement to the problem-based approach. The asset-based approach draws strongly on the theoretical notion of salutogenesis, or how health, instead of disease, is being produced. The salutogenic model, developed by Antonovsky, (1996) focuses on the resources that people have to ensure their wellbeing and health. Core in this model is the Sense of Coherence (SOC), this means the extent to which people experience the world as comprehensible, meaningful and manageable. According to

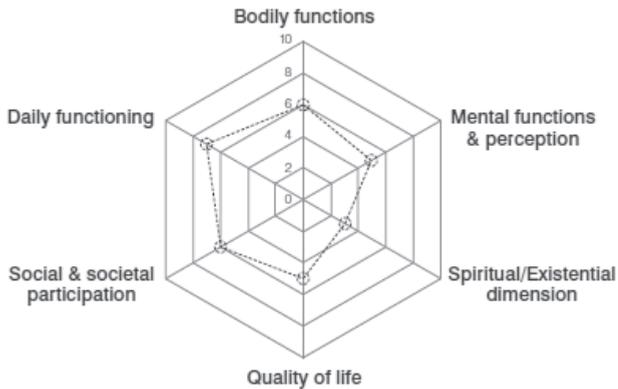
the theory about salutogenesis, a higher SOC enables people to feel healthy and make healthier life choices (35, 36). Asset-based health promotion links up to these resources and tries to strengthen them. This is reflected in methods applied in health promotion, like community asset mapping, appreciative inquiry and participatory appraisal (37).

### **1.2.2 Asset-based approaches in the Netherlands**

The asset-based approach is recently becoming particularly meaningful in the Netherlands because of two important national policy developments. Firstly, the coordination of services in the social domain is decentralised from national government to municipalities. Municipalities develop new local policies in relation to these services that link up with specific local contexts and perspectives, needs and possibilities of local communities. These policies and their implementation differ from municipality to municipality; however, enhancing citizens' own strength is a core element in all new local policies in the social domain.

The enhancement of people's own strength relates to the second development. Dutch policies currently promote a 'participation society' in which citizens rely on their own resources to retain a high level of wellbeing, albeit supported by public agencies wherever necessary (38). This requires that the abilities and qualities of citizens and communities are recognized, acknowledged, and supported by those public agencies. It also requires that there is space for citizens and communities to develop new, community based and tailor-made solutions to local challenges. One important example of how the new 'participation society' is implemented is new legislation on spatial planning, in which participation is mandatory. However, the abilities and capacities of local communities may vary both geographically and across, for example, socioeconomic groups. Therefore, participation procedures and methods need to be adapted to these abilities and capacities, in order to safeguard environmental equity (39).

The focus on self-reliance in Dutch policies is reflected in the use of a health concept where health is understood as "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" (40). This 'positive health' concept, containing six dimensions (Figure 2), places a stronger focus on health than on health problems or disease. (41). Therefore, it is considered to fit in with asset-based approaches. However, it is also debated because of exactly this focus and the absence of consideration of contextual and structural societal factors affecting people's health (42, 43).



**Figure 2.** Dimensions of 'positive health'. Source: Huber et al., 2014

### 1.2.3 Utilising communities' knowledge

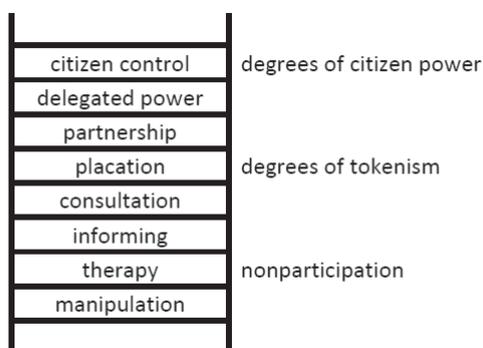
As health promotion is starting to becoming more inclusive towards communities and more asset-based, researchers and health promoters have also started to consider how the evidence base for health promotion can be adapted to this new paradigm. Traditionally, the evidence base for health promotion was for a large part built on epidemiological data and health researchers considered the randomised controlled trial as the 'gold standard' to further develop this evidence base (e.g., 44). Critics of this approach have argued, firstly, that the resources and experiential information of communities were too easily overlooked and therefore were under-utilised. Secondly, they claimed that the expert view on health problems might not be recognised as such by the target groups of health promotion. This may lead to interventions to address the problems that are less effective as compared to interventions that are based on joint views developed with the target groups. And, thirdly, critics of the 'purely epidemiological' approach emphasise the importance of contextual factors in health promotion and its success or failure (45-49). One of the ways to include such contextual factors is by engaging the target groups in the research process. The result is 'socially robust' knowledge that includes both scientific and lay, local and traditional knowledge and that is developed in dialogue with stakeholders and the public in general (50). This approach towards knowledge links up with the Whole of Society approach in health promotion discussed under 1.1.3 (20). It is also related to notions about the power of (groups of) lay people to provide accurate estimations or predictions: the wisdom of crowds (51).

However, 'better' or more complete knowledge, so that interventions or policies can be more effective, is not the only consideration underpinning the engagement of lay people in knowledge production. Corburn (52), discussing the arguments for inclusion of local knowledge in environmental health research argues that participation, by including the voice of underprivileged groups, also promotes democratic decision-making, equity and (environmental) justice. More generally speaking, one could add that citizen and community participation in knowledge production may promote 'knowledge democracy' (53) a situation where knowledge is not restricted to a scientific elite but is freely available to all.

### 1.2.4 Participation

In this thesis, citizen and community participation is a core theme. Following the World Health Organization, participation is defined as: "a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change" (54 p10).

This definition however is rather generic and in practice, participation can take different shapes. In 1969, Arnstein developed a 'ladder' to describe different levels of participation (55). This ladder contains different rungs that represent different levels of participation, from 'nonparticipation' through various degrees of 'tokenism' to 'citizen power' (Figure 3).



**Figure 3.** Ladder of participation. Source: Arnstein, 1969

The focus, in Arnstein's ladder, on power suggests that only this element reflects the value of participation processes. Arnstein's model does not address the question who exactly

is participating and how power is distributed between groups of citizens. The actual participation mechanisms and the meaning of participation for the citizens themselves also remain out of sight (56-58). In other words, in health promotion, participation entails more than including people in decision-making and it is important to look at both methods and impacts on health (behaviour), self-efficacy and empowerment of the target groups.

## 1.3 PURPOSE OF THIS THESIS

### 1.3.1 Research question

The aim of this thesis is to advance knowledge that supports the development of active engagement of citizens as partners in HiAP, employing an asset-based approach. One of the assets of citizens is their experiential knowledge. Although tapping this knowledge is common in health promotion practice in the Netherlands, for example in needs assessment, much is yet unknown about the possibilities of joint knowledge *production* with and by citizens themselves, or *Citizen Science*. The thesis therefore focuses on the main question:

*“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?”*

The thesis draws on two case studies carried out in the Netherlands where the practical application of citizen engagement in developing knowledge for HiAP was studied, one case study focusing on health promotion professionals’ perceptions of neighbourhood health assets and three explorations of the literature on an international level.

### 1.3.2 Outline of this thesis

This thesis contains six chapters based on the six studies exploring methods, benefits and challenges of Citizen Science approaches for public health in different ways. Table 2 provides an overview, per chapter, of these studies.

Chapter 2 contains a theoretical exploration of the value, possibilities and challenges of application of Citizen Science in public health research. It describes the background of Citizen Science and presents a typology of different types of Citizen Science, illustrated with examples. The challenges for public health Citizen Science are discussed. A model of possible benefits of Citizen Science application in public health is presented.

Chapter 3 describes a case study in a low-SES neighbourhood. In this neighbourhood, citizen scientists interviewed fellow residents to gather knowledge about the community's views on health assets in their neighbourhood. Such knowledge, as discussed under section 1.2.3, is crucial for the application of a 'Whole of Society' approach. The chapter focuses on the impact of participation on these citizen scientists.

Chapter 4 focuses on citizen participation in Health Impact Assessment (HIA) as a specific type of Citizen Science approach in public health. HIA is an *ex ante* assessment of the expected impacts of a project, policy or program, producing evidence to support HiAP. This chapter describes how, in scientific papers, community engagement in HIA is described and what the experiences in practice examples are. This was studied by carrying out a scoping review, including different types of scientific and grey publications.

Chapter 5 describes a case study of stakeholder engagement in a specific HIA process. The case concerned two workshops on Health Impact scoping. The study focused on the question whether the engagement of citizens and other stakeholders in health 'scoping', i.e. the determination of possible health impacts, can contribute to consensus-building between these different groups.

Chapter 6 describes the results of a scoping review about neighbourhood auditing, or the systematic assessment of those aspects of a neighbourhood that are important for community health and well-being. Adapting the neighbourhood to accommodate health needs of the residents requires cooperation between health and other stakeholders, for example in the field of spatial planning, housing or transport. Neighbourhood auditing provides evidence that can be used to support such local HiAP. The active participation of citizens in such audits, other than as respondents, can be considered as a Citizen Science approach. Many instruments for neighbourhood auditing are available; the scoping review was carried out to answer the question which instruments include residents or communities in the audit process and how such inclusion can be described.

Chapter 7 describes a field study of perceptions of local health promotion professionals in a low-SES neighbourhood on how they perceive the health assets for residents, present in this neighbourhood. This study was carried out in the same neighbourhood as the study described in Chapter 3.

The thesis is finalized by Chapter 8 that contains a general discussion leading to answers to the central question of this thesis. This chapter also presents a set of implications for practice, research, and policy.

**Table 2.** Overview of studies underlying this thesis

Chapter	Study question	Methods applied
2. Citizen Science for Public Health	<p>What is the value of Citizen Science in public health?</p> <p>a. What approaches exist in Citizen Science?</p> <p>b. What are challenges for Citizen Science application in public health research?</p> <p>c. How could Citizen Science promote better citizen engagement in public health policies and better health?</p>	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	<p>What impacts were experienced by citizen scientists participating in a public health research project?</p>	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	<p>How is community participation in HIA currently perceived and how is it put to practice?</p> <p>a. How do practitioners and researchers view community participation in HIA?</p> <p>b. What methods are used for community participation in HIA?</p> <p>c. What are the experiences and effects of community participation in HIA?</p>	Scoping review in scientific and grey 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	<p>Did stakeholder and resident engagement in Health Impact scoping lead to consensus?</p> <p>a. In what way did the HIS workshops influence stakeholder perspectives on health and a healthy living environment?</p> <p>b. What level of actual and perceived consensus on these perspectives was reached at the HIS workshops?</p> <p>c. What were the perceived factors that contributed to or hindered the development of consensus on health and a healthy living environment?</p>	Participatory Action Research contributing to setup of scoping workshops (methods and concepts). Questionnaires, observation, interviews.

**Table 2.** (continued)

Chapter	Study question	Methods applied
6. Resident participation in neighbourhood audit tools - a scoping review	Which participative systematic neighbourhood auditing tools exist and how can these tools be characterized? a. Which participative audit tools are available? b. What level of resident participation is present in these audit tools? c. What do these tools measure? d. What (participation) methods are applied in these tools?	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? a. What is the professionals' perception of health and of residents' health status? b. What is the professionals' perception of available health assets in the neighbourhood and the way residents use these assets?	Interviews, Nominal Group Technique.

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# CHAPTER 02



# Citizen Science for public health



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## **ABSTRACT**

Community engagement in public health policy is easier said than done. One reason is that public health policy is produced in a complex process resulting in policies that may appear not to link up to citizen perspectives. We therefore address the central question as to whether citizen engagement in knowledge production could enable inclusive health policy making. Building on non-health work fields, we describe different types of citizen engagement in scientific research, or 'Citizen Science'. We describe the challenges that Citizen Science poses for public health, and how these could be addressed. Despite these challenges, we expect that Citizen Science or similar approaches such as participatory action research and 'popular epidemiology' may yield better knowledge, empowered communities, and improved community health.

We provide a draft framework to enable evaluation of Citizen Science in practice, consisting of a descriptive typology of different kinds of Citizen Science and a causal framework that shows how Citizen Science in public health might benefit both the knowledge produced as well as the 'Citizen Scientists' as active participants.

## 2.1 INTRODUCTION

In the Nieuw-West district of Amsterdam in the Netherlands, a local community work organization proposes a project in which local residents, or ‘health ambassadors’, collect community views, requirements and concerns about health. One of the core values of this project is openness to all health topics that might come up. The project proponents discuss their ideas with the district council. The council is enthusiastic about the idea, but requests that the project should focus on overweight, as district obesity rates are high. It takes some time for the city council to abandon this preset idea: despite such high rates, obesity might not be the main priority of the residents in this community, and discussions with the community might yield a host of other important issues.

This anecdote illustrates the challenges posed by citizen participation in public health policy. On one hand, policy makers want to link up with community needs. Indeed, in the Netherlands, this wish underpins recent fundamental policy shifts, moving national-level responsibilities in the social and health domain to municipalities, and promoting participative approaches rather than professionally driven approaches.

On the other hand, policy development is a complex process. Policy makers refer to expert driven (epidemiological) data to underpin their priorities, as in the case described above, but the utilization of such knowledge is not a straightforward one-to-one implementation (1). Indeed, evidence is only one of many factors in the process of ‘juggling’ to create health promotion policies (2). As a result, policies may not appear to reflect citizens’ views and everyday experiences, even if they have been well considered, and citizens often do not recognize the policies as being relevant to themselves (3-5). This is probably even more so in those countries, such as the Netherlands, where local public health bodies are not governed by elected representatives of residents, but rather by appointed officials or civil servants<sup>1</sup>. Citizen engagement in knowledge development, or ‘Citizen Science’, may prove useful. Citizen Science is defined as “the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort or surrounding knowledge or with their tools and resources” (6). It first developed as a way to facilitate data collection, mainly in the natural sciences field. Since then, Citizen Science has developed in other work fields as well, for example in historical research, technology development, and the social sciences.

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1. For overviews of the different ways that countries organise their public health system, see, for example, the Health Systems and Policy Monitor of the European Observatory on Health Systems and Policies <http://www.hspm.org/mainpage.aspx>

The aim of this paper is to explore the value of Citizen Science in public health. We begin by describing approaches in Citizen Science; discuss challenges for Citizen Science application in public health research; discuss how Citizen Science could promote better citizen engagement in public health policies and better health; and finally provide an evaluation framework.

## 2.2 CITIZEN SCIENCE – A TYPOLOGY

To consider Citizen Science in public health we need to understand the different forms of this approach. An EU in-depth report (7) describes three taxonomies classifying Citizen Science. Firstly, Roy et al (8) categorize Citizen Science by number and spread of participants ('local' or 'mass') and 'thoroughness' (investment of time and resources). Moreover, projects<sup>2</sup> can be 'contributory' (led by experts), community-led, or co-created. Or, in the terminology used by King et al (9), *for* the people, *with* the people, or *by* the people.

Wiggins and Crownston (10) classify projects according to aims: action, conservation, investigation, virtual, or education. In 'action' projects, citizens and scientists jointly address local issues and concerns. 'Conservation' projects focus on managing natural resources. 'Investigation' projects focus on answering scientific questions. In 'virtual' projects, activities are carried out remotely. 'Education' projects aim at improving citizens' knowledge.

The third taxonomy, by Haklay (11), classifies Citizen Science projects by volunteer engagement levels. In 'crowd sourcing' projects (level 1), citizens are used as sensors or provide computing power. At level 2 ('distributed intelligence') citizens learn basic skills before they collect and interpret data. In 'participatory science' (level 3) citizens co-decide about research questions and types of data to be collected. Level 4 is 'extreme' Citizen Science, or collaborative science. Although the term 'extreme', commonly used in the discourse about Citizen Science, seems to indicate a rare novelty, this is not necessarily so. For example, as early as in the late nineties, full engagement of all stakeholders, including citizens, in all research stages, was listed as one of the nine key principles of community based participatory research (12). For Citizen Science, 'extreme' indicates that citizens, are in full charge of the research and professionals are not included to any great extent (see, for example, 13).

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2. In literature about Citizen Science, activities are usually referred to as 'projects'. We have noted that very often such activities are long-term and ongoing, and the term 'process' might be more suitable. However, in this paper we have adopted the usual terminology.

We have combined these three partly overlapping taxonomies into a single descriptive framework of Citizen Science project characteristics (Table 1). The first characteristic is the aim of citizen engagement. We have generalized the ‘conservation’ aim to a broader aim: the creation of ‘collective goods’. The second characteristic is level of participation, ranging from crowdsourcing to ‘extreme’ Citizen Science. The third characteristic is (geographical) size: either mass or local. From the original typologies we have excluded the on-site or remote (virtual) dichotomy. Most likely, in the near future the number of (partly) remote projects will grow, and it will be possible for local projects to be virtual as well. Moreover, this feature overlaps with ‘size’. We have also excluded the ‘thoroughness’ characteristic, as conditions and circumstances define research capacity need, which is not a core characteristic of Citizen Science projects in itself.

**Table 1.** Citizen Science descriptive characteristics

Characteristic	Description
Aims	<ol style="list-style-type: none"> <li>1) Investigation: aimed at answering scientific questions</li> <li>2) Education: aimed at educational goals</li> <li>3) Collective goods: public health, management of infectious diseases, protect and manage natural resources.</li> <li>4) Action: citizens and scientists collaborate to address local concerns</li> </ol>
Approaches	<ol style="list-style-type: none"> <li>A. Extreme Citizen Science. Citizens in charge from problem definition, data collection and analysis, to interpretation and knowledge development</li> <li>B. Participatory science: Participation of citizens in problem definition and data collection</li> <li>C. Distributed intelligence               <ol style="list-style-type: none"> <li>a) Citizens as basic interpreters</li> <li>b) Volunteered thinking</li> </ol> </li> <li>D. Crowd sourcing               <ol style="list-style-type: none"> <li>a) Citizens as sensors</li> <li>b) Volunteered computing</li> </ol> </li> </ol>
Size	<ol style="list-style-type: none"> <li>i) Local</li> <li>ii) Mass</li> </ol>

Two examples—the ‘Galaxy Zoo’ project and the ‘Arctic Hunters’ project—show how this framework can be applied.

The ‘Galaxy Zoo’ project started in 2007 by asking citizens to help classify selected images of galaxies from the Sloan Digital Sky Survey, in order to increase research capacity. By 2009 over 200,000 people were involved. The project links up with other work fields, brought together in the ‘Zooniverse’, and educational activities were developed as

a spin-off activity (14-16). On the basis of our checklist we have characterized the project as 1Caii (aim: investigation, approach: distributed intelligence, citizen as basic interpreters, size: mass).

The Arctic Hunters project explores the potential of using digital resources to help Arctic coastal subsistence hunters to handle the impacts of climate change. This project combines traditional ecological (lay) knowledge with scientific expertise to develop a mobile technology embedding different ontologies and interpretations of sea ice. The technology is designed with the community and reflects their ways of hunting, their learning methods and their knowledge (17-19). On the basis of our checklist we have characterized the project with the code 4Aii (aim: action, approach: extreme Citizen Science, size: local).

## **2.3 REPORTED BENEFITS OF CITIZEN SCIENCE**

Citizen Science is reported to yield benefits for scientists, policy makers, lay people and communities (6). These can be grouped in three categories: increased research capacity, better knowledge, and citizen benefits.

Increased research capacity, one of the main reasons for initial Citizen Science development (20), refers to the need for larger quantities of data and the need for larger numbers of analyses. The main advantage, thus, is shared workload (6, 21). Indeed, some authors consider labor-intensive projects requiring mass field data collection as being 'ideally suited' for Citizen Science application (6, 22, 23). An example, besides 'Galaxy Zoo', is a Dutch project where lay people help decipher 16th and 17th century letters provided to them through the project's web system (24).

A need for better knowledge, the second category of benefits, was another driver for Citizen Science development, building on the idea that adding lay, local and traditional knowledge to scientific knowledge could improve the scientific knowledge produced and therefore more effectively respond to complex societal problems (6, 25). One reason is that this provides complementary data (26). In addition, the engagement of citizens may improve research strategies, or lead to novel research methods. Ottinger (27) describes how activist lay researchers of air quality showed that measuring peaks of emissions was as relevant for determining health risks as the usual procedure of monitoring long term averages. Thirdly, citizen engagement is viewed as producing more 'socially robust' knowledge (28) that is acceptable and trustworthy to the general public, for example – in the field of knowledge development on cancer screening –

acknowledging citizens' feelings of doubt and fear regarding their decision whether to participate in screening programs.

The third category of benefits of Citizen Science is advantages for lay participants. A literature study regarding the benefits to citizens of participation in scientific research (29) yielded a list of ten main benefits. Case studies where a Citizen Science tool was applied in 10 neighbourhoods in the United States, Latin America, and Israel (9) showed similar benefits (Table 2). The first six citizen benefits in this overview are all related to so-called 'scientific literacy': increased knowledge about the topic studied, insight into science in general, and new skills and abilities—in short, 'what citizens want to know'. Many Citizen Science projects include these as a project goal, and assess accomplishment (30). One example is the E-bird project which explicitly provides amateur bird watchers with new skills and knowledge – which in turn improves the quality of the data collected (31).

**Table 2.** Claims about Citizen Science participant benefits (source: Haywood 2014, King 2016)

Citizen Science participant benefit
Enhanced science knowledge and literacy (e.g. knowledge of science content, science applications, risks and benefits of science, and familiarity with scientific technology)
Enhanced understanding of the scientific process and method
Improved access to science information (e.g. one-on-one interaction with scientists, access to real-time information about local scientific variables)
Increases in scientific thinking (e.g. ability to formulate a problem bases on observation, develop hypotheses, design a study, and interpret findings)
Improved ability to interpret scientific information (e.g. critical thinking skills, understanding basic analytic measurements)
Science demystified (e.g. reducing the 'intimidation factor' of science, correcting perceptions of science as too complex or complicated, enhancing comfort and appreciation for science)
Strengthened connections between people, nature, and place (e.g. place attachment and concern, establishment of community monitoring networks or advocacy groups)
Empowering participants and increasing self-efficacy (e.g. belief in one's ability to tackle scientific problems and questions, reach valid conclusions, and devise appropriate solutions)
Increases in community-building, social capital, social learning and trust (e.g. science as a tool to enhance networks, strengthen mutual learning, and increase social capital among diverse groups)
Changes in attitudes, norms and values (e.g. about the environment, about science, about institutions)
Citizen scientists take action to influence policy and/or improve living environment
Citizen scientists gain access to broader (policy making) networks

Haywood and King both mention additional benefits that are less 'cognitive'. They include community development, empowerment, and change of attitudes, values and norms, action to improve the environment, and engagement in policy making. It is reported that lay researchers start using and applying the knowledge and abilities acquired, and strive to change their environment or their behavior (6, 21, 22, 32, 33). Reportedly, the educational value of Citizen Science has helped reduce social exclusion (6).

## 2.4 FORERUNNERS OF PUBLIC HEALTH CITIZEN SCIENCE

Recently, the use of Citizen Science has been booming as a result of the need for mass data, growing confidence in and valuation of the input of lay people, and technological development (6, 8, 14, 34). Apparently, Citizen Science is rare in public health: a recent overview of 'good examples' produced for the European Commission contained no public health-related Citizen Science projects (6). It seems that the largest part of Citizen Science work is carried out in the fields of biology, conservation and ecology, although Citizen Science in other work fields may remain unpublished as it is not primarily focused on scientific gain (35). Indeed, some approaches in public health research strongly resemble Citizen Science. One of these is (participatory) action research, defined as a "participatory process concerned with developing practical knowledge, in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities" (36). Participatory action research can definitely be seen as a Citizen Science approach. However, the two are not exactly the same: as the action part refers to the focus on taking action to bring about social change, addressing specific problems and developing interventions – or preparing decisions - to solve them (37, 38), Citizen Science may also be carried out without such a preset focus on action. Furthermore, in the health sciences participatory research "is conducted by a coalition of researchers, community members, patients, health professionals or other stakeholders" (Hughes 2008, p. 385), resembling a strong involvement of citizens, similar to code **4A** (aim: action, approach: extreme Citizen Science) (Table 1). In Citizen Science, citizens can also be engaged in research activities in other, less intensive, ways.

Another similar approach is 'popular epidemiology', in which lay persons join experts to collect –mostly environmental- data that lead to specific health outcomes (39), or 'street science', a process in which communities actively engage in problem definition, framing of research questions, and decision-making about study design (40) Like (participatory) action research, these are, again, closely connected to social mobilization and problem

solving. A related process is Health Impact Assessment (HIA); community engagement can be part of all steps in HIA (41-43).

## 2.5 CHALLENGES FOR THE APPLICATION OF CITIZEN SCIENCE IN PUBLIC HEALTH

The development of public health Citizen Science may build on the forerunners described above, and learn from them, in particular since public health issues are linked to our personal lives, and ethical considerations in research such as data ownership or informed (community or individual) consent are urgent in this field (44). Moreover, public health issues can be the topic of public dispute, for example in the case of large-scale livestock farming, where the economic development of a region has to be weighed against possible health impacts in terms of environmental damage or zoonosis' transmission risk. In such situations, the distinction between knowledge development and advocacy or political activism may become blurred. A sense of distrust in science as something that can be manipulated based on stakeholder's preferences may then be the result, rather than a genuine dialogue and better understanding of science. Seeking connections between citizens and experts on the one hand, and safeguarding research quality on the other hand therefore requires carefully balanced management of Citizen Science research processes (45).

Apart from these fundamental issues, the application of Citizen Science in public health poses a number of additional, partly related, challenges when put to practice.

First of all: why would lay people be bothered to engage in scientific research? Studies of Citizen Science participant motivations show that people have different—sometimes multiple—reasons for participating (6, 8, 14). These include intrinsic interest in a topic, being part of a community, contributing/helping, learning, or the enjoyment of research activities. Citizen Science projects correspondingly use various engagement strategies (6, 8, 21, 46, 47).

Such motivations resemble those found in a Dutch study on volunteers in health promotion (48): the wish to contribute to a greater (health) goal, personal development, the wish to help others when asked, and the wish to be an example and inspiration for others. Citizen Science engagement strategies from other work fields may therefore work well in public health research.

Secondly: when lay people are engaged, do they really represent the group that needs to be represented, geographically, or socially? Brown, for example, observes that

women often play an important role in popular epidemiology, which he ascribes to the (family) roles of women combined with a relationship-centered world view, and thus stronger awareness of the potential health impacts of toxic factors (49). Such over- or underrepresentation may impact on study results. In researcher-controlled Citizen Science projects gathering mass data, this need not be a major issue. Indeed, large scale research where citizens act as ‘sensors’, is already applied in epidemiology: for example, in studies in which people wear measurement devices (50). In small-scale and more participative studies, lay researcher selection may cause bias. However, it may also be an asset: lay researchers can access ‘hard to reach’ study populations as ‘peer researchers’ (51).

Thirdly: how to weigh the scientific and social value of citizen-generated knowledge? And: do volunteers have adequate capabilities and competences? Views of professionals and lay people—a systems view versus experienced reality—may be difficult to reconcile (5), and researchers sometimes disqualify lay research outputs as unscientific (27, 52). One solution may be training: often a part, and sometimes an aim, of Citizen Science projects (52). Another solution would lie in enabling dialogue between scientists and lay people instead of ‘professionalizing’ lay people, widening research scope and generating information on community features that are key in understanding the community’s health problems (39). Such dialogue could even induce methodological innovation. For example, local residents who participated as lay researchers in Amsterdam, the Netherlands, stated that the number of children eating snacks outdoors reflect neighborhood health (53); and that therefore, existing health indicators should be amended by new, observational, ones.

Fourthly, will Citizen Science *per se* promote participatory policy development? Projects with citizens as ‘sensors’, led by scientists with little connection to local issues, will not necessarily do so. However, more community-driven research may effectively empower people to participate in local policy making (6, 39, 49). Citizens regard access to information and knowledge as a key condition for participation (54) and a review about community based health research in the United States showed that the more the community was in control of the research, the more community members took action to create better health (55). As participation in research activities may enhance a sense of community and develop new community values and norms (29), this may also be true for public health research and therefore boost active health policy engagement. King et al, mentioned before, provided an example of the latter: the ‘Our Voice’ framework, a Citizen Science approach developed to assess healthy neighbourhoods with residents. Within ‘Our Voice’ a digital tool was developed enabling citizen scientists, in particular people in underprivileged districts, to gather data, mostly on how their environment

enhances or hinders physical exercise. King et al report that, in several cases where the tool was applied, citizen scientists afterwards undertook concrete actions to improve their environment and/or developed engagement in local policy making, including engagement at the request of local government (9). Finally: can this approach really improve the health of the population? We think this is certainly possible. Citizen Science may not only increase participants' 'health literacy', i.e. 'the skills and capacities that enable people to exert greater control over their health' (56), and an important condition for adequate health behavior (57). It may also enhance their 'sense of coherence', i.e. the degree to which they experience the world as comprehensible, meaningful, and manageable. A high SOC is reported to promote better health (58). On a community level Citizen Science may promote community values and social cohesion; these are important factors that contribute to community health (59).



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

**Table 3.** Case examples of Citizen Science benefits in Health Impact Assessment

Bubble in figure 1*	Case example
1.Involvement of citizens (residents)	Community representatives (Aboriginal community) participated in HIA Steering Group and decided on scope and methods of an HIA on a broad set of government measures to protect children and families (NTER). Health impact indicators are based on Aboriginal concept of health (60).
2.Inclusion of lay and local knowledge	Community experiential knowledge was key to specifying relations between those social determinants considered meaningful by the community, and individual and community mental health. The pathways thus developed served as a basis for an HIA on policy regarding the use of arrest records in employment decisions (61).
3.Increased research capacity	Community representatives collect data about resident qualifications of current situation and experiences with earlier cut-downs on bus services (survey, interview) in a HIA on public transport (62).
4.Health literacy	Residents engaged in an HIA on local health hazard control policy were provided information about legal frameworks, policies and health hazards. They reported increased knowledge on health hazards, the social determinants of health, and the need to address these (63).
5.Empowerment	Residents representing a local community assessed potential health impacts of a plan to create an outdoor recreation area nearby, using the local community health vision as a starting point. They prepared a set of recommendations providing points of attention and proposals to adapt the project plan (64).
6.Community building, social capital, social learning, trust	An HIA on a regional transport policy explicitly aimed at building co-working relations between community and different agencies. Evaluators of the HIA observed that some, though not all, community members thought this was accomplished (65).
7.Changes in attitudes, norms, values	HIA of remediation of a former industrial site included HIA training of community members. This resulted in a more positive attitude towards HIA (66).
8.Participation in public health governance 9.Sense of Coherence	→ 10.Community health

\*The numbers refer to the bubbles in Figure 1

Figure 1 shows an overview of potential Citizen Science benefits, including both ‘better knowledge’ and advantages for citizens themselves and their health. Health Impact Assessments (HIA), mentioned before, may illustrate how some of these benefits, such as resident empowerment, are actively pursued (Table 3). In relation to HIA, there is discussion about advantages and disadvantages of citizen engagement, resembling similar issues in Citizen Science in general; in particular issues regarding selection of participating citizens, their competences, and the value of knowledge gathered by or with citizens (67). These issues and their potential scientific, political and ethical consequences must be addressed in Citizen Science practice, as they should be in HIA practice.

## 2.6 FUTURE DIRECTIONS FOR PUBLIC HEALTH CITIZEN SCIENCE

Over the past years, various deliberative methods such as citizens' juries and citizens' dialogues have been developed to enable meaningful contributions by citizens to policy development (68, 69). However, although these methods facilitate the transfer of knowledge from experts to lay people, they are applied within short time frames, and therefore allow little space for joint knowledge development (70). Citizen Science engages people for a longer period of time, which may help to strengthen and sustain an active role for citizens, both in research and in the application of the knowledge produced in policy development.

Of course we need to be aware of the challenges and potential downsides of Citizen Science in Public Health. For example, how are local needs weighed against the needs of wider population groups, both geographically and socially? How to prevent tokenism, where participation of residents is used to provide a false impression of 'democratic' decision making? The approach still needs a lot of practice testing (30). Our framework, combining descriptive characteristics of Citizen Science (Table 1) and its potential effects on health, health governance and the knowledge system (Figure 1), presents a basis for studying, comparing and exploring the opportunities and limitations of public health Citizen Science. Such practice testing may yield practical guidance for public health Citizen Science, for example how to link up with local contexts, how to determine the appropriate level of citizen engagement, or how to ensure stakeholder commitment.

We believe that, despite all the questions and doubts, Citizen Science has much to offer for public health research. Citizen Science as a way to collect data with lay people's help may be particularly useful in the field of infectious diseases. For example, bird flu outbreaks may be more rapidly detected with the help of a network of citizen scientists such as hobby farmers or bird watchers. Lay people's input can also be helpful for environmental health monitoring. A recent example is the I-Spex project in which thousands of citizen scientists submitted air quality measurements (71), a mass crowd sourcing approach for a collective aim – in our table: 3Dii.

Citizen Science in public health can also inform local policy makers about residents' perceptions and views, and provide access to lay knowledge. This may enable policy makers to address resident concerns, and 'empower' them to strike a balance between such concerns and other (health and other) priorities. But most importantly, Citizen Science, applied as an inclusive approach, has the potential to boost the participation of citizens in public health policy processes by increasing health literacy, empowerment and community cohesion, creating new attitudes and values, and producing a stronger sense of coherence.

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# CHAPTER 03



Public health Citizen Science.  
Perceived impacts on citizen scientists.  
A case study in a low income  
neighbourhood in the Netherlands.



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## ABSTRACT

Citizen Science, or the active participation of lay people in research, may yield crucial local knowledge and increase research capacity. Recently, there is growing interest for 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, the so-called 'Health Ambassadors', 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 life styles 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 citizen scientists 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, embedment in broader health promotion strategies and long-term engagement of citizen scientists should be pursued to accomplish this.

### 3.1 INTRODUCTION

Citizen Science, or the active participation of lay people in scientific research, other than as research objects or respondents, has important advantages for science. It adds important knowledge and insights that may help solve complex problems (1) and it may reduce the work load for researchers in labour-intensive projects, for example by gathering large amounts of data, or data that are difficult to obtain for researchers due to factors like geographic spread or hard to reach populations (2). The approach also yields benefits for the people participating as citizen scientists, for example by enhancing scientific literacy or public knowledge about specific topics (3-6).

One of the fields where Citizen Science could be applied very well, and where such impacts on citizen scientists may be particularly important, is public health and health promotion research. Community participation in general is strongly advocated in health promotion. The Ottawa Charter on health promotion emphasises 'strengthening community action' as one of its core strands of action (7). Partnership between researchers and community members is considered as an important opportunity to empower communities to take action for better health (8-14).

However, in practice, the knowledge base for health promotion strategies is often limited to expert-driven knowledge and an epidemiological paradigm (15, 16). This was not the case in Amsterdam, the Netherlands. Here, local policy makers aimed at developing a 'bottom-up' health policy for a disadvantaged neighbourhood and decided to set up a Citizen Science project for that. The project's main aim was to yield important grassroots information on views, needs and concerns of the community that could assist to design a more inclusive policy for this so-called 'priority' neighbourhood. Residents, cooperating as peer interviewers, could not only reach out to hard-to-reach groups in the neighbourhood like elderly people or people with a migration background, but could also provide important contextual and 'insiders' information that would be helpful in the analysis of the data gathered. However, this was not the only aim of the project; the project team was keen to ensure that the project benefited the citizen scientists participating by enhancing their understanding the broader determinants of health and their personal competences. The project was intended to provide new opportunities and possibilities for residents to become actively engaged in improving the community's health. Assessing the impacts on the citizen scientists was, therefore, a core element of the project's design.

This paper focuses on these impacts. It aims to contribute to the 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?*

## **3.2 METHODS**

To be able to understand the impacts of participation on the citizen scientists, on which this paper focuses, information about the setting and the project is necessary. In this section, these are described. We also describe the study design and the methods applied to evaluate the impacts on the citizen scientists.

### **3.2.1 Setting**

The project took place in 2014-2015 in Sloterveer, a disadvantaged neighbourhood in Amsterdam, the Netherlands. A project team led by 'Eigenwijken', a local community work organisation that represents, supports and activates Sloterveer residents was formed to set up the project. The evaluation of the impacts on the citizen scientists was carried out within this project by researchers that participated in the project team.

Sloterveer faces many health and other challenges, including overweight, mental health problems, loneliness, poverty and a poor liveability. Over 60% of the population is of non-western migrant origin (17). Residents are considered as 'hard to reach' for local (public health) policy makers. The local District Council initiated the project. Although the project was planned for 2014, due to the enthusiasm of the District Council about its results, it was prolonged to 2015. This means that one group of citizen scientists was enrolled in 2014 and a second group in 2015. The project aim was to gather information about resident views concerning potential neighbourhood health assets, as a basis for local policy. In the project, the citizen scientists were named 'Health Ambassadors'. In this paper however, we will refer to them as the 'citizen scientists'.

The project stages were: training of citizen scientists, data collection by citizen scientists, and reporting and analysis of results. Training, the first stage, 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, one additional meeting was organised as a kick-off to the interview stage and a printed guideline how to organise interviews was developed and provided. The citizen scientists were trained in five to eight person groups applying an ‘experiential learning’ approach (18), with a focus on learning processes rather than on attaining fixed end points. The citizen scientists were stimulated to link their personal day-to-day experiences to the training content and by doing so, create new knowledge that combines both. Three main topics were addressed in the training. Firstly, the perspective on health as ‘the ability to adapt and self-manage in the face of social, physical, and emotional challenges’ (19) was explained and discussed. The second topic in the training was techniques to recruit interviewees and carry out group interviews, based on ‘motivational interviewing’ (20). Thirdly, 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 was explained and discussed (21). Table 1 provides a schematic overview of the training.

**Table 1:** Training overview

Session	Topics	Methods	Materials
Training day 1	<ul style="list-style-type: none"> <li>• Introduction of group members and trainers to one another</li> <li>• Introduction to the project</li> <li>• Health definitions (including ‘Positive Health’)</li> </ul>	Group discussion, storytelling, mini lectures	Flip chart
Training day 2	<ul style="list-style-type: none"> <li>• Interview techniques and attitudes</li> </ul>	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	<ul style="list-style-type: none"> <li>• Interview techniques and attitudes</li> <li>• Health determinants (including Egan model)</li> <li>• Next steps in project</li> </ul>	Group discussion, video, mini lectures	Powerpoint slides, video examples of interview techniques, flip chart
Kick-off meeting	<ul style="list-style-type: none"> <li>• Recruitment of interviewees</li> <li>• Reporting</li> <li>• Next steps</li> </ul>	Joint dinner, group instruction	Handout with tips for planning of interviews Reporting form ‘My Group’s Story’

The training was carried out in 3 half-day sessions within a six-week time span and was evaluated by a questionnaire focusing on satisfaction level of the citizen scientists with the training in general as a preparation for the research work and as a process. It contained open questions asking for further needs. The over-all satisfaction level was 8.2 on a 10 point scale for 2014 and 8.0 for 2015. Several citizen scientists from the group enrolled in 2014 had advised to better match people with different educational or language level in different groups. This was implemented in 2015; citizen scientists then rated the training level as well-matched to their needs and knowledge level.

In the second stage, citizen scientists collected data during six weeks. This was started off by the kick-off dinner meeting mentioned before, celebrating the finalisation of their training, and providing instructions and the printed guideline to help them set up the interviews. The topics of these interviews were: 'what aspects of the neighbourhood do residents view as health enhancing (health assets) and what aspects need to be improved (barriers for health)'. Moreover, the citizen scientists asked residents 'which action the residents themselves could develop to improve the community's health'. Even though they had been trained, for example by role play, to carry out group interviews, the citizen scientists were explicitly invited to apply other methods that they might prefer, like one-to-one interviews. Indeed, there was large variety in ways of interviewing, settings, and interviewees. Some citizen scientists interviewed family and friends, others interviewed random people. Interviews took place in homes, schools, shops, community meeting places and in the street. The citizen scientists reported having purposefully searched for different 'voices', for example by interviewing youngsters or old people. According to the citizen scientists, these groups were often not listened to by the professionals in the neighbourhood. Neighbourhood community workers, assisted by students from the Amsterdam University of Applied Sciences (SU, KK, JW, and SKK), provided practical support for the citizen scientists during data collection, for example by supporting them in developing their own strategy to engage residents in interviews. The citizen scientists interviewed a total of 316 fellow residents; one trained citizen scientist did not manage to carry out interviews due to personal circumstances, but remained a group member in all project stages. The citizen scientists recorded the results of the interviews on an easy to fill out form.

The third project stage, result reporting and analysis, consisted of discussion of the interview results in focus groups, 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).

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

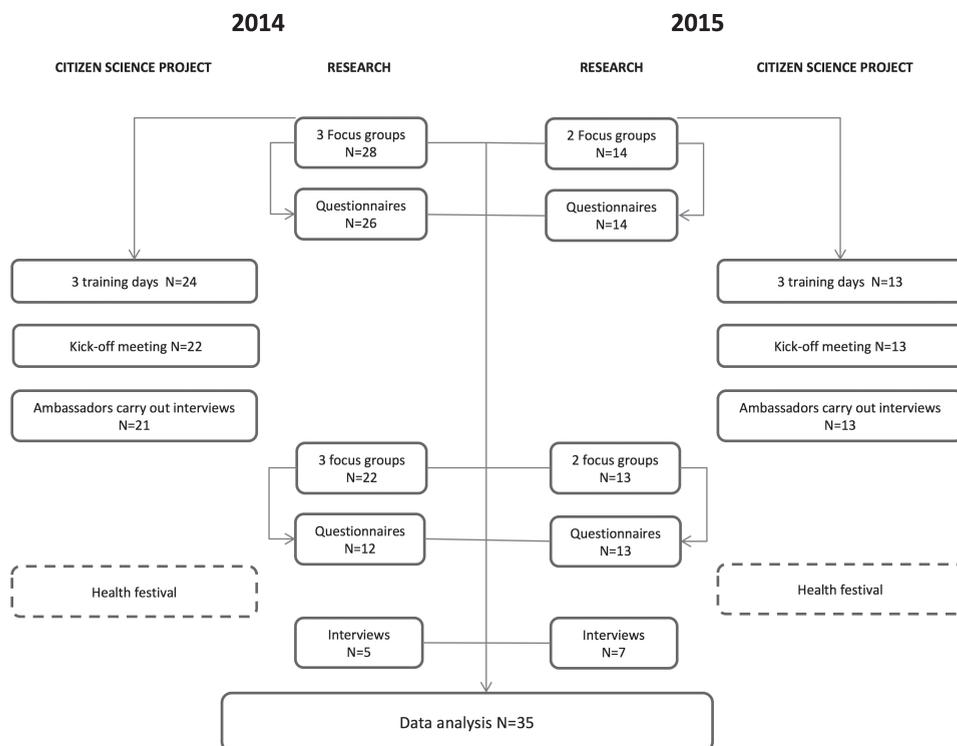
Health enhancing neighbourhood features	Barriers for health in the neighbourhood
<ul style="list-style-type: none"> <li>• Attractive and abundant public greenery, in particular the Sloterpas lake</li> <li>• Further enhancement options: public toilets, more and safer, well-kept children's playgrounds, free or inexpensive public sports facilities for adults</li> <li>• Transport and connectivity is rated good. Public transport is rated as excellent</li> <li>• Further enhancement option: improve traffic safety around schools</li> <li>• Social and health facilities are abundant and good quality</li> <li>• Further enhancement option: better communication to provide residents with information about the availability of these services</li> </ul>	<ul style="list-style-type: none"> <li>• Insufficient information about healthy lifestyles, insufficient health promotion activities</li> <li>• One-sided local economy with a small variety of shops; abundance of unhealthy food choices and junk food stores</li> <li>• Unhealthy behaviour of people in the streets, in particular junk food and soft drink consumption</li> <li>• Poverty as such is a health threat; moreover it is a barrier for people to adopt healthy life styles</li> <li>• Poor social cohesion and lack of intercultural exchange, loneliness and a sense of unsafety; lack of meeting places for social contact</li> <li>• Litter in public space, lack of litter disposal facilities and resulting pests. Inadequate environmental behaviour of residents</li> <li>• Poor quality housing, unhealthy indoor environment and dwellings that are too small for the size of families living there</li> </ul>

This was presented back to the citizen scientists, the community and the District council in a report and two brochures (22-24). 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, the 2014 citizen scientists organised a neighbourhood health festival in the community centre. The 2015 group repeated this. Community workers (KK, SU, and JW) and students supported them. At the health festival, each citizen scientist received a 'Health Ambassador' certificate confirming their participation in the project. The results of the project were used, as planned, 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 these 'ambassadors for health' will be developed for the other neighbourhoods in the larger Nieuw-West area (25, 26).

### 3.2.2 Study design

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.



**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.

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 (27).

Figure 1 provides an overview of the project after the initial recruitment, both for the citizen scientists enrolled in 2014 and in 2015.

### 3.2.3 Participant selection

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 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 Sloterveer, 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 like courses or social groups.

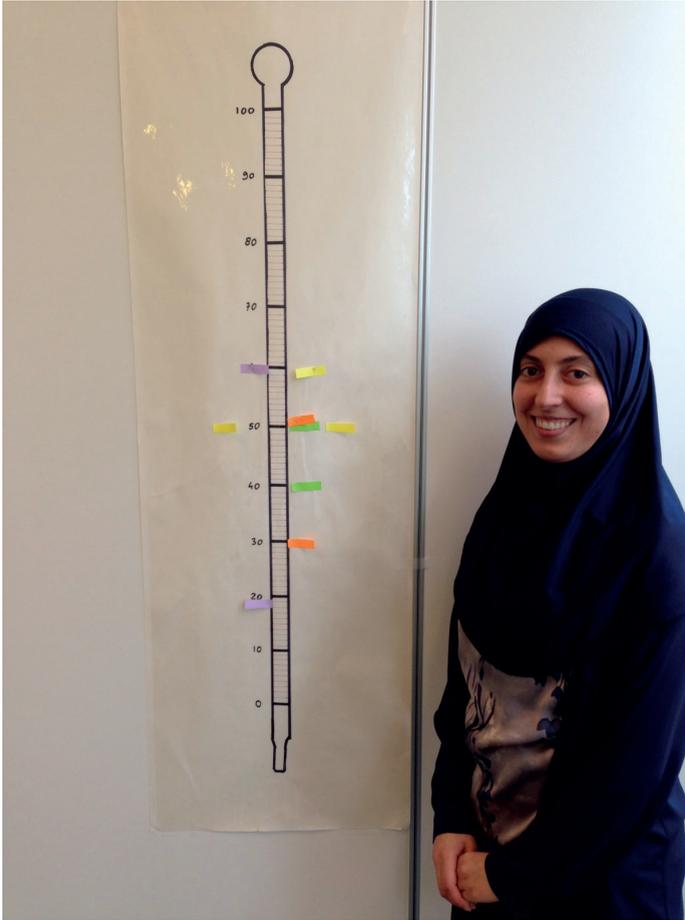
Initially, 42 citizen scientists were recruited. In 2014, six persons dropped out. Four of these decided not to participate immediately after the initial focus groups (see under 'data collection') which they had attended out of personal interest, but not with the aim of participating in the project; two other citizen scientists dropped out later due to personal circumstances. In 2015, one person dropped out for personal reasons. In total 35 citizen scientists remained engaged throughout the project. All citizen scientists 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.

### 3.2.4 Data collection

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 video recorded and transcribed verbatim.

The main topic in the focus groups held before the project activities started was how the citizen scientists perceived the health of the neighbourhood. It was started off by individually 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 and the neighbourhood's health. These focus groups also served to facilitate the citizen scientists in getting acquainted with the project team and each other.



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

In the focus groups after the citizen scientists had carried out their Citizen Science tasks two topics were central: the information collected and their personal experiences as citizen scientists. These focus groups also provided an opportunity for the citizen scientists to share and discuss experiences.

All citizen scientists were 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. Interviews were recorded and transcribed verbatim. Examples of questions were: 'How do you feel about the project Healthy Sloterveer?', '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 both focus group rounds described before, the citizen scientists filled out a structured questionnaire. Items included personal data, two visual analogue scales rating personal and neighbourhood health (28), the Chew three-item Health Literacy (HL) scale, Dutch version (29) and the 13 item Sense Of Coherence (SOC) scale (Dutch version) (30). 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 (31-33). The SOC-13 scale has been translated and applied in different parts of the world with different (educational) groups - a worldwide review looking into the validity of the scale suggests that it is interculturally stable (31) The SOC scale copyright holders granted permission for its use in this study.

### 3.3 ANALYSIS

Analysis of the qualitative data was carried out through descriptive and thematic coding (34). The codebook for descriptive coding was based on a model of benefits for citizen scientists that we presented in an earlier paper (6). 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' (35 p2076). 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 (Table 3).



**Figure 3:** Model of Citizen Science benefits (Source: 6).

**Table 3:** Codebook and code descriptions.

Code name / description	Inclusion criteria	Exclusion criteria
<b>HL Finding info</b> 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
<b>HL Applying health info</b> 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
<b>Emp Options for personal action</b> 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
<b>Emp Options for collective action</b> 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
<b>Comm Social capital</b> Referring to one's own social network and access to broader social networks	Include when referring to one's own networks/access to 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

**Table 3:** (continued)

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

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 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 solely used 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 (29). 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  $\text{SOC} \leq 67$  as 'low' and  $\text{SOC} \geq 68$  as 'high' (36).

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.

## 3.4 RESULTS

### 3.4.1 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, many were homemakers or unemployed. Several non-western migrants participating stated they had followed a university education in their country of origin. The income level of the citizen scientists was low to moderate. Four citizen scientists had paid work while the others were homemakers, unemployed, pensioners, or received social benefits. One was a student. Table 4 shows background data of the citizen scientists. Except for the gender composition of the groups, the citizen scientists 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 Sloterveer, over 60% of the inhabitants are of migrant origin, in particular Turkish and Moroccan, and 37-41% of the inhabitants have low literacy levels (17).

**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		

### 3.4.2 Focus group and interview results

In this section, we discuss the results of the focus groups and interviews. First some generic results are described. Then the main personal impacts are described, in line with the themes identified. 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.

#### 3.4.2.1 Generic results

The main reason 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 wished to contribute to that.

*'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 Sloterveer'*

(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 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 Sloterveer'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.

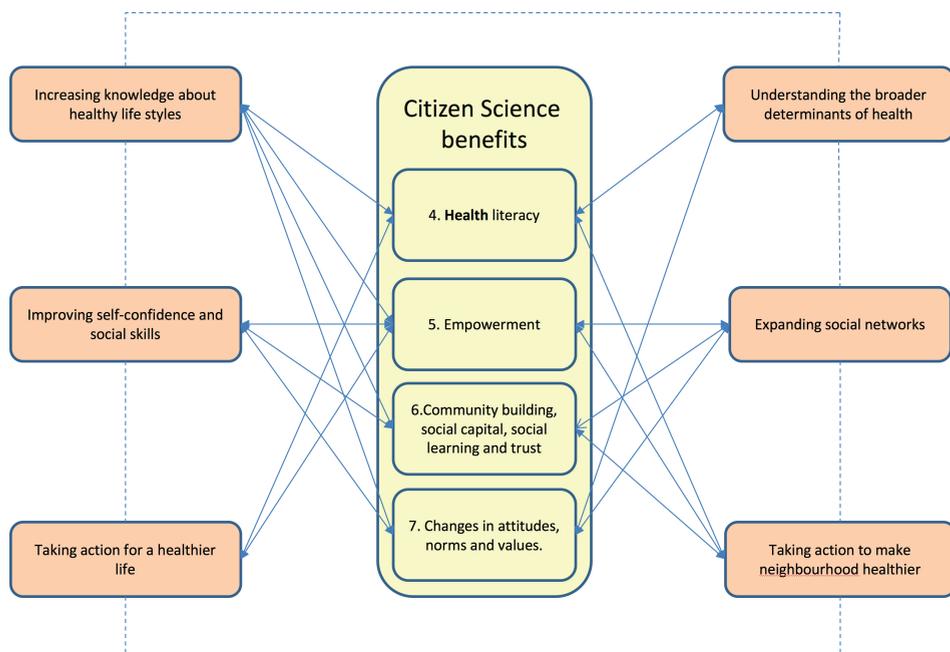
*'I think it is a beautiful way to collect people's ideas and to use that information to do something good for them. At first I thought, 'Healthy Sloterveer', what's that? It is useless! But after I had joined the project I saw how effective this can be'*

(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.

### 3.4.2.2 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; each code 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).



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

#### ***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 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 I 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 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'*  
(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 other. 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 Sloterveer, 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 Sloterveer, 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 Sloterveer 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. Firstly, 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 as 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.

The citizen scientists 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 environment. 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 life styles for their fellow residents. This was one of the reasons to develop and carry out a health festival. However, several said more was needed, and asked for more training to become lay health extension workers, running 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 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 on 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 this problem was something they could not help solve.

### **3.4.3 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 that filled out both questionnaires or parts of it, we compared scores before and after the project. Table 5 shows an overview of scores and of the comparisons.

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 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.

**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.

<b>Rating of personal health (scale 0-10)</b>		<b>Av.</b>		<b>Av.</b>	
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 – after project (N=20)	Before	6.67	After	6.24 (P=0.2161)	
<b>Rating of neighbourhood health (scale 0-10)</b>		<b>Av.</b>		<b>Av.</b>	
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 – after project (N=17)	Before	5.29	After	5.35 (P=0.4270)	
<b>Adequate/ inadequate HL (score range 0-4; ≥ 2 adequate)</b>		<b>N</b>		<b>N</b>	
<b>HL (in)adequacy before project (N=30)</b>	<b>Adequate</b>	<b>22</b>	<b>Inadequate</b>	<b>8</b>	
<b>HL (in)adequacy after project (N=20)</b>	<b>Adequate</b>	<b>18</b>	<b>Inadequate</b>	<b>2</b>	
<b>Paired comparison HL scores (in)adequacy (N=17)</b>	<b>N</b>		<b>N</b>		
<b>HL (in)adequacy before project</b>	<b>Adequate</b>	<b>14</b>	<b>Inadequate</b>	<b>3</b>	
<b>HL (in)adequacy after project</b>	<b>Adequate</b>	<b>17</b>	<b>Inadequate</b>	<b>0</b>	
		<b>Av</b>		<b>Av</b>	
<b>Paired comparison average HL scores (N=17)</b>	<b>Before</b>	<b>2.63</b>	<b>After</b>	<b>3.14</b> (P=0.0045)	
<b>SOC scores (range 13-91, ≥68 'high', ≤ 67 'low')</b>		<b>N</b>		<b>N</b>	
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	
		<b>Av.</b>		<b>Av.</b>	
Paired comparison SOC scores before- after (N=15)	Before	63.21	After	63.28 (P=0.4884)	

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 that filled out the SOC scale and 'low' for 13 citizen scientists. After participation, of those that 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.

### 3.5 DISCUSSION AND CONCLUSIONS

The aims of the Sloterveer 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.

The project may be classified as a *collaborative* project in the classification of Shirk et al. (37) because the citizen scientists were engaged in both carrying out interviews and analysing the results in the meetings described in this paper (see Table 6 for Shirk's classification). 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.

#### 3.5.1 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 of all, the citizen scientists changed their view on health and acquired an *understanding of the broader determinants of health*. Secondly, they *increased knowledge about healthy life styles* and reflected on these in relation to their personal habits. This materialised in the third impact: *taking action for a healthier life*. Fourthly, the citizen scientists reported having developed new social competences; related to this, they reported *improved self-confidence and social skills*.

**Table 6:** Models of PPSR according to Shirk et al. (2012)

Model of Public Participation in Scientific Research	Description
Contractual projects	Projects “where communities ask professional researchers to conduct a specific scientific investigation and report on the results”
Contributory projects	Projects “which are generally designed by scientists and for which members of the public primarily contribute data”
Collaborative projects	Projects “which are generally designed by scientists and for which members of the public contribute data but also help to refine project design, analyse data, and/or disseminate findings”
Co-created projects	Projects “which are designed by scientists and members of the public working together and for which at least some of the public participants are actively involved in most or all aspects of the research process”
Collegial contribution	Projects “where non-credentialed individuals conduct research independently with varying degrees of expected recognition by institutionalized science and/or professionals”

Fifthly, the citizen scientists *expanded their social networks across cultural boundaries*. The sixth impact reported 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 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 like poor housing and loneliness, while, on the other hand, identifying unexpected positive neighbourhood aspects like 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 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 under 781 Dutch persons of 18 years and older, that showed high SOC for 386 persons and low SOC for 395 persons (36). They showed no meaningful changes. Although an increase of SOC scores seems possible, this requires intensive interventions focused on empowerment and development of reflection capabilities (38-40). Probably, the 'Healthy Sloterveer' project lacked that high degree of intensiveness.

Of course, SOC scores of the Ambassadors must be interpreted with caution as they experienced the questions in the SOC scale as complicated and therefore may have misunderstood questions. Other Dutch researchers came across similar problems in measuring SOC of people with a low educational level (41) but as yet, there are no validated alternatives that are better suited to similar target groups.

### **3.5.2 Citizen Science and health promotion**

Overlooking the results, two aspects in particular stand out: 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, 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 this. Citizen Science, for example in environmental monitoring, has been reported to increase social capital and social cohesion (42-44). Our case shows that this might be true, not only for monitoring focusing 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. As described above, learning occurred 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 (13). 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 self-development, recognition and status as a role model, and meaningful relationships (45). 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 consider this a 'threat' to the scientific quality of the data collected, may have enhanced their feeling of ownership of the project.

The project in Sloterveer 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. 46, 47).

### 3.5.3 Strengths and weaknesses of this study

The impacts of the Healthy Sloterveer project on the citizen scientists themselves were studied, 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 in this public health Citizen Science project. Moreover, the model helped to get an overview on 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 self-reported impacts: citizen scientists may have provided socially desirable answers. Other possibilities to study impacts of this Citizen Science 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 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 in these experiences.

### 3.5.4 Lessons learnt and further steps

In conclusion, we have shown that public health Citizen Science may not only help collect local information, but can also 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<sup>3</sup>. Moreover, the approach seems to benefit citizen scientists with low educational levels. The methods applied, including the training and support of such 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 up a partnership between the citizen scientists and the researchers. However, although the citizen scientists did take 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 researchers and citizen scientists (14, 48).

Moreover, the health promoting potential of public health Citizen Science projects, like all health promotion, can only be meaningful if embedded in broader, longer lasting strategies (49). Indeed, short-lived 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 that exactly this effect might occur when they referred to their sense of powerlessness when they could not answer the questions of the people they interviewed. We recommend therefore that public health Citizen Science should not be restricted to projects with short duration, but rather 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 up 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.

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3. The Ottawa Charter is a joint document under the guidance of the World Health Organization, that provides directions for the development of health promotion. See: <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>

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## COMPETING INTERESTS

The authors declare that they have no competing interests.

## 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%20Netherlands%20Code%20of%20Conduct%20for%20Academic%20Practice%202004%20%28version%202014%29.pdf>

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# CHAPTER 04



# Community participation in Health Impact Assessment. A scoping review of the literature



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## ABSTRACT

Currently, the engagement of local communities in Health Impact Assessment is becoming more and more important. A scoping review was performed to take stock of visions, methods and experiences in this field.

A combined Scopus and Medline search yielded 100 articles in scientific journals. The final selection consisted of 43 papers, including case studies, evaluation studies, reviews, and opinion papers. After analysis, consultation of four experts was performed to check preliminary study outcomes. A grey literature web search was performed to check and complement the results.

Results show that community participation is generally considered a core element in HIA. Views as expressed in the papers concern, firstly, the need for and value of local knowledge, secondly, the adherence to or application of democratic values and, thirdly, empowerment of communities. Three categories of methods are used in relation to community participation, often in combination: methods to facilitate knowledge elicitation, to ensure the inclusion of communities in the HIA process, and to build community capacity to participate in policy development. However, the theoretical or practical underpinning of the choice for specific methods is mostly not presented. The experiences described in the papers mainly focus on the access to local knowledge and its usability as a source of evidence in the HIA process. Described effects of community participation are (improved) relations between communities and local agencies, policy makers and professionals and the empowerment of community members. Although these effects are ascribed to community participation, many papers do not provide support for this conclusion beyond the retrospective perception of participants. Expert consultation and additional analysis of the grey literature supported the results derived from the scientific literature and provided more in-depth knowledge. In the grey literature theoretical frameworks, methods and tools for community participation in HIA were more extensively reported as compared to the scientific literature.

We conclude that the visions, methods and experiences concerning community participation show that a participative approach may contribute to better, context specific knowledge. It appears that participative HIA has health promotion potential as it helps develop responsive policies.

To accomplish this, HIA should, firstly, be better embedded in broader health promotion programmes. Secondly, the methods and approaches for community participation applied in HIA should be theory-informed and well described. The grey literature offers entry points. Finally, more robust and systematic evaluation and research is needed to assess the impact of HIAs on communities and policies.

## 4.1 INTRODUCTION

Living and working circumstances are meaningful determinants of health, but are largely shaped by policies outside the health sector itself. Therefore, protecting and improving the health of populations requires intersectoral cooperation, or 'Health in All Policies'. Over the past 20 years, Health in All Policies has become an approach that is widely recognized and advocated in public health (1). One important milestone is the report of the Commission on Social Determinants of Health, proposing intersectoral action in several work fields such as education, employment, and urban planning in order to reduce socioeconomic health inequities (2). The Health in All Policies approach includes Health Impact Assessment (HIA) as a key tool. Although HIA was – and is - also practiced outside the framework of HiAP, the development of HiAP provided an important boost. HIA stimulates other sectors to include health in their policy consideration, it creates transparency and accountability for decision-making, and it provides evidence that demonstrates the impacts of non-health policies on population health. As such, HIA helps to create health-enhancing policies, programmes or projects through intersectoral cooperation (3-7). 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' (8 p.4). Over the past 20 years, HIA has become an established process in many parts of the world. The basic steps of HIA are screening, scoping, appraisal and reporting. The exact methods applied and the depth of the assessment can vary. A large number of guidelines and directions have been produced to date, to ensure quality of HIA (see, for example, 9). In line with the HiAP principles, most guidelines recommend that HIAs should engage communities that are affected by the plan, programme or policy assessed (10).

Currently, the engagement of local communities in HIA is becoming more and more important. On one hand, because the economic crisis placed the 'welfare state' under pressure: citizens in 'participation societies' are expected to take more charge of their own, and other people's well-being than before (11). On the other hand, there is a call for transparency and inclusiveness of policy processes. This is, for example, reflected in the field of environmental planning; national and international legislation nowadays require that communities be engaged in the planning process. Participation is defined as 'a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change' (12).

Given its growing importance in both health and environmental planning, it is important to take stock of visions, methods and experiences with community participation in HIA. Although the topic is often included in broader evaluation studies, views and practices of HIA researchers and practitioners regarding community participation have not yet been studied in a systematic way. Therefore, the aim of our study is to learn more about how community participation in HIA is currently perceived and how it is put to practice. Of course, community participation is also practiced in other types of Impact Assessment, like Environmental Impact Assessment (EIA). However, there are important differences that may shape views, methods and experiences regarding community participation, linked to the different work fields from which the various types of IA originate. For example, there are differences in legal frameworks, but also differences in methods and procedures. In this paper, we focus on HIA to gain a deeper understanding of this specific type of IA.

We focused on three questions:

- a) How do practitioners and researchers view community participation in HIA?
- b) What methods are used for community participation in HIA?
- c) What are the experiences and effects of community participation in HIA?

## 4.2 METHODS

We carried out a scoping review (13), a method that allows to study different kinds of literature in order to gain a broad overview of a specific work field, including, for example views, procedures and points of debate (14). For the data charting and analysis stage we applied the more extensive process described by Levac et al. (15).

We initially focused on publications in the scientific literature; these could include different types of publications, for example original research, review, or opinion articles. Based on guidance provided by the researchers, a library scientist (WtH) developed a proposal for an electronic database search strategy in MEDLINE and Scopus. After review and fine-tuning of this proposal by the researchers this search was implemented (Table 1). Two researchers independently carried out title screening and subsequent abstract screening. Categories were 'include', 'exclude', and 'uncertain'. Differences in categorization were discussed and final decisions were taken by consensus (LDB, EU).

**Table 1.** Search strategy: applied mesh terms and key words

AND		
Health impact assessment	Co-creation	Engagement process
	Community participation	Participation
Community health impact	Community involvement	Consumer participation
	Involvement	Community-institutional relations
Community health	Community partners	Community networks
	Community stakeholders	Interinstitutional relations
Impact assessment	Local stakeholders	Cooperative behavior
	Community engagement	Public opinion
Public health impact	Engaging communities	Social responsibility
	Community opinion	Social values
Outcome and process assessment (health care)	Community empowerment	Interviews
	Empowering communities	Sociology
	Community-based participation	Medical
Risk assessment	Population engagement	Community members or citizen
	Engaging population	Civilian
	Public involvement	Inhabitants
	Involvement persons	Lay people
	Social participation	Lay participation
	Public participation	Lay participants
	Population participation	Local group
	Civic participation	Neighborhood
	Civic engagement	Neighborhood committee
	Focus group	Residents
	Diverse partnership	Publics
	Human rights	Populations.
	Participatory approach	Community opinion
	Participatory process	Community concern
	Participatory mechanism	Community level

Exclusion criteria were:

- Paper does not provide information on visions, methods or experiences and impact regarding community participation in HIA
- Paper was not published after 2000 in peer-reviewed journal (in English)
- Paper does not concern HIA in OECD countries.

An excel data chart and criteria for data charting were developed and proofed by simultaneous pilot data extraction from four papers. Further data charting was carried out as an iterative process, providing space for the researchers to adapt the chart and criteria during the charting stage. We charted the following background data: date of publication, setting and country, type of paper and aim of the paper/study. We used these data to create a descriptive overview of the papers included in our study – Levac et al refer to this as ‘quantitative’ analysis (15).

To enable thematic analysis or, in the wording of Levac et al., ‘qualitative’ analysis, concerning views, (first research question) we charted data on: definition of participation, reasons/values for community participation, disadvantages of community participation. For thematic analysis concerning methods (research question 2) we charted data on: methods applied for community participation, description of people/communities involved. For analysis concerning experiences and impacts (research question 3) we charted data on: experiences, results and gaps, recommendations regarding community participation. For the analysis relating to the first two research questions, we utilized data extracted from all papers; for the third research question, we utilized only the data extracted from the papers describing HIA case studies. The data charted, for each category, included both descriptive summaries of the information provided in the papers as well as relevant text fragments.

Output tables of each data category were produced and studied. For each table, the data included were given thematic labels (coding). The last step consisted of further elaborating the themes identified by revisiting the original papers (LDB) and discussion in the project team (LDB, EU, JS, AW). In this step, close reading was applied as a way to recognize implicit issues that were ‘hidden’ in the text.

The results and a set of implications for the broader field of HIA practice and research were presented to four HIA experts with expertise in the field of community participation in HIA for member checking, as recommended in the scoping review method. These experts were recruited through our own networks (opportunity sampling). We ensured that we found persons with extensive knowledge about HIA and community empowerment, demonstrated by relevant publications in this field. An important criterion was that that we had no joint interests with these persons. They received an expert consultation file containing information about the study, a summary of the results and a set of implications for policy, practice, research. In addition, the file contained four questions:

1. Do you recognize these outcomes in general?
2. Are there any elements that you find surprising?
3. Are there any issues relating to the broader implications for research and practice that need to be adapted or amended?
4. What other comments do you wish to provide?

Each question was accompanied by the explicit invitation to explain one’s answer.

In addition, we carried out a web search for grey literature. Search terms were identical to those applied in the scientific literature. Exclusion criteria were:

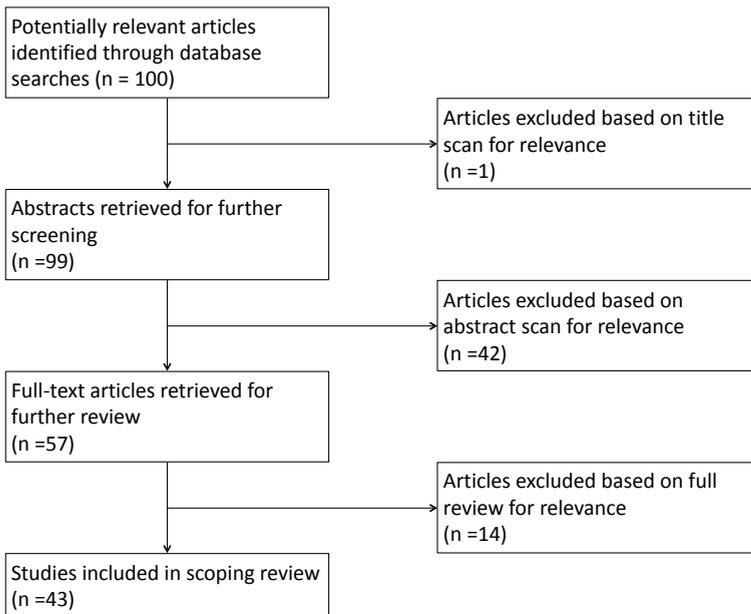
- Document does not provide information on visions, methods or experiences and impact regarding community participation in HIA
- Document was not published after 2000 (in English)
- Document does not concern HIA in OECD countries.

Data were extracted using the same categories applied to the scientific literature. The extracted data were studied to identify insights that were additional to, or distinctly different from, the results of the analysis of the scientific literature.

### 4.3 RESULTS

In this section, we first discuss the outcomes of the scientific paper search and analysis. Then we describe the outcomes of the expert consultation and the grey literature check.

The final selection of scientific papers consisted of 43 papers (Figure 1). All papers are listed in Additional file 1. In 17 out of 43 papers, community participation was the main topic. Table 2 shows an overview of the background features of the papers.



**Figure 1.** Selection process

The qualitative analysis of the data resulted in the identification of 11 themes (Table 3). These themes are discussed in section 3.1

**Table 2.** Descriptive information of the included studies

		Number of papers
<i>Countries</i>	United Kingdom	14
	United States	11
	Not applicable	8
	Canada	4
	Israel	2
	Ireland	1
	Australia	1
	Spain	1
	Hungary	1
<i>Year of publication</i>	2001	1
	2003	2
	2004	3
	2005	3
	2006	1
	2007	3
	2008	2
	2010	2
	2011	5
	2012	5
	2014	4
	2015	7
<i>Duration of HIA</i>	< 2 months	2
	2-12 months	3
	>12 months	3
	Not applicable/ not clear	33
<i>Guidelines mentioned</i>	Yes	20
	Not mentioned	23
<i>Type of paper</i>	HIA case study	21
	Opinion paper	9
	Methodological paper	4
	Review	5
	Other	4

### 4.3.1 Views on community participation in HIA

Although community participation is an important topic in all papers and the central theme in 17 out of 43 papers, an explicit definition is only given in one paper. Elliott and Williams state that “Public participation means inclusion in arguments about knowledge and science as much as it means involvement in decision making, and it means above

all the critical questioning and sometimes debunking of experts' claims to privileged understanding" (16 p233). In addition, one other paper commented exactly on this absence of clarity in defining community participation (17). The authors of this paper argue that vague and inconsistent use of different terminology, leads to controversies in the HIA community about whether and how community participation should be part of HIA. They propose replacing the term community participation by 'public involvement' as an alternative umbrella concept, providing more space for various participation practices and less room for misunderstanding between representatives of different streams or traditions in HIA.

**Table 3.** Themes per study question

Study question	themes			
<i>1 Views on community participation in HIA</i>	1A Participation as a core element in HIA	1B Knowledge produced by participation	1C Democratic values	1D Empowerment
<i>2 Methods applied for community participation in HIA</i>	2A Variation of methods	2B Methods for knowledge elicitation, for community influence and for capacity building	2C Description and theoretical underpinning of methods	
<i>3 Experiences with community participation in HIA</i>	3A Community based knowledge	3B Relations between communities and other stakeholders	3C Empowered communities	3D Measuring impacts of community participation in HIA

Nevertheless, community participation is generally, but not unanimously, considered as a regular aspect or core element of HIA (theme 1A). This does not mean that it is also considered unproblematic: many authors are aware of practical disadvantages and difficulties: organizing effective community participation is considered 'difficult' or 'complicated'. Lack of resources, in terms of time, funding, but also skills of the assessment team, is frequently mentioned as a major barrier. Some authors state that, in some instances, participation is undesirable, for example in the case of extremely technical and complicated assessments (18) or in cases where collecting and reviewing reliable evidence is the core aim of the HIA (17).

The views on community participation do not only concern the (quality of) the HIA itself, but also the potential effects of the HIA on communities and policies. There are three broad categories of considerations that shape the views on community participation of

HIA researchers and practitioners. These categories are, firstly, access to local knowledge, secondly, democratic values and inclusive decision-making and thirdly, empowerment of communities (respectively, theme 1B, 1C and 1D). Within these broad categories, different authors have different points of view, and the relative importance given to these categories of considerations differ.

#### ***4.3.1.1 Views referring to access to local knowledge***

Many papers, firstly, refer to local knowledge and the potential contribution of community participation to tap this knowledge to strengthen the evidence base for decision-making. This evidence base, according to many authors, is not always complete and data may not be available: collecting information from the community may fill this gap. It may furthermore help identify issues or problems otherwise overlooked. Community participation is considered as a good method to gather specific information about local circumstances, adding up to expert knowledge and providing a deeper insight into the impact of a project or policy on the personal lives of people, their experiences, concerns, and opinions. Several authors claim that such knowledge will improve insight into how the social determinants of health are impacted in specific contexts. In addition to these advantages, that relate to evidence that can be used to underpin decision-making, it transpires from the papers studied that community participation may challenge the nature and valuation of knowledge itself. It serves as a way to examine expert knowledge (19), share power between researchers and communities (20) and promote objectivity by including knowledge from different sources (21).

At the same time, some authors express doubt about the reliability of the knowledge presented by community members. They question the accuracy of that knowledge; for example Parry and Stevens state that community knowledge may not be 'true' (22). According to Parry and Stevens, and others sharing their vision, this endangers the objectivity and impartiality, and consequently the value of the assessment.

#### ***4.3.1.2 Views referring to democratic values***

Strengthening local democracy and implementing democratic values seems to be a major driver for the inclusion of communities in the HIA process. According to many authors, community participation in HIA can contribute to social and environmental justice and equity. It may promote accountability and transparency in decision-making and lead to policies that include community needs and incorporate or respect local values. For example Iroz states: "Relationships, capacity, and empowerment may offer benefits to community development that are distinct from those that result from the incorporation of community priorities in planning decisions – though the latter remains the primary goal of HIA practice (*italics LdB*)" (23 p. 284).

Equity is commonly seen as a basic value in HIA: it is mentioned as such in many papers and referred to 'between the lines' in others. Nine papers explicitly state that equity is promoted by participation, in particular of underprivileged, migrant or traveller communities. However, this requires thoughtful planning and application of processes and some state that these need better consideration or development. For example, McCallum, Ollson and Stevanovic state that, although community engagement is vital to promote equity, there is inconsistency in methods applied to attain this (24).

More generally speaking, community based HIA is sometimes perceived as a practical mechanism to set off more generic improvements in decision-making processes. A paper describing the HIA of the Commonwealth Games in Glasgow, 2014, for example, describes that policy makers may change their public engagement routines because of participative HIA (25). In addition, several authors claim that community based HIA has practical advantages for democratic processes, by helping to build public support for decisions, trust, a reduction of conflict and of conflict-related financial costs, and reducing delays in project execution. However, some authors state that stakeholders in politically sensitive situations may perceive community based HIA as a threat. For example, Bacigalupe et al. explain that in southern European countries decision makers, having little or no experience with HIA, may be concerned that the process will damage their position (26).

Although most authors see community participation as a contribution to the application of democratic values in decision making and as an opportunity to enhance local democracy, some, on the contrary, state that it can be a threat as well. For example Parry and Stevens raise an ethical concern that communities, in particular those that are disadvantaged or vulnerable, might be pressurized to agree on decisions that negatively impact their well-being (22). Others warn for poorly performed engagement processes that can hinder meaningful community participation, and instead lead to tokenism, disappointing and harming these communities (19 p113).

#### ***4.3.1.3 Views referring to empowerment***

Empowerment, in particular of disadvantaged groups, is the most frequently mentioned benefit of community participation in HIA. It is perceived as a necessary condition for the democratic decision-making mentioned above, because it contributes to building community capacities to influence decision-making processes, during and after the HIA process. The expectation is that this can effectuate social and political change. In addition, participation in HIA, according to many authors, helps to educate and inform communities. It may increase communities' health awareness and their interest in the HIA. According to several papers, participation in HIA may have a healing effect

on groups that have been neglected; it may improve social cohesion and, eventually, contribute to better health. Mahoney et al. (2007), mentioned before, therefore state that HIA often seems to be a way of health promotion.

Appropriate engagement methods for such groups are perceived as an important condition for these effects to take place; a specifically important issue is recruitment of groups that are considered hard to engage, distrusting the process or feeling disengaged from decision-making. A related concern is the representativeness of participants; this is also seen as a threat to the quality of the evidence base for the HIA: underrepresentation of specific groups may result in one-sided knowledge.

Moreover, it is agreed that the benefits for communities do not happen automatically; capacity building, in particular training of the community representatives engaged in the HIA – and sometimes of other stakeholders like decision makers or experts- is considered as a key component of the participation process.

### **4.3.2 Methods for community participation**

The papers studied show that there is not one method of community engagement that is considered to fit all contexts or populations: a large variety of methods (Table 4) for community participation is described (theme 2A). They also show that methods are combined in different ways and for different aims.

#### **4.3.2.1 Types of methods applied**

The methods applied for community participation in HIA can be divided in three main categories (theme 2B).

First, knowledge or opinion elicitation methods, in particular, focus groups and interviews are frequently mentioned, with community meetings and workshops coming next. Although a survey under HIA practitioners in the UK showed a preference for focus groups (27), frequently different knowledge elicitation methods are combined. For example, one HIA case study, concerning water and sanitation, describes how a lack of data on different aspects of the local water and sanitation system and its performance is amended: by organizing public meetings and conducting interviews with key persons, a survey, focus groups, and individual discussions (28).

The second category of methods includes specific procedures and structures to promote and secure the community's influence in the HIA. An example of such methods, frequently described, is inclusion of community representatives in an HIA Steering Group.

Thirdly, methods are described that are instrumental in building capacity for communities to participate in the HIA process, in particular training.

**Table 4.** Overview of methods in relation to community participation

Methods	Papers	# Papers
<b>Knowledge elicitation methods</b>		
Focus groups	6, 9, 10, 18, 28, 31, 42, 56, 61, 67, 73, 80, 83, 90	14
Interviews:	6,18, 28, 31, 47, 56, 61, 67,73, 78, 98	11
Broad community meetings	18, 28, 6,9, 38,44,60,61,67, 99	10
Survey	6,9,38,42,67,73	6
Workshops (a.o. rapid appraisal workshop)	18, 28, 38, 41, 56, 73	6
Engagement in data analysis/interpretation/ report writing	16,21, 98	3
Informal discussions	33, 9, 61	3
Small group meetings (18) or discussion groups (47)	18,47	2
Walking tour (44: walkability assessment)	33, 44	2
Engagement in research tool development	9,83	2
Representatives consult community	16	1
outreach through trained resident scientists	61	1
Photovoice	44	1
Group interviews	31	1
Engagement in evidence analysis	98	1
<b>Methods to warrant community influence</b>		
Steering Group/decision making participation <sup>a</sup>	9, 21, 25, 31, 33, 55, 72	7
Community invited to comment on draft report	18, 47, 67, 72	4
Public communication	31, 38,67	3
Stakeholders/key informants included in scoping	31, 90	2
Community members participate in developing recommendations	21, 41	2
Establish community networks	31	1
<b>Methods for capacity building</b>		
HIA training	21, 55, 83, 72	4
Other		
e-mail	18	1
Summer camp	28	1

<sup>a</sup> in one case, participants were representatives of community based organisations

#### **4.3.2.2 Description of methods in case studies**

The majority of the HIA case studies provide little detail about the methods applied (theme 2C). For example, many papers report that public meetings were organized, but do not describe the exact focus of the meetings, how the meetings were structured and who participated in the HIA. There is large variety in the number of community members involved, ranging from two to 'over 450' persons. Exact numbers of participants are provided in four papers. Participants are reported to be recruited from 'the community' or 'stakeholders' without a specific definition of the selected group. In many cases, the selection criteria for participants are not described, or there is no selection, for example, when larger, public events are organized to provide for the participation of a community. The case studies also do not describe on what theoretical or practical grounds specific methods were applied, and the underlying assumptions about their efficacy are usually not made explicit. Exceptions were, for example, a case study that described why the locations where community meetings were held were selected (29) and a case study that provided details on methods applied to recruit participants (20).

A number of papers in our selection explicitly address the lack of detail in the description of methods applied, stating that current processes and methods to engage communities in HIA fall behind what is considered good HIA practice and recommending that guidance or new methods should be developed (22,24,29-32). Other authors refer to existing frameworks from other work fields, that could guide community participation in HIA, for example McCartney et al. who mention the National Standards for Community Engagement (33, 25). One paper describes a set of criteria for effective participation in HIA developed in a two-day expert meeting (34).

#### **4.3.3 Experiences and effects**

In this section, we describe experiences and effects that came forward in the papers studied. Many of the case study papers included in our study contain accounts of 'what happened'; what went well and what barriers for meaningful community participation were encountered, how the input of the community was used and what role the HIA played in the decision making process. In general, the case studies tend to focus on describing successes in procedures and outcomes. The reviews that we found provide a more generic overview. Three topics stand out when studying the experiences reported. The first of these is access to lay or local knowledge (theme 3A). Secondly, experiences are reported concerning relations between communities and local agencies (theme 3B), policy makers and professionals. Thirdly, we found experiences concerning development of community empowerment (theme 3C).

#### 4.3.3.1 Experiences concerning access to local knowledge

The access to local knowledge is an important topic, discussed in HIA case studies. A review, carried out in the UK, looked into the use in HIA of different types of evidence, including community knowledge. This survey under 52 HIA practitioners showed that community knowledge was the second most utilized source of evidence, after review of existing literature, but before expert opinion (35). Bourcier et al. state, based on their study of 23 cases in the United States combined with interviews and a survey, that effective community participation is a key factor for HIA to be successful in integrating health considerations non-health policies (36).

Case studies report that the participation of the community provided insight in the community's needs and concerns. The information collected is considered 'useful' or 'valuable' and authors report that it helps deepen the understanding of context specific conditions and impacts. A case study about an HIA on housing and area renewal in an underprivileged Welsh neighbourhood describes the engagement of residents in the HIA steering group, as key informants and as participants in a public meeting. According to the authors, the residents' role was not only to provide information, but also to contribute to the interpretation of that information and the other evidence collected; they were 'sense-makers' that helped combine scientific with experiential knowledge. For example, they underlined the importance of family and community relationships for the sense of belonging of the people in this neighbourhood, and this helped to better understand the concerns they had about the implications of interventions in the local environment (37). Another case study provided examples of contextual knowledge that helped 'rank' the importance of several impacts of a project, e.g. safety at home versus safety in public space (38). Several authors describe experiences where the knowledge of community members is essentially different from expert knowledge and combining these two types of knowledge is challenging. In one case, a steering group consisting of community members and professionals was split up, as the gap between the two different paradigms was considered counterproductive. In addition, the authors state that not only the knowledge put forward differed but that the community members also lacked the skills for effective participation. They conclude that effective community engagement is difficult to accomplish in HIA practice (39). Kearney interviewed community members and other stakeholders to assess, prospectively, how their views would influence the feasibility of a planned community based HIA on a regeneration masterplan and concluded that the knowledge put forward by the community would enrich the process, but that professionals had little confidence in the capacities of community members to 'responsibly' participate in the HIA (40). Some authors report that they had difficulties engaging a representative or large enough group of people from the community and therefore the reliability of the community input was poor.

#### **4.3.3.2 Experiences concerning relations between communities and other stakeholders**

Most authors report that the participation of communities in HIA helped create a common understanding and that this resulted in new organizational structures that support the relations between communities and policy makers and other local stakeholders, during, but also after the HIA. They also describe that this enables higher policy involvement of residents. An example is a paper describing an HIA on water and sanitation in an underprivileged area at the Mexican border of the US. A high proportion of the population were migrants and the population experienced a feeling of having been neglected. The HIA prompted residents to become interested in the water issues and to visit Council meetings to hear more about the issue. In addition, residents set up a local policy initiative for community safety. The authors state that the HIA, because of its open way of communicating and engaging people, increased trust of the community in policy actors (28). However, some authors describe how a lack of trust, on the contrary, hampered the participation process. They describe communities with specific social and historical backgrounds, or communities that had been disappointed by policy development procedures or outcomes. One example is the case study about an HIA on a waste incinerator where the planning process was organized in such a way that the HIA could not realise its potential to effectively address the community's concerns or engage the community in the considerations about the project. The resulting anger and suspiciousness added up to pre-existing feelings of powerlessness in this community (41).

#### **4.3.3.3 Experiences concerning empowerment**

The third topic is the empowerment of communities. Gilhuly et al. (42) describe three case studies where communities gained access to information and data that they could use to influence decision-making. The residents in these communities were actively involved by contributing to the research and disseminating the outcomes. Several studies describe how the HIA led to the development of community advocacy groups that lasted after the HIA was finalized. Empowerment was also reported to be accomplished through learning processes. In some cases, these learning processes were actively stimulated by providing HIA training to community members. In one case, the training was provided after the actual HIA to further enhance the learning that had occurred during the process (39). The learning processes described in the papers do not only concern knowledge about a specific issue, like water or waste, or participation capacity, but also insight in health and its broader determinants. Several papers report that health awareness was created both in communities and under decision makers.

It is striking that the studies focusing on one, or a few, specific HIAs, claim that the HIA contributed to empowerment, learning, health awareness or policy engagement, but that most of the papers do not describe how these effects were assessed (theme 3D). Instead, the effects reported are mainly backed up by a description of specific steps taken by community members or by citing remarks or personal accounts of participants in the HIA. It is also striking that the question whether the participation of communities in the HIA, had a detectable influence on policy decisions is hardly addressed. One exception is an evaluation study of 55 HIAs in Australia and New-Zealand that reported that the involvement of the community was one of the factors that contributed to the effectiveness of HIAs to influence policies (43).

#### 4.3.4 Expert reflections and grey literature check

In this section we describe the expert reflections on the preliminary results and the grey literature check.

##### 4.3.4.1 Expert reflections

The experts consulted recognised the summary of the results presented to them. They provided a few specific comments, which we summarise here:

- *Public participation is very much driven by tradition, habits, culture of different countries.*  
Although only one paper refers to this, it is an important issue and we reflect on it in our discussion of limitations in section 5.
- *How can participation in HIA harm communities? What examples are there of such cases?*  
This question is briefly addressed in section 3. However, it is true that concrete examples counterproductive effects of the participation are almost absent in the papers. In relation to this, we feel that one other expert made a valid point:
- *There may be a positive publication bias resulting in an overrepresentation of successful cases of participation.*  
We reflect on this in our discussion of limitations in section 5.
- *It seems that equity, as a basic value in HIA is missing in the results.*  
We carried out a rapid review of all papers in our study and concluded that this is a relevant question as the issue was often mentioned. We have included the findings in section 3.
- *Community capacity building is an important issue, in addition to empowerment.*  
This issue is addressed in section 3.

- *Community participation helps add new knowledge that cannot otherwise be accessed.*

This aspect was not touched upon on detail in the expert consultation file, but is addressed extensively in section 3.1.1.

- *The absence of theoretical or practical underpinnings on choice of methods or appropriateness needs to be viewed against the context and goal of the paper at the time.*

This observation is addressed in the Discussion (section 5).

- *What criteria was used to make the judgement about 'random' evidence for the effects of participation on the community?*

We had used the term 'random evidence' in the expert consultation file to summarise the types of information (see section 3.3.3) given to support the reported impacts of participation.

#### **4.3.4.2 Grey literature check**

The grey literature search yielded 18 documents. Of the documents identified, we excluded 5 that did not concern participation in HIA. Another 2 documents were excluded because they were PowerPoint presentations that provided little information. We excluded 1 document which turned out to be a web site and 1 additional document as this (web based) document was no longer available. We excluded one document which turned out to be published as a scientific paper, already included in our scientific paper search. We added 1 document which was identified as the second and additional part of an included document. In total, we studied 9 documents (Additional file 2) focusing on what additional or different information these documents provided as compared to the scientific literature studied.

The data extracted from the grey literature showed a similar picture as the data from the scientific literature search. Two aspects however, were slightly different. Firstly, in the grey literature there seems to be more extensive reference to theoretical frameworks underpinning community engagement in HIA as compared to the scientific literature. For example, the Human Impact Partners & Group Health Research Institute (44) gives an overview of different participation levels in HIA, building on the classification of participation of the International Association for Public Participation (45). Another document, a book chapter about the PATH (People Assessing Their Health) method, elaborates on the theoretical foundations of the methods applied in community meetings (46). In particular, storytelling as a way to relate people's personal experiences to the policy assessed was explained, building on theories of Freire, Labonté and Kolb. And the National Collaboration Centre for Healthy Public Policy (Canada) promotes further development of the theoretical foundations of community engagement in HIA

(47). Secondly, methods and procedures were explained more in-depth as compared to the scientific papers studied. In particular, five documents that were prepared as instruction or guidance for HIA performance provided detailed methodological information (46-50). The report of Human Impact Partners & Group Health Research Institute, mentioned before (44), looked into the impact of community based HIA on civic agency. By evaluating a range of HIAs in the North Americas, it shows that not the application of specific engagement methods, but rather the number of approaches applied had an impact on effective community participation. Moreover, the authors recommend not only that local networks and key persons should be involved in the HIA process, but also that long term community engagement should be promoted to realise community empowerment. A similar recommendation is given in Coady's book chapter (46).

## 4.4 DISCUSSION

This scoping review was carried out to assess 1) how practitioners and researchers view community participation in HIA, 2) what methods and tools are used for community participation in HIA and 3) what the experiences and effects of community participation in HIA are.

In relation to the first question, we found that community participation is generally considered a core element in HIA. Only few authors think this is not necessarily the case in all HIAs as this may be unpractical or the topic is too complicated. The three main reasons why communities should be included in HIA 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 Gothenburg Consensus Paper (8) seems to have been particularly influential in its recommendations that communities should participate in HIAs. It is frequently mentioned to substantiate claims about the value of, and need for, community participation.

In relation to the second study question, we found that, in the papers included in our study, the methods applied show high variation. Several methods are combined within one HIA, or one method is applied to serve several different aims at once. The focus is on methods for knowledge elicitation, structures and procedures to ensure the inclusion of communities in the HIA process, and capacity building. The theoretical or practical underpinning of the choice for specific methods and their appropriateness for application in a given HIA is mostly absent in the scientific papers. However, grey literature provides more detail as to methods as well as to their theoretical basis.

In relation to the third study question, we found that, in the papers included in our study, experiences with community participation in HIA are mostly described in positive terms. The experiences concern 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, although some random information is usually provided to support such claims.

Overlooking the results of our study, three generic aspects stand out. These are, firstly, the importance ascribed to lay knowledge, secondly, the value –based nature of community participation in HIA, and, finally, the lack of conceptual and methodological clarity.

In relation to the value of lay knowledge, the first aspect, we found that such knowledge is considered as useful and important for the field of HIA, enriching and amending expert knowledge about the potential health impacts of a project, plan or program on a population. The practices described in the papers included in our study confirm this. The methods applied to engage communities clearly aim at gathering such local and lay knowledge for the HIA process and the experiences reported show that such knowledge is considered useful. However, it remains unclear whether the value of lay knowledge equals that of expert knowledge – no cases were described where lay and expert knowledge ‘clashed’.

The second aspect, the emphasis on values in promoting inclusion of communities in HIA, is demonstrated by the two most important reasons authors mention for the inclusion of communities: putting democratic values to practice and empowerment of, in particular, underprivileged groups. These are two reasons that refer to moral, and in some cases political considerations, and not necessarily to quality of the HIA itself. Even the knowledge gathering dimension of community based HIA, apparently a more ‘technical’ aspect, is less instrumental as it might seem; the way that lay knowledge is discussed seems to relate to similar values, for example amending expert knowledge with new, community-based perspectives that would otherwise have been neglected. This is a strength of HIA; Raphael argues that what makes public health effective is its embedment in a system of values (51). In addition, participation is one of the core elements in the Ottawa Charter’s strategies for Health Promotion (52,53). It appears that HIA has the potential to contribute to health promotion by engaging and empowering communities. To fulfil its health promoting potential, HIA, which is currently carried out as a ‘stand-alone’ exercise, should be embedded in broader health promotion

programmes, as health promotion can only be effective as a coordinated approach (54,55). This seems to be confirmed by the grey literature (44,46).

The lack of conceptual and methodological clarity, the third aspect, surprised us. Although community participation is perceived as a core element, few scientific papers define what that really means. More importantly, it remains unclear how the values related to community participation in HIA are implemented in practice and what the effects are. Decisions on participation processes seem to be made based on pragmatic considerations and apparently there is little focus on evaluation of the participatory processes and their outcomes. Claims regarding impacts of the community participation on the people concerned are not often supported by strong evidence. This resembles the situation in other types of impact assessment, for example (Strategic) Environmental Impact Assessment (EIA) (56,57,58). Impact assessment, in general, is carried out to inform decision-making, and not primarily for scientific purposes. This may explain the apparent lack of attention for theoretical underpinning and thorough evaluation of the methods applied and their (expected) results. Moreover, a number of papers were written at a time where HIA was a newly developing process in the region concerned; therefore their focus may have been on explaining what HIA is and what its benefits are, rather than on in-depth description of methodological issues. In addition, scientific papers provide much less space for such extensive descriptions and elaborations than grey literature such as reports and guidance documents.

Now that HIA has become more widespread as a process in several parts of the world, there is space for its further development. For the engagement of communities in HIA this could mean a stronger focus on the theoretical underpinning of methods - and a reflection of that focus in scientific publishing about HIA. The guidance documents we identified in the grey literature provide important starting points. In addition, procedures and principles as developed for Participatory Action Research can be helpful. Like participatory HIA, this approach aims at combining knowledge development with social action, it contains an element of joint learning, and capacity building for communities 59.

Better description and evaluation of possible benefits of community engagement in HIA for knowledge as well as for communities is equally important at this stage of HIA development. Examples of possible frameworks for evaluation are available both from the HIA field itself 34 as well as from related work fields such as Citizen Science (60).

A limitation of our study was, initially, that we focused on papers that were published in scientific journals. We were aware that that we might have missed, for example,

cases that present a robust evidence base for the methods applied, or where claims made about empowerment are supported by thorough evaluation. The member check carried out by consulting four experts in the field, as well as the search in grey literature, confirmed our findings, but also provided additional information that helped to obtain a more balanced view on these issues.

A second limitation is the search for papers in English. This may have provided a skewed image. In English-speaking countries like the United Kingdom, Canada and Australia, participatory HIA is common; therefore, we are not surprised that the majority of the papers identified concerned those countries. However in other countries, for example, in Germany and in the Netherlands, a strong focus in HIA development has been on modelling and participation is weakly developed (61,62). Country-specific scoping reviews in non-Anglo-Saxon countries, for example Francophone, Spanish speaking, or German speaking countries, may produce a different 'landscape' of views and practices.

## **4.5 CONCLUSIONS AND RECOMMENDATIONS**

Our study shows that community participation in HIA is claimed to have important impacts on the knowledge produced by the HIA as well as on communities that participate. However, are these claims realistic? Overlooking the results, we conclude that they are partly supported by practice, as represented in our study of scientific (and grey) literature. Community participation does seem to contribute to better, context specific knowledge. But how certain are the impacts on communities? For example, as community empowerment is a long-term process that requires sustained and systematic support (63,64), it seems improbable that one stand-alone HIA could empower a community when no other actions are taken. It is also striking that, where community participation is concerned, procedures do appear to be pragmatic rather than systematic, while HIA itself is claimed to be systematic and evidence-based.

We believe that community participation in HIA links up to the value system of a democratic and egalitarian society. Moreover, it has the potential, in addition to its other goals, to contribute to health promotion. Community participation in HIA contributes to policies that, building on local knowledge, and engaging target groups, address issues that are important, for these groups - in ways that are locally acceptable and appropriate. In other words, it contributes to responsive policies. However, this does not happen automatically. Therefore, we recommend that, firstly, community based HIAs link up more closely to existing health promotion programmes or strategies. Secondly, theory-informed and explicit decisions should be made on methods and approaches

concerning the inclusion of communities in HIA. Thirdly, work should be undertaken to establish more robust evaluation of the possible effects of community participation in HIA on knowledge, communities and policies.

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# CHAPTER 05



# We are all experts! Does stakeholder engagement in Health Impact Scoping lead to consensus? A Dutch case study



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## **ABSTRACT**

Stakeholder engagement in Environmental Impact Assessment (EIA) and Health Impact Assessment (HIA) provides opportunities for inclusive environmental decision-making contributing to the attainment of agreement about the potential environmental and health impacts of a plan. A case evaluation of stakeholder engagement was carried out to assess its effect in terms of consensus-building. The case consisted in two health impact scoping workshops engaging 20 stakeholders: policy-makers, experts and residents. A Participatory Action Research approach was adopted. Methods included observation, semi-structured questionnaires and interviews. Analysis methods consisted of several coding rounds, in-depth reading and discussion of Atlas.ti output reports, as well as studying questionnaire results. 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. To avoid disappointment and conflict in later project development, explicit acknowledgment and acceptance of disagreements should be included as a ground rule in future stakeholder engagement processes.

## 5.1 INTRODUCTION

Involving stakeholders throughout the environmental impact assessment (EIA) and health impact assessment (HIA) process is broadly advocated (1, 2). One of the reasons is that this provides opportunities for more inclusive environmental decision-making, in particular regarding local communities' concerns and needs. Such engagement requires a shift from a 'rationalistic' and 'technocratic' approach to one that takes the requirements and views of all stakeholders, including local communities, into account (3-5). 'Deliberative' processes, involving groups that are affected by policies or projects, are claimed to be potentially helpful in collecting relevant local experience and knowledge, developing solutions and addressing the concerns of local communities (6). For example, local stakeholder engagement in HIA is reported to provide knowledge that is not available from existing data sources (7, 8). At the same time there is no guarantee that the voices of local communities are heard, and stakeholder engagement can also turn into a mere bureaucratic exercise (9). Also, stakeholders may lack the skills and knowledge to be able to participate, and they may require opportunities for learning (10). Evaluation of the participation processes is therefore important. Key evaluation components are representation, process structure, information used and outcomes and decisions (11). In this paper, we focus on evaluation of consensus-building as an aspect of 'outcomes and decisions'. Consensus-building can lead to changes in the points of view of stakeholders; how that happens and why is a question that requires further research (12). This paper describes a Dutch practice case of stakeholder engagement. In particular we focus on stakeholder perceptions of the level of consensus attained ('perceived consensus') and their respective views on the issues at stake ('actual consensus'). In the Netherlands, the issue of stakeholder and resident engagement is particularly urgent because of recent political developments promoting the development of a 'participation society' (13). Such a participation society requires that various stakeholders, including citizens, in a partnership with governmental agencies and professionals, take responsibility for the well-being of everybody. The case concerned two workshops for health impact scoping (HIS) in a Dutch town, which were organised within the framework of a large, and much debated, infrastructure project. The workshop outputs were intended to contribute to knowledge about the potential health impacts of this project, adding to the knowledge already provided in an EIA procedure that had been finalised previously. The evaluation focused on three main questions:

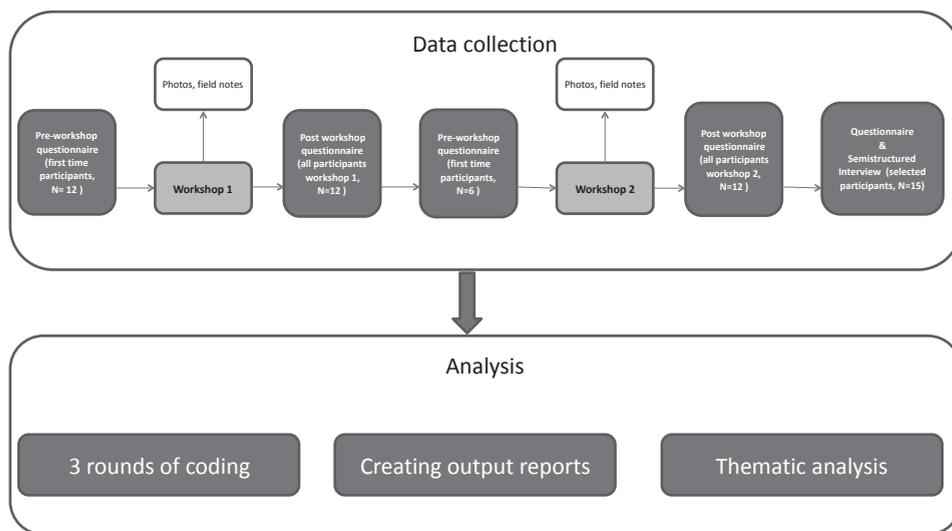
- In what way did the HIS workshops influence stakeholder perspectives on health and a healthy living environment?
- What level of actual and perceived consensus on these perspectives was reached at the HIS workshops?

- What were the perceived factors that contributed to or hindered the development of consensus on health and a healthy living environment?

This paper first describes the methods applied. Then results and analysis are presented. Finally, conclusions and lessons learnt for EIA practice are discussed.

## 5.2 METHODS

A participatory action research (PAR) approach (14) was applied: a researcher (LdB) provided conceptual (health definitions, dimensions of a healthy environment) and methodological (group work methods) input for the development of the HIS workshops. Moreover, this researcher was present during the workshops. The workshop developers, who also conducted the workshops (LG, MS), provided input in post-workshop evaluation interviews (KYC) and commented on the preliminary evaluation report that formed the basis of this paper. Thus, intervention development (workshops) and knowledge development (evaluation) were closely linked and were carried out in collaboration with those affected by the infrastructure project. Multiple methods (questionnaires, observation and interviews) were applied for data collection (LdB, KYC), and qualitative data analysis (LdB, KYC, AW and JS) was carried out (Figure 1).



**Figure 1.** Study process overview

### 5.2.1 Local setting

The case we studied concerns a Dutch town of 26,000 inhabitants. A major rail and road infrastructure development was planned, substantially increasing passenger and cargo transport through the town centre (15). This was part of a national development plan (16). An EIA for this project had already been carried out, commissioned by the project developer, and mitigating measures, with a focus on noise pollution, had been proposed. The plan and the EIA report had been presented to residents. However, residents still had serious concerns and opposed the plan. Residents set up an action committee, and multiple complaints were filed. In particular, residents claimed that health impacts had not been appropriately addressed (15). The Municipality therefore commissioned the Municipal Health Authority to develop and carry out two HIS workshops with local and national stakeholders including residents. Evaluation was included in the development process right from the start (LdB).

### 5.2.2 HIS workshops

The workshops were carried out by Municipal Health Authority staff (LG, MS), and the results were described in a report for the Municipality (17). The first workshop aimed at developing a joint vision on a healthy environment, combining the knowledge and perceptions of all participating stakeholders (hereafter referred to as 'the participants'), i.e. experts, policy-makers and residents. The health definitions of the World Health Organization and Huber et al. (18) were explained, and the interaction between health and the environment was discussed using the model of sustainable communities developed by Egan (19). In the second workshop, the joint vision was applied to the infrastructure development plan, and potential health impacts were identified. These are described in the Results section. The Municipality selected 39 participants, including residents, on the basis of a variety of roles, and personally invited them. This procedure was followed as the Municipality wanted to have key persons on board, but had insufficient time and resources to carry out meetings with larger groups of stakeholders. The workshops consisted of a combination of introductory lectures, providing knowledge about health models and health impacts, and group work, developing a 'joint vision' on a healthy environment for the local community. Group work was also carried out to apply this vision to the infrastructure plan. To support cooperation between lay and expert participants, two main rules were maintained throughout the workshops. The Chatham House Rule (20) states that participants may freely use information received during a meeting, but may not reveal the speaker's and other participants' identity or affiliation. The 'Everybody is an Expert Rule' was designed by the workshop developers and states that every participant is an expert in his/her specific role and domain when participating in the workshops. The aim of this rule was to create a level playing field

among participants and explore knowledge, experiences and insights from a variety of roles and views.

### **5.2.3 Data collection**

Firstly, participants filled out a questionnaire at the start of the workshops. This questionnaire contained two open questions, one asking HIS participants for their definition of health, and one about desirable outcomes of the workshops. A five-point-scale question asked them to rate the importance of health in transport infrastructure project planning. Secondly, photos were taken during the workshops (LdB) that were later used to help the participants recollect their experiences when interviewed. Thirdly, participants filled out an evaluation form after each workshop, rating the instructiveness of the workshops, positive/negative atmosphere, level of satisfaction and amount of room to express their views on a 5-point scale, and rating the workshop as a whole on a 10-point scale. This questionnaire also contained two open questions: what went well during the workshops, and what could be improved. Participants were asked if they were willing to be contacted for an individual interview afterwards. Fourthly, 15 (out of 20) participants who had given their permission were contacted by email for a post-workshop interview. Three respondents declined because of a lack of time, and 12 participants agreed. Interviews were conducted, nine months after the workshops, by one researcher (KYC), either at the office of the respondents or in their home. The first part of the interview consisted in showing the respondents photos taken during the workshops and asking them to comment. The aim of this procedure was to help them recall how they experienced the workshops. Subsequently, they filled out a questionnaire containing questions about participation, learning, atmosphere in the workshops as well as satisfaction, after which the actual interview took place. The semi-structured interviews focused on how respondents experienced the workshops, and on how this influenced their views on health and a healthy environment. Interviews were recorded by voice recorder, transcribed verbatim and sent back to the interviewed participants for review.

### **5.2.4 Data analysis**

Data were coded in Atlas.ti by two independent coders (KYC, LDB). A code book was developed containing codes for each of the research questions, and adapted after coding of the first three interviews. Codes for health definitions (research questions a and b) were initially based on Huber's model of health containing six dynamic dimensions: bodily functions, mental functions & perception, spiritual/existential dimension, quality of life, social & societal participation and daily functioning (21), and later adapted to contain four additional codes: 'free of diseases and risk exposure', 'health is totality',

'health is subjective', and 'other health-defining elements', all based on the data studied. Codes for perceptions of a healthy environment (research questions a and b) were based on Egan's model of sustainable communities (19), which had also been used during the workshops. Two codes, 'healthy living environment is totality' and 'other elements of a healthy-living environment' were added. Codes for perceived factors that contributed to or hindered consensus-development (research question c) were based on a synthesis of three, partly overlapping, models of consensus-building, listing:

- conditions under which striving for consensus in group decision-making is appropriate or inappropriate (22);
- key differences among stakeholders that cause conflict and thereby hinder the achievement of consensus (23);
- participant-related, process-related and result-related factors that may promote or obstruct consensus in decision-making (24).

This synthesis was carried out by combining all factors into one set of codes and removing overlapping factors. The resulting set of codes was amended by codes based on aspects that are specifically relevant in impact assessment stakeholder engagement processes (25, 26). Codes and their sources are provided in Appendix 1. After coding, output reports were compared; differences were studied and adapted (KYC, LdB and AW). Final output reports were produced and read in-depth by two researchers, leading to the extraction of lessons learnt (LDB, KYC). The lessons were discussed with two additional researchers (AW, JS).

### 5.3 RESULTS

The first workshop yielded a set of criteria for a healthy local environment, which the Municipal Health Authority (LG, MS) presented to participants at the start of the second workshop. Then a list of potential health impacts was created by the participants based on the application of these criteria to the plan. These included health impacts related to connectivity, safety of transportation routes for hazardous substances, quality of houses and housing environment and business climate/local economy. Outcomes were described in a report (17). This report also provided recommendations for modifications to the plan as well as recommendations for meaningful engagement of residents and other local stakeholders. The report was later used by the municipality

to negotiate a modification of the plan; in particular, large stretches of noise screens cutting through the town were replaced with tunnel constructions. Decisions about the exact shape, size and location of these constructions were taken, based on a survey

involving all residents, jointly commissioned by the Ministry, the Province and the Municipality.

### 5.3.1 Participants

Because of tight time frames regarding the HIS workshops, only seven participants attended both workshops, seven attended only the first workshop and six only the second one. In total, 20 participants, from regional and national levels, and including experts, policy-makers and residents, attended (Table 1). Of these, four were residents: two of these were active opponents of the plan, and the other two were a local professional and a resident.

### 5.3.2 Stakeholders' perceptions regarding health and a healthy living environment

Most participants added new elements to their health definitions after the workshops. In pre-workshop questionnaires 'environmental interaction', 'free of disease and risk exposure' and 'mental condition' were most often mentioned as elements that define health, followed by 'physical condition', 'sense of wellbeing' and 'health is totality'. In the post-workshop interviews, 'environmental interaction', 'free of disease and risk exposure' and 'mental condition' were elements that were, again, often mentioned. However, the participants more often made reference to 'autonomy' as a central aspect of health.

*'Health means being able to live one's life in a kind of free environment and being able to take one's own decisions about how to stay healthy'*

Although in post-workshop interviews 'environmental interaction' was less frequently mentioned than 'autonomy', participants' expressions demonstrated that this interaction was nevertheless considered very important:

*'...every human being, yeah, every person, yeah, every sensible person so to speak, who knows what health is, and who knows how miserable one can feel, knows that health is not just: I have the flu or I don't have the flu. But (he/she knows) that it is also something you can DO in your environment'*

**Table 1.** Overview of stakeholders participating

#	Role/position	Attended workshops	Final quest. & interview
1	Municipality, policy adviser	1+2	Yes
2	Municipality, policy adviser	1+2	Yes
3	Ministry of Infrastructure and Environment	1	No
4	Municipality, policy adviser	1+2	Yes
5	Region North East Brabant , policy adviser	1	No
6	Fireguard at Noord-Brabant Province and resident	1+2	Yes
7	Resident & staff member institution for visually handicapped people	1+2	Yes
8	Policy adviser, Provincial Health Board	1	No
9	Resident representative	1	Yes
10	Resident representative	1+2	Yes
11	Municipality/External adviser	1	Yes
12	Municipality, policy adviser*	1+2	No
13	Noord Brabant Province/ policy adviser Health	1	Yes
14	Noord Brabant Province/ policy adviser Health	1	Yes
15	Policy maker, Municipality*	2	No
16	Adviser healthy urban planning, National Bureau for Infrastructure	2	Yes**
17	Noord Brabant Province/ policy adviser Health	2	Yes
18	Adviser environmental noise at National Bureau for Infrastructure	2	Yes**
19	Manager at National Bureau for Infrastructure	2	Yes**
20	Adviser at National Bureau for Infrastructure	2	No

\* 2 persons did not fill out start-up questionnaires

\*\* joint interview stakeholder 16,18,19

Several participants indicated that the workshops had widened their definition of health. They expressed a sense of continuity, adding new aspects to their pre-existing view. Some referred to the broader perception of health as a new discovery for themselves.

*'It happened rather clearly for me. Yeah, really surprising. I think: Oh, so this is health, too!'*

*'...I had an idea about health, in my world, but I could not look past the blinkers. And during the workshops my world became larger. I could see further, see more, so that I changed my views somewhat... And I became... how would you put it... somehow wiser...'*

Health definitions shifted towards a sense of openness and flexibility, including participants' personal experiences, for example 'staying away from doctors', or 'having a harmonious family life'. The slightly 'medical' concept 'mental condition', frequently mentioned before the workshops, seems to have become a less important element, while the related, but more 'subjective', 'sense of wellbeing' became a slightly more central element in participants' health definitions.

*'I think it is very important that people feel well in their environment, whatever that environment may be. People should feel well... and then: one can still feel well despite being ill. That was one of the eye openers, the definition of health'*

Moreover, the notion of health as a subjective state, which had not been mentioned before, came up strongly after the workshops.

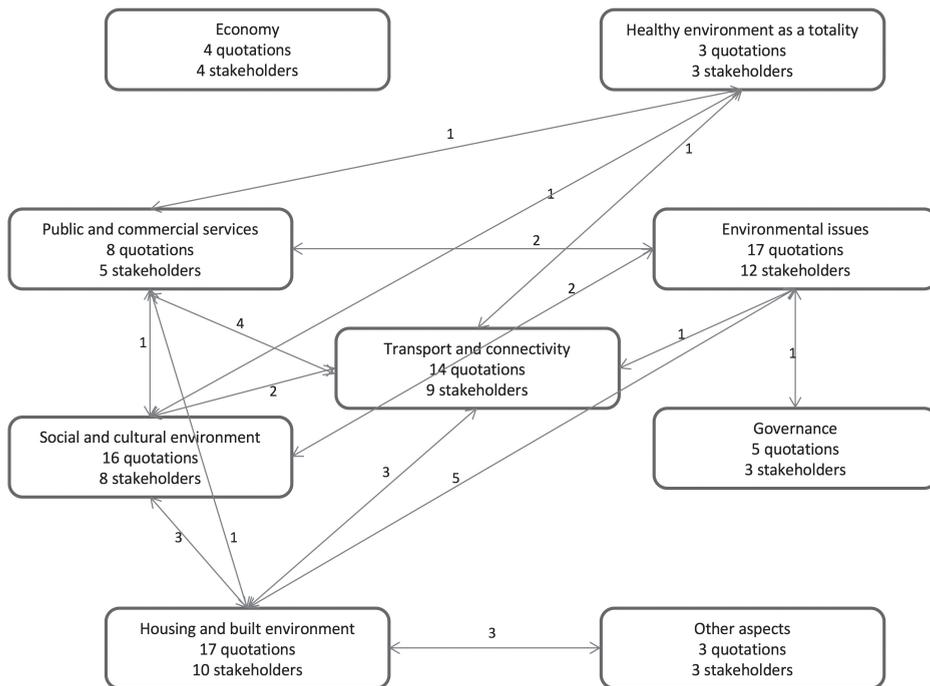
*'... Health is, to some extent, very subjective. One person rushes to the doctor to get sleeping pills, just in case a cargo train might pass by, and, yeah, another person is not bothered too much'*

When talking about their definition of a healthy living environment, participants not only mentioned a broad range of dimensions (Table 2), but they frequently linked different aspects to one another (Figure 2). Moreover, participants explicitly stated that a holistic approach is needed when reflecting on what constitutes a healthy living environment:

*'... Everything is connected... Look, when we talk about a good environment... before you know it we are talking about another topic... I am talking about decibels, but I also want people to cross that road safely. And there, you are already in a different... then you are talking about transport and accessibility, but also social issues. Because you don't want people to remain at home and wait for home care to call or not call. So before you know it... and here you can already see it, you go full circle'*

**Table 2.** Dimensions of healthy living environment

Dimensions of healthy living environment	# mentioned	# participants	Example quotes
Environmental dimensions	17	12	For me a healthy environment means an environment where I can move freely, where water, soil and air are of sufficient quality, that one can grow one's own vegetables without falling ill
Housing and the built environment dimensions	17	10	The spatial quality of your environment, either having to gaze at a concrete wall or a beautiful tree, a park
Social and cultural dimensions	16	8	The quality of the people around, at work, at home, in the sports club, that is really important
Transport and connectivity dimensions	14	9	Something very important here... I am in a working group for accessibility that ensures that, whenever there is poor pavement or obstacles for people in wheelchairs or for blind people with a walking stick, that services are called, and something is done about it.
Public and commercial service dimensions	8	5	Yeah, if we have to go to den Bosch (another city, the authors) for shopping, and also for recreation, theatre, film, why on earth are we here?
Governance dimensions	5	3	What I find important... In our town we found that there should be openness of governance, not just at the municipality but also at other governing bodies that play a role
Economy dimensions	4	4	Yeah ... economy is important, I can live in a beautiful place, but if I lose my job, or if I get broke, or something happens around me... I don't have to travel far for work, you know, that also has an impact on your health, that is obvious
Healthy living environment as a totality of all dimensions	3	3	Maybe it sounds too easy, but they are all connected, everything is important
Other dimensions	3	3	Trains should go, cars should drive, a lot of things should go on, work needs to get done. But with as little nuisance as possible, so to speak



**Figure 2.** Dimensions of a healthy local environment as mentioned in interviews

### 5.3.3 Healthy living environment: consensus?

According to the final questionnaires that respondents filled out at the occasion of the interviews, and in contrast with the outcomes of these interviews, participants did not feel that the HIS workshops had deeply changed their perception of health and a healthy environment (Table 3). At the same time they did indicate that a shared vision had been accomplished after the workshops.

In the interviews, participants confirmed that they had experienced a common understanding of what constitutes a healthy environment, despite differences regarding minor aspects.

*'In the final report, there is this fantastic image, in three words... **Before** the workshops, **during** the workshops, **after** the workshops. Before the workshops all arrows pointed in every direction, during the workshops there were question marks, exclamation marks, etcetera. And after the workshops: all arrows in the same direction. I found that striking, it totally reflected the feeling that I had about the workshops'*

**Table 3.** HIS workshops impact according to stakeholders (by questionnaire)

Scores on 5-point scale	Vision on health changed after attending WS1 n=9	Vision on healthy living environment changed after attending WS1 (n=9)	Shared vision on healthy environment after attending WS1 (n=9)	Vision on health changed after attending WS2 (n=10)	Vision on healthy living environment changed after attending WS2 (n=10)	Shared vision on healthy living environment after attending WS2 (n=10)
	4	3	4	3	3	3
	5	5	4	5	5	3
	4	3	4	4	3	4
	4	4	4	4	4	4
	1	1	5	1	1	5
	4	4	4	4	4	4
	4	4	3	3	4	2
	4	4	4	4	4	3
	3	2	4	3	3	4
				3	3	4
<b>Average</b>	<b>3,5</b>	<b>3,5</b>	<b>4</b>	<b>3,5</b>	<b>3,5</b>	<b>4</b>

Answer categories: 1 totally disagree - 2 disagree - 3 neutral - 4 agree - 5 totally agree

However, participants expressed different interpretations of how this ‘shared vision’ had come about. Some participants indicated that it developed during the workshops. Others reported that there had been, right from the beginning, a common starting point, where workshop participants agreed on the issues at stake in this town – even though their opinions on how to approach these issues might differ. And some participants stated that there was a greater sense of agreement during the first workshop, as compared to the second one.

The high degree of consensus that participants reported, however, was not confirmed when they were asked specifically what dimensions of a healthy living environment they thought the participants agreed or disagreed about with each other. Besides the dimension ‘transport and connectivity’ (eight perceived this as agreed, three as disputed), no other elements were perceived as agreed upon by more than half of the interviewed participants. Moreover, for the dimensions that the participants considered as agreed upon, there was disagreement on what exactly was at stake and how important that was.

*'This was about (...), for example, people who are less mobile and who cross the railway crossing, people with a visual impairment, and sometimes with psychiatric problems. Anyway, the need to cross, and that this may cause dangerous situations. That is sort of, erm, I find that less important in the context of the project as a whole'*

*'Consensus with the residents, about the issue of safety for vulnerable groups, that was mentioned, but NOT for everyone at the table'*

### **5.3.4 Consensus: contributing factors**

What helped create a perceived common understanding, and what hindered the participants? The most important factor, as perceived by them, that contributed to the development of consensus was the decision-making mechanism, in particular the way the HIS workshops were organised. This was mentioned by all participants interviewed. They praised the preparation of the stakeholder workshops, the lucid introduction of the proceedings during the gatherings, the clear explanation of the applied theories and methods used, the good atmosphere, and the good process-monitoring by the facilitators during the workshops.

*'I thought it was just great, the introduction, the drive (of the facilitators), how they tried to get people together. And everyone sees: Hey, we have to change our view. That was the best part of it!'*

Using health and a healthy living environment as the main topic of the workshops, instead of focusing directly on the infrastructure development and related political processes, was mentioned as a stimulus for shared vision development. Some participants considered health as 'relevant for everyone', 'connected to other topics' and 'not threatening'.

*'You can see that health is a topic that connects people. That was very clear for the people in the workshops. Health is not threatening, that helped build a bridge'*

The proposed infrastructure plans were named as a 'common enemy' or 'urgent problem' that was 'on everyone's agenda', and this was, in the perception of several participants, a common interest that promoted cooperation between all stakeholders.

The mix of participants with different backgrounds and roles was also frequently mentioned. It provided the opportunity for various stakeholders to listen to one another and become more familiar with each other's point of view. This open approach, instead

of a focus on controlling and directing process and outcomes, was considered a positive contribution to consensus-building.

*'Everyone has their own little island, and finally all these islands came together, so that went very well'*

*'When you see that there is a new arena, a new role (...) to enter into a dialogue with residents and the municipality... It sticks in my mind. A good step that should be acknowledged'*

Some interviewees, however, voiced concern about the absence of 'key' stakeholders: on the one hand representatives of, for example, the Ministry of Infrastructure and Environment, and on the other hand residents with more varied backgrounds and interests and representatives from various interest groups. Another difficulty encountered was the difference in participants taking part during the first and the second workshops.

*'I think that, well that is my opinion, that one should basically have the same people around the table all the time, at the second workshop too. Because then you can build on, with people from the first part'*

Interviewees mentioned the sharing of information as a factor that enabled good communication. As mentioned earlier, interviewees indicated that their horizon had been widened. They also valued the transparency displayed by the municipality that shared information and strategies with other stakeholders, including residents.

*'The contact between the municipality and the residents is fabulous, and that is because the municipality is very transparent. They don't just share facts, but also share the strategies with residents, discuss with residents: which strategies do you have, which ones do we have, yeah...'*

However, some participants complained about information overload, in particular about 'abstract theories' about health and healthy environments.

*'Yes, for sure, the explanation was very clear. But it was still highly theoretical, everything we were told... And eh, model Lalonde and this and that, and everything at once...'*

A very important enabling factor was trust. The Municipal Health Authority was mentioned as a trusted and impartial actor to organise and facilitate the workshop.

Respect for different points of view during the workshops was another aspect identified as a factor leading to trust and development of a shared vision. The Chatham House Rule and Everybody is Expert rule were considered to have set the stage for a positive atmosphere and outcome of the workshops.

*'We listened well to one another; we paid attention to each other during the discussion, like... I think there was respect for one another, and for each other's opinion... There were different folks... It was a very mixed group of people'*

A few enabling factors came up that were not related to the workshops, but rather to the existing local situation, such as past cooperative experience, formal and informal contact and communication among stakeholders, and the subjective experience and general satisfaction of the residents living in the area. News items in the media concerning health and living environment were mentioned by stakeholders as a factor that strengthened the urge of community members to become engaged.

### **5.3.5 Barriers to consensus-building**

The most important hindering factor as experienced by participants was the incompatibility of mental models. Some participants claimed that those who attended the workshops had 'different backgrounds', 'different roles' and 'different cultures', and that a few participants displayed 'technical' and 'conservative' approaches, showing little understanding for other stakeholders' views. Other participants stated that people working in the field of 'hard infrastructure' generally do not take those with a 'health and community' background very seriously.

*'... Health people... policy advisers for health, but also staff members of the Municipal Health Authority or the Provincial Health Board, or, in short, all people working on health... I notice sometimes that you are seen as an activist. You advocate health, just like people from Greenpeace advocate the environment... and they think this is just one small aspect. "OK, fine, I've heard you as an activist, and now we'll proceed with business, the project. I've heard you, I've checked a box, I've talked to you, thank you and goodbye". Well, it happens, it is a feeling that I get when I talk to my colleague about this case'*

*'Different goals' of project management staff and residents were also mentioned as possible hindering factors. Differences between national economic interests and local living environment interests were perceived as a source of conflict. And hidden interests, related to those goals, were mentioned as barriers.*

*'Yes, I think that different stakeholders, the stakeholders were at that table whilst secretly keeping their own interests in mind. That is a disturbing factor when you are trying to get to a joint vision'*

One participant explicitly claimed that more attention should have been paid to the investigation of the values behind the views and interests of participants. Others mentioned distrust of national government and infrastructure project management as a major hindering factor for consensus-building. Multiple examples were given by various participants on this aspect. 'Sneaky', 'lack of information and transparency' and 'general distrust of government' were all named as reasons for distrust.

*'No, they keep information back. So I even think that the Ministry and the infrastructure organisations keep information away from the municipality, because they fear the municipality, with its transparent approach towards citizens... And then they say... yes, well, it will be all over the place...'*

Moreover, lack of knowledge about possible alternatives to the proposed infrastructure plans by national government and project management was mentioned as a hindering factor. National government and national project management were also said to withhold information from other stakeholders. The lack of effective communication from the government was also named as a hindering factor. In particular there had been insufficient clarity about the policy-making process and insufficient feedback to the citizens about policy consultation. Participants said that news items in the media concerning health and living environment had been causing concern. However, participants explained that all this had taken place prior to, and outside the scope of, the HIS workshops.

Finally, the timing of the workshops in the infrastructure development process was identified as a possible drawback as regards the development of consensus. Some people found it was quite late in the policy decision process and doubted whether the workshops would be helpful in influencing further decision-making.

*'Personally, I think that one should start this kind of process much earlier, with this Health Impact Assessment, with residents of course'*

## 5.4 CONCLUSIONS, LESSONS LEARNT AND FURTHER RESEARCH

### 5.4.1 Conclusions

In our study, we firstly focused on whether stakeholders' perceptions of health and a healthy environment changed after the workshops. Questionnaire data suggest that participants did not change their pre-existing views much: many respondents ticked the category 'neutral'. In contrast, in the interviews participants stated that changes did take place in the way they view health and the relationship between health and the (physical and social) environment. Therefore it seems that, rather than dramatic changes in perceptions, these perceptions were broadened to include a wider range of environmental elements as relevant health determinants. The participants appear to have developed a more holistic picture of health. Moreover, this picture seems less 'formalistic': the participants claimed that after the workshops they had developed the notion that health includes subjective experiences.

As interviews provide more space to elaborate on issues than questionnaires, the broadening of views on health and a healthy environment we identified may have been the effect of these different research methods before and after the workshops. Moreover, there was a time gap between workshops and interviews. However, as the respondents explicitly and rather unanimously claimed that the workshops changed the way they viewed health and health-relevant environmental factors, it does seem plausible that their participation in the workshops at least partly had this impact.

Our second research question concerned the level of perceived and actual agreement about views on health and healthy environments. The stakeholders in the workshops perceived a high level of agreement concerning their views on health and healthy environments. However, looking more closely at specific dimensions of a healthy environment we found a discrepancy between this perceived degree of consensus and the degree to which the actual *content* of their views match. There were meaningful differences between participants on what environmental aspects were important for the community's health, and what issues should be addressed in an adapted plan. Instead of creating absolute consensus, therefore, the workshops might have created 'a sense of consensus' among stakeholders.

Thirdly, we looked at factors that promoted or hindered consensus-building in the perception of the participants. Promoting factors included 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. 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 agreement between all stakeholders.

### 5.4.2 Lessons learnt

The case provides several lessons. First of all, the participants felt that the workshops provided an opportunity to actively participate in the policy-forming process. However, the workshops were organised after the actual EIA had been carried out and time constraints caused discontinuity in the composition of the stakeholder group involved. For the same reason the residents were a minority in the workshops. The level of participation, in any case for the residents, may be considered relatively low, and could be labelled 'consultation' (27) or perhaps 'advising' (28). Despite this, the process seems to have had an impact on policies; instead of a narrow focus on noise reduction in the mitigation plan, community concerns and needs, for example, connectivity and safety were also discussed, leading to alternative, more expensive, mitigation measures. This case should therefore be viewed as a first step towards more meaningful participation in a national setting where this is currently absent.

The second lesson is that health is a topic that has the potential to connect different stakeholders; everyone can understand and relate to the value of health both for individual residents and for society at large. The focus on health and a healthy living environment brought up issues that had been neglected in the EIA procedure, in particular those issues that are not catered for in the regulatory framework for EIA, such as wellbeing and neighbourhood connectedness. The focus on health also provided the local stakeholders, including residents, with a legitimate reason to strengthen their engagement in the policy process. Reinforcing local stakeholder engagement links up with the concept of a participation society: if citizens and other stakeholders are to take greater responsibility for the well-being of everybody, they should also be allowed to play a more active role in decision-making.

The third lesson concerns the role of learning in stakeholder engagement. Stakeholders stated that they gained new insights and broadened their views. But, more importantly, this learning process was an opportunity to deal with differences in stakeholder roles, frames of mind and personal preferences. The workshops seem to have served as a (collective) learning mechanism, containing three important elements described in the theory of experiential learning (29). First of all, a process approach was applied, in which knowledge was not only transmitted (lectured) but also developed (creating a joint

vision) and applied (case application in the project). Secondly, the learning took place in, and was explicitly linked to, a social context with different stakeholders, where all participants were encouraged to share their expert or lay knowledge with one another. Moreover, the learning was linked to a wider social environment, i.e. the policy arena where decisions about infrastructure development were made. Or, in Kolb's words, a transaction took place between objective conditions and subjective experience (29). Thirdly, the transmission of knowledge apparently also changed the participants' perceptions of reality, opening up new ways to look at and reflect on health issues in relation to the environment. Such social and organisational learning processes are not only vital for individual cases such as the one we studied, but in a broader context they are also meaningful for the further development of EIA 'culture' (4).

The fourth lesson relates to the gap between perceived and actual consensus. The joint learning experience described above seems to have been important as a means of creating a 'level playing field' and space for all stakeholders to express their views. Lay and local knowledge and personal experiences were acknowledged, and combined with 'expert' knowledge. The shift towards 'subjective' experience in the way participants defined health shows the impact of this process. This exchange, combined with the mutual trust and respect experienced by stakeholders, apparently resulted in the creation of a 'sense of consensus'. This may by itself reduce conflict; empathy, understanding and empowerment are important elements of stakeholder involvement in environmental problem-solving (26). However, a 'false' impression of joint visions can also pose a risk of stakeholder disappointment, as the resulting expectations might not be met in further planning and implementation. It would be a mistake to presume that deliberative processes are essentially beneficial to everybody; power imbalances and unequal access to information cannot always be solved in the stakeholder engagement process (8); this must be taken into account and addressed before genuine and inclusive deliberation can take place (11). Cuppen et al. (30) argue that acknowledging and accepting different frames of thinking and mind-sets is an essential requirement for fruitful public participation, and for local communities to voice their concerns and be heard. The participants in the HIS workshops did clearly recognise different roles or positions, differences in information access and related mental models. 'Frame reflexivity', explicitly identifying these differences, would have made sense from the participants' point of view. The two ground rules of the HIS workshops that worked so well to create a sense of consensus should therefore be amended by a third ground rule: the agreement to disagree.

### 5.4.3 Further research

As a pilot for further research, this evaluation of the HIS workshops shows that it is worthwhile to apply a PAR approach in studies about stakeholder participation in EIA. PAR empowers stakeholders to communicate and cooperate and it promotes collaboration across sectors (31). The PAR approach directly contributes to practice, enabling action and learning processes by continuous assessment and feedback, and should therefore be an integrated stream in the whole process (32). In this specific case researchers and local practitioners cooperated closely, acknowledging each other's expertise and knowledge, in developing methods and concepts for the workshops, empowering local practitioners to carry out a fruitful project and carrying out the research activities, both during the workshops and later on. The PAR approach thus reflects the value of participation in EIA in general: the researcher practises what (s)he preaches. Further research should focus on deepening our understanding of the role of (joint) experiential learning in the effective engagement of residents and other stakeholders. We also need to learn more about the handling of differences in positions, opinions and interests. Moreover, as this case concerned only the scoping stage, experiments including other IA stages are needed to develop a more comprehensive insight into how to attain better inclusion of stakeholders in EIA and to respond more appropriately to (health) impacts and community concerns.

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# CHAPTER 06



# Resident participation in neighbourhood audit tools - a scoping review



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## ABSTRACT

**Background:** Healthy urban environments require careful planning and a testing of environmental quality that goes beyond statutory requirements. Moreover, it requires the inclusion of resident views, perceptions and experiences that help deepen the understanding of local (public health) problems. To facilitate this, neighbourhoods should be mapped in a way that is relevant to them. One way to do this is participative neighbourhood auditing.

**Aims:** This paper provides an insight into availability and characteristics of participatory neighbourhood audit instruments.

**Methods:** A scoping review in scientific and grey literature, consisting of the following steps: literature search, identification and selection of relevant audit instruments, data extraction and data charting (including a work meeting to discuss outputs), reporting.

**Results:** In total, 13 participatory instruments were identified. The role of residents in most instruments was as 'data collectors'; only few instruments included residents in other audit activities like problem definition or analysis of data. The instruments identified focus mainly on physical, not social, neighbourhood characteristics. Paper forms containing closed-ended questions or scales were the most often applied registration method.

**Conclusions:** The results show that neighbourhood auditing could be improved by including social aspects in the audit tools. They also show that the role of residents in neighbourhood auditing is limited; however, little is known about how their engagement takes place in practice. Developers of new instruments need to balance not only social and physical aspects, but also resident engagement and scientific robustness. Technologies like mobile applications pose new opportunities for participative approaches in neighbourhood auditing.

## 6.1 INTRODUCTION

Since more and more people live, work and play in urban areas, the pressure on these areas is going to increase. This has implications for the health of the residents of cities, because their physical and social living environment contains many health relevant factors. A well-facilitated, clean, and safe physical urban environment is a necessary, but not the only requirement for a healthy city. The urban environment also has the potential to enhance or hinder healthy lifestyles and behaviours, for example physical exercise, and in this way impact on people's health (1-3).

More and more (local, national, and international) authorities and various parties work towards a healthy urban environment. These include health promoters, environmental health experts, district community workers and municipal health coordinators. It has become clear that healthy urban environments require careful planning and a testing of environmental quality that goes beyond the requirements of statutory limits. It is also becoming apparent that healthy urban planning requires the inclusion of resident views, perceptions and experiences that help deepen the understanding of local (public health) problems (4). In short, resident participation is a key factor in the development and application of successful policies in the field of urban environments.

In order to develop and implement plans for a healthy urban environment that link up with the residents' perceptions, it is important that the local situation of neighbourhoods and their populations be mapped in a way that is relevant to them. There are several ways to map neighbourhood characteristics. One option is to collect resident or other stakeholder views by surveys. Another possibility is to derive information about the characteristics of a neighbourhood (such as noise levels, air pollution concentrations, amount of green space, number of people within a certain area) from existing registries of data at neighbourhood level and/or postal code area level that is nationally or locally available. This is usually done by means of a Geographic Information System (GIS). In this paper, we focus on a third method, namely neighbourhood auditing which means obtaining insight into the characteristics of neighbourhoods by systematically visiting and observing them.

The purpose of most audits is to collect information about the neighbourhoods that cannot be derived from secondary data or registries (e.g. the number of trees, the width of sidewalks), in order to get a more complete picture: certain neighbourhood characteristics can only be measured properly by means of direct observations (e.g. the architectural character, maintenance of the landscape, the 'look and feel' of a place (5, 6). It is questionable, however, whether these types of observations reflect what

people find important in their neighbourhood when it comes to health and whether they are able to capture related contextual factors that modify, increase or reduce neighbourhood environmental impacts (7). For example, the mere presence of a cycle path (expert observation) does not necessarily mean people want to use it (resident perspective) (8). Insight in resident experiences and relevant contextual factors requires a 'Citizen Science' approach in neighbourhood auditing, that is the active participation of lay people in audit design, data collection and/or analysis. Haklay describes different levels of citizen engagement in research (9). Not only can citizens help collect larger quantities of data or new information, citizen involvement in knowledge generation is also reported to produce knowledge that is more relevant to them (10). Citizen Science also has the potential to educate and empower residents as active people in their living environment (11). To realize this resident engagement in neighbourhood auditing, tools are needed that facilitate their input and involvement.

Several audit tools have been developed in recent years. Nickelson and colleagues (12) presented 31 neighbourhood audit instruments in a comprehensive overview. They carefully registered the domains and sub domains that were assessed for each instrument. Although their review might help researchers to select or develop an instrument to meet their own specific needs, it does not provide any information about whether, and how, residents (can) participate in the application of the different tools. With a view to continuing to build further on Nickelson's work, we therefore carried out a scoping review (13) to establish which participative systematic neighbourhood auditing tools exist and how these tools can be characterized. The scoping review method is a suitable approach to study key concepts in different types of publications (14, 15). As we intended to identify participatory tools, described in both existing scientific and grey literature about resident participation for neighbourhood auditing instruments, a scoping review is an appropriate method. Scoping reviews are less useful when the aim is to assess the quality of evidence presented. This study, being descriptive, did not require such assessment.

We are going to use the outcomes of our study as an input for the development of a participatory neighbourhood audit tool to be applied in the Netherlands (16). New Dutch legislation on urban planning is currently being implemented, in which resident participation is a key element. In order to achieve this, local planners and policy makers need certain tools. Our 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 (e.g. paper form containing close-ended questions, photos, or a website).

## 6.2 METHODS

### 6.2.1 Identification of relevant publications

Systematic literature search was carried out to identify publications which:

- had been published in a (peer reviewed) scientific journal or as grey literature. In this last category we will find reports, websites, conference proceedings etc., AND
- describe one or more neighbourhood audit tools, AND
- had been published between the first of January 2010 and the first of January 2015, AND
- had been published in English or Dutch language.

Since we intend to develop a Dutch audit instrument, we used search terms in both English and Dutch. By studying several well-known audit instruments (17-19) we developed a set of search terms (Appendix, Table 1a and 1b).

One researcher (JD) searched for scientific studies and published articles in the scientific database Scopus, which provides the largest abstract and citation index for peer-reviewed literature. Scopus was selected because this database includes MedLine and EMBASE and includes not only biomedical disciplines but also, for example, journals in Health Sciences, Life Sciences, Social Sciences or Humanities. These are important areas in relation to the topic of our review.

Another researcher (AH) simultaneously carried out a systematic search of grey literature in the Google open database. Given that grey literature search often provides many hundreds of hits, we decided to view only the first 20 hits because we assumed that they best matched the search terminology. This assumption was tested by taking samples of hits after the first 20 and we found no relevant titles. Overall, 99 publications were identified.

### 6.2.2 Selection of relevant instruments

We checked whether the publications described a neighbourhood audit instrument (in some cases the tool described was a different type, e.g. a playground scan and these were excluded) and this yielded 68 instruments.

Next, we checked whether residents were involved in the development of the audit instrument and/or whether residents were involved in the implementation of the audit instrument. If at least one of these criteria was met, the audit tool was classified into

the 'resident participation' category. If none of the criteria was met, the publication was classified in the 'no resident participation' category.

We applied the rules that interviewing or surveying residents about their neighbourhood was not considered to be participation, while consulting residents about the content of an audit instrument was. When it was not possible to classify a paper, it was classified in the 'unknown' category.

The first researcher (AH) selected all the publications that fulfilled the resident participation criteria and a second researcher (LdB) independently carried out the same procedure for verification. Selections were compared and differences discussed. In the event of disagreement, a third researcher (EvK) was asked to advice. As a result, a list of 13 participative instruments was created (see under results: Table 2).

### 6.2.3 Data extraction

For the 13 participative audit tools described in the selected papers, data extraction was carried out by one researcher (AH). Only characteristics of the *audit tool* described were extracted from the papers. The following data was extracted about each selected instrument: Author (if available), instrument name, and country of origin.

To answer our research questions we also extracted data on the registration method and type of Citizen Science approach. Table 1 shows how we determined these aspects. We also extracted the topics, or *domains* covered by each instrument, as well as more specific matching characteristics, or *sub domains* within those domains. An example is the 'amenities for outdoor public spaces' domain with, among other things, characteristics like public restrooms, street furniture and trash bins as matching sub domains.

We used Nickelson's (12) domain and sub domain classification and added two new domains, namely *people and behaviours* (referring to observation and registration of presence of persons in the public space audited and their activities at the moment of observation) and *local business and economy* (referring to the presence of commercial and public facilities). These domains were added on the basis of our previous research in the Netherlands, where residents helped define necessary elements of a healthy neighbourhood. The (health) behaviour of people in public space, and the availability and accessibility of commercial and public services were considered highly important by these residents (20). Sub domains for these two additional domains were developed, based on the information presented by the selected instruments. A meeting was set up (AH, LdB, EvK) to discuss data extraction output tables and perform necessary corrections.

**Table 1.** Data extraction: classifying registration methods and Citizen Science approach

Classification	Classify when	Do not classify when
<b>Registration methods*</b>		
Digital checklist	Digital checklist is main registration method during data collection (e.g. tablet)	Digital checklist only used for data processing after actual audit
Paper checklist	Paper checklist is main registration method during data collection	Paper checklist only used as guidance, but actual data registration carried out in another way
Digital application/tool	Any other digital applications, e.g. camera or audio used as main registration method	These applications only used as accessories during registration
Web site	Web site is used as main registration method, e.g. in case of auditing using street view images	Web site only used for data processing or data presentation
Unknown	Information about method of registration could not be found	Any other method of registration is applied
<b>Citizen Science approaches**</b>		
Extreme Citizen Science	Residents involved in problem definition, data collection, analysis and interpretation.	Residents involved in parts of these but not all Professionals, but not residents, are involved as resident representatives
Participatory science	Residents involved in problem definition and data collection	Residents only involved in one of these Professionals, but not residents, are involved as resident representatives
Distributed intelligence	Residents involved as volunteered thinkers and interpreters, providing lay input to the audit	Resident contributions not used for shaping or applying the audit process, not for analysis purposes
Crowd sourcing	Residents involved as informers carrying out data collection.	Residents play a passive role, i.e. no active data collection but e.g. being interviewed

\*source: Nickelson, Wang (12)

\*\*source: Haklay (9)

## 6.3 RESULTS

### 6.3.1 Instrument selection

Our literature search yielded a total of 68 audit instruments (excluding 18 cases where there was no description of the instrument or where the original publication could not be retrieved) (Figure 1). The majority of these instruments (54) were found in the scientific literature (2 duplicates removed). The remaining 14 instruments (1 duplicate removed) were found in grey literature. The 68 selected audit instruments were investigated to determine the presence of resident participation in the audit instrument development or implementation. Instruments were divided among the 'resident participation', 'no resident participation' and 'unknown' categories when it was impossible to answer the questions about resident involvement in the instrument development or implementation. After exclusion of those instruments that were classified as 'no resident participation' and 'unknown', 13 audit instruments which involved residents in the instrument development or implementation remained. Most of these instruments (9) originated from the US, while 2 instruments originated from the Netherlands, one from Canada and one from the UK. A list of all non-participative instruments (47) and instruments classified in the 'unknown' category (8) with references is available in the Appendix, Tables 2 and 3.

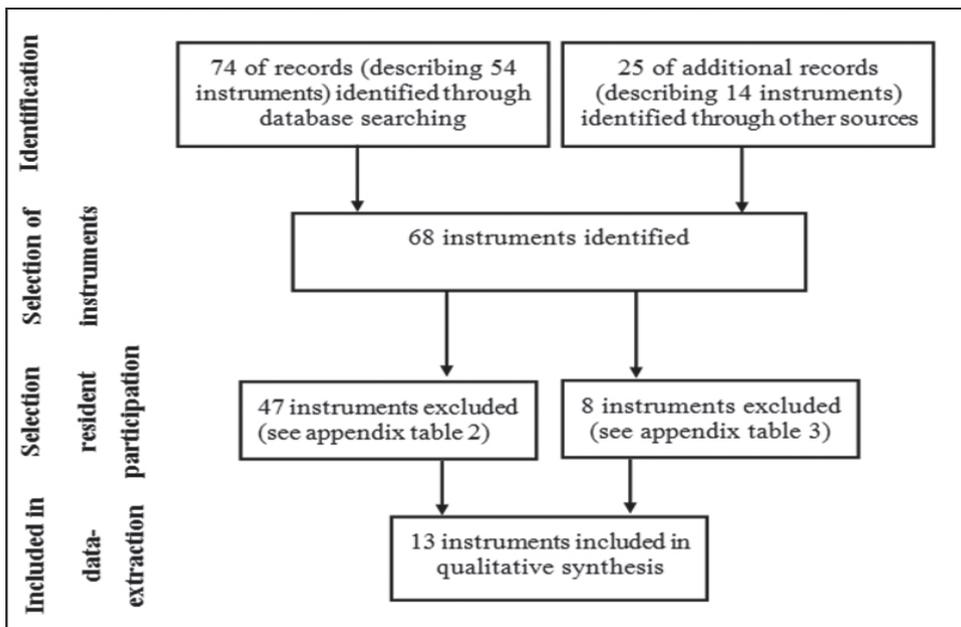


Figure 1. Flow chart data extraction

### 6.3.2 Instrument characteristics

Characteristics of the 13 selected participative audit instruments are shown in Table 2. A remarkable fact is that the BEAT Neighbourhood Assessment tool (Ecoplan 2009) and the Sidewalks and Street Survey (N/A, 2010) apparently were the only two instruments with resident involvement at the 'extreme Citizen Science' level. Residents were involved in these instruments during the whole process of problem definition, data collection, data analysis and data interpretation. The BEAT instrument provides a paper checklist with three-point scales for residents or community groups to audit the quality of an area with a special focus on sustainable and active transportation. Each question and the answer categories are explained in understandable, non-'scientific' language. This checklist also provides open questions that guide resident based analysis as well as follow-up (e.g. the definition of alternatives or actions to take). The Sidewalks and Streets Survey provides a tool kit for organizers (either a professional or a community group) of a walkability audit including a workshop plan, supporting presentations, example invitation letters etc., and a checklist which can be adapted to the needs of a community. Residents that participate also help analyse the audit results. Four instruments involved residents at the 'participatory science' level in problem definition and data collection. The instrument described by Anderson et al., (2014) was the only instrument involving residents at the 'distributed intelligence' level and invited residents to act as basic interpreters and thinkers in their New Hampshire Liveable Walkable Communities Toolkit with residents joining in the designing of 'community goals' as a starting point for the audit. Most instruments (6) involve residents at the Citizen Science 'crowd sourcing' level where they are involved as informers or data collectors. In the Neighborhood Observational Checklist (30) for example, residents collect data in a prescribed way, supervised by researchers.

### 6.3.3 Registration methods

Table 2 shows that most audits (11) were conducted with use of a paper checklist which auditors could fill in with a pen or pencil. The tool of Buman et al., (2013) consisted of tablet-based data collection of audio narratives and photographs whereas the tool of Zenk et al., (2007) consisted of a digital checklist used with handheld computers. The register method of Kleiboer et al., (2012) used a different method. Participating residents used a map of their neighbourhood and placed green stickers at spots that they thought were positive spots and red stickers at spots that they thought were negative spots.

**Table 2.** Characteristics of included instruments

Author (if available)	#	Instrument name (if available)	Country of origin*	Level of Citizen Science**	Registration method†	Domains covered††
Agentschap NL (21)	1	Wijkscan zwerfafval [Community litter scan]	1	2	2	1, 2, 6, 7, 8, 10, 12, 13, 15, 18, 21
Anderson (22)	2	New Hampshire Liveable Walkable Communities Toolkit	2	3	2	1, 2, 4, 6, 7, 8, 10, 11, 13, 14, 15, 16, 19, 20, 21, 22
Brownson, Hoehner (23)	3	St. Louis Audit Tool – Checklist Version	2	4	2	1, 2, 3, 4, 6, 7, 10, 11, 12, 13, 14, 15, 16, 17, 19, 21, 22
Buman, Winter (24)	4	The Stanford Healthy Neighborhood Discovery Tool	2	4	3	<i>Unknown</i>
EcoPlan (25)	5	BEAT Neighborhood Assessment (Built Environment & Active Transportation)	3	2	2	1, 2, 4, 6, 7, 8, 10, 11, 12, 13, 14, 15, 16, 19, 20, 21, 22
Kleiboer and Broens (26)	6	Beleef je wijk! [Experience your neighborhood!]	1	2	5	‡
O'Hanlon and Scott (27)	7	The Walkability Assessment Tool	2	4	2	1, 4, 6, 7, 8, 10, 11, 12, 13, 14, 15, 16, 19, 21
Robinson, Carson (28)	8	Rural Active Living Assessment tool	2	4	2	1, 3, 4, 6, 7, 8, 11, 13, 14, 15, 16, 19, 21
Welch, Benfield (29)	9	LEED - ND	2	2	2	1, 4, 6, 7, 10, 13, 14, 15, 17, 18, 19, 21
Zenk, Schulz (30)	10	Neighborhood Observational Checklist	2	4	2	1, 2, 5, 6, 7, 8, 10, 12, 13, 14, 15, 16, 17, 19, 21, 22
Zoellner, Hill (31)	11	CBPR intervention	2	4	2	1, 2, 3, 4, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21
AARP (32)	12	Sidewalks and Street Survey	2	1	2	1, 2, 7, 10, 11, 12, 13, 14, 15, 19, 20, 22
Preston City Council (33)	13	The Community Mapping Toolkit	4	1	2	‡

\*1= The Netherlands, 2= US, 3= Canada, 4= UK

\*\*1=Extreme Citizen Science, 2=Participatory science, 3=Distributed intelligence, 4= Crowd sourcing , 5= Unknown

†1=Digital checklist, 2=Paper checklist, 3=Digital application/tool, 4=Website, 5=Other/ unknown

†† 1= Amenities for outdoor public spaces, 2= Architecture/ building characteristics, 3= Barriers, 4= Cycling environment, 5= Ethnic identification, 6=Land uses, 7= Landscaping/ nature features, 8= Maintenance/ appearance, 9= Neighborhood identification/ legibility, 10= Parking and driveways, 11= Pedestrian environment, 12= Physical disorder, 13= Recreational uses/ public spaces, 14= Safety, 15= Sidewalks, 16= Signs, 17= Smell/ pollution/ noise, 18= Steepness, 19= Streets/ traffic, 20= Views/ enclosure, 21= Local business and economy, 22= People and behaviors

‡ To be determined by participating residents

### 6.3.4 Measurement indicators

An overview of all the identified domains and the numbers of sub domains measured by all the instruments included, is shown in Table 3. The number of domains assessed with the audit tools ranged from 12 to 20.

The most commonly assessed domains were *amenities for outdoor public space* (10 instruments), *landscaping/ nature features* (10 instruments), *recreational uses/ public spaces* (10 instruments), and *sidewalks* (10 instruments). The least commonly assessed domains were *ethnic identification* (1 instrument), *neighbourhood identification/ legibility* (1 instrument), *barriers* (3 instruments) and *steepness* (3 instruments). The additional domain *local business and economy* was assessed by 9 instruments and the *people and behaviours* domain by 5 instruments.

A top 3 of the most measured sub domains by all included instruments are listed in the Appendix, Table 4. Domains with the highest numbers of measured sub domains are classified at the top of the table. The *amenities for outdoor public space* domain measures comfort features such as street comfort facilities. The *bus stops/transit stops* sub domain was measured by 8 instruments, *playground, sports equipment* by 6 instruments and *street furniture* by 6 instruments as well. The sub domain of *street trees* from the *landscaping/ nature features* domain and the sub domain of *sidewalks* from the *sidewalks* domain were measured by 9 instruments. Only 3 instruments measured the sub domain *grade/steepness/slope* in the *steepness* domain. In 3 cases the domains to be measured depended on the resident input with residents being asked about their assessment of the environment in general terms, without a predetermined list of specific elements or aspects. The Community Asset Mapping Toolkit in particular provides a lot of space for personalized input. It only requires residents to look at the broad categories of 'individual, community and institutional assets' and provide their personal assessments of these (33). Only one instrument measured the sub domain of *neighbourhood monuments/markers/banners* in the domain of *neighbourhood identification/ legibility*. In addition, only one instrument measured the 9 sub domains in the *ethnic identification* domain. These sub domains included measurements comprising businesses with diverse ethnic orientation (African American, Latinos, African, Caribbean, Mexican, Cuban, Spanish etc.), matching signs, symbols, advertisement, symbols and murals. A total overview of all domains and corresponding sub domains is shown in the Appendix, Table 5.

**Table 3.** Identified domains, numbers of sub domains in each domain (more extensive information in Appendix, Table 4)

Domain	# sub domains	Study number of neighborhood audit instruments (see Table 2)													N (%) <sup>a</sup>
		1	2	3	4*	5*	6	7	8	9	10	11	12	13*	
Amenities for outdoor public space	16	1	1	12	-	-	2	2	1	3	9	8	5	-	10 (76.9)
Landscaping/ nature features	17	4	3	10	-	-	3	8	8	5	10	4	4	-	10 (76.9)
Recreational uses/ public spaces	3	13	1	6	8	-	2	11	3	3	9	2	1	-	10 (76.9)
Sidewalks	24	1	4	4	-	-	13	6	2	5	13	9	13	-	10 (76.9)
Land uses	14	3	4	3	-	-	2	7	3	7	1	8	0	-	9 (69.2)
Parking and driveways	12	1	2	3	-	-	1	0	2	1	6	4	2	-	9 (69.2)
Safety	25	0	1	6	-	-	2	2	2	13	3	2	3	-	9 (69.2)
Streets/ traffic	36	0	2	12	-	-	10	11	2	8	16	14	13	-	9 (69.2)
Local business and economy	6	2	2	2	-	-	2	2	4	2	2	2	0	-	9 (69.2)
Architecture/ building characteristics	20	3	1	2	-	-	0	0	0	2	1	2	1	-	7 (53.8)
Cycling environment	11	0	3	4	-	-	3	3	3	0	5	8	0	-	7 (53.8)
Maintenance/ appearance	13	8	2	0	-	-	2	1	0	7	4	1	0	-	7 (53.8)
Pedestrian environment	17	0	3	5	-	-	16	7	0	0	10	12	17	-	7 (53.8)
Physical disorder	23	4	0	12	-	-	2	0	0	12	4	2	7	-	7 (53.8)
Signs	21	0	2	11	-	-	0	1	0	9	1	1	0	-	6 (46.2)
People and behaviors	13	0	2	7	-	-	0	0	0	9	0	2	2	-	5 (69.2)
Smell/ noise/ pollution	3	0	0	3	-	-	0	0	0	1	3	2	0	-	4 (30.8)
Views/ enclosure	4	0	2	0	-	-	0	0	0	0	2	2	2	-	4 (30.8)
Barriers	10	0	0	5	-	-	0	2	0	0	1	0	0	-	3 (23.1)
Steepness	1	1	0	0	-	-	0	0	1	0	1	0	0	-	3 (23.1)
Ethnic identification	9	0	0	0	-	-	0	0	0	9	0	0	0	-	1 (7.69)
Neighborhood identification/ legibility	2	0	0	0	-	-	0	0	0	0	1	0	0	-	1 (7.69)
<b>Number of assessed domains</b>		12	16	17	-	-	13	13	12	17	20	17	12	-	

\* To be determined by participating residents, a Total number (%) of instruments assessing domain. #SD = number of sub domains.

## 6.4 DISCUSSION

### 6.4.1 Main results

In total, we identified 68 audit tools. In 13 cases, residents were involved in auditing. In six of the 13 cases, residents were involved by carrying out data collection. In only 2 cases, citizens were involved in problem definition, data collection, and analysis and interpretation of the data that were collected.

Within the 13 instruments that involved citizens, we identified 22 different domains and more than 150 sub domains. In addition to Nickelson (12), we extended the number of domains with one domain involving *business and economy*, and another domain concerning *people and behaviour*. Within the list of domains and sub domains, the focus is mostly on the physical characteristics of the neighbourhood.

Most of the 13 instruments were paper forms, usually containing close-ended questions or scales. There was only one digital tool available. The Stanford Healthy Neighborhood Discovery Tool is suitable for tablets.

### 6.4.2 The engagement of citizens

Although the developers of several of the evaluated tools claim the instrument involves residents, we judged that only two tools really engaged them at all the different stages. Although we studied the available information and discussed how each instrument should be classified in terms of resident involvement, the exact determination of the type of resident involvement was difficult for a number of instruments, as the information was often unspecific or could be interpreted in different ways. It would therefore be worthwhile to study how resident involvement takes place in practice, for example by an in-depth evaluation of these instruments' local application.

It is possible that we may have missed some other, more participatory, tools for 2 reasons. Firstly, our grey literature search was restricted to the first 20 hits. However, testing the assumption that after 20 hits no relevant publications came up, we found no indication that we missed important tools. Secondly, resident-centered audit instruments may be developed and used at a very local level. We wonder whether these instruments will always be presented on the web, let alone in a scientific journal. Both Dutch tools were found by searching the web and many more, in other languages, may be available that we are not aware of due to the language criterion we applied. We also suspect that some tools might not even be retrievable using multi-language web searches. Although we

cannot be completely certain that we have found all relevant tools, we do think, given the overall outcomes, that our conclusions are probably justified.

### **6.4.3 Physical and social aspects combined**

The strong focus on the physical characteristics of the neighbourhood that we found is similar to what Nickelson et al (2013) and other researchers (5, 6, 34) found in their overviews about audit tools. Although social neighbourhood characteristics were, to some extent, also included in the evaluated audit tools, the way this was done was highly variable. In addition, it seems that physical characteristics were often used as proxy for the resident behaviours and the social infrastructure in a community (e.g. condition of public recreational spaces and buildings, litter, vandalism). This implies an important pitfall in that these proxies might not capture the behaviour of the residents that actually live in the neighbourhood/community or street that is audited, nor the social quality of the area. Although not specifically included in our review because, strictly spoken, they do not fit in the definition of *neighbourhood* audit instruments, we are aware of instruments that specifically register behaviour of people in specific types of public places, for example parks, playgrounds or school environments (35-39). These tools involve the use of momentary time sampling techniques in which systematic periodic scans of individuals and contextual factors are made within predetermined target areas. These instruments may provide interesting approaches that could be included in participative neighbourhood audit tools. After all, residents may be at least as interested in the social quality of their living environment as in physical aspects. The challenge is how to combine momentary measurements of targeted areas within a neighbourhood, for which a lot of observations are needed, with the measurement of more general physical features of neighbourhoods.

### **6.4.4 New directions in neighbourhood auditing**

For future development of neighbourhood audit instruments two aspects are important. Firstly, the aim of the instruments has to be clear. The main reason for the observed diversity of domains and sub domains included in the evaluated audit tools and audit tools in general might be that the aims of the different tools differ from each other. As Nickelson (12) stated, audit tools have been developed to meet the particular needs of different stakeholders, namely researchers, local authorities, local health workers, and sometimes citizens. An important question to consider then is whether the aim is to acquire knowledge for science and policy or to gather information on how the local population perceives their community and the opportunities and barriers for health within their community. These aims may be compatible, but it is a matter of give and take. The application of scientific indicators and a strong focus on inter-rater

reliability may be useful for research purposes, but may not appeal to residents as it provides little space for their views and concerns. A resident-based way of auditing may help include individual or collective subjective assessments, but these are difficult to handle for scientists, in particular for those with a background in quantitative disciplines like environmental epidemiology. Moreover, researchers may tend to build on approaches that are common in their specific work field and that are considered 'good practice'. Including subjective elements may not fit into the mainstream paradigm of neighbourhood auditing.

Secondly, it is important to explore new possibilities based on modern technologies. The strong focus on paper-and-pencil tools surprised us although it is understandable from a 'historical' point of view since an assessment of the instruments makes it clear that a lot of audit instruments are developed on the basis of earlier versions. However, new technologies like mobile applications have now become available, that could potentially support broader resident engagement, and more extensive participatory data collection. People can, for example, turn their smartphone into an environmental monitoring sensor by means of an app (40). Neighbourhood auditing instruments based on these new technologies need to be carefully developed in order to be both attractive for residents and useful for researchers.

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# CHAPTER 07



# Neighbourhood health assets: perceptions of local professionals in a Dutch low-SES neighbourhood. A qualitative study



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## ABSTRACT

**Aim of the study:** Asset-based approaches have become popular in public health. As yet it is not known to what extent health and welfare professionals are able to identify and mobilise individual and community health assets. Therefore, the aim of this study was to understand professional's perceptions of health and health assets.

**Methods:** In a low-SES neighbourhood, 21 health and welfare professionals were interviewed about their definition of health and their perceptions of the residents' health status, assets available in the neighbourhood's environment, and the way residents use these assets. A Nominal Group Technique (NGT) session was conducted for member check. Verbatim transcripts of the semi-structured interviews were coded and analysed using Atlas.ti.

**Results:** The professionals used a broad health concept, emphasizing the social dimension of health as most important. They discussed the poor health of residents, mentioning multiple health problems and unmet health needs. They provided many examples of behaviour that they considered unhealthy, in particular unhealthy diet and lack of exercise. Professionals considered the green physical environment, as well as health and social services, including their own services, as important health enhancing factors, whereas social and economic factors were considered as major barriers for good health. Poor housing and litter in public space were considered as barriers as well. According to the professionals, residents underutilized neighbourhood health assets. They emphasised the impact of poverty on the residents and their health. Moreover, they felt that residents were lacking individual capabilities to lead a healthy life. Although committed to the wellbeing of the residents, some professionals seemed almost discouraged by the (perceived) situation. They looked for practical solutions by developing group-based approaches and supporting residents' self-organisation.

**Conclusions:** Our study shows, firstly, that professionals in the priority district Sloterveer rated the health of the residents as poor and their health behaviour as inadequate. They considered poverty and lack of education as important causes of this situation. Secondly, the professionals tended to talk about barriers in the neighbourhood rather than about neighbourhood health assets. As such, it seems challenging to implement asset-based approaches. However, the professionals, based on their own experiences, did perceive the development of collective approaches as a promising direction for future community health development.

## 7.1 BACKGROUND

In public health, 'asset-based' approaches have become increasingly popular as a potential way to improve health at the community level (1-3). Such approaches focus on linking up with both individual and community capacities and capabilities, including (creating) important opportunities for community health in the neighbourhood's social and physical environment, for example walkability of the local spatial design, educational and social facilities, or employment options. Asset-based approaches are developed to be applied in communities; hence instead of focusing on individuals, they work primarily on the community level (1, 3). For health and welfare professionals working in communities applying this asset-based approach means that they need to be able to identify, find and mobilise these assets, in coordination with the residents. This may not be unproblematic, as many professionals have been trained and have worked in a medically oriented system that traditionally emphasised delivering services to 'passive' citizens (4, 5).

However, two important national policy developments in the Netherlands urge professionals to more closely link up to the discourse of asset-based approaches. Firstly, a policy transformation regarding public health and welfare takes place that may be understood as a shift from 'caring for residents', to stimulating residents' own capacities to look after their own, and each other's health and wellbeing (6). Policy makers are assuming that this policy shift will help improve the population's health and, above all, lead to lower health care costs. Currently experiments are carried out to test this assumption (see, for example, 7, 8). In relation to this development, Dutch policy makers are embracing the new concept of 'positive health' as the individual capacity to self-manage and being able to cope with setbacks and difficult circumstances. 'Positive health' was introduced by Huber et al. (9), arguing that the usual focus on 'disease' and 'disability' is no longer appropriate in modern age where early detection leads to 'ill' people without symptoms, and where many people can live a good life with a well-managed chronic condition. Positive health gets a lot of attention in the Netherlands (10).

A second important policy development is the so-called 'priority neighbourhoods' policy. The 40 most disadvantaged neighbourhoods in the Netherlands, diagnosed to have an accumulation of health and social problems, receive special governmental support (including finances) to develop and carry out integrated programmes to upgrade the neighbourhood. Recent evaluation has indicated that the programmes implemented under this policy in these 'priority districts' have benefited, or have the potential to benefit the health of the communities in these areas by creating a more

health-enhancing physical and social environment (11-13), but not all interventions by themselves generated the expected health impact. For example, investment in green areas as a stand-alone intervention did not seem to have a meaningful influence on the health status of the residents (14). Although this policy is not explicitly labelled as 'asset-based', it can be understood to link up with this approach, seeking to develop opportunities for better health in disadvantaged communities.

In sum, the promise of asset-based approaches at the community level and recent policy developments urge professionals to work according to these approaches, in particular in the 'priority districts'. However, as far as known, in practice asset-based approaches are only applied occasionally. In order to understand why this - apparently - is such a challenge for professionals, the aim of this paper is to report on the perception of professionals, based in a 'priority district', on health, neighbourhood assets and residents' capacities to create and maintain good health. The following two research questions were addressed:

- What is the professionals' perception of health and of residents' health status?
- What is the professionals' perception of available health assets in the neighbourhood and the way residents use these assets?

## **7.2 METHODS**

### **7.2.1 Setting and recruitment of professionals**

The setting for this study is the Amsterdam neighbourhood of Slotermeer (Box 1) (15-18). Slotermeer is one of the 'priority neighbourhoods' included in the national improvement program.

In Slotermeer, we interviewed a varied group of professional health and care workers, in order to obtain a broad range of different visions and approaches (purposive sampling) [17]. We selected names of professionals by using the categories 'health' and 'welfare' of the social map of the neighbourhood (19). In addition, we applied the 'snowball' method, asking professionals we knew in the neighbourhood to provide contacts. In total 45 professionals were invited to participate in the study by e-mail and telephone follow-up. Criteria for inclusion of professionals were that the professionals 1) had worked in the neighbourhood of Slotermeer for at least one year and 2) had a good command of Dutch.

21 professionals volunteered to participate in the study (Table 1). All of them fulfilled the inclusion criteria. The other 24 professionals were unable to take part because of either lack of time or unavailability during the interview period. Seven of the professionals who participated in the interviews also participated in a Nominal Group Technique (NGT) session (20). This method allows a group of people to creatively think up and rank possible decisions or solutions to a problem. A NGT session consists of individual brainstorming, joint listing of all alternative decisions or solutions identified by the participants, subsequent discussion of each item and one or more rounds of individual rating, after which the total score per item is calculated. Fourteen professionals indicated that they did not have time or interest to participate in the NGT session.

**Box 1.** Background details about Sloterveer neighbourhood

Amsterdam-Sloterveer (26.000 residents) is located in the city district Nieuw-West, on the west side of Amsterdam outside the city centre. It is a so-called 'garden suburb' built after the Second World War, implementing the vision of the urbanist Van Eesteren<sup>14</sup> with plenty of light, air and space; part of Sloterveer is a protected city view. Sloterveer is considered as a problem neighbourhood. Statistics for several health determinants, like smoking, unhealthy diet and lack of physical exercise, as well as for health parameters like obesity, diabetes, depression and suicide compare negatively to those in other parts of the city<sup>15</sup>. 29% of the residents reports severe loneliness; in Amsterdam as a total the severe loneliness rate is 11%<sup>16</sup>. The population includes more families and children, compared to other city districts. The 23% proportion of residents over 55 is similar to the Amsterdam average. The neighbourhood faces severe socioeconomic problems like high unemployment and debts, and residents rate the liveability as low in comparison to residents in other neighbourhoods<sup>17</sup>. Three out of ten households (28%) have a low income and a breadwinner with low educational level, which is 15% in Amsterdam overall<sup>16</sup>. However, the neighbourhood has many active residents, amongst others in the highly successful 'neighbourhood living rooms' where residents meet for social activities. The cultural composition of the population is very diverse and over 60% are 'Amsterdammers' of non-western origin<sup>16</sup>.

**Table 1.** Overview of interviewed professionals

Type of organisation	Professional N=21	Role in health and welfare system
GP Practice	General practitioner (GP) (n=2)	Medical doctor trained for primary and family care. Provides primary medical services and is gatekeeper to hospital and specialist care. To provide out of office care country-wide, GPs cooperate in regional out of office GP posts. Coverage 100% under the (mandatory) health insurance system.
	Doctor's assistant (n=2)	Trained assistant to the GP, providing front office services and assisting in care provision. Coverage 100% under the (mandatory) health insurance system.
	GP nurse (n=3)	Doctor's assistant with extended training, providing counselling and mentoring to patients with chronic diseases like diabetes or COPD. Works under the supervision of the GP. Coverage 100% under the (mandatory) health insurance system. Coverage 100% under the (mandatory) health insurance system.
	Dietician (n=2)	Provides services in primary care for patients with specific dietary needs as well as preventive services. Coverage under the (mandatory) health insurance system for a limited number of consultations per patient.
Other health care organisation	Community nurse (n=2)	Provides home based care services to patients in their personal living environment, e.g. based wound care, care for terminally ill etc. Coverage 100% under the (mandatory) health insurance system.
	Youth health care doctor (n=1)	Provides preventive services for youth 0-18. Refers children/youth with health or other problems to GP or specialised services. Coverage 100% by all Dutch municipalities under the Public Health Act.
	Physiotherapist (n=1)	Provides physiotherapy as a primary care service. Coverage under the (mandatory) health insurance system for a limited number of consultations per patient.
	Midwife (n=1)	Provides pregnancy care and counselling and birth care including both home and hospital birth. Is a recognised medical professional. Refers to gynaecologist in case of complications. Coverage 100% under the (mandatory) health insurance system.
Welfare organisation	Family coach (n=1)	Provides family-based coaching services. Coverage under the (mandatory) health insurance system for a limited number of consultations per client.
	Community worker (n=2)	Provides community services, building and supporting community groups. Financed through municipal budget for social services. Stationed in community centre.
	Youth worker (n=2)	Provides community services focused on youth. Financed through municipal budget for social services. Usually stationed in community centre.
	Volunteer coordinator (n=1)	Provides support for volunteers and volunteer services in the community, including volunteers in social support, welfare work, elderly people's care, etc. Financed through municipal budget for social services.
	Social worker (n=1)	Provides support for families and individuals with a variety of challenges including financial, social and mental problems. Refers to care system if needed. Financed through municipal budget for social services.

## 7.2.2 Interviews and Nominal Group Technique

We used a semi-structured interview protocol. In the first part of the interview, addressing the first research question, the professionals were asked how they defined health, how they perceived the health status of residents, and what they thought residents and professionals could do to maintain good community health or improve it. Examples of questions were: 'What is health, according to you?', 'How healthy are the people in Sloterveer?' and 'What possibilities do residents have, to do something about their health?.'

The second part concerned the assets for health in the living environment perceived by the professionals. These were described broadly as 'features of the neighbourhood that provide possibilities for health' as the term 'assets' has no Dutch synonym. To illustrate what 'assets' are and to challenge the professionals to think about a broad range of neighbourhood assets we used the 'Egan wheel' (21) which contains seven neighbourhood dimensions. Box 2 contains a summary of the interview protocol.

Subsequently we organised a member check with the interviewed professionals: we conducted a NGT session to verify first analysis results (22). In this session, we shared the interview results with the professionals. Subsequently they were invited to comment. Then, the NGT technique was applied to answer the central question: "What are best options in the neighbourhood environment that could contribute to improve the community's health?".

## Box 2. Summary of interview protocol

### 1. Introduction to the interview

### 2. Introductory question: What is health in your opinion?

- What should it be like ideally
- What can one do for her/his own health?

### 3. Main questions:

- How healthy are Slotermeer's residents?
- What is needed to make Slotermeer healthier?
- What can you contribute to a healthy neighbourhood?
- What features are available in the neighbourhood that contribute to health?
- What options do residents have to maintain good health?
  - What knowledge do they have?
  - Where do residents find knowledge?
  - What material resources do they have to maintain health?
  - Do residents want to work on their health?
  - What abilities do residents have to work on their health?
    - Why (not)?

### 4. Explanation on Egan Wheel

### 5. Per dimension:

- What goes well?
- What needs to be improved?
- What features are available that contribute to health?
- What are opportunities?
- What is needed?
- What is possible?
- What factors are most important to make the neighbourhood healthier?

### 6. Final question:

- Is there anything that needs to be added?
- How did you experience this interview?

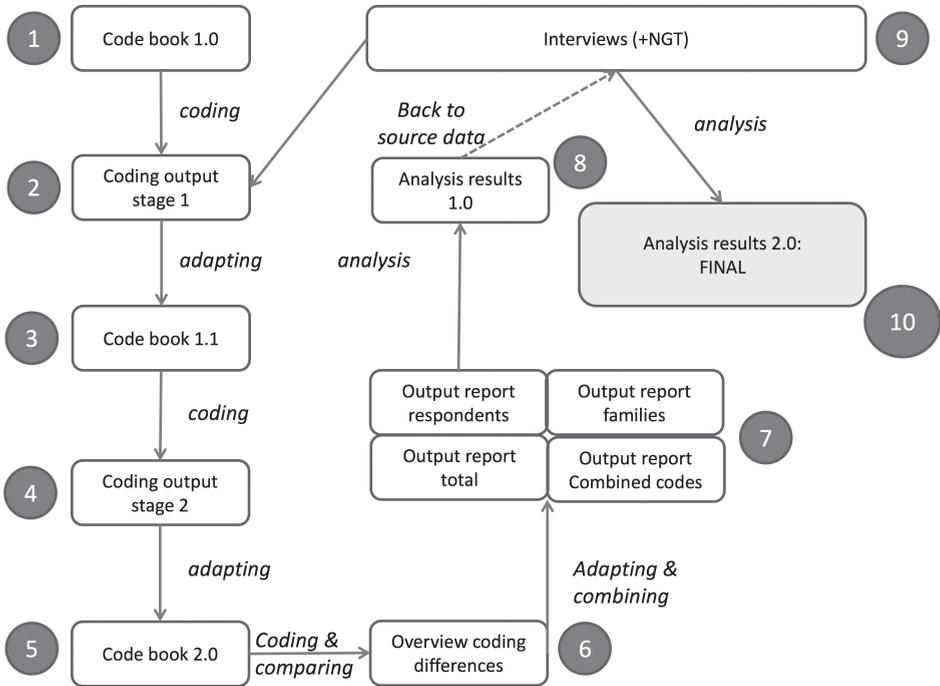
### Additional questions:

please explain, why is this so, can you give an example, what about specific groups, etc



### 7.2.3 Codebook development and analysis

The development of the codebook and analysis of data was an iterative process involving 10 steps (Figure 1).



**Figure 1.** Overview of analysis process

An initial codebook (version 1.0) was developed (step 1) based on concepts used in the research questions (e.g. health, health status) and the methods (e.g. wheel of Egan). The codebook has been refined during the coding process: after coding 1 interview transcript (steps 2 and 3), and after coding 5 interview transcripts (steps 4 and 5). The final codebook (version 2.0) (Additional file 1) contained:

A) Codes to identify text fragments that provided information on the professionals' definition of health and the health status of the residents. During the coding process the two initial codes ('health definition' and 'health status') were amended by two new, *bottom-up*, codes, 'health behaviour' and 'action for health', both frequently mentioned by the professionals.

B) Codes to identify text fragments that provided information on the professionals' perceptions of neighbourhood assets (based on the Egan model (21)).

C) Codes to identify text fragments referring to individual capabilities. For these, we used Nutbeam's model of health literacy describing the ability to find, understand, and apply knowledge that is needed to maintain one's health (23) as this seemed a useful model to identify residents' individual capabilities as they were described by the professionals.

D) As we found that professionals frequently referred to *unavailable* health assets we created additional *bottom-up* codes to identify neighbourhood 'assets' and 'deficits'.

Two codeurs simultaneously coded all interview transcripts into Atlas.ti using the codebook and adapting it during the process as described. Differences in coding were adapted based on mutual agreement. A list of 23 unresolved items was submitted to a third researcher for final coding decisions (Figure 1, step 2-6).

Various structured code-output reports (by code or code combinations, by code family, by respondent) as well as analytic memos drawn up during coding were used for thematic analysis (axial coding) (24) (Figure 1, step 7-8). Finally, initial analysis results were compared to the source data, both interviews and NGT, for verification, before final analysis reports were drawn up (Figure 1, step 9-10).

## 7.3 RESULTS

### 7.3.1 Perceptions of health and of residents' health status

The professionals gave several broad definitions of health. The majority of the professionals talked about health and a healthy lifestyle as a means for being able to function properly in day-to-day life and cope with problems. This was illustrated by expressions like 'feeling good about yourself', 'to be able to do what you want to do', and 'to be happy and just have energy to get things done'. Such definitions resemble Huber's new concept of health described before (9); echoes of the well-known WHO definition of health as a state of physical, mental and social wellbeing were also abundant in the interviews. However, no professional explicitly named their definition as such.

In discussing health definitions more in-depth, the professionals primarily defined health as a social phenomenon. They talked frequently about people's need to help and support others and the importance of maintaining meaningful relationships.

*“You have social bonds and you have a mutual feeling of health because, if you can do something for someone else and therefore feel valuable in society, you will also be healthier. If you can do something for someone else” (Resp 5).*

At the same time, and often even in the same sentence, they defined health as (the absence of) disorders or risk factors, as self-reported health (by residents) and as health in the sense of healthy *behaviour*: when talking about their health definition the professionals rapidly started discussing the residents’ unhealthy lifestyle.

The professionals were concerned about the residents’ health. They assessed community health as poor; referring, in particular, to obesity, loneliness and depression. They considered unhealthy lifestyles and behaviours as the main cause of this.

*“So, mental problems are abundant. And people have poor food habits; you see a lot of overweight, a lot of diabetes, a lot of high blood pressure, and many people who just have inexplicable pain. For example there is a lot of abdominal pain that cannot be explained” (Resp 8).*

The professionals did not mention any individual strengths or capacities of residents that might help them remain healthy. Instead, they focused on two individual barriers for health. First and foremost, they indicated that the residents’ unhealthy behaviour, for example with regard to nutrition and physical exercise, was caused by poverty. Secondly, they perceived a lack of knowledge or insufficient capabilities of residents, hindering healthy life styles.

*“In the supermarket, in the afternoon, you see youngsters walk around with red bull, energy drinks and potato chips. So it [healthy behaviour, LdB] all starts at home. I think many parents try, but fail; and the question is, what helps them explain to their children that this is basically unhealthy behaviour” (Resp 2).*

A number of professionals had difficulty with the language and with certain cultural views of ethnic minorities living in the neighbourhood who perceived health ‘differently’, talked about it ‘differently’ and behaved unhealthily.

*“In some cultures, for example, being overweight is an indication of status, and that you are doing well in life. At the same time, it is really detrimental to your health. Perhaps that is why people attach less importance to healthy eating and living” (Resp 4).*

### 7.3.2 Neighbourhood health assets

Although the interview was aimed at identifying health assets, the professionals, instead, talked much about problems and barriers for health. Various professionals believed that the neighbourhood as a whole did not support the health of residents. In general, they expressed a pessimistic perspective on Sloterveer.

*“The truth is that there are all kinds of factors that influence health and, in Sloterveer, they are almost all negative” (Resp 5).*

A more detailed discussion about each different dimension of the Egan model, offered a more varied perspective on the environment. The professionals interviewed identified both positive and negative aspects of the neighbourhood’s physical and social environment (Table 2). Dimensions that, according to the professionals, contained predominantly positive aspects were ‘Services’, ‘Housing and the built environment’, and ‘Transport and connectivity’. The other dimensions, ‘Governance’, ‘Environmental’, ‘Social and cultural’ and ‘Economy’ were considered to contain mostly negative aspects (or absent health assets).

Linkages between different neighbourhood dimensions, or assets/deficits appeared, for example litter in the streets (environment dimension) was linked to lack of social responsibility (social and cultural dimension). This was confirmed by code co-occurrence: text fragments were frequently coded for more than one dimension.

All professionals regarded the, in their eyes plentiful, *Services* dimension (healthcare, social activities and social services) as the most important contributor to health. This included the services they provided themselves. A few professionals devoted some of their free time to activities with local residents, for example by leading a walking group, with a view to activating residents. The professionals referred to the range of services on offer as cohesive, accessible and usable for residents. They were positive about how these services were coordinated and talked not only of their own work, but also about activities of the other professionals that they considered valuable.

*“So professionals in the neighbourhood collaborate in all kinds of different ways. And these initiatives are successful because we can easily contact each other” (Resp 11).*

**Table 2.** Identified opportunities and problems in the living environment

Neighbourhood dimensions (Egan 2004)	Asset	# mentioned*	deficit	# mentioned*
<b>(+) Services</b>	Many services available	32 (13 resp)	Budget cuts	10 (7 resp)
	Accessible/adapted to community needs	21 (10 resp)	Poor link to community	7 (6 resp)
	Cooperation	7 (6 resp)		
<b>(+) Housing and the built environment</b>	Green space / Sloterpas lake	29 (15 resp)	Poor housing	18 (15 resp)
	Renovated dwellings	5 (5 resp)	Small dwellings for large families	5 (5 resp)
			Unsafe	5 (4 resp)
			insufficient green space/ clean area	4 (2 resp)
<b>(+) Transport and connectivity</b>	Public transport and connectivity	13 (13 resp)		
<b>(-) Governance</b>			No insight in public administration	7 (7 resp)
<b>(-) Environmental</b>			Rubbish in the streets	10 (10 resp)
<b>(-) Social and cultural</b>	Many activities	12 (8 resp)	Poor social cohesion	19 (11 resp)
	Culture mix (positive)	4 (4 resp)	Insufficient culture mix	13 (8 resp)
<b>(-) Economy</b>			Poverty	42 (17 resp)
			One-sided economy	8 (8 resp)
			Unemployment	7 (4 resp)
			Unhealthy food supply	5 (5 resp)

\* This concerns the number of times the issue was presented in the interviews. In brackets: number of professionals bringing the issue forward.

At the same time, however, the professionals referred to three important barriers to appropriately deliver their services. Firstly, half of the professionals also believed that communication about the range of services linked up insufficiently with residents' perceptions, and wanted to change that. Secondly, they pointed out that cutbacks have led to impoverished and fewer services. And finally, they referred to bureaucracy and complex regulations as a hindrance to the health of, and care for, residents.

*"...whenever I visit a group of care avoiders, one of the first things I do is help them with the administration. Because there is far too much of it and they don't know how to do it and then they receive a reminder (...) What is particularly distressing is that the human dimension has just gone. All the rules and regulations are not making it any easier" (Resp 9).*

The second most important health-enhancing dimension was *Housing and the built environment*. The local greenery, containing attractive parks and the Slotterplas - a recreational lake- was often mentioned and was mostly referred to as an important asset benefiting community health. The built infrastructure however was rated negatively. The professionals were of the opinion that the dwellings in the neighbourhood were of poor quality and too small for the size of the households living there. They also thought that not enough houses were available that were fit for residents to live in. A few professionals indicated that the built living environment was unsafe, due to inhabitable empty buildings.

*"There are a lot of empty buildings, people engage in fraudulent practices and there are cannabis plantations in garages and that kind of thing" (Resp 5).*

Thirdly, *Transport and connectivity* was a dimension that the professionals considered health enhancing. The professionals regarded the *traffic infrastructure* in Sloterveer as safe, and public transport as excellent, particularly for elderly people and people with disabilities.

Of the dimensions rated mainly as less beneficial to resident health, the *Governance* dimension was rated least negative: the professionals did not have much to say about this dimension. However, they implicitly criticised local government by stating that they did not really have an insight into how public administration actually contributed to the health of residents. They expressed a desire for more visibility of policy makers for themselves, for residents and for other stakeholders. According to the professionals, this would enable them, residents and other stakeholders to better understand and respond to local health and other health-relevant policies.

For the *Environment* dimension, also rated negatively during the interviews, the only issue mentioned was rubbish in the streets. The professionals blamed that on residents who 'did not understand that rubbish belongs in rubbish bins'.

Most professionals considered the *social infrastructure* in the neighbourhood to be insufficient despite the many social and cultural activities. The social cohesion in the neighbourhood was assessed as being low. According to the professionals, there was little contact between residents and residents did not take any responsibility for their neighbourhood. They considered improving the social infrastructure as a matter deserving urgent attention. Although a few described the 'lively' mix of cultures as positive, most professionals regarded the dividing lines between the various cultural groups of the neighbourhood as a major problem.

*"It is not at all harmonious. If I look at my own neighbourhood (=Slotermeer, Ldb) all the Turkish people live close together, as do the Moroccans, with the Dutch people ending up living somewhere else. I do not see any harmony" (Resp 7).*

Lastly, all the professionals referred to the *Economy* dimension in the neighbourhood exclusively in negative terms: a one-sided range of shops, far too many 'unhealthy eateries' and, above all, poverty. Professionals told us that residents were hampered in their health and healthy behaviour by unemployment, debts, insufficient money for food or other essentials and the excessive cost of medical care. They made it clear that they were personally affected by this.

*"Hardly anyone has a job. So it is quite a unique situation. There are a lot of people who are in debt management. I have to say that I sometimes find this very shocking. When I hear how little people have to survive on every month" (Resp 20).*

### **7.3.3 How do residents use neighbourhood health assets?**

The professionals indicated that, due to their poverty-stricken situations and lack of capabilities, residents made too little use of assets available in the neighbourhood. The reasons, poverty and lack of capabilities, are the same reasons that professionals gave for residents' poor health state and unhealthy behaviour.

*"Then we also have to take account of the incomes of the people who live here, which are fairly low, so I don't think people are queueing up to register with the local gym. That is also why you only see Turkish and Moroccan women walking around the Sloterpas in the summer" (Resp 4).*

According to the professionals the residents' low level of education also played a role because they had little knowledge about health and therefore did not make proper use of the care services provided, for example due to low levels of patient compliance, or because they did not know how to find and access the care and support they needed. In short, they felt that facilities were sufficiently available, but failed to get the residents inside. Many professionals interviewed believed that their efforts produced few results. The statements by some of them express a personal feeling of powerlessness or despondency.

*"To put it in very general terms, there is little knowledge. However, it is these people who actually have more than the average number of health-related problems. A huge number of residents barely attended primary school, for example (...) People have absolutely no idea how their body works" (Resp 18).*

The professionals talked about possible solutions and about the ways they tried to help residents overcome health barriers and to use available assets for health. They said they tried to offer services that linked up more effectively with residents' needs. A very important solution mentioned by many professionals was to develop collective approaches, for example in the form of group consultations. A number of professionals applied this approach successfully. The professionals also regarded independent collective action of residents on health issues as a key opportunity and wanted to support this.

*"You expect a whole lot from people and some of them need real guidance. Having said that, you do see it happening. For example, groups of women get together in the neighbourhood and then you have all kinds of things going on at the same time. They have social contacts, they go on walks, they can discuss their problems and exchange experiences" (Resp. 13).*

### **7.3.4 Results of Nominal Group Technique session**

The results of the NGT session (Table 3) confirmed the results of the interviews. In the NGT session, the green infrastructure and the transport system were predominantly mentioned as health assets, while the social infrastructure of the neighbourhood ought to be reinforced. Lack of social cohesion was considered a key issue in this neighbourhood. The professionals participating provided two types of solutions for this lack of social cohesion: one was to more effectively use health assets in the physical environment, in particular to upgrade green spaces to become real meeting places for residents. The other, and maybe even more important solution according to

professionals, was found in organising or stimulating collective and self-organisation approaches in the community.

**Table 3.** Results of NGT session: top 5 issues

Neighbourhood health asset	How this can be meaningful
Group activities for residents	Provides opportunities for physical exercise and sports and reduces loneliness. Group activities should be promoted and enhanced
Volunteers and volunteer groups	Self-organisation, as an effective approach to tackle health problems, should be stimulated
Community meeting places	Meeting places strengthen social cohesion and help reduce loneliness
Social support service point	This is needed, but currently unavailable. Residents fail to find their way to facilities and services due to poor literacy
Parks and playgrounds	These are available and can be used more effectively and intensively to improve community health

## 7.4 DISCUSSION

This study was performed to assess the perceptions of local health and welfare professionals in relation to the asset-based approach, which is advocated in the field of public health and represented in Dutch policy directions.

Firstly, our study shows 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. They emphasised the role of poverty, unemployment and lack of education as barriers for healthy behaviour and provided many examples of this. In particular poverty was a topic that came up repeatedly, and the professionals seemed almost discouraged by the problems this caused to the residents' health, health behaviour and (unmet) health needs. Nevertheless, they were deeply committed to the wellbeing of the residents; they tried whatever possible to assist them and help solve their problems.

Secondly, it transpired that 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 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. When asked about the way in which residents used the existing health-related opportunities, the professionals indicated that, due to a lack of individual capacities (powerlessness and ignorance) and poverty, the residents were unable to make effective use of the existing health assets.

The perceptions of the professionals are partly supported by views of Sloterveer residents themselves. A separate study, reported in Dutch, that we carried out with Sloterveer residents as 'citizen scientists' who interviewed fellow residents, focused on the health assets as perceived by them (25). The residents interviewed rated the green environment in the neighbourhood as health-supporting. They also thought poverty and the poor quality of local housing posed barriers to health. The study further showed that residents felt unsafe and were annoyed by litter in public space. This links up with professionals' views. An interesting difference comes up regarding residents' need for information and education on health issues observed by the citizen scientists. On one hand, this matches the lack of health knowledge the professionals perceived under the residents. On the other hand, however, the residents expressed optimism: they felt that such knowledge could and ought to be transferred. Indeed, the citizen scientists themselves felt that their interview activities strengthened their own knowledge, as well as their personal abilities to take action for health. Moreover, the citizen scientists reported having extended their personal network and stated that discussing health would be a good way to improve the social cohesion in Sloterveer.

The conclusion would appear to be justified that the perceptions of the Sloterveer health and welfare professionals focus more on barriers for health (of which several, like poverty and cultural differences, lie outside the health sector), than on assets, and therefore do not yet match the current Dutch policy. This confirms Dunston's (4) observation mentioned before: implementation of a new approach in day-to-day practice does not happen by itself. As we described, the Dutch interpretation of the asset-based approach contains a strong focus on individual capacities. The professionals seemed unable to detect the residents' individual capacities, but saw mainly inabilities. This corresponds to the findings of a Dutch study of the use of 'strength-based' families and children sessions, a method whereby clients themselves have to develop proposals for resolving their issues. In practice, the care providers had difficulties to mobilise their clients' own capabilities (26). Janssen et al (27) argue that such 'misfits' have their origins in differences in the work cycles between policy and practice (and research); while in the policy cycle much depends on political opportunity, values of political parties, and a focus on broad societal challenges, in the practice cycle the focus is on creating concrete value

for those in need and practical applicability. A solution may be, as Dunston suggested, to invest in development of the professionals' capacities (4). In addition, Janssen's solution, exchange between policy makers and professionals, may prove valuable to create a better balance between what policy makers expect and what professionals can do. Although the professionals in Sloterveer perceived few individual capacities, they did identify opportunities for resident empowerment in promoting the *combined* power of residents living in the neighbourhood. This combined power, or 'community capacity' is then not merely the sum of individual residents' capacities but a whole that is more than the sum of the parts. Moreover, the professionals themselves, being present in the neighbourhood and highly motivated to contribute to residents' wellbeing, can be considered part of that community capacity. Reinforcing the local social infrastructure in the neighbourhood, which the professionals stated was an urgent challenge, could be more beneficial for community health than the individual approach. Moreover, the discussions based on the Egan Wheel helped to identify the interconnectedness of the different social and physical dimensions of the neighbourhood. Indeed, the national investment program for priority districts, focusing on the community level and addressing a range of aspects in that community's environment in an integrated way, seemed promising in terms of improving community health (28). In other words, the practice-based solutions brought forward by the professionals seem to link up well with the theoretical concepts and approaches underpinning this program.

In the introduction, we mentioned the concept of 'positive health'. Several authors who responded to Huber's original paper in the British Medical Journal proposing this concept (8 out of 23 responses) observed that this concept was inadequate as it does not address important health determinants nor (socioeconomic) health inequalities (29). Also a more recent operationalisation of 'positive health', identifying six personal health dimensions (bodily functions, mental functions & perception, spiritual/existential dimension, quality of life, social & societal participation, and daily functioning) (30), does not include the impact of factors in the living environment. Our study confirms that, also from the point of view of professionals working in local practices, 'positive health' as it is currently defined, may seem appealing, but provides little direction for effective health promotion for low-SES groups.

The results of our study must be interpreted with a certain degree of cautiousness. After all, the group of professionals was relatively small. Having said that, it was varied in composition meaning that a more complete picture has been obtained than if only GPs or social workers had been interviewed. An important strength of the study is that it consisted of in-depth interviews yielding an abundance of information about the perspectives of these professionals. The outcomes of the interviews, confirmed by the

NGT session results, also match what is already known about Sloterveer. The available quantitative data about the neighbourhood, for example the figures on loneliness (see Box 1) match with the picture of a neighbourhood with poor social cohesion.

This study focused on the perceptions of professionals. The contribution of residents is an essential element for the realisation of this approach. Their own perceptions about the health of their community were not included in the study. Additional research with residents, like the study we carried out separately, offers a good opportunity to collect the missing information. For such studies Participatory Action Research may be an appropriate method as it has the potential to empower communities and strengthen social networks (31). It is precisely in priority neighbourhoods such as Sloterveer, where the social quality of the living environment is below average, that such a study approach can both collect information and improve the health of residents by implementing this information in practice.

## **7.5 CONCLUSIONS**

Our study shows, firstly, that professionals in the priority district Sloterveer rated the health of the residents as poor and their health behaviour as inadequate. They considered poverty and lack of education as important causes of this situation. Secondly, the professionals tended to talk about barriers in the neighbourhood rather than about neighbourhood health assets. As such, it seems challenging to implement asset-based approaches. However, the professionals, based on their own experiences, did perceive the development of collective approaches as a promising direction for future community health development.

## **DECLARATIONS**

### **Ethics approval and consent to participate**

All interviewees were informed in writing about the aim of the study. All gave their verbal permission for the information in the interviews to be used for scientific research, subject to anonymity.

The study protocol was reviewed by the Clinical Expertise Centre of the National Institute for Public Health and the Environment. Based on this review, they determined that the research plan does not fall under the scope of the Dutch law on medical research involving humans (WMO).

### **Consent for publication**

All interviewees were provided with the manuscript and were given the opportunity to respond. All interviewees cited in the manuscript agreed in writing to publication of the study results.

### **Availability of data and material**

The datasets generated and analysed during the current study are not publicly available due to our responsibility to guarantee anonymity, but are available from the corresponding author on reasonable request.

### **Authors' contributions**

LDB contributed to preparation of interview protocols, prepared analytic framework, carried out coding and analysis, and prepared all versions of the manuscript.

EU contributed to the analytic framework and carried out coding and analysis.

AH prepared and performed interviews as well as NGT session, prepared transcripts, and performed preliminary analysis.

AW contributed to the analytic framework, to the coding process as a third researcher, to analysis and writing.

AJS contributed to the analytic framework, analysis and writing.

All authors read and approved the final manuscript.

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# CHAPTER 08



# General discussion





## 8.1 INTRODUCTION

The research question of this thesis was:

*“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?”*

As explained in the Introduction to this thesis (Chapter 1), the Whole of Government approach, as a basis for HiAP, needs to be complemented by a Whole of Society approach in which citizens and communities play a major role. We explored ways in which *Citizen Science*, i.e. the active participation of citizens in research, other than as research objects, can contribute to HiAP.

This is the first study, as far as known, in which this approach, as a contribution to HiAP, is addressed. Therefore, an important component of the thesis was the development of a theoretical model to describe, analyse and evaluate Citizen Science in public health (Chapter 2). This theoretical model is based on an exploration of knowledge about Citizen Science in other work fields and insights gained by approaches in public health citizen like participatory action research.

The benefits and challenges in the *practical* application of Citizen Science to support HiAP were explored in three ways. Firstly, by two case studies: one evaluating the impacts of a Citizen Science project in a low-SES neighbourhood in the Netherlands on the citizen scientists (Chapter 3) and one on stakeholder engagement in Health Impact scoping (Chapter 5). Secondly, by carrying out two scoping reviews. The first scoping review concerned community participation in Health Impact Assessment (HIA) because HIA is a key tool for HiAP (Chapter 4). Its results provide insights derived from scientific and grey literature. The second scoping review concerned neighbourhood auditing (Chapter 6). A neighbourhood audit is a systematic assessment of the state of a neighbourhood and those aspects that are important to the health of residents. Thus, it provides evidence that can be used to support local HiAP. In the scoping review, the availability of neighbourhood audit instruments that include residents was explored by looking into scientific and grey literature.

The third way to explore benefits and challenges was by exploring the perceptions, of local professionals, of neighbourhood health assets (Chapter 7). A study, in which local health and welfare professionals were interviewed, was conducted in the same neighbourhood as the Citizen Science project reported on in Chapter 3.

In subsection 8.2, the results of the case studies and scoping reviews will be discussed in relation to the research question. In subsection 8.3 the strengths and limitations of this thesis are discussed. Subsection 8.4 contains concluding remarks and explores possible ways forward in the application of citizen engagement in developing the knowledge base for HiAP.

## **8.2 SUMMARY AND REFLECTION ON OUTCOMES OF CASE STUDIES AND SCOPING REVIEWS**

Citizen engagement in knowledge development for HiAP, or Citizen Science for HiAP, can have different forms. In this thesis, we have focused on three important generic ways to implement a Citizen Science approach. The first one is carrying out a Citizen Science project with lay researchers in their own neighbourhood, as described in Chapter 3. The second, very specific form of Citizen Science is the engagement of communities in Health Impact Assessment (Chapter 4 and 5). The third way to implement a Citizen Science approach is citizen engagement in neighbourhood auditing (Chapter 6). Table 1 provides a summary of the outcomes of the theoretical exploration (Chapter 2), the different case studies and scoping reviews and their results in relation to the research question.

**Table 1.** Summary of methods, benefits and challenges per chapter

Chapter	Citizen Science methods	Benefits	Challenges
2. Citizen Science for Public Health	<ul style="list-style-type: none"> <li>• Typology of Citizen Science projects, based on aim, approach in the way citizens are engaged (ranging from being data collectors to being in full control of the project) and size (local or mass)</li> </ul>	<ul style="list-style-type: none"> <li>• Increased health literacy</li> <li>• Empowerment</li> <li>• Community building, social capital, social learning and trust</li> <li>• Changes in attitudes, norms and values</li> <li>• Increased Sense of Coherence</li> <li>• Increased participation in public health governance</li> <li>• Lay, local and traditional knowledge added to scientific knowledge</li> <li>• Increased research capacity</li> </ul>	<ul style="list-style-type: none"> <li>• How to engage citizens?</li> <li>• How to address representativeness?</li> <li>• How to weigh scientific and societal value of the knowledge produced?</li> <li>• How to ensure that the participation leads to stronger engagement of citizens in the policy process?</li> <li>• How can this approach lead to better health?</li> </ul>
3. Public health Citizen Science; perceived impacts on citizen Scientists. A case study in a low income neighbourhood in the Netherlands	<ul style="list-style-type: none"> <li>• Recruitment by trusted community work centre and mouth-to-mouth</li> <li>• Group meetings</li> <li>• Training (in group) focused on knowledge and personal competences</li> <li>• Trained citizen scientists perform interviews</li> <li>• Support during interview stage (personal, by guideline and by easy to fill out form)</li> <li>• Support for self-organised resident initiatives</li> </ul>	<ul style="list-style-type: none"> <li>• Citizen scientists have better understanding of health and broader health determinants</li> <li>• Citizen scientists have increased knowledge about health and healthy lifestyles</li> <li>• Citizen scientists took action for a healthier life</li> <li>• Self-confidence and social skills of citizen scientists enhanced</li> <li>• Social networks of citizen scientists expanded across cultural boundaries</li> <li>• Citizen scientists took action for a healthier neighbourhood</li> <li>• Increased (measured) health literacy</li> <li>• A set of insights on neighbourhood health assets and barriers</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of (expected) follow-up, causing a sense of powerlessness</li> <li>• Practical organization needs improvement</li> </ul>

Table 1. (continued)

Chapter	Citizen Science methods	Benefits	Challenges
4. Community participation in Health Impact Assessment. A scoping review of the literature	<ul style="list-style-type: none"> <li>Community participation as a core element in HIA</li> <li>Knowledge or opinion elicitation methods, in particular, focus groups, interviews, community meetings and workshops</li> <li>Procedures and structures to promote and secure the community's influence in the HIA, in particular Steering Group participation</li> <li>Capacity building, in particular training</li> <li>Multi-method approaches and large variety of methods</li> </ul>	<ul style="list-style-type: none"> <li>Access to lay or local knowledge, improving understanding of local context and improving knowledge base for policy/decision making</li> <li>Adherence to or application of democratic values</li> <li>Improved relations between communities and local agencies</li> <li>Community empowerment</li> </ul>	<ul style="list-style-type: none"> <li>How to select participants and avoid tokenism</li> <li>Cases provide little detail about who are participating and how selection/recruitment took place</li> <li>Cases provide little detail about the methods applied and little information on theoretical or practical considerations underpinning method selection</li> <li>Communities may lack knowledge and capabilities for meaningful participation</li> <li>How to evaluate impacts like empowerment and policy engagement</li> <li>How to embed HIA in broader health promotion strategies</li> </ul>
5. We are all experts! Does stakeholder engagement in Health Impact Scoping lead to consensus? A Dutch case study	<ul style="list-style-type: none"> <li>Two subsequent workshops in which stakeholders and residents jointly 1) define joint vision on healthy living environment and 2) apply the vision to infrastructural plan</li> <li>Selection based on ensuring variety of roles of participants; personal invitation</li> <li>Lectures introducing health (determinants) concepts and model of healthy living environment</li> <li>Small group work</li> <li>Group discussion</li> <li>Chatham House Rule</li> <li>'Everybody is an expert' rule</li> </ul>	<ul style="list-style-type: none"> <li>Joint (experiential) learning</li> <li>Better include community needs in policy development, complementing environmental aspects as defined in regulatory Environmental Impact Assessment framework</li> <li>Health, as a topic, has the potential to connect different stakeholders</li> <li>Enables local stakeholders, including residents, to strengthen their engagement in the policy process</li> <li>Policy adapted to better address community needs</li> </ul>	<ul style="list-style-type: none"> <li>Difficulties in timing and effectiveness of engaging residents and other stakeholders</li> <li>False suggestion of consensus can lead to disappointment and conflict later in policy process</li> </ul>

**Table 1.** (continued)

Chapter	Citizen Science methods	Benefits	Challenges
6. Resident participation in neighbourhood audit tools - a scoping review	<ul style="list-style-type: none"> <li>Resident participation in neighbourhood auditing is not common</li> <li>Residents participate mostly in data collection; 2 (out of 13) instruments include residents in all project stages, e.g. define aspects to be audited, collect data, help analyse results)</li> <li>Tools used: Pencil-and-paper checklists, tablet-based tool to record narratives and photos, digital checklist</li> <li>Exact application of tools not described</li> </ul>	<ul style="list-style-type: none"> <li>To gather information on how the local residents perceive their community and the opportunities and barriers for health within their community</li> </ul>	<ul style="list-style-type: none"> <li>New technologies are still in development stage, how to ensure that these are resident-friendly?</li> <li>How to balance, on one hand, relevance for residents and, on the other hand, scientific robustness</li> </ul>
7. Neighbourhood health assets: perceptions of local professionals in a Dutch low-SES neighbourhood. A qualitative study	<p><i>Methods to improve resident health (not necessarily Citizen Science methods)</i></p> <ul style="list-style-type: none"> <li>Collective health promotion</li> <li>Organising or stimulating collective and self-organisation approaches in the community</li> </ul>	<p><i>Benefits of collective approaches (not necessarily Citizen Science methods)</i></p> <ul style="list-style-type: none"> <li>Improved social cohesion</li> <li>Health</li> </ul>	<ul style="list-style-type: none"> <li>Challenges for resident health improvement (not necessarily Citizen Science methods)</li> <li>Poor education</li> <li>Poverty and unemployment</li> <li>Lack of social cohesion (including cultural differences)</li> </ul>

## 8.2.1 Methods for citizen engagement in knowledge development for HiAP

This section discusses the most important findings of the case studies and scoping reviews regarding the methods for citizen engagement. Citizen engagement in knowledge production for HiAP is still new, as explained in Chapter 2. Therefore, standard methodologies on how to ensure and manage citizen participation in these Citizen Science approaches are not readily available. Moreover, there is a large variety in Citizen Science applications. Chapter 2 presented a classification based on Citizen Science approach, aim of citizen participation and level of participation. These aspects influence the methods applied. Moreover, the way communities and citizens are involved in knowledge development may vary according to the topic. In Chapter 2, differences between Citizen Science in the natural sciences and public health were discussed. Such differences have an impact on the way projects are conducted. A study concerning bees and their behaviour, for example, may necessitate other methods for citizen engagement than one looking at the opinions of patients about hospital care quality. Citizen Science for HiAP, therefore, possibly requires specific methods and procedures fit for this work field.

### Box 1. Classification of case studies in Slottermeer and Vught (Chapter 3 and 5)

#### **Slottermeer (Chapter 3)**

Aim: Collective goods. Researchers and residents cooperated to create knowledge that may serve as input to improve the neighbourhood's health

Approach: Participatory science. Residents participated in problem definition, data collection, and interpretation of data

Level: Local

#### **Vught (Chapter 5)**

Aim: Action. Residents and other stakeholders participated to address local concern about the possible impact of infrastructural plan

Approach: Distributed intelligence. Residents and other stakeholders as interpreters.

Level: Local

Overlooking the citizen engagement case studies (Chapter 3 and 5, Box 1), the study under Slottermeer professionals (Chapter 7) and the scoping reviews (Chapter 4 and 6) 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. Secondly, the creation of social networks appears to be closely linked to Citizen Science approaches.

### **Learning**

Increased skills and knowledge and increased 'scientific literacy' is one of the impacts, and often an explicit aim of Citizen Science in general. Chapter 2 describes that many Citizen Science projects include educational activities aimed at learning. Learning was an essential ingredient in the case study on citizen scientists in Amsterdam (Chapter 3) as well as in the case in Vught (Chapter 5). An important aspect in the Amsterdam case was training of the citizen scientists. This training contained knowledge about health and its social determinants. The influence of the social and physical living environment on health was explained using a translated version of the Egan model (1). This knowledge transfer was combined with strengthening personal competences relevant for the citizen scientists' research activities, for example, supporting them in their attempts to engage fellow-residents for interviews. In the Vught case, there was a focus on joint learning of all participants: residents as well as other stakeholders were involved. Here, again, core issues were concepts of health and those factors that affect people's health and health behaviour, using the Egan model to refer to the living environment.

In HIA in general, learning is an important aspect of the participation of communities. The scoping review on community participation in Health Impact Assessment (Chapter 4) revealed that one of the methods applied to enable such participation was training of community members. The details of such training were not described. However, what is clear, is that, similar to the case studies in this thesis, in HIA in general, learning is linked to concrete issues that are relevant to the participants on a personal level, as this always takes place in the framework of a specific local context and in relation to concrete policy proposals. Examples of training include topics like water or waste, but also generic understanding of health and its determinants.

This approach, where learning is stimulated by the confrontation between the knowledge transferred, including abstract concepts or models, and the concrete experiences of the participants, can be considered 'experiential learning', a term coined by Kolb (2). As Kolb explains, bringing knowledge and experience together in this way provides meaning and vividness to the –new, experiential- knowledge thus produced by the participants. In experiential learning, the process is more important than fixed outcomes and the learning is action-oriented, aiming at the application of knowledge in the participants' own context.

Experiential learning, where knowledge and action are so closely related, is highly relevant for Citizen Science for HiAP, because HiAP is by definition an action-focused approach, aiming to resolve important ‘wicked’ health challenges. The same, can be argued, is true for health promotion research in general (3).

Learning is not only an important element for the citizens contributing to knowledge development; cocreation in knowledge development entails mutual learning for both the community and researchers (4). For HiAP, other stakeholders, in particular local professionals, may need to be engaged in this joint learning process as well. Local professionals in Sloterveer (Chapter 7) have little confidence in the knowledge and capabilities of local residents to identify and utilize neighbourhood health assets. Their approach to improving the health of residents is mainly deficit-based. The scoping review concerning citizen participation in neighbourhood audit tools reveals a similar, expert-based approach in which residents’ knowledge has no place. Developing asset-based approaches in public health, however, does not happen by itself; it requires a change of both professional and organizational cultures and values. A shift towards the application of asset-based approaches can be promoted by developing the public health work force through formal training, empowering them to explore and experiment new ways to operate with their target groups (5, 6). Learning processes of professionals and communities or citizens need not take place in separate ‘streams’; indeed, dialogue with target groups may be a useful way to develop new knowledge, competences and attitudes. In the Vught case (Chapter 5), both residents and professionals developed a broader and more holistic perception of health. The learning process happened by confronting different points of view, listening to one another and reflecting on differences and commonalities. In HIA in general, the input of communities is perceived as a way to access knowledge that would otherwise not be available to the professionals engaged in the Impact Assessment – thus as a way of learning more about those communities (Chapter 4).

### ***Social networks***

Citizen Science brings people together in networks or communities of ‘lay researchers’ that help the participants to develop new (scientific and other) competences and knowledge (Chapter 2). Wallerstein (7) argues that joint critical thinking about the local context helps build community capacity and empower individuals within that community. This was also an important aspect in the case studies in Amsterdam and Vught (Chapters 3 and 5). The element of group-based learning was at the core of the approaches applied in these cases. The citizen scientists in Amsterdam, like the participants in the scoping workshops in Vught, developed their views and knowledge by sharing and discussing them in the group. There was also space to discuss different

points of view. The citizen scientists in Amsterdam emphasized that they learnt to respect, acknowledge and understand people with another cultural background. In the Vught evaluation, it became clear that mutual respect and trust were supported by the two ground rules of the workshops. These rules were the Chatham House Rule (8) and the 'Everybody is an Expert' rule, the latter designed by the workshop developers. In HIA, group based approaches are important methods to engage communities and access local knowledge. Moreover, inclusion of community members in a HIA Steering group is frequently mentioned in the literature studied (Chapter 4).

This group-based aspect of Citizen Science links up to the theory and practice of health promotion. Strengthening community action is one of the four Ottawa Charter key areas (9). Community-based approaches are important in health promotion; these approaches are applied widely in a multitude of health promotion strategies and interventions worldwide. An important element is the empowerment of communities or community groups, strengthening them to take joint action for their community's health. It is this notion that one might recognize in the statements made by the professionals in Amsterdam, interviewed about health and health assets in the neighbourhood (Chapter 7). The focus on individual self-sufficiency in current Dutch health and wellbeing policies, linked to the concept of 'positive health' as the ability to adapt and self-manage (10), does not seem to resound in the way these professionals perceive the local situation. Instead, they advocated developing or applying approaches where the focus would be on group (or community) empowerment rather than on individual empowerment. They mentioned examples like health promotion in peer groups or self-organisation of residents as possible ways forward. Although, in the perception of these professionals, residents, on an individual level, underutilised important neighbourhood assets, community-based assets approaches seem to hold a promise for the improvement of the neighbourhood's health. This would require developing a collective conceptualisation of 'positive health' as an enrichment of the current focus on individual capacities. Moreover, it would require to link this 'positive community health' to environmental factors and living circumstances that pose opportunities -and barriers- to community health. Such approaches could include the joint development of views and knowledge with residents.

On a more generic level, the group-based character of Citizen Science approaches can be considered as particularly meaningful in the framework of HiAP. The Whole of Society approach, which is essential for effective HiAP, by definition requires cooperation of different societal actors, including citizens, to address joint health challenges. The groups and networks built up through Citizen Science projects may provide a mechanism that enables residents to act as partners in such cooperation.

## **8.2.2 Benefits of citizen engagement in developing a HiAP knowledge base**

In Chapter 2, a model of possible benefits of Citizen Science was presented. The benefits may be divided in two categories, namely benefits for knowledge development and benefits for citizen scientists. Both types of benefits were addressed in the case studies and scoping reviews underlying this thesis.

### ***Benefits for knowledge development***

In Citizen Science literature, the expansion of (quantitative) research capacity is often mentioned as the main benefit for knowledge development (Chapter 2). However, this may be only partly true for Citizen Science in the framework of HiAP which takes place in a complex social context. In that context, all kinds of practical, ethical, political or social issues may arise, requiring thoughtful planning and management throughout the project. The Sloterveer case (Chapter 3) illustrates this. Although the citizen scientists managed to reach out to a large group of residents, enhancing data collection capacity, considerable effort was invested in training and ongoing support of the citizen scientists. In sum therefore, working with citizen scientists - in this case- probably did not reduce time investment. The enhancement of 'qualitative' research capacity was more important: the citizen scientists functioned as trusted key persons without whom it would have been difficult to establish contact and perform interviews with this local population.

This thesis shows that Citizen Science for HiAP, in addition to –possibly- increasing research capacity, benefits knowledge development in three other, qualitative, ways. Firstly, Citizen Science yields contextual information that is useful as a background against which HiAP strategies can be developed. Secondly, Citizen Science helps balance one-sided information by providing insider knowledge. Thirdly, Citizen Science has the potential to yield socially robust knowledge, i.e. knowledge that is contextualised and that is developed in an iterative process between scientists, society and citizens (11). The case studies and scoping reviews in this thesis illustrate how types of benefits could materialise in practice.

The first type of knowledge benefits is discussed in the scoping review on Community participation in HIA (Chapter 4). This scoping review showed that the contribution of communities and citizens to the knowledge needed for HiAP is a key consideration underpinning community participation in HIA. The input of communities in the HIA process provides knowledge that helps to understand the local context. This, subsequently, enables the development of appropriate and effective policy options

that link up with that local context. Indeed, ideally, an effective HIA should lead to adaptations of proposed policies, plans or programs in order to protect or improve the health of a population or population group (12).

The second type of knowledge benefits can be observed in the case study in Vught (Chapter 5), where resident knowledge provided new insights that were pertinent to the local situation. One of the insights was that noise or noise reduction was not the only issue at stake, but that connectivity within the community was at least as important. This could only be known by engaging and listening to residents, who held important information on, for example, the needs of people with visual impairments living in Vught.

Such knowledge and insights need, of course, not always be collected by a Citizen Science approach. Other strategies, like interviewing residents, pose alternatives. The added value of Citizen Science is the creation of the third type of knowledge benefits, socially robust knowledge. This is created by combining lay and expert ways of understanding reality and initiating dialogues in which they are compared, confronted and integrated. Balancing different views, perceptions and ways of knowing might sometimes require a 'partisan' position where researchers explicitly and intentionally side up with underprivileged groups, strengthening voices that are seldom heard (13). The result, socially robust, shared knowledge, including such currently underutilised 'lay' knowledge, can underpin ways forward to address wicked (health) problems (11, 14). However, the extent to which such knowledge is created might depend, at least partly, on the type of Citizen Science approach applied. Table 2 shows the potential knowledge benefits of different Citizen Science approaches, assuming that the extent to which citizens or communities play an active part in a project has an impact on these potential benefits.

The role of Citizen Science in attaining socially robust knowledge is illustrated by the cases in this thesis. In Vught, it was the development of a joint vision, with residents and other stakeholders, on a healthy living environment, and the application of that vision on an infrastructural plan, that created the basis for adaptation of the infrastructural plan. In Amsterdam, the local professionals had the impression that residents (Chapter 7) underutilized available local health assets. Studying the neighbourhood with residents provided the 'insider's view' of residents regarding these assets but also enhanced the citizen scientists' abilities to interact with their environment: a first step towards socially robust knowledge and, at the same time, towards improvement of the situation observed by the professionals.

**Table 2.** Citizen Science approaches and potential knowledge benefits

Approaches	Potential knowledge benefits		
	Insiders' knowledge	Contextual knowledge	Socially robust knowledge
E. Extreme Citizen Science. Citizens in charge from problem definition, data collection and analysis, to interpretation and knowledge development	++	++	++
F. Participatory science: Participation of citizens in problem definition and data collection	++	++	++
G. Distributed intelligence c) Citizens as basic interpreters d) Volunteered thinking	+-	+-	--
H. Crowd sourcing c) Citizens as sensors d) Volunteered computing	+-	--	--

Improving the knowledge base for HiAP by applying Citizen Science is a new -and promising- perspective, rather than regular practice. Much still needs to be developed, experimented, and evaluated. An example of a work field where Citizen Science may develop is neighbourhood auditing. The scoping review on instruments currently applied in this work field (Chapter 6) showed that, in these instruments, the focus is on expert views, rather than on the lived experience of residents. The 'objectiveness' of expert evaluation of a neighbourhood seems to be core and there is a strong focus on inter-rater reliability. For these audits to yield socially robust knowledge, residents would need to be engaged, not merely as informants, but as partners in the auditing process. The scoping review showed that first steps are taken to design more participative auditing instruments and procedures aiming at production of enriched, socially robust, knowledge.

### ***Potential benefits for citizen scientists***

As explained in Chapter 2, public health Citizen Science may contribute to health promotion goals. The benefits for citizen scientists, as included in the model developed, are increased health literacy, empowerment, community building, social capital, social learning, trust, and changes in attitudes, norms and values. More indirectly, the model (Figure 1) shows that impacts can be expected on the citizen scientists' Sense of Coherence (SOC) and participation in public health governance.



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

The case studies about citizen scientists in Amsterdam (Chapter 3) and about Health Impact Scoping in Vught (Chapter 5) illustrate how these benefits may materialize. In both cases, the participants reported to have enhanced their knowledge about health and the impact, on health, of the living environment. In Amsterdam, health literacy was increased. In Vught, there was an impact on mutual understanding, based on respect and trust between residents and other stakeholders. In Amsterdam, the citizen scientists extended their social networks beyond their own cultural group. In both cases, the participants felt empowered by the process, being listened to, having learnt new skills, and being placed in a new position as ‘experiential experts’. Attitudes, in particular attitudes regarding other people, like other cultural groups (Amsterdam) or national and local stakeholders (Vught) changed: working and communicating with one another, as well as joint learning helped to create a sense of deepened understanding. The topic health was, in both cases, experienced as an issue that helps connect people with different (cultural or professional) backgrounds.

Not all benefits were measured or otherwise assessed in both studies (Table 3). Moreover, as explained in Chapter 3, in reality, different impacts are intertwined with one another and hard to separate as depicted in the model. However, the model proved to be a good framework as a starting point for analysis, as it helps identify impacts while also showing how these are linked to one another.

The scoping review on community participation in HIA (Chapter 4) revealed that similar impacts are expected on the communities engaged in HIA, in particular empowerment. However, it is also clear that exactly these impacts are not well documented as yet.

**Table 3.** Impacts measured in case studies in Vught (A) and Sloterveer (B)

Benefit	8. Active participation in health governance	9. Sense of Coherence	4. Health literacy	5. Empowerment	6. Community building, social capital, social learning, trust	7. Changes in attitudes, norms, values
Measured	-	B	B	-	-	-
Otherwise assessed	B	-	-	B, A	B, A	B,A
Not assessed	A	A	A	-	-	-

The impacts on SOC were evaluated in the case study in Amsterdam by measuring SOC before and after using the SOC-13 scale; no significant change in SOC could be detected. There are indications that health promotion interventions do have the potential to strengthen SOC, by helping the target group to identify everyday life stressors and the resources that could help address these stressors (15). For Citizen Science approaches to have this impact, therefore, they would need to be directed differently and it is questionable whether this is a requirement that can be met in the framework of HiAP focused Citizen Science work. However, they could identify stressors and resources on a community level that may then be addressed by other intervention strategies.

It is unclear to what extent active participation in governance was stimulated – this was not looked into in the studies in Vught and Amsterdam. It must be noted however, that in both cases, the citizens participating expressed doubt about future policy development and what influence they would be able to exert on these policies. The scoping review on community participation in HIA showed that it is common, in the field of HIA, to expect that participation stimulates policy engagement in the longer run. However, this still needs to be demonstrated in practice – evaluation on this issue is still lacking. One important condition may be sustained engagement in the Citizen Science process and embedment in broader HiAP strategies. Community health promotion requires a long-term approach as activating and sustaining community groups takes time (16). The same may be true for Citizen Science as a practice promoting both health and engagement in health governance.

### 8.2.3 Challenges for citizen engagement in developing a HiAP knowledge base

The studies in this thesis showed that Citizen Science for HiAP, as a novel practice, deserves further development. Two challenges need to be addressed regarding the participation of communities: firstly, which community members to engage and, secondly, how to engage these community members. A third, more fundamental, challenge relates to the scientific and societal quality of the research.

The first challenge refers to the selection of citizen scientists: finding and inviting the right people. Different groups may also have different interests, knowledge and capabilities. The Vught case (Chapter 5) showed that residents engaged felt that a broader group should have been invited. The chapter on the scoping review about community participation in HIA (Chapter 4) showed that several authors were concerned that selected participants might not represent the community or that they would be unfit to meaningfully participate. They stated that this might lead to tokenism or to making communities responsible for decisions that harm their wellbeing. The professionals interviewed in the underprivileged Sloterveer neighbourhood in Amsterdam (Chapter 7) expressed a similar concern about the abilities of the local community to identify and use neighbourhood assets. However, Chapter 3 shows an example of an effective Citizen Science project in that same neighbourhood where residents, as citizen scientists, provided valuable input. When starting a Citizen Science project it is necessary to be precise in defining what exact groups will be engaged, because different groups may have different interests, insights and needs. In any given case of citizen engagement in knowledge development for HiAP it will be necessary to 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. Health promotion focusing on addressing community needs, in general, has to deal with such (ethical as well as practical) questions (17), and Citizen Science approaches for HiAP are no exception here.

Secondly, when it is clear who should participate, 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. This may necessitate cooperation with local community development work and community health work as performed in the case in Sloterveer (Chapter 3). One promising way is also to engage (trained) community key persons (18). However, more is needed if Citizen Science is to support HiAP. Participation should entail more than merely collecting data, for example discussing research questions and analysis. There needs to be an ongoing dialogue about shared –or disputed– knowledge between researchers and citizen scientists. The results of the research should be shared and an

action perspective should be included (19). Here, once again, it is possible to build on the wealth of experience and knowledge available in health promotion, in particular in Participatory Action Research (PAR) (20), as this approach inherently combines research with a focus on action for health improvement.

On a more fundamental level, questions might be raised about the quality of the research carried out with communities or citizens (21). There are different strategies that may offer solutions to ensure scientific quality. First of all, to be clear about the goals of the research. It makes a difference if it is aimed, for example, at collecting and comparing (epidemiological) data or at deepening insight into the experiences of local people. The typology of Citizen Science (Chapter 2) shows different Citizen Science aims and approaches. Secondly, the methods should be clear, including the role of the citizen scientists. Basically, this is not different from any other quality requirements for research. The scoping review on HIA (Chapter 4) showed that the methods applied in this field seem to lack theoretical and empirical underpinning.

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. Once again, this requirement does not only refer to Citizen Science projects, but to other research as well (22). The challenge, however, would be to develop evaluation tools or methods that are fit for Citizen Science projects in relation to HiAP. Current evaluation tools, for example as developed by the Evaluating Research in Context (ERiC) partnership in the Netherlands (23) are rather generic and do not explicitly include community benefits. Moreover, in public health currently the results of collective approaches are often measured at the individual level. Herens (24) provides an example of multilevel evaluation of community interventions that may be helpful, assessing results on the individual, group, community and program level. Similar evaluative frameworks could be developed for Citizen Science projects, including 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.

### **8.3 STRENGTHS AND LIMITATIONS**

A strength of the research carried out as the basis for this thesis is the combination of different methods. A theoretical exploration was carried out, as well as qualitative field studies and scoping reviews. Moreover, different qualitative methods were applied. In

one of the case studies, qualitative methods were combined with the application of a questionnaire.

Access to lay knowledge and experience, adding depth and richness to available (epidemiological) knowledge is one of the benefits of Citizen Science. The qualitative perspective applied in this thesis links up with this aspect; therefore it is a suitable approach to explore Citizen Science application for HiAP.

Two of the three case studies in thesis were carried out as Citizen Science projects. The method applied to evaluate these case studies can be categorized as Participatory Action Research. This is, again, an approach that suits the topic. Citizen Science is a joint effort between scientists and lay people; in Citizen Science approaches for HiAP this includes public health (and other) professionals as well. Therefore, not only communities or citizens take on a new role, the same is true for both the researcher and local professionals. In this case, there was a close connection between the researcher, professionals and the group studied: the researcher conducted focus groups and interviews, but was also present at important meetings of the citizen scientists groups. This is a second strength of the research underlying this thesis. Brown (25) describes how, in environmental health research with local communities, the personal commitment of the researcher to the community involved and aspects like empathy and trust are important factors determining the quality of the research. The impact of shifting roles of researchers, professionals and citizen scientists is a topic that was not studied in this thesis. However, it is a topic that deserves attention in further work developing Citizen Science approaches for HiAP.

A limitation of this thesis is that the case studies were small scale, local field studies that did not specifically address all possible benefits and challenges for Citizen Science in the framework of HiAP. To be able to draw more generic conclusions about the impacts of Citizen Science in practice, more extensive research over longer times and in more places is needed. However, Citizen Science is just developing. It seems realistic to expect that this kind of broader evaluation will only be possible in several years.

A second limitation, for the scoping reviews, is the search strategy which was focused on publications in English, therefore possibly missing relevant publications in other languages. As scientific literature is published more and more often in English, it is not very probable that this may have seriously influenced the outcomes of the study; however, additional research in different languages may be useful in future, in particular looking into smaller, locally based projects.

## 8.4 CITIZEN SCIENCE FOR HIAP – WAYS FORWARD

This thesis has explored Citizen Science approaches as a way to support HiAP. It shows that the Whole of Society approach, needed for effective HiAP (26) may be enriched by including communities and citizens in the knowledge basis underpinning this approach. The socially robust knowledge thus produced can be important input to effectively address health challenges. The thesis showed that a variety of methods may be applied in Citizen Science in the framework of HiAP, but also, that theoretically and practically underpinning the methods still needs attention. The thesis also provides insight in possible benefits for the citizen scientists. Citizen Science in the field of public health links up with asset-based approaches, recognizing and enhancing the abilities and skills of communities and citizens to address health challenges. More fundamentally, Citizen Science, as a participatory research practice, links up with important societal values underpinning health promotion: democracy, transparency in decision-making and equity. Citizen Science may help ensure that the concerns of citizens and communities are heard and legitimized. Labonte (16) argues that truly empowering health promotion, or in his words, ‘transitive’ empowerment, taps into the complexity of daily life experiences of citizens. The Dutch Social and Cultural Report 2014 describes that underprivileged groups with little social, cultural, economic and personal capital experience discomfort with differences in society (27). One aspect of that discomfort is distrust in scientists, whom they perceive as part of a societal elite. As demonstrated in this thesis, participation in Citizen Science may benefit these groups by increasing their knowledge, social networks and strengthening their influence on local decision-making, in short, it may increase their societal opportunities. Moreover, dialogue between scientists and these groups may, in itself, be useful in the light of creating a better mutual understanding. Whether this will decrease their generic sense of discomfort remains a question. Still, it seems worthwhile to explore the possibilities that Citizen Science has to offer for these groups – preferably in a bottom-up process.

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. This requires substantial input in terms of time, attention and possibly budgets. However, it may provide important contributions to the resolution of current wicked health problems. Four strategic directions are important:

- 1) Methodological innovation in research underpinning HiAP is necessary, firstly in terms of improving the balance between qualitative and quantitative methods.

The knowledge base for HiAP, to be supportive for the Whole of Society approach needed to address wicked health problems, needs to provide a multidimensional perspective. Such a perspective connects quantitative and epidemiological knowledge with qualitative knowledge, including lay, local and traditional knowledge of communities and citizens. Secondly, innovation may come across 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 is a necessary requirement to ensure that the approach yields the benefits described in this thesis. In particular, (experiential) learning is a key element in Citizen Science for HiAP, especially where underprivileged groups are concerned. Methods to enhance abilities of communities and citizens to act as co-researchers need to be further developed and tested in practice. Investing in citizen scientists does not only yield better or more (contextual) knowledge; it may also aim at creating community capacity, knowledge and skills as well as community networks that support community engagement in local HiAP processes.
- 3) Connecting Citizen Science approaches with broader HiAP strategies is needed if the knowledge developed with and by communities and citizens should contribute to these strategies. Reversely, HiAP strategies should rely on a knowledge base built by applying different methodologies, including Citizen Science approaches.
- 4) Finally, evaluation of community participation in creating a HiAP knowledge base is needed. In such evaluation, both societal and scientific quality should be addressed. Moreover, it should be multiperspective (community/citizen, policy, professional and other stakeholder perspectives), multidimensional (process, methods and outcomes) and multilevel (individual, group, community and program or policy). Such evaluation requires a mixed method approach (28, 29), perhaps involving the target groups engaged in the projects; community based evaluation may further empower these groups (30). The benefits of Citizen Science model presented in Chapter 2 could serve as a starting point for a framework for evaluation of HiAP Citizen Science approaches.

Box 2 shows a summary of the recommendations for policy, practice and research.

**Box 2.** Summary of recommendations for policy, practice and research

**General recommendation**

- Detect gaps in the HiAP knowledge base in cooperation with all stakeholders, including communities, and discuss how these stakeholders could contribute to address these knowledge gaps.

**Recommendations for policy**

- Broaden up the knowledge basis for decision making with knowledge developed by carrying out Citizen Science projects;
- Stimulate the development of such knowledge, for example by commissioning community based Health Impact Assessment of proposed policies, programmes or projects;
- Stimulate the formation and ongoing support of community groups that could contribute to knowledge development for HiAP.

**Recommendations for practice**

- Develop asset-based approaches with the target groups using joint knowledge development with these target groups as a strategy;
- Support communities in building skills for knowledge creation.

**Recommendations for research**

- Carry out experiments with various innovative Citizen Science approaches;
- In research design, planning and budgeting, consider the options for engagement of citizens in the research process;
- Plan ‘valorisation’ of knowledge production with communities: contribution to broader HiAP strategies and continued community engagement after finalization of research projects;
- Develop (participatory) evaluation frameworks and methods for HiAP Citizen Science projects.

## 8.5 IN CONCLUSION

This thesis has explored the methods, benefits and challenges of applying Citizen Science approaches in developing a HiAP knowledge base. This was the first exploration around this topic, as far as known.

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.

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# SUMMARY





## 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.



## SAMENVATTING (SUMMARY IN DUTCH)

Integraal Gezondheidsbeleid (IGB), een horizontale beleidsstrategie waarin alle relevante (beleids)sectoren samenwerken, wordt internationaal beschouwd als een hoeksteen van de gezondheidsbevordering. Effectief IGB vraagt om zowel een ‘Whole of Government’ aanpak, dat wil zeggen samenwerking tussen beleidsmakers, als een ‘Whole of Society’ aanpak, ofwel samenwerking met en tussen stakeholders in de samenleving. In Nederland is er al sinds de jaren ‘80 van de vorige eeuw sprake van IGB. In eerste instantie lag de nadruk op de samenwerking tussen actoren binnen het beleid; tegenwoordig wordt dit echter aangevuld door een nationaal programma waarin de samenwerking met maatschappelijke partners centraal staat. Dit proefschrift gaat over de mogelijke rol van Citizen Science, ofwel burgerwetenschap, als manier om bij te dragen aan de kennisbasis voor IGB, in het bijzonder aan de Whole of Society aanpak. Citizen Science, dat wil zeggen de actieve bijdrage van burgers aan wetenschappelijk onderzoek, sluit aan bij de *asset benadering* en burgerparticipatie die belangrijke elementen zijn in de moderne gezondheidsbevordering.

De kernvragen van het proefschrift waren:

*“Wat zijn mogelijke methoden om burgers te betrekken bij het ontwikkelen van de kennisbasis voor Integraal Gezondheidsbeleid (IGB) en wat zijn de uitdagingen en voordelen die deze betrokkenheid biedt?”*

Het proefschrift is gebaseerd op een aantal onderdelen. Allereerst is een theoretische verkenning rond de toepassing van Citizen Science in de publieke gezondheid uitgevoerd. Ten tweede zijn twee empirische studies uitgevoerd aangaande toepassing van Citizen Science in Nederland. Ten derde zijn twee literatuurstudies volgens de ‘scoping review’methode uitgevoerd. Ten slotte is een studie uitgevoerd waarin percepties van gezondheidsprofessionals in een wijk in een Nederlandse stad centraal stonden.

**Hoofdstuk 1** geeft een overzicht van de achtergronden van IGB als strategie om gezondheid te bevorderen en complexe problemen, de zogenaamde ‘wicked problems’ aan te pakken. Zulke problemen, zoals de overgewicht-epidemie en de hardnekkige gezondheidsverschillen tussen mensen met verschillende sociaaleconomische posities, kunnen alleen aangepakt worden door samenwerking en afstemming tussen verschillende werkvelden. IGB vereist een ‘Whole of Government’ benadering: beleidsactoren bundelen hun krachten om maatschappelijke uitdagingen het hoofd te

bieden. Daarnaast is een 'Whole of Society' aanpak noodzakelijk waarin maatschappelijke actoren, waaronder ook burgers en buurten<sup>4</sup>, meedoen.

De participatie van burgers en buurten is een centrale actielijn in de gezondheidsbevordering. Naarmate burgers en buurten meer betrokken worden bij de gezondheidsbevordering beginnen onderzoekers en gezondheidsbevorderaars ook te overwegen hoe de kennisbasis aan dit nieuwe paradigma kan worden aangepast. Het betrekken van burgers en buurten in kennisontwikkeling voor IGB kan cruciale contextuele en lekenkennis opleveren waar IGB op voort kan bouwen. Bovendien sluit deze burgerbetrokkenheid aan bij noties omtrent kennisdemocratie.

Het hoofdstuk sluit af met het presenteren van de onderzoeksvragen die aan het proefschrift ten grondslag liggen:

*“Wat zijn mogelijke methoden om burgers te betrekken bij het ontwikkelen van de kennisbasis voor Integraal Gezondheidsbeleid (IGB) en wat zijn de uitdagingen en voordelen die deze betrokkenheid biedt?”*

## **Overzicht van het proefschrift**

Het proefschrift bestaat uit zes hoofdstukken, gebaseerd op de zes studies waarin methoden, voordelen en uitdagingen van Citizen Science in de publieke gezondheid op verschillende manieren worden onderzocht. Tabel 1 geeft een overzicht, per hoofdstuk, van deze studies. Een theoretische verkenning van de mogelijke toepassing van Citizen Science in de publieke gezondheid public health is uitgevoerd om een algemeen beeld te geven van soorten Citizen Science en hun mogelijke voordelen voor de publieke gezondheid (Hoofdstuk 2). Twee empirische studies zijn uitgevoerd waarin de toepassing van Citizen Science is geëvalueerd (Hoofdstuk 3 en 5). Twee literatuurreviews volgens de 'scoping review' methode zijn uitgevoerd om de literatuur over twee specifieke toepassingsgebieden van Citizen Science te onderzoeken: Health Impact Assessment, ofwel gezondheidseffectschatting, (Hoofdstuk 4) en wijkschouw (Hoofdstuk 6). Eén empirische studie betrof de percepties van professionals in de gezondheidsbevordering, in een lage-SES wijk, van de kansen ('assets') die de wijk voor bewoners biedt (Hoofdstuk 7). De algemene discussie geeft, gebaseerd op de bevindingen van de deelonderzoeken, antwoord op de centrale vragen van

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4. In de Engelstalige tekst van dit proefschrift is sprake van 'communities'. Dit is een term die niet goed vertaalbaar is in het Nederlands; een community kan een geografisch bepaalde groep mensen omvatten, maar het kan ook gaan om mensen die door bijvoorbeeld gemeenschappelijke belangen of belangstelling verbonden zijn. In deze samenvatting wordt de geografische aanduiding 'buurten', dan wel 'burgers en buurten', gebruikt.

het proefschrift en presenteert aanbevelingen voor praktijk, onderzoek en beleid (Hoofdstuk 8).

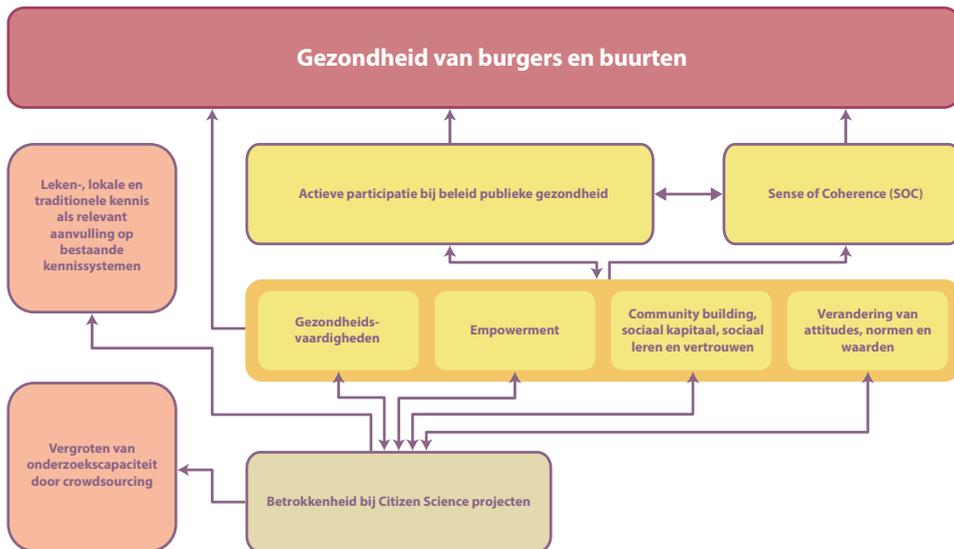
**Tabel 1.** Overzicht van de studies die aan het proefschrift ten grondslag liggen

Hoofdstuk	Onderzoeksvraag	Onderzoeksaanpak
2. Citizen Science voor de publieke gezondheid	Wat is de waarde van Citizen Science voor de publieke gezondheid?	Verkenning van de literatuur over Citizen Science in andere werkvelden en toepassing van verkregen inzichten op het werkveld van de publieke gezondheid.
3. Publieke gezondheid en Citizen Science; ervaren effecten op burgeronderzoekers. Een empirische studie in Nederland	Welke effecten hebben de burgeronderzoekers in een onderzoeksproject op het gebied van de publieke gezondheid ervaren?	Participatief actieonderzoek, bijdragend aan opzetten van Citizen Science project (concepten, methoden, en materialen). Focusgroepen, interviews, vragenlijst.
4. Community participatie in Health Impact Assessment. Een literatuurstudie volgens de scoping review methode	Hoe wordt nu aangekeken tegen de participatie van burgers en buurten in HIA en hoe wordt dit in de praktijk gebracht?	Literatuurstudie volgens de scoping review methode (wetenschappelijke en grijze literatuur) en terugkoppeling met experts.
5. Iedereen is expert! Leidt betrokkenheid van stakeholders bij Health Impact Scoping tot consensus? Een Nederlandse casus	Leidde het betrekken van stakeholders en bewoners in Health Impact Scoping tot consensus?	Participatief actieonderzoek, bijdragend aan het opzetten van scoping bijeenkomsten (methoden and concepten). Vragenlijsten, observatie, interviews.
6. Bewonersparticipatie in wijkschouw-instrumenten. Een literatuurstudie volgens de scoping review methode	Welke participatieve systematische wijkschouw-instrumenten bestaan er en welke kenmerken hebben deze?	Literatuurstudie volgens de scoping review methode (wetenschappelijke en grijze literatuur).
7. Gezondheidsondersteunende aspecten (assets) in de wijk: percepties van lokale professionals in een Nederlandse lage-SES wijk. Een kwalitatief onderzoek	Wat zijn de percepties van professionals, werkend in een aandachtswijk, over gezondheid, gezondheidsondersteunende aspecten van de wijk en de vermogens van bewoners om gezond te leven en gezond te blijven?	Interviews, nominale groepstechniek.

**Hoofdstuk 2** geeft een overzicht van de achtergronden van Citizen Science en verkent mogelijke manieren om deze werkwijze in de publieke gezondheid toe te passen. Citizen Science ontstond als eerste in de natuurwetenschappen; tegenwoordig zijn er ook toepassingen in andere werkvelden, bijvoorbeeld in historisch- en

sociaalwetenschappelijk onderzoek en in de ontwikkeling van technologie. Voorbeelden van Citizen Science projecten zijn het 'Galaxy Zoo' project waarbij leken beelden van sterrenstelsels classificeren en het Nederlandse 'Gekaapte brieven' project waarbij vrijwilligers brieven uit de 16de en 17de eeuw ontcijferen.

Citizen Science projecten kunnen op lokaal niveau of op grote schaal ('massa') worden uitgevoerd. Ze variëren van benaderingen waarbij burgers als 'sensoren' fungeren tot 'extreme Citizen Science' waarbij de burgers aan het roer staan. Het oogmerk kan zijn om 'pure' wetenschappelijke kennis te ontwikkelen, maar ook zijn er mogelijk educatieve of maatschappelijke doelen. Uit de literatuur komen drie mogelijke voordelen van Citizen Science naar voren. Allereerst wordt de onderzoekscapaciteit vergroot door gebruik te maken van de hulp van vrijwilligers. Ten tweede kan Citizen Science betere kennis opleveren door aanvullende informatie, door nieuwe onderzoeksmethoden of -protocollen en door 'sociaal robuuste kennis' te ontwikkelen. Ten derde kan Citizen Science voordelen opleveren voor de burgeronderzoekers: 'wetenschapsvaardigheid', versterking van buurten, empowerment, verandering van attitudes, waarden en normen. Bovendien kan Citizen Science burgers stimuleren om in actie te komen om hun omgeving te verbeteren. Meedoen aan Citizen Science kan ook betrokkenheid bij (lokale) beleidsvorming opleveren.



**Figuur 1.** Effecten van Citizen Science op gezondheid, gezondheidsbeleid en het kennissysteem.

De mogelijke voordelen van Citizen Science, vertaald naar het veld van de publieke gezondheid, zijn verbeeld in een model. Dit kan dienen als basis voor het verder verkennen, bestuderen en vergelijken van de mogelijkheden en beperkingen van Citizen Science in de publieke gezondheid (Figuur 1).

Er bestaan ook al vergelijkbare benaderingen in de publieke gezondheid en de gezondheidsbevordering zoals participatief actieonderzoek. Bij de verdere ontwikkeling van Citizen Science in de publieke gezondheid kunnen deze als voorbeeld dienen.

Toch zijn er zeker ook uitdagingen. Een belangrijk vraagstuk is de motivatie en selectie van deelnemers. Ook kan de representativiteit van de deelnemers in relatie tot de doelgroep problematisch zijn. Er zijn vragen aangaande de kwaliteit van het, door burgers uitgevoerde, onderzoek. Ten slotte is het nog de vraag of toepassing van Citizen Science in de publieke gezondheid daadwerkelijk zal leiden tot meer inclusief beleid - en tot betere gezondheid. Deze vragen verdienen serieuze overweging bij de verdere ontwikkeling en toepassing van Citizen Science in de praktijk van het publieke gezondheidsonderzoek.

**Hoofdstuk 3** beschrijft hoe 35 burgerwetenschappers meededen aan een lokaal Citizen Science project in de publieke gezondheid in een aandachtswijk in Nederland. Welke effecten van deze participatie hebben zij zelf ervaren?

Het doel van het project was om informatie te verzamelen over de opvattingen en visie van bewoners ten aanzien van gezondheidsbevorderende aspecten in de wijk ('health assets'). Daarnaast was het project erop gericht om de burgerwetenschappers te stimuleren om zich actief met gezondheid in de wijk bezig te gaan houden. Na een training interviewden de burgerwetenschappers medebewoners. De evaluatie van dit project werd uitgevoerd als participatief actieonderzoek; de methoden omvatten focusgroepen, interviews en een vragenlijst waarin naast vragen over de persoonlijke gezondheid en die van de buurt ook vragen stonden om gezondheidsvaardigheden en 'Sense of Coherence' (SOC) te meten. Uit de resultaten blijkt een aantal nauw aan elkaar verbonden effecten van het project op de burgerwetenschappers. Ten eerste verwierven de burgerwetenschappers een beter begrip van de brede sociale determinanten van gezondheid. Ten tweede verwierven zij nieuwe kennis over gezonde leefstijl en begonnen ze na te denken over hoe deze kennis zich verhiel tot hun huidige gewoonten. Ten derde brachten ze veranderingen in hun persoonlijk leven aan om hun gezondheid te verbeteren. Ten vierde gaven zij aan dat ze nieuwe sociale vaardigheden hadden opgebouwd en dat hun zelfvertrouwen was toegenomen. Ten vijfde breidden ze hun sociale netwerken uit waarbij ze grenzen tussen culturen doorbraken. Het zesde

effect dat de burgeronderzoekers rapporteerden was dat het project hen ertoe had gebracht om gezamenlijke actie te ondernemen om de buurt gezonder te maken. Hoewel er geen betekenisvolle veranderingen optraden in de beoordeling van hun eigen gezondheid of die van de buurt, noch in de SOC scores, bleken na het project de scores wat betreft gezondheidsvaardigheden wél significant hoger dan daarvóór.

De uitkomsten laten zien dat het project mogelijk als een gezondheidsbevorderende interventie heeft gefungeerd. Bovendien lijkt de benadering winst op te leveren voor mensen met een laag opleidingsniveau. Om deze voordelen vast te houden en versterken is echter langduriger betrokkenheid van de burgerwetenschappers noodzakelijk.

**Hoofdstuk 4** beschrijft een onderzoek over Health Impact Assessment (HIA ofwel Gezondheidseffectedchatting), een instrument dat een hoofdrol speelt bij IGB. HIA is 'een combinatie van procedures, methoden en instrumenten waarmee de effecten van beleid, programma's of projecten op gezondheid van de bevolking kunnen worden beoordeeld, evenals de verdeling van die effecten binnen de bevolking'. Het onderzoek bestond uit een literatuurstudie met behulp van de scoping review methode, om visies, methoden en ervaringen rondom de participatie van burgers en buurten bij HIA in kaart te brengen.

Een gecombineerde search in Scopus en Medline, gevolgd door het screenen van titels en samenvattingen leverde 43 artikelen uit wetenschappelijke tijdschriften op, waaronder case studies, evaluatiestudies, reviews en opiniërende artikelen.

De gegevens uit deze artikelen werden in kaart gebracht, waarbij er ruimte was om gedurende het proces, dus incrementeel, de criteria en de indeling van het gegevensbestand (de 'data chart') aan te passen. Thematische analyse van de gegevens leverde voorlopige resultaten op die ter toetsing werden voorgelegd aan vier experts. Daarnaast werd een analyse van grijze literatuur uitgevoerd.

De review liet zien dat participatie van burgers en buurten als kernelement van HIA wordt beschouwd. De belangrijkste redenen hiervoor, zoals in de literatuur genoemd, waren, ten eerste, toegang tot nieuwe of aanvullende lokale kennis, ten tweede, het in de praktijk brengen van democratische waarden, en ten derde empowerment van burgers en buurten. De resultaten lieten verder zien dat er in de praktijk grote variatie is wat betreft toegepaste methoden of combinaties van methoden. Er is meestal geen sprake van theoretische of praktische onderbouwing van de keuze voor specifieke methoden en hun geschiktheid voor toepassing bij HIA. Ervaringen met burgerparticipatie bij HIA worden meestal in positieve termen beschreven, waarbij de nadruk ligt op de waarde

van de kennis die burgers en buurten inbrengen, de samenwerking tussen burgers en andere lokale actoren en de empowerment van burgers en buurten. Het is echter vaak onduidelijk hoe deze in de case studies gerapporteerde effecten gemeten zijn.

Het hoofdstuk eindigt met de aanbeveling om participatieve HIA meer aan bestaande gezondheidsbevorderingsprogramma's en –strategieën te koppelen om hiermee de verwachte effecten ook daadwerkelijk te realiseren. Daarnaast moeten beslissingen over methoden en benaderingen voor het betrekken van burgers en buurten expliciet genomen worden op basis van theoretische onderbouwing. Ten slotte moet er gewerkt worden aan goede evaluatie van de mogelijke effecten van burgerparticipatie in HIA op kennis, buurten en beleid.

**Hoofdstuk 5** beschrijft de evaluatie van Health Impact Scoping in een kleine Nederlandse gemeente waarbij lokale actoren, inclusief bewoners, betrokken waren. In twee health impact scoping workshops werden de mogelijke gezondheidseffecten van een groot infrastructureel project bekeken. Het betrof een grootschalige aanpassing van weg- en spoorinfrastructuur waarbij een substantiële toename van passagiers- en goederentransport door het centrum van de gemeente werd verwacht. De evaluatie van deze casus was gericht op het ontstaan van consensus tussen actoren als mogelijk effect van deze workshops. De werkwijze was die van participatief actieonderzoek. Er werd gebruik gemaakt van observatie, halfgestructureerde vragenlijsten en halfgestructureerde interviews. De gegevens zijn geanalyseerd met behulp van een codeboek. De deelnemers gaven aan dat hun perspectief op gezondheid in relatie tot omgeving verbreed werd; ook rapporteerden zij dat er gedeelde perspectieven ontstonden. Desondanks bleven belangrijke verschillen bestaan. Blijkbaar was er eerder sprake van een gevoel van consensus dan van een werkelijke overeenstemming tussen deelnemers over de belangrijkste onderwerpen. De geïnterviewden gaven aan dat de soepele organisatie van de workshops, de ruimte voor eenieder om zijn/haar gezichtspunten en belangen kenbaar te maken en het onderling vertrouwen tussen de deelnemers het ontstaan van consensus bevorderden. Gezondheid en gezonde leefomgeving werden bovendien als niet-bedreigende onderwerpen beschouwd, waar iedereen mee overweg kan. Verborgene belangen, slechte communicatie door landelijke actoren en verschillende mentale modellen of denkwijzen werden gezien als barrières voor het ontstaan van overeenstemming. Men bracht dit in verband met de verschillende (professionele) rollen die eenieder te vervullen had. Desondanks hebben deze factoren het proces om tot (gepercipiëerde) overeenstemming te komen niet volledig geblokkeerd.

Concluderend kan gesteld worden dat de benadering die in deze setting is toegepast een eerste stap in de richting van meer betekenisvolle participatie bij ruimtelijke inrichting kan zijn. Gezondheid als onderwerp schijnt verschillende actoren én burgers te kunnen verbinden en hun betrokkenheid bij beleidsontwikkeling te versterken. Gezamenlijke leerprocessen boden kansen om met verschillen in rollen, denkwijzen en persoonlijke voorkeuren om te gaan. Uitgaande van de visie van de deelnemers zou het echter goed zijn geweest deze verschillen ook meteen aan het begin expliciet te maken. Het artikel eindigt met de aanbeveling om het verhelderen en accepteren van verschillen van mening en inzicht als grondregel toe te passen bij toekomstige participatieprocessen.

**Hoofdstuk 6** beschrijft een literatuurstudie volgens de scoping review methode over het onderwerp bewonersparticipatie in instrumenten voor wijkschouw. Wijkschouw is gericht op het verkrijgen van inzicht in kenmerken van wijken door deze systematisch te bezoeken en observeren. De doelen van deze studie waren om participatieve wijkschouw-instrumenten te vinden, de verschillende niveaus van participatie in instrumenten te beschrijven, een overzicht te krijgen van welke wijkenmerken deze instrumenten meten en, ten slotte, om de methoden die in de instrumenten toegepast worden te beschrijven. Eerst werd op systematische wijze naar wetenschappelijke en grijze literatuur gezocht, in, respectievelijk, Scopus en Google. De gegevens werden in een data chart ingevoerd en geanalyseerd.

De search leverde uiteindelijk 13 instrumenten op waarbij sprake was van bewonersparticipatie. In 6 hiervan waren bewoners betrokken bij dataverzameling. In slechts 2 gevallen waren bewoners betrokken bij probleemdefinitie, dataverzameling en –analyse en interpretatie van de verzamelde gegevens. De artikelen beschreven echter niet in detail hoe de bewoners precies betrokken werden. Binnen de 13 participatieve instrumenten vonden we 22 verschillende domeinen en ruim 150 subdomeinen van wijkenmerken, voornamelijk met een focus op de fysieke kenmerken van de wijk. Dit laatste betekent ook dat er sprake is van een mogelijke valkuil: deze kenmerken zijn misschien niet de juiste indicatoren die iets zeggen over gedrag van bewoners die daadwerkelijk in de geschouwde wijk wonen, noch over de sociale kwaliteit van de omgeving. De meeste van de 13 instrumenten bestonden uit papieren formulieren, doorgaans bevatten deze gesloten vragen of vragen met een in te vullen schaalverdeling. Er waren twee digitale instrumenten, één voor de tablet en één voor een kleine ('hand-held') computer. Het hoofdstuk eindigt met de aanbeveling om, ten eerste, de wijze van betrekken van bewoners in praktijken diepgaander te onderzoeken. Daarnaast zouden nieuwe methoden kunnen worden onderzocht om gedrag van bewoners en sociale kenmerken van een wijk in kaart te brengen, in het bijzonder door combinaties van tijdgebonden metingen op bepaalde tijdstippen met het beschrijven van algemene

fysieke wijkenmerken. Ten derde moet verkend worden hoe nieuwe technologieën, zoals mobiele applicaties, bredere betrokkenheid van bewoners en participatiever dataverzameling mogelijk kunnen maken. Ten slotte moet bij de ontwikkeling van nieuwe participatieve wijkschouw-instrumenten aandacht uitgaan naar een dilemma: wetenschappelijke wijkschouw is meestal minder participatief, terwijl participatieve wijkschouw niet robust en systematisch genoeg lijkt om degelijke wetenschappelijke analyse en resultaten mogelijk te maken.

**Hoofdstuk 7** beschrijft een studie waarin gezondheids- en welzijnsprofessionals in een Nederlandse aandachtswijk werden geïnterviewd over hun opvattingen over gezondheid en gezondheidsbevorderende aspecten ('health assets') in deze wijk. In een aandachtswijk is sprake van een opeenstapeling van sociale (inclusief gezondheid) en economische uitdagingen.

Een gevariëerde groep van 21 professionals is geïnterviewd om een breed scala van verschillende visies en benaderingen in beeld te brengen. Er werd gebruik gemaakt van een halfgestructureerd interviewprotocol. Om uit te leggen wat 'assets' zijn en om de professionals uit te dagen om na te denken over veel verschillende soorten assets in de wijk gebruikten wij het 'Wiel van Egan', dat zeven dimensies van een wijk omvat. Zeven van de geïnterviewde professionals deden na het interview ook mee in een Nominale Groeps Techniek (NGT) sessie die georganiseerd werd om de resultaten te toetsen.

De studie liet zien dat de professionals een brede opvatting over gezondheid hadden en dat ze daarbij vooral de nadruk legden op de sociale aspecten van gezondheid en van gezondheidsgedrag, bijvoorbeeld het belang van onderlinge hulp en steun tussen bewoners. Tegelijk bleken de professionals de bewoners als ongezond te beschouwen. De professionals zagen verschillende fysieke wijkenmerken, zoals groenvoorzieningen, als assets voor gezondheid, maar spraken ook vaak over aspecten als slechte woningen en afval op straat die de gezondheid juist schaden. De professionals beschouwden de diensten die voor bewoners in de wijk beschikbaar waren, waaronder ook hun eigen aanbod, als belangrijke ondersteuning voor gezondheid, hoewel ze ook twijfels hadden over in hoeverre dit aanbod effectief en bereikbaar genoeg was. Volgens de professionals was de sociale kwaliteit van de wijk onvoldoende en zou deze dringend verbeterd moeten worden. De professionals benadrukten dat zij vonden dat bewoners onvoldoende vaardigheden en kennis hadden om gezond te kunnen leven en gaven hier veel voorbeelden van. Zij vonden dat armoede, werkloosheid en gebrek aan scholing gezond gedrag belemmerden en het de bewoners onmogelijk maakten optimaal gebruik te maken van de assets voor gezondheid in de wijk. De professionals zagen het versterken van collectieve kennis en vaardigheden, bijvoorbeeld door

groepsmatige gezondheidsbevordering of door het ondersteunen van zelforganisatie van bewoners, als goede mogelijkheid om de gezondheid van bewoners te verbeteren. Ze gaven daarbij aan dat dit wellicht zinvoller zou zijn dan gezondheidsbevordering via een één-op-één benadering.

**Hoofdstuk 8** vat de resultaten van de voorgaande hoofdstukken samen. Het hoofdstuk bevat aanbevelingen ten aanzien van toekomstige toepassing van Citizen Science voor IGB. Omdat de participatie van burgers in de kennisproductie voor IGB nog nieuw is zijn gestandaardiseerde methoden om deze participatie tot stand te brengen en te realiseren nog niet beschikbaar. Bovendien is er veel variatie wat betreft soorten Citizen Science, doelen en het nagestreefde niveau van participatie. Deze aspecten hebben ook invloed op de toe te passen methoden. Tot slot kan het onderzoeksonderwerp van een Citizen Science project implicaties hebben voor de manier waarop burgers en buurten worden betrokken. Om al deze redenen zijn er misschien specifieke methoden en aanpakken voor Citizen Science ten behoeve van IGB nodig.

### **Citizen Science methoden en -aanpakken**

Uit de case studies met bewoners en andere stakeholders, het onderzoek onder professionals in Slotermeer en de scoping reviews die voor deze dissertatie zijn uitgevoerd komen twee belangrijke aspecten naar voren die betrekking hebben op methoden voor Citizen Science in relatie tot IGB. Ten eerste blijkt leren een belangrijk onderdeel te zijn van IGB-gerichte Citizen Science. Verbeterde vaardigheden, nieuwe kennis en toegenomen 'scientific literacy' zijn belangrijke effecten en zelfs vaak een expliciet doel van Citizen Science in het algemeen. Het leren in Citizen Science is 'experientieel', dat wil zeggen dat het leerproces actiegericht is en dat dit leerproces wordt gestimuleerd door de overgedragen kennis, concepten en modellen te toetsen aan, en verrijken met, de eigen concrete ervaringen van de burgerwetenschapper. In het kader van IGB zouden onderzoekers en andere belanghebbenden, zoals de professionals voor wie asset benaderingen nog moeilijk in de praktijk te brengen zijn, eveneens betrokken kunnen worden bij deze leerprocessen.

Ten tweede blijken groepsbenaderingen van belang te zijn. Deze bevorderen het tot stand komen van netwerken van burgeronderzoekers die ook kunnen bijdragen aan de kracht van buurten en de bewoners daarvan. Dit aspect sluit aan bij de theorie en praktijk van de gezondheidsbevordering. De groepen die ontstaan door Citizen Science projecten kunnen ook een mechanisme vormen waardoor bewoners partners kunnen worden in IGB.

## **Voordelen en uitdagingen van Citizen Science benaderingen**

Dit proefschrift laat zien dat Citizen Science, naast -mogelijke- vergroting van de onderzoekscapaciteit, bijdraagt aan kennisontwikkeling door het toevoegen van contextuele informatie en 'insiders' kennis die belangrijk zijn voor het ontwikkelen van IGB strategieën. Bovendien kan Citizen Science bijdragen aan het tot stand komen van sociaal robuuste kennis, dat wil zeggen gedeelde kennis die ontstaat in een iteratief proces tussen wetenschappers, samenleving en burgers. Zulke kennis kan helpen om te bepalen welke wegen bewandeld moeten worden om complexe ('wicked') problemen aan te pakken.

De case studies en de scoping reviews laten ook zien welke uitdagingen er zijn ten aanzien van de betrokkenheid van burgers en buurten. Ten eerste komt de vraag, wie dan precies betrokken moeten worden, steeds weer naar voren. Bij kennisontwikkeling voor IGB moet voorkomen worden dat de rol van de burgeronderzoeker slechts een symbolische is; alle stemmen moeten gehoord kunnen worden. Het is belangrijk te bekijken welk mandaat deelnemers hebben om te spreken namens hun buurt of groepen daarbinnen. Ten tweede is een vraag hoe personen en groepen te bewegen tot deelname en hoe te zorgen dat hun betrokkenheid beklijft. Vooral is specifieke expertise rondom het betrekken van achterstands- of gemarginaliseerde groepen van belang. Een veelbelovende aanpak lijkt daarnaast te zijn om lokale professionals of (getrainde) sleutelpersonen uit de buurt te betrekken. Voor blijvende betrokkenheid van burgeronderzoekers is bovendien niet alleen een voortgaande dialoog over gedeelde, of juist betwiste, kennis tussen hen en de onderzoekers nodig, maar ook actiegerichtheid.

De derde uitdaging betreft de kwaliteit van de geproduceerde kennis. Citizen Science voor IGB streeft een maatschappelijk doel na, namelijk het samen met belanghebbenden ontwikkelen van integrale aanpakken voor gezondheid. Kwaliteit betekent daarom niet alleen wetenschappelijke, maar ook maatschappelijke waarde. Dit houdt in dat het onderzoek niet alleen voor de deelnemers nuttig moet zijn, maar ook voor een bredere groep belanghebbenden die betrokken zijn bij integrale 'Whole of Society' aanpakken. Mogelijk kunnen nieuwe evaluatieraamwerken voor Citizen Science projecten worden ontwikkeld, die kunnen worden gebruikt om zowel de wetenschappelijke waarde als de bijdrage aan burger- en stakeholder netwerken voor IGB in kaart te brengen.

## **Hoe verder**

De verschillende hoofdstukken in dit proefschrift overziend lijkt de conclusie gerechtvaardigd dat Citizen Science zeker kan bijdragen aan IGB. Citizen Science moet

echter niet gelijkgesteld worden aan 'goedkope dataverzameling' of 'gemakkelijke wetenschap'. Om de mogelijke bijdrage van Citizen Science aan IGB te realiseren moet de benadering verder ontwikkeld worden. In het proefschrift worden vier ontwikkelingsrichtingen aanbevolen:

- 1) Methodologische innovatie door een betere balans tussen kwalitatieve en kwantitatieve methoden en door technologische mogelijkheden te verkennen zoals 'quantified self' benaderingen en mobiele apps die burgers in staan kunnen stellen om eigen onderzoek uit te voeren dan wel aan grootschalige projecten mee te werken.
- 2) Investeren in burgeronderzoekers zodat zij de mogelijke voordelen ondervinden die in dit proefschrift beschreven zijn.
- 3) Verbinden van Citizen Science benaderingen met bredere IGB strategieën om deze strategieën daadwerkelijk te versterken.
- 4) Evaluatie van IGB-gerichte Citizen Science benaderingen, waarbij deze vanuit verschillende perspectieven, dimensies en niveaus beoordeeld worden.

## **Concluderend**

Het lijkt aannemelijk dat de toepassing van Citizen Science kan bijdragen aan sociaal robuuste kennis ter onderbouwing van IGB. Daarnaast kan het bijdragen aan het creëren of versterken van 'Whole-of-Society' netwerken van burgers, buurten en andere belanghebbenden, een belangrijke randvoorwaarde voor effectief IGB. Ten slotte kan Citizen Science toepassing vinden als een gezondheidsbevorderende interventie die burgers en buurten versterkt en ondersteunt bij het aanpakken van hun behoeften op het gebied van gezondheid. Citizen Science is echter nog nieuw binnen de publieke gezondheid, hoewel het overeenkomsten vertoont met bestaande aanpakken als participatief actieonderzoek. Er zijn nog vragen ten aanzien van de selectie van deelnemers en de toe te passen methoden. Bovendien moet er kritisch gekeken worden naar de wetenschappelijke en maatschappelijke waarde van de resultaten van IGB-gerichte Citizen Science projecten. De benadering moet daarom niet alleen verder ontwikkeld, maar ook in de praktijk toegepast en geëvalueerd worden.





# ADDITIONAL FILES





## CHAPTER 4

### **Additional file 1: Complete overview of scientific papers included, with abstracts**

#### ***1) MEDLINE SEARCH***

Bacigalupe, A., et al. "Health impact assessment of an urban regeneration project: opportunities and challenges in the context of a southern European city." *J Epidemiol Community Health*. 2010; 64(11): 950-955.

**BACKGROUND:** Social values and the political context have an influence on the use and spread of health impact assessment (HIA). In Spain, there is little experience in HIA but some regional governments are already introducing it. The aim of this article is to describe the health impacts of a local regeneration project to improve accessibility in a neighbourhood of Bilbao (Spain), and discuss the main difficulties, opportunities and challenges of the process, considering the specificities of the social and political context.

**METHODS:** A concurrent and prospective assessment, based on a broad model of health, was carried out following the Merseyside guidelines. A literature review, community profiling and qualitative data collection were undertaken. Profound involvement of members of the community and key informants was judged as essential in the HIA process.

**RESULTS:** The overall expected effect of the new lifts, roads, park and the rainwater collection system was positive. Uncertain or negative impacts were identified in some of those areas, and also concerning the burying of four high-voltage power lines. Historical and current characteristics of the community were highly influential on the way local people perceived the project and its impacts. Likewise, the way in which processes of planning and implementation were developing also played an important role.

**CONCLUSION:** The spread of HIA in southern European countries will depend on the progressive introduction of values underlying HIA, as well as on the promotion of intersectoral work, a better knowledge of the social model of health and community's participation in policy making.

Bourcier, E., et al. "An evaluation of health impact assessments in the United States, 2011-2014." *Prev Chronic Dis*. 2015; 12: E23.

**INTRODUCTION:** The Center for Community Health and Evaluation conducted a 3-year evaluation to assess results of health impact assessments (HIAs) in the United States and to identify elements critical for their success.

**METHODS:** The study used a retrospective, mixed-methods comparative case study design, including a literature review; site visits; interviews with investigators, stakeholders, and decision makers for 23 HIAs in 16 states that were completed from 2005 through 2013; and a Web-based survey of 144 HIA practitioners.

**RESULTS:** Analysis of interviews with decision makers suggests HIAs can directly influence decisions in nonhealth-related sectors. HIAs may also influence changes beyond the decision target, build consensus and relationships among decision makers and their constituents, and give community members a stronger voice in decisions that affect them. Factors that may increase HIA success include care in choosing a project or policy to be examined; selecting an appropriate team to conduct the HIA; engaging stakeholders and decision makers throughout the process; crafting clear, actionable recommendations; delivering timely, compelling messages to appropriate audiences; and using multiple dissemination methods. Challenges to successful HIAs include underestimating the level of effort required, political changes during the conduct of the HIA, accessing relevant local data, engaging vulnerable populations, and following up on recommendations.

**CONCLUSION:** Results of this study suggest HIAs are a useful tool to promote public health because they can influence decisions in nonhealth-related sectors, strengthen cross-sector collaborations, and raise awareness of health issues among decision makers.

Chadderton, C., et al. "Health impact assessment in the UK planning system: the possibilities and limits of community engagement." *Health Promot Internation*. 2013; 28(4): 533-543.

This paper explores the use of health impact assessment (HIA) as a means of facilitating community engagement in spatial planning. The paper discusses the background to the development of HIA as a tool for assessing the likely impact of policies and wider changes on health with a view to building those into planning and decision-making, and describes the evolution of HIA into more participatory forms. It then goes on to describe a case-study of plans for a waste incinerator in an inner-city area in the UK, where HIA was used in response to community concerns about the development as a means of building in the views of local people to the decision-making around the plan.

We describe in detail how the HIA was conducted and additional research undertaken within a timescale set by the planning processes. We discuss the difficulties involved in conducting any kind of research-based HIA so rapidly and in a situation of multiple, competing stakeholder interests. We argue that although the HIA failed to influence the final decisions in this particular instance it does, nonetheless, provide a model for how to create 'knowledge spaces' in which different perspectives and information can be brought around the table to create more democratic approaches to planning for waste.

Chilaka, M. A. "Evidence-based health impact assessment (EBHIA): a situation report." *Int J Health Plann Manage.* 2011; 26(2): 213-222.

This research was carried out to ascertain the different types and sources of evidence commonly applied to the Health Impact Assessment (HIA) process in the United Kingdom; and to also examine the factors that influence the derivation and usage of the different types of evidence. A questionnaire survey of 52 HIA practitioners who had conducted a total of 103 HIAs over a 3-year period was carried out, followed by semi-structured interviews of 11 practitioners to gain deeper insights into the questionnaire findings. Ten different sources of evidence were seen to have been applied to the HIA process. Literature review was discovered to be the most commonly utilized source of evidence, having been used by 37 out of 52 practitioners (71.2%) and in 83.5% of the 103 HIAs. Engagement with local residents was second in terms of usage by practitioners (69.2%) and expert opinion was third, having been used by 67.3% of respondents. Other sources of evidence included completed HIA reports, survey, modelling and Delphi exercises. The findings point to efforts to ensure that predictions are grounded on robust sources of evidence, although several issues need to be addressed in the pursuit of evidence-based HIA (EBHIA). Copyright © 2010 John Wiley & Sons, Ltd.

Douglas, M. J., et al. "Developing principles for health impact assessment." *J Public Health Med.* 2001; 23(2): 148-154.

**BACKGROUND:** Policies and practice in many sectors affect health. Health impact assessment (HIA) is a way to predict these health impacts, in order to recommend improvements in policies to improve health. There has been debate about appropriate methods for this work. The Scottish Executive funded the Scottish Needs Assessment Programme to conduct two pilot HIAs and from these to develop guidance on HIA.

**METHODS:** Case study 1 compared three possible future scenarios for developing transport in Edinburgh, based on funding levels. It used a literature review, analysis of local data and the knowledge and opinions of key informants. Impacts borne by different

population groups were compared using grids. Case study 2 assessed the health impacts of housing investment in a disadvantaged part of Edinburgh, using published literature, focus groups with community groups and interviews with professionals.

**RESULTS:** Disadvantaged communities bore more detrimental effects from the low transport investment scenario, in the areas of: accidents; pollution; access to amenities, jobs and social contacts; physical activity; and impacts on community networks. The housing investment had greatest impact on residents' mental health, by reducing overcrowding, noise pollution, stigma and fear of crime.

**CONCLUSION:** Although there is no single 'blueprint' for HIA that will be appropriate for all circumstances, key principles to inform future HIA were defined. HIA should be systematic; involve decision-makers and affected communities; take into account local factors; use evidence and methods appropriate to the impacts identified and the importance and scope of the policy; and make practical recommendations.

Elliott, E. and G. Williams "Developing public sociology through health impact assessment." *Social Health Illn.* 2008; 30(7): 1101-1116.

The renewed interest in 'public sociology' has sparked debate and discussion about forms of sociological work and their relationship to the State and civil society. Medical sociologists are accustomed to engaging with a range of publics and audiences inside and outside universities and are in a position to make an informed contribution to this debate. This paper describes how some of the debates about sociological work are played out through a 'health impact assessment' of a proposed housing renewal in a former coal mining community. We explore the dynamics of the health impact assessment process and relate it to wider debates, current in the social sciences, on the 'new knowledge spaces' within which contentious public issues are now being discussed, and the nature of different forms of expertise. The role of the 'public sociologist' in mediating the relationships between the accounts and interpretations of lay participants and the published 'evidence' is described as a process of mutual learning between publics, professionals and social scientists. It is argued that the continued existence and development of any meaningful 'professional sociology' requires an openness to a 'public sociology' which recognises and responds to new spaces of knowledge production.

Haigh, F., et al. "What makes health impact assessments successful? Factors contributing to effectiveness in Australia and New Zealand." *BMC Public Health.* 2015; 15: 1009.

**BACKGROUND:** While many guidelines explain how to conduct Health Impact Assessments (HIAs), less is known about the factors that determine the extent to which HIAs affect health considerations in the decision making process. We investigated which factors are associated with increased or reduced effectiveness of HIAs in changing decisions and in the implementation of policies, programs or projects. This study builds on and tests the Harris and Harris-Roxas' conceptual framework for evaluating HIA effectiveness, which emphasises context, process and output as key domains.

**METHODS:** We reviewed 55 HIA reports in Australia and New Zealand from 2005 to 2009 and conducted surveys and interviews for 48 of these HIAs. Eleven detailed case studies were undertaken using document review and stakeholder interviews. Case study participants were selected through purposeful and snowball sampling. The data were analysed by thematic content analysis. Findings were synthesised and mapped against the conceptual framework. A stakeholder forum was utilised to test face validity and practical adequacy of the findings.

**RESULTS:** We found that some features of HIA are essential, such as the stepwise but flexible process, and evidence based approach. Non-essential features that can enhance the impact of HIAs include capacity and experience; 'right person right level'; involvement of decision-makers and communities; and relationships and partnerships. There are contextual factors outside of HIA such as fit with planning and decision making context, broader global context and unanticipated events, and shared values and goals that may influence a HIA. Crosscutting factors include proactive positioning, and time and timeliness. These all operate within complex open systems, involving multiple decision-makers, levels of decision-making, and points of influence. The Harris and Harris-Roxas framework was generally supported.

**CONCLUSION:** We have confirmed previously identified factors influencing effectiveness of HIA and identified new factors such as proactive positioning. Our findings challenge some presumptions about 'right' timing for HIA and the rationality and linearity of decision-making processes. The influence of right timing on decision making needs to be seen within the context of other factors such as proactive positioning. This research can help HIA practitioners and researchers understand and identify what can be enhanced within the HIA process. Practitioners can adapt the flexible HIA process to accommodate the external contextual factors identified in this report.

Hargrove, W. L., et al. "Healthy vinton: a health impact assessment focused on water and sanitation in a small rural town on the US-Mexico border." *Int J Environ Res Public Health*. 2015; 12(4): 3864-3888.

We conducted a Health Impact Assessment (HIA) focused on water and sanitation in Vinton, TX, a small rural town on the U.S./Mexico Border. We present the Vinton HIA as a case study to inform the practice of HIA in rural limited resource communities with higher than average levels of unemployment and poverty, and limited infrastructure. Household surveys, focus groups, and interviews provided quantitative and qualitative data on water sources and quality, sanitation practices, and community health. We found that some of the current water sources in Vinton did not meet drinking water standards for total dissolved solids and arsenic; the majority of septic tanks were not managed properly; and there was a short-term risk of water scarcity due to prolonged drought in the region. Prevalent ailments reported by participants included stomach problems, diarrhea, and skin problems. These ailments can be related to arsenic and/or biological organisms in water. The positive direct and indirect health impacts of improved water and sanitation in Vinton included: reduced gastrointestinal illnesses and skin disorders; improved water quality, quantity, and pressure; reduced risks from failing septic systems; increased property value; potential economic growth; and enhanced quality of life. The negative direct and indirect impacts included: residents' initial and monthly costs; increased property taxes; increased debt by local government; and the need for ongoing support from changing elected decision makers. The unique challenges in completing this HIA included: (a) limited available data; (b) a culture of fear and distrust among residents; (c) residents' lack of education, awareness, and civic discourse regarding water and sanitation issues and their impact on public health; and (d) lack of civic discourse and participation in the democratic process. An important outcome of the HIA was the characterization of local water supplies, which motivated and empowered the community members to become more involved in civic discourse concerning their water supplies. Results are transferable to similar low-income rural communities worldwide where residents are lacking in information about their water supplies and in political "voice".

Hoehner, C. M., et al. "Page Avenue health impact assessment: building on diverse partnerships and evidence to promote a healthy community." *Health Place*. 2012; 18(1): 85-95.

The Page Avenue health impact assessment (HIA) was focused on a redevelopment in Missouri. This case study describes a comprehensive HIA led by an interdisciplinary academic team with community partners, as well as compliance with North American HIA Practice Standards. Some of the key lessons learned included: (1) interdisciplinary teams are valuable but they require flexibility and organization; (2) engaging community stakeholders and decision-makers prior to, during, and following the HIA is critical to a successful HIA; and (3) HIA teams should not be too closely affiliated with decision-

makers. It is hoped that this case study will inform future HIAs. Copyright © 2011 Elsevier Ltd. All rights reserved.

Jones, J., et al. "Local perspectives of the ability of HIA stakeholder engagement to capture and reflect factors that impact Alaska Native health." *Int J Circumpolar Health*. 2014; 73: 24411.

**BACKGROUND:** Health impact assessment (HIA) is a process used to inform planning and decision making in a range of sectors by identifying potential positive and negative health effects of proposed projects, programs, or policies. Stakeholder engagement is an integral component of HIA and requires careful consideration of participant diversity and appropriate methodologies. Ensuring that the engagement process is able to capture and address Indigenous worldviews and definitions of health is important where Indigenous populations are impacted, particularly in northern regions experiencing increases in natural resource development activities on Indigenous lands.

**OBJECTIVE:** Investigate local participant perspectives of an HIA of a proposed Alaska coal mine, with a focus on the ability of the HIA process to capture, reflect, and address health concerns communicated by Alaska Native participants.

**DESIGN:** A qualitative approach guided by semi-structured interviews with purposeful sampling to select key informants who participated in the coal mine HIA stakeholder engagement process.

**RESULTS:** QUALITATIVE DATA IDENTIFIED THREE KEY THEMES AS IMPORTANT FROM THE PERSPECTIVE OF ALASKA NATIVE PARTICIPANTS IN THE ALASKA COAL MINE HIA STAKEHOLDER ENGAGEMENT PROCESS: (i) the inability of the engagement process to recognize an Indigenous way of sharing or gathering information; (ii) the lack of recognizing traditional knowledge and its use for identifying health impacts and status; and (iii) the inability of the engagement process to register the relationship Indigenous people have with the environment in which they live. Issues of trust in the HIA process and of the HIA findings were expressed within each theme.

**CONCLUSIONS:** Recommendations derived from the research identify the need to acknowledge and incorporate the history of colonialism and assimilation policies in an HIA when assessing health impacts of resource development on or near Indigenous lands. These historical contexts must be included in baseline conditions to understand particular vulnerabilities and potential health risks and impacts. Further, HIA practitioners should recognize the range of definitions for "health" and demonstrate

this recognition throughout the stakeholder engagement process, as well as in the HIA recommendations and suggested mitigations.

Kang, E., et al. "Health impact assessment as a strategy for intersectoral collaboration." *J Prev Med Pub Health*. 2011; 44(5): 201-209.

**OBJECTIVES:** This study examined the use of health impact assessment (HIA) as a tool for intersectoral collaboration using the case of an HIA project conducted in Gwang Myeong City, Korea.

**METHODS:** A typical procedure for rapid HIA was used. In the screening step, the Aegi-Neung Waterside Park Plan was chosen as the target of the HIA. In the scoping step, the specific methods and tools to assess potential health impacts were chosen. A participatory workshop was held in the assessment step. Various interest groups, including the Department of Parks and Greenspace, the Department of Culture and Sports, the Department of Environment and Cleansing, civil societies, and residents, discussed previously reviewed literature on the potential health impacts of the Aegi-Neung Waterside Park Plan.

**RESULTS:** Potential health impacts and inequality issues were elicited from the workshop, and measures to maximize positive health impacts and minimize negative health impacts were recommended. The priorities among the recommendations were decided by voting. A report on the HIA was submitted to the Department of Parks and Greenspace for their consideration.

**CONCLUSIONS:** Although this study examined only one case, it shows the potential usefulness of HIA as a tool for enhancing intersectoral collaboration. Some strategies to formally implement HIA are discussed.

Kosa, K., et al. "Rapid health impact appraisal of eviction versus a housing project in a colony-dwelling Roma community." *J Epidemiol Community Health*. 2007; 61(11): 960-965.

**BACKGROUND:** During implementation of a community development project involving a severely disadvantaged Roma community, the community was threatened with eviction. Two scenarios, eviction with placement on the waiting list for social housing versus a replacement housing development, were identified and specified. A health impact assessment (HIA) was carried out to inform subsequent negotiations.

**AIMS:** To assess the health effects of eviction in comparison with that of a housing project for a Roma community; to make recommendations on short-term and long-term benefits of the two scenarios in order to inform the local government; and to develop a demonstration HIA that can act as a model for other disadvantaged Roma populations.

**METHOD:** A prospective assessment, based on a broad model of health, was carried out to assess health effects of a housing project compared with eviction. By design, it ensured full involvement of members of the community, local decision makers and relevant stakeholders.

**RESULTS AND CONCLUSION:** This HIA identified numerous positive and some probable negative health effects of a housing project. Despite the uncertainty around some of its predicted effects, the overall health benefit of a housing project clearly outweighed that of eviction. Although the immediate financial advantages of eviction for the municipal government are clear, this example provides further evidence to support the adoption of a statutory requirement to assess both economic and health outcomes. It also provides an example that other Roma communities can emulate.

Lester, C. and M. Temple "Rapid collaborative health impact assessment: a three-meeting process." *Public Health*. 2004; 118(3): 218-224.

A three-meeting process for collaborative health (inequality) impact assessment [H(I)IA] of a proposed new road is described in which local residents worked with professionals to produce a jointly agreed evidence-based report. Collaborative H(I)IA provided a forum for people to express fears that they believed had been ignored, and for planners to understand the concerns of the community and the health impacts of developments on the most vulnerable. The report has been passed to those who will influence the future of the road development plan and a decision is awaited.

Lester, C. and M. Temple. "Health impact assessment and community involvement in land remediation decisions." *Public Health*. 2006; 120(10): 915-922.

This paper describes a collaborative health impact assessment (HIA) of land remediation options at the site of a former smokeless fuel factory, where action had been delayed by conflict between stakeholders. The likely impacts of the processes involved on the physical and mental health of the community were examined in terms of the relevant scientific and medical literature, history of the site and evidence of local people. Although all remediation options were likely to have some adverse health effects, they could be mitigated by making choices based on the best evidence. The steering group concluded that the adverse effects of remediation would be relatively short term and

could be justified by the medium- to long-term benefits of removing toxic substances. The HIA steering group's recommendations were accepted by the project working group, resulting in the resolution of long-running conflict between the residents, activists and those responsible for site remediation, which has now commenced.

Maclennan, C. F., et al. "Derby district redevelopment in Colorado: case study on the health impact assessment process." *J Environ Health*. 2012; 75(1): 8-13.

Health Impact Assessment (HIA) is a tool that is increasingly utilized in the U.S. to shape policies that may impact the public's health. Domestic examples of HIAs and the process by which they were conducted, however, are rarely documented in the peer-reviewed literature. Through an existing relationship with the planning department in Commerce City, Colorado, Tri-County Health Department (TCHD) was able to identify a proposed redevelopment plan as a candidate for an HIA. The HIA focused on potential effects of the proposed redevelopment of Commerce City's historic Derby District on residents' physical activity and nutrition-related behaviors. This article describes the HIA process used by TCHD. Several sources of data were used, including participatory community input on walkability and safety, local health behavior data, and maps of health-influencing environmental characteristics. Using a variety of information sources including community input and local health behavior data can be useful in conducting HIAs and impacting policies. Local health departments should consider cultivating ongoing collaborative partnerships with municipal planning departments and community groups to conduct HIAs and to implement recommendations.

McCartney, G., et al. "A health impact assessment of the 2014 Commonwealth Games in Glasgow." *Public Health*. 2010; 124(8): 444-451.

**OBJECTIVE:** To influence the planning of the 2014 Commonwealth Games such that the positive impacts are maximized and the negative impacts are mitigated.

**STUDY DESIGN:** Participatory health impact assessment (HIA).

**METHODS:** A participatory HIA was performed using standard World Health Organization methods. A scoping event was held to involve decision makers in the process and to identify the key areas for consideration. A large community engagement exercise and a systematic review were conducted as part of the evidence-gathering phase. The results of the HIA were reported to the key decision makers involved in the Glasgow City Council legacy strategy.

**RESULTS:** The likely net health impact of hosting the Commonwealth Games was uncertain. It was suggested that the main mechanisms through which impacts were likely to be felt were: the economy; civic pride; engagement in decision making; the provision of new infrastructure; and participation in cultural events. A series of recommendations was produced in order to maximize positive health benefits and mitigate negative impacts.

**CONCLUSIONS:** HIA is a useful tool for engaging communities and decision makers in the public health agenda. HIAs of major multi-sport events are limited by a lack of quality evidence and the inability to predict impacts reliably. Copyright 2010 The Royal Society for Public Health. Published by Elsevier Ltd. All rights reserved.

McDowell, T. L., et al. "Working through bound liberation: a community engagement framework for health partnerships." *Prog. community health partnersh.* 2014; 8(4): 465-470.

**BACKGROUND:** A community-academic partnership was developed to implement a community-based participatory research project within Chicago's Englewood community.

**OBJECTIVES:** We explain how Mental Health Impact Assessment (MHIA) ensures that mental health and health inequities are considered in decision making by using a systematic process that engages populations most likely to be impacted by those decisions.

**METHODS:** We report on the process of developing an MHIA by engaging community partners to evaluate and predict potential mental health outcomes of an employment policy.

**LESSONS LEARNED:** We describe the principle of working through bound liberation, resulting in a bidirectional engagement between academics and community partners. We highlight lessons and challenges of our engagement process.

**CONCLUSIONS:** Effectively joining in solidarity with community partners was critical for project success, but community capacity needs to be increased to support future projects.

Mindell, J. S., et al. "A review of health impact assessment frameworks." *Public Health.* 2008; 122(11): 1177-1187.

**BACKGROUND:** Consideration of health impacts of non-health sector policies has been encouraged in many countries, with health impact assessment (HIA) increasingly used worldwide for this purpose. HIA aims to assess the potential impacts of a proposal and make recommendations to improve the potential health outcomes and minimize inequalities. Although many of the same techniques can be used, such as community consultation, engagement or profiling, HIA differs from other community health approaches in its starting point, purpose and relationship to interventions. Many frameworks have been produced to aid practitioners in conducting HIA.

**OBJECTIVE:** To review the many HIA frameworks in a systematic and comparative way.

**STUDY DESIGN:** Systematic review.

**METHOD:** The literature was searched to identify published frameworks giving sufficient guidance for those with the necessary skills to be able to undertake an HIA.

**RESULTS:** Approaches to HIA reflect their origins, particularly those derived from Environmental Impact Assessment (EIA). Early HIA resources tended to use a biomedical model of health and examine projects. Later developments were designed for use with policy proposals, and tended to use a socio-economic or environmental model of health. There are more similarities than differences in approaches to HIA, with convergence over time, such as the distinction between 'narrow' and 'broad' focus HIA disappearing. Consideration of health disparities is integral to most HIA frameworks but not universal. A few resources focus solely on inequalities. The extent of community participation advocated varies considerably.

**CONCLUSION:** It is important to select an HIA framework designed for a comparable context, level of proposal and available resources. [References: 94]

Miramontes, L., et al. "Including migrant populations in health impact assessments." *Bull World Health Organ.* 2015; 93(12): 888-889.

In 2010, there were 214 million international migrants worldwide, a number that is projected to double by 2050.<sup>1</sup> Migrants' motives for leaving their countries of origin include employment and education opportunities, escape from conflict and discrimination and the desire to raise families in economically and politically stable environments.

New migrants are often healthier than the general population on arrival, but their health may deteriorate after settlement,<sup>2</sup> due to unfamiliar social conditions, infectious

diseases, or restricted access to health services. Cultural and linguistic barriers may contribute to poor delivery of health services. The 61st World Health Assembly called on all Member States to “promote migrant-sensitive health policies”<sup>3</sup> Some subgroups – especially refugees – have a greater burden of infectious diseases and mental disorders than the indigenous population.<sup>4</sup> Guidelines have been developed to assist health workers in the clinical management of migrating populations.<sup>4</sup> However, there are no explicit decision-support tools for policy-makers to ensure health equity for migrants. Here we discuss how health impact assessment can account for the needs of migrant populations.

Mittelmark, M. B. “Promoting social responsibility for health: health impact assessment and healthy public policy at the community level.” *Health Promot Internation*. 2001; 16(3): 269-274.

The 1997 Jakarta Declaration on Health Promotion into the 21st Century called for new responses to address the emerging threats to health. The declaration placed a high priority on promoting social responsibility for health, and it identified equity-focused health impact assessment as a high priority for action. This theme was among the foci at the 2000 Fifth Global Conference on Health Promotion held in Mexico. This paper, which is an abbreviation of a technical report prepared for the Mexico conference, advances arguments for focusing on health impact assessment at the local level. Health impact assessment identifies negative health impacts that call for policy responses, and identifies and encourages practices and policies that promote health. Health impact assessment may be highly technical and require sophisticated technology and expertise. But it can also be a simple, highly practical process, accessible to ordinary people, and one that helps a community come to grips with local circumstances that need changing for better health. To illustrate the possibilities, this paper presents a case study, the People Assessing Their Health (PATH) project from Eastern Nova Scotia, Canada. It places ordinary citizens, rather than community elites, at the very heart of local decision-making. Evidence from PATH demonstrates that low technology health impact assessment, done by and for local people, can shift thinking beyond the illness problems of individuals. It can bring into consideration, instead, how programmes and policies support or weaken community health, and illuminate a community’s capacity to improve local circumstances for better health. This stands in contrast to evidence that highly technological approaches to community-level health impact assessment can be self-defeating. Further development of simple, people-centred, low technology approaches to health impact assessment at the local level is called for.

Parry, J. and A. Stevens "Prospective health impact assessment: pitfalls, problems, and possible ways forward." *BMJ*. 2001; 323(7322): 1177-1182.

#### SUMMARY POINT

- Proponents of health impact assessment claim that it can inform policy and decision making to maximise benefits and minimise negative impacts on health.
- Current health impact assessment is insufficiently rigorous to make robust assumptions on the magnitude or even the direction of the health impacts of policy interventions
- Review of the literature and consultation with stakeholders are the key tools of health impact assessment, but both have associated problems.
- Validation of the predictions of health impact assessment raises issues such as the accurate measurement of health and the use of control populations
- Local decision makers should adopt a process of mini health impact assessment, involving the use of available evidence, little quantifications, and limited consultation
- Full (maxi) health impact assessment should be undertaken only in a rigorous and effective way, involving robust methods and evaluation after implementation

Parry, J. and J. Wright "Community participation in health impact assessments: intuitively appealing but practically difficult." *Bull World Health Organ*. 2003; 81(6): 388.

Whilst ideal, participation may simply not be possible for the majority of HIAs. Those working on HIA should not apologize for this: if an assessment has not got the time or resources to bring about meaningful community participation, is it wise to attempt it at all?

Pursell, L. and N. Kearns "Impacts of an HIA on inter-agency and inter-sectoral partnerships and community participation: lessons from a local level HIA in the Republic of Ireland." *Health Promot Internation*. 2013; 28(4): 522-532.

This study evaluates the impacts of a locally based health impact assessment (HIA) on community participation, inter-sectoral and inter-agency partnership in local decision and policy-making processes. The methods comprised a series of semi-structured interviews with key informants followed by thematic analysis of transcribed responses. The study revealed a number of positive impacts among both community and service providers. A particularly advantageous impact was the facilitation of community learning through a local action group formed as a recommendation of the HIA that provided community development and HIA training. During the HIA process all participants

increased their knowledge of health determinants and recognized a broader range of evidence sources for local decision-making. Participants also developed a greater understanding of each other's roles and perspectives. Additionally, the study revealed a number of barriers to HIA. Differing views on the role of HIA were evident whereby community members tended to regard HIA as an advocacy tool for local issues impacting on health in their locality, while service providers perceived its role more in terms of networking and collaboration. A key area remaining to be tackled in terms of partnership working is the approach of service agencies to enabling meaningful community participation in local decision-making processes. In this respect, attention to the cultural dimension of inter-sectoral working, and the need for training for both service agency staff and community members prior to or at the initial stages of HIA are required. Such changes could facilitate more meaningful community inclusion and help to address the current power imbalance between these two sectors.

Rogerson, B., et al "A simplified framework for incorporating health into community development initiatives." *Health Aff.* 2014; 33(11): 1939-1947.

Community development seeks to address the consequences of poverty through initiatives that improve housing, economic opportunity, service availability, and community capacity. There is growing recognition that the fields of community development and public health have much in common with regard to target populations, objectives, and challenges. Individual and neighborhood-level poverty are well-documented risk factors for illness and premature death. But relatively few developers systematically analyze how their projects could affect the health of the target community. Tools and metrics that facilitate incorporating health into planning, financing, and implementing new community development projects and programs will foster more widespread and productive collaboration between these two fields. We propose a simple framework to facilitate the identification and measurement of potential health effects, actions to optimize anticipated positive impacts, and strategies to mitigate potential negative impacts. The framework is drawn from an analysis of health impact assessments and includes four elements: identifying the health status of the population served, considering neighborhood-level influences on health, building design features important to health, and incorporating community engagement and capacity-building activities into the initiative. Copyright Project HOPE-The People-to-People Health Foundation, Inc.

Tennant, K. and C. Newman "Greater Granville Regeneration Strategy." *N S W Public Health Bull.* 2007; 18(9-10): 169-171.

An urban regeneration health impact assessment (HIA) was conducted collaboratively with three major government agencies and the local community in 2005 and 2006 to identify health impacts of a major land use strategy outlined in the consultant's report for the Greater Granville Regeneration Plan - Stage 1 (Sydney: Hassall Pty Limited, 2005). Health impacts were identified and agreed recommendations were developed to ameliorate negative impacts, with a formal partnership agreement to progress implementation and monitoring. The Granville HIA has been influential in changing major policy initiatives of Parramatta City Council and the NSW Department of Housing, contributing to positive health outcomes for the Granville community.

Wright, J., et al. "Participation in health impact assessment: objectives, methods and core values." *Bull World Health Organ.* 2005; 83(1): 58-63.

Health impact assessment (HIA) is a multidisciplinary aid to decision-making that assesses the impact of policy on public health and on health inequalities. Its purpose is to assist decision-makers to maximize health gains and to reduce inequalities. The 1999 Gothenburg Consensus Paper (GCP) provides researchers with a rationale for establishing community participation as a core value of HIA. According to the GCP, participation in HIA empowers people within the decision-making process and redresses the democratic deficit between government and society. Participation in HIA generates a sense that health and decision-making is community-owned, and the personal experiences of citizens become integral to the formulation of policy. However, the participatory and empowering dimensions of HIA may prove difficult to operationalize. In this review of the participation strategies adopted in key applications of HIA in the United Kingdom, we found that HIA's aim of influencing decision-making creates tension between its participatory and knowledge-gathering dimensions. Accordingly, researchers have decreased the participatory dimension of HIA by reducing the importance attached to the community's experience of empowerment, ownership and democracy, while enlarging its knowledge-gathering dimension by giving pre-eminence to "expert" and "research-generated" evidence. Recent applications of HIA offer a serviceable rationale for participation as a means of information gathering and it is no longer tenable to uphold HIA as a means of empowering communities and advancing the aims of participatory democracy.

## 2) *SCOPUS search*

Benkhalti Jandu, M., et al. "The inclusion of migrants in health impact assessments: A scoping review." *Environmental Impact Assessment Review.* 2015; 50: 16-24.

This article reports the findings of a scoping review assessing the extent and ways in which migrants have been included in health impact assessments (HIAs) and HIA evaluations worldwide. A total of 117 HIAs and two HIA evaluations were included. Only 14% of hand-searched HIAs mentioned migrants, 5% analysed migrants and only 2% included them in their recommendations. Nonetheless, migrants would be expected to be part of the analysis based on the reasons for which migrants were most commonly mentioned. Although the majority of HIAs included in the review mentioned migrants in baseline conditions and impact analysis steps, migrants were seldom included in recommendations. Furthermore, the use of frameworks or tools guiding the completion of an HIA was negatively associated with the inclusion of migrants in recommendations. This is a pivotal risk of frameworks not mentioning migrants. Although workshops and stakeholder engagement were a frequent way of including migrants in HIAs, this usually involved organizations representing migrants, and only seldom included members of the migrant community themselves. The main barriers to including migrants in the HIA impact analysis were the lack of available data on migrants and the significant additional resources required to gather and analyse additional data on migrants. Guidance is needed on ways to optimally include migrants in HIAs and ensure that recommendations for mitigation measures are optimal. © 2014 .

Cameron, C., et al. "Facilitating communities in designing and using their own community health impact assessment tool." *Environmental Impact Assessment Review*. 2011; 31(4): 433-437.

Reducing health inequities and improving the health of communities require an informed public that is aware of the social determinants of health and how policies and programs have an impact on the health of their communities. People Assessing Their Health (PATH) is a process that uses community-driven health impact assessment to build the capacity of people to become active participants in the decisions that affect the well-being of their community. The PATH process is both a health promotion and a community development approach that builds people's ability to bring critical analysis to a situation and to engage in effective social action to bring about desired change. Because it increases analytical skills and provides communities with their own unique tool to assess the potential impact of projects, programs or policies on the health and well-being of their community it is an empowering process. PATH was originally used in three communities in northeastern Nova Scotia, Canada in 1996 when the Canadian health care system was being restructured to a more decentralized system. Since then it has been used in other communities in Nova Scotia and India. This paper will describe the PATH process and the use of the community health impact assessment as well as the methodology used in the PATH process. The lessons learned from PATH's experiences of

building capacity among the community in Canada and India will be presented. © 2010 Elsevier Inc.

Chilaka, M. A. "Drawing from the well of community participation: an evaluation of the utility of local knowledge in the health impact assessment process." *Community Development*. 2015; 46(2): 100-110.

Engagement with local residents is increasingly being used as a source of evidence for making health impact assessment (HIA) predictions. However, there have been criticisms about the community engagement process and the value of evidence derived from it. This study aims to investigate the constraints of engagement and to gage the usefulness of local knowledge to the HIA evidence base. Questionnaire responses were collected from 52 HIA practitioners in the United Kingdom, and interviews were conducted with 11 practitioners (8 of whom also completed the survey). Forty-two of the 52 respondents (81%) had undertaken engagement with local residents, and the techniques used for community engagement were focus groups (76%), workshops (52%), questionnaire surveys (43%), interviews (41%), and other less common approaches (14%). Interestingly, while more than one-third of the practitioners found engagement difficult, nearly all of them rated local knowledge to be a useful or very useful source of evidence. It is vital, therefore, to understand ways of minimizing the constraints encountered in the community engagement process in order to fully tap into local knowledge and strengthen the evidence base of the HIA process. © 2015, © 2015 Community Development Society.

Elliott, E. and G. Williams "Developing a civic intelligence: Local involvement in HIA." *Environmental Impact Assessment Review*. 2004; 24(2): 231-243.

Public involvement and participation in policy development and implementation is becoming an increasingly prominent feature of social life. However, as politics and policy become ever more concerned with 'evidence,' the relationship between 'expert evidence' and political judgements and decisions becomes ever more complicated. For this reason, public participation increasingly has to mean inclusion in arguments about information, evidence and knowledge as much as it means straightforward involvement in decision making. Such involvement can involve critical questioning of a kind that can challenge and sometimes debunk experts' claims to privileged understanding. One practical arena in which knowledge-based policy and politics is being expressed is in health impact assessment (HIA). This paper describes a health impact assessment of housing options in a former mining village in South Wales in order to illustrate the contributions that local people can make to both evidence and decision making. This

case study exemplifies an emerging civic intelligence that challenges a traditional demarcation between different forms of expertise and creates public spaces that provide the basis for new opportunities of democratic renewal. © 2003 Elsevier Inc. All rights reserved.

Gilhuly, K., et al. "Using health impact assessment in community development to improve air quality and public health." *Community Development*. 2011; 42(2): 193-207.

Air pollution contributes to asthma, allergies, lung function impairment, cardiovascular disease, and premature mortality. Transit-oriented development, roadway expansion, new residential and commercial development, and pollution mitigation projects impact local and regional air quality. This article discusses the use of Health Impact Assessment (HIA) by community advocates, public health and city planning departments, and regulatory agencies to ensure health impacts are considered in decision-making processes that affect air quality. HIAs encourage collaboration among diverse stakeholders, including communities facing health inequities. HIAs also use data and analysis to predict health outcomes of proposed planning and policy decisions. This article describes the collaborations, empirical assessment tools, communication and advocacy strategies, findings, recommendations, and outcomes of the following HIAs: a transit-oriented station area plan in Pittsburg, CA, grade separations funded through a policy to levy a fee on all port containers passing through major ports in California, and a freeway expansion in Los Angeles, CA. © 2011 Community Development Society.

Greig, S., et al. "Promoting sustainable regeneration: Learning from a case study in participatory HIA." *Environmental Impact Assessment Review*. 2004; 24(2): 255-267.

The object of the health impact assessment (HIA) was to inform economic development of a neighbourhood in Sheffield (England) and to use HIA as a tool to increase the participation of local communities in strategic development decisions. Community profiling and literature review was followed by analysis and prioritisation of policy and health impacts, and recommendations for policy change. A series of Standing Conferences were used to bring community, statutory and private sector perspectives together for debate. The paper reflects upon the extent to which the economic, environmental, and social HIA recommendations have been implemented, 2 years on. It concludes that most progress has been made where lobbying and action by local groups has been able to bring about change. Unsurprisingly regional and national policy making has proved harder to influence. Involvement of two community partnership groups was important in building community involvement. The learning is summarised in a 10 point list of factors which enable HIA to make a difference. It is concluded that

participatory HIA can not only assist in identifying the integrated solutions which sustainable development requires, but also helps form the partnerships and alliances required to realise such solutions. © 2003 Published by Elsevier Inc.

Harris, E. C., et al. "Humboldt county general plan update health impact assessment: A case study." *Environmental Justice*. 2009; 2(3): 127-134.

As a tool for deliberately planning for and optimizing the ways in which we design our environments, Health Impact Assessment (HIA) holds promise for achieving environmental justice and health equity. This case study describes the application of HIA to updating a rural county's General Plan. Humboldt County, California is currently considering three development plans to accommodate future population growth, and the described HIA process successfully identified and analyzed potential health outcomes associated with each. Although the General Plan Update process is not yet complete as of this writing, the HIA has already accomplished one of its initial goals, which was to build awareness of health impacts related to planning decisions among county agencies, project decision-makers, participating community members, and the general public. Another noteworthy outcome of this process, which is intended to aid in planning future equitable and just communities, was the development of the "Rural Healthy Development Measurement Tool," a tool for considering health in rural development decisions. © Copyright 2009, Mary Ann Liebert, Inc. 2009.

Iroz-Elardo, N. "Health impact assessment as community participation." *Community Development Journal*. 2015; 50(2): 280-295.

Health impact assessment (HIA) is a tool by which prospective policies and plans are evaluated for their potential impact on human health outcomes. This interdisciplinary practice uses community-based approaches to examine social determinants of health. This paper critically examines the prevailing belief that HIA practice in the US context increases community democracy, equity, and social justice through evaluations of three HIAs: Clark County (Washington) Bicycle and Pedestrian HIA, Lake Merritt BART Station Area Plan HIA (Oakland, CA), and the I-710 Corridor HIA (Southern California). By tracing community interests, I demonstrate HIA's potential as a community development tool. HIAs with a robust advisory committee; attention to social determinants of health and healthy equity; and adequate time for scoping health issues are likely protective of community. However, political pressures and limited resources easily compromise this potential, suggesting that practitioners should explicitly create community engagement plans and release the HIA in a timely manner. © Oxford University Press and Community Development Journal. 2014.

Kearney, M. "Walking the walk? Community participation in HIA: A qualitative interview study." *Environmental Impact Assessment Review*. 2004; 24(2): 217-229.

Although community participation is seen as central to the practice of health impact assessment (HIA), effective engagement of local people is notoriously difficult to achieve and risks being tokenistic. This qualitative study, set in a deprived estate in northwest England, examined how community participation in the proposed HIA of a Regeneration Masterplan would be affected by the attitudes and experiences of key stakeholders. In-depth interviews were conducted with 12 stakeholders drawn from officials, representatives and local residents linked to the regeneration programme. The results suggest that there may be a large gap between professional rhetoric and the reality of community participation, and that barriers to community participation in HIA may be substantial and institutionalised. If these barriers are to be overcome, it is essential to acknowledge the existence of this rhetoric-reality gap and to address the training and resource needs of both professionals and community members. © 2003 Elsevier Inc. All rights reserved.

Kemm, J. "The future challenges for HIA." *Environmental Impact Assessment Review*. 2005; 25(7-8): 799-807.

Health Impact Assessment has made impressive progress over the past 10 years achieving greater clarity over the nature of HIA, understanding that different methods were appropriate for different contexts and accepting that a variety of types of evidence were needed. However areas remain where further progress is needed. Much progress has been made on how HIA informs decision makers but HIA practitioners still need greater understanding of decision making processes and how HIA should relate to them. Predicting the future consequences of following different options is a key element of HIA but there is still need for more robust methods of prediction and in particular better prediction of the magnitude of impacts. Few HIA reports adequately describe the distribution of impacts between different groups and this is another area where improvement is needed. Considerable progress has been made in clarifying the role of participation in HIA but the practice has often been less impressive than the rhetoric. HIA practitioners also need to become more critical in evaluating their activities. In the future it is likely that commercial organisations and EIA practitioners will become more involved in HIA and quality control of HIA practice will become even more important. © 2005 Elsevier Inc. All rights reserved.

Kwiatkowski, R. E. (2011). "Indigenous community based participatory research and health impact assessment: A Canadian example." *Environmental Impact Assessment Review*. 2011; 31(4): 445-450.

The Environmental Health Research Division (EHRD) of the First Nations and Inuit Health Branch, Health Canada conducts science-based activities and research with Canadian Indigenous communities in areas such as climate change adaptation, environmental contaminants, water quality, biomonitoring, risk assessment, health impact assessment, and food safety and nutrition. EHRD's research activities have been specifically designed to not only inform Health Canada's policy decision-makers but as well, Indigenous community decision-makers. This paper will discuss the reasons why Indigenous community engagement is important, what are some of the barriers preventing community engagement; and the efforts by EHRD to carry out community-based participatory research activities with Indigenous peoples. © 2010 Elsevier Inc.

Kwiatkowski, R. E., et al. "Canadian Indigenous engagement and capacity building in health impact assessment." *Impact Assessment and Project Appraisal*. 2009; 27(1): 57-67.

Consultations with concerned stakeholders are a cornerstone to effective impact assessment, not only within Canada, but internationally as well. The environment is of paramount importance to Indigenous communities, as many continue to rely heavily on the land and natural resources for their subsistence, including their socio-economic, cultural, spiritual and physical survival. Indigenous communities want reassurances from governments and industry that negative impacts associated with projects, programs or policies in their territories will be minimized and that positive impacts will be maximized. Communities want to be involved in the development, implementation and interpretation of the impact assessment report to assure themselves of the environmental, social, spiritual and health impacts associated with the exploitation of the local natural resources. This paper presents efforts by the Environmental Health Research Division of the First Nations and Inuit Health Branch, Health Canada, to assist Indigenous communities in carrying out community-based research to improve health and well-being by building and supporting their capacity to identify, understand and control impacts associated with projects, programs or policies implemented within their territories. © IAIA 2009.

Mahoney, M. E., et al. "Community participation in HIA: Discords in teleology and terminology." *Critical Public Health*. 2007; 17(3): 229-241.

Core HIA documents, researchers and practitioners assert the significance of community participation in health impact assessment. Despite the rhetoric, there has been little critical examination of the role of community participation in HIA. Knowledge and debate regarding what constitutes community participation and how it may best be achieved is often confused and opinion is divided as to its usefulness and appropriateness for HIA. This paper does not seek to argue the merits or drawbacks of community participation; rather, the authors explore the origins and character of the current discord around public participation in HIA and provide a lexicon for moving practice and discussion forward. The authors argue that the origins of the participation problem stem from: (1) unexplored tensions within the Gothenburg consensus paper and other formative documents in the development of HIA; (2) inherent tensions arising from the dual origins of HIA, specifically Environmental Impact Assessment (EIA) and Healthy Public Policy (HPP); and (3) a lack of rigour and clarity relating to the terminology of community participation where community participation is used as a 'catch all' phrase for every situation without critical examination. In order to move debate forward, the authors advance a model, the Typology of Public Involvement in HIA, for guiding discussion of community participation. This model comprises a set of context-specific HIA approaches with varying degrees of public involvement. The model also presents a suite of defined terms for understanding and discussing participation.

McCallum, L. C., et al. "Advancing the practice of health impact assessment in Canada: Obstacles and opportunities." *Environmental Impact Assessment Review*. 2015; 55: 98-109.

Health Impact Assessment (HIA) is recognized as a useful tool that can identify potential health impacts resulting from projects or policy initiatives. Although HIA has become an established practice in some countries, it is not yet an established practice in Canada. In order to enable broader support for HIA, this study provides a comprehensive review and analysis of the peer-reviewed and gray literature on the state of HIA practice. The results of this review revealed that, although there is an abundance of publications relating to HIA, there remains a lack of transparent, consistent and reproducible approaches and methods throughout the process. Findings indicate a need for further research and development on a number of fronts, including: 1) the nature of HIA triggers; 2) consistent scoping and stakeholder engagement approaches; 3) use of evidence and transparency of decision-making; 4) reproducibility of assessment methods; 5) monitoring and evaluation protocols and, 6) integration within existing regulatory frameworks. Addressing these issues will aid in advancing the more widespread use of HIA in Canada. © 2015 Elsevier Inc.

Negev, M. "Knowledge, data and interests: Challenges in participation of diverse stakeholders in HIA." *Environmental Impact Assessment Review*. 2012; 33(1): 48-54.

Stakeholder participation is considered an integral part of HIA. However, the challenges that participation implies in a multi-disciplinary and multi-ethnic society are less studied. This paper presents the manifestations of the multiplicity of sectors and population groups in HIA and discusses the challenges that such diversity imposes. Specifically, there is no common ground between participants, as their positions entail contradictory knowledge regarding the current situation, reliance on distinct data and conflicting interests. This entails usage of multiple professional and ethnic languages, disagreements regarding the definition of health and prioritizing health issues in HIA, and divergent perceptions of risk. These differences between participants are embedded culturally, socially, individually and, maybe most importantly, professionally. This complex picture of diverse stakeholder attributes is grounded in a case study of stakeholder participation in HIA, regarding zoning of a hazardous industry site in Israel. The implication is that participatory HIAs should address the multiplicity of stakeholders and types of knowledge, data and interests in a more comprehensive way. © 2011 Elsevier Inc.

Negev, M., et al. "Stakeholder participation in health impact assessment: A multicultural approach." *Environmental Impact Assessment Review*. 2013; 43: 112-120.

The literature on impact assessment (HIA) registers the importance of stakeholder participation in the assessment process, but still lacks a model for engaging stakeholders of diverse ethnic, professional and sectorial backgrounds. This paper suggests that the multicultural approach can contribute to HIA through a revision of the generic 5-step HIA model, and its implementation in a metropolitan plan in Southern Israel. The health issue scoped by the stakeholders in the HIA is related to land uses in the vicinity of the national hazardous industry and hazardous waste site. The stakeholders were representatives of the diverse populations at stake, including rural Bedouins and Jewish city dwellers, as well as representatives from the public sector, private sector, non-governmental organizations and academia. The case study revealed that a multicultural stakeholder participation process helps to uncover health issues known to the community which were not addressed in the original plan, and provides local knowledge regarding health conditions that is especially valuable when scientific data is uncertain or absent. It enables diverse stakeholders to prioritize the health issues that will be assessed. The case study also reveals ways in which the model needs revisions and improvements such as in recruitment of diverse participants. This paper presents a multicultural model of HIA and discusses some of the challenges that are faced when

HIA is implemented in the context of current decision-making culture. © 2013 Elsevier Inc.

Parry, J. M., et al. "Criteria for use in the evaluation of health impact assessments." *Public Health*. 2005; 119(12): 1122-1129.

This paper reports the conclusions of a recent workshop that was established to discuss how health impact assessments (HIAs) might be evaluated. The main purposes of HIA are: (a) to predict the consequences of different decisions; (b) to make the decision-making process more open by involving stakeholders; and (c) to inform the decision makers. 'Prediction', 'participation' and 'informing decision makers' are thus the three domains in which HIA should be evaluated. In the 'prediction' domain, process criteria scrutinize the methods used to see if it is likely that they would produce reliable predictions. Outcome criteria involve verifying the predictions, but this is frequently impractical and predictions for the counterfactual (the option not chosen) can never be verified. In the 'participation' domain, process criteria examine the ways in which stakeholders were involved, while outcome criteria explore the degree to which the stakeholders felt included. In the 'informing decision makers' domain, process criteria are concerned with the communication between decision makers and those doing the HIA, and should reflect upon the relevance of the HIA content to the decision makers' agenda. Outcome criteria explore the degree to which the decision makers considered that they had been informed by the HIA. This paper concludes with suggestions for the types of information that should be included in HIA reports in order to permit the readers to make an assessment of the 'quality' of the HIA using the three domain criteria outlined above. © 2005 The Royal Institute of Public Health. Published by Elsevier Ltd. All rights reserved.

## **Additional file 2: Complete overview of ‘grey’ papers included, with abstracts**

Antigonish Town and Community Health Board. Community Health Impact Assessment Tool (CHIAT). Antigonish: Antigonish Town and Community Health Board; 2002.

The Antigonish Town and County Community Health Board (ATCCHB) has developed this Community Health Impact Assessment Tool to assist groups and organizations in thinking about what it takes to make and keep our community healthy. The factors listed in the Assessment Worksheet (page 6) are based on the priorities identified by the community during a series of 57 focus groups that were held throughout the town and county from November 1999 to February 2000. These priorities have been used by the ATCCHB to:

- Develop its Mission, Vision and Values (March 2000)
- Prepare a Community Health Plan for 2001 – 2003
- Articulate a Vision of a Healthy Community (page 2) that reflects what our community considers to be the fundamental principles against which various programs and policies can be “assessed”.

Chadderton C, et al. Involving the Public in HIA: An evaluation of current practice in Wales. Cardiff: Welsh Health Impact Assessment Support Unit;2008.

### ***BACKGROUND***

A key feature of health impact assessment (HIA) is the involvement of stakeholders and experts who may be affected, involved in the implementation of, or have specialist knowledge of the ways in which policies, programmes and projects impact on the health and well being of the population. In previous papers researchers at the Welsh Health Impact Assessment Support Unit (WHIASU) have argued that members of the public are crucial to the success of policy implementation and the holders of local knowledge and personal experience that makes a valuable contribution to HIA, whilst recognising that there may be reluctance as well as practical difficulties in involving members of the public (Elliot and Williams 2002 & 2004).

In Wales HIAs have been conducted at many levels of governance and to different degrees of depth on a range of proposals (Elliott et al 2008). Members of the public have also conducted HIAs with the support of the unit. This research presents the opportunity to assess the ways in which members of the public have been involved in HIA in Wales and the impact this has had on both the HIA itself and on the decision making process.

## ***AIMS***

A number of key research questions are addressed:

- What impact does public involvement in health impact assessment have on the processes and outcomes?
- In what ways and to what extent have members of the public/communities been involved in HIA?
- How does the public sector view public/community involvement in HIA?
- What are the differences between community initiated HIA and those in which members of the public are involved as part of the HIA process?
- What are the key enablers and inhibitors of public involvement in HIA?
- What is the role of community groups in HIA?
- What are the issues associated with public sector involvement in community initiated HIA's?

## ***METHODS***

The literature reviewed included both published and grey literature on theories of public involvement in general and its application to HIA in particular. With regard to HIA the literature reviewed included theoretical papers that considered the nature of lay and professional knowledge production in HIA, typologies of public involvement and construction of public engagement as part of wider risk assessment discourses. In addition the review included HIA reports which involved members of the public and previous empirical studies that have assessed the role of public engagement in HIA. A case study approach to the research was adopted as it was considered important by the research team to systematically present results and develop theory grounded in the experience of subjects participating in real events. Five case studies from across Wales were selected for inclusion in the research; three from North Wales and two from South and West Wales. Cases were selected in order to cover a broad range of health impact assessment topics, geographical areas, varying levels of public and community involvement and size of HIA. Twenty-eight interviews were conducted with members of the public, representatives from community and user groups and statutory and voluntary sector representatives, all of whom were involved in the health impact assessment.

## ***LESSONS FROM CASE STUDIES***

- Key benefits of public involvement in HIA are the contribution of local knowledge and personal experience, the building of relationships, empowerment and advocacy.

- Key risks are the raising of expectations, consultation fatigue, upsetting the balance of the process, only engaging with the 'usual suspects' and managing input.
- The weight and status awarded to lay views and knowledge differs depending on the HIA in question
- Enablers of public involvement include utilising existing links, the use of appropriate facilitation techniques and providing updates on the HIA
- Inhibitors include lack of time, lack of confidence, and apathetic attitude, the use of jargon and terminology that may not be user friendly, existing community tensions and mis-selling of HIA.
- Sensitivity of the issue, lack of awareness and cognitive dissonance were suggested as inhibitors from the statutory sector perspective. Community initiated HIA – A Welsh Case study example
- Community initiated HIA brings communities together for a common cause and helps to build relationships both between communities and between the public and statutory organisations
- Community initiated HIA requires some level of statutory sector involvement in order for it to be a material consideration in the planning process
- When conducted in a reliable and balanced manner, community HIA can provide a valuable evidence base and support for existing protest campaigns

### **CONCLUSIONS AND RECOMMENDATIONS**

Within Wales members of the public and representatives from community groups take an active role in health impact assessment, either through participation in HIA workshops, attending focus groups or sitting on the steering group for the HIA. The majority of the respondents who were interviewed as part of this research reported that they had found their involvement in the HIA to be a positive experience, and that they welcomed HIA as a vehicle for them to be able to voice their views to decision makers. For many this was the first opportunity they had to interact with the statutory sector in this way. Community initiated HIA was considered separately in this report due to the fact that it differs from 'top down' HIA in a number of significant ways, notably in terms of the influence and status. It is envisaged that the future of HIA in a community setting would be that communities would be in a position to be able to carry out HIAs for themselves, without the aid of an organisation such as WHIASU that supported the HIA considered within this research. However, this raises issues such as the ability of the community carrying out the HIA to maintain balanced and non-partisan viewpoint, particularly if the HIA was relating to emotive issues, as was the case here. There is a risk that communities might be considered 'over-emotional' and holding insufficient 'expert knowledge' to be able to conduct an HIA that is balanced and reliable, and both

members of the public and public sector representatives interviewed relating to this case expressed concerns that a HIA conducted solely by the community would lack the status and credibility to be used as a material consideration when making planning decisions. How this is addressed is a source of discussion but if we are looking at this HIA as an example of how to conduct such research many issues were raised that would need to be taken into consideration by other communities who may be considering using HIA as a tool for protest. As was the case with the other HIAs considered as part of this research the issue of managing input was paramount. Public and community involvement in HIA has been deemed problematic, with members of the public being seen as a barrier to change and holding insufficient knowledge to be able to make a positive contribution to the process. Public sector representatives interviewed as part of the research focused on the fact that it is members of the public who are affected by the issues or projects relating to the HIA, that the proposed changes would take place within their communities, and that they held the knowledge and value of personal experience to be able to effectively inform the HIA, and highlighted that these positive contributions outweighed any of the more problematic issues. The role of the statutory sector within HIA varies, with representatives being involved in workshops, steering groups, facilitation roles and advisory roles. Issues were raised as to the capacity of the statutory sector to engage effectively with communities. The HIA process served to build relationships both between communities and also between the public sector and members of the public as it brought into contact people who may otherwise not have interacted with one another, and enabled the sharing of viewpoints. Consultation and engagement with members of the public is increasingly encouraged within the public sector at the local, regional and national level, meaning that it is essential to build capacity for engagement on both sides in order to ensure a mutually beneficial and effective relationship.

Coady, M. Community-Driven Health Impact Assessment: A Promising PATH for Promoting Community Learning and Social Responsibility for Health". Handbook of Research on Adult and Community Health Education: Tools, Trends, and Methodologies. V. C. X. Wang. Hershey, PA, IGI Global; 2014: 17-34.

Highly participatory local health impact assessment processes can be used to identify and encourage practices and policies that promote health. They also foster community learning that can increase a community's capacity to improve local conditions for a healthier community. This chapter examines a Community-Driven form of Health Impact Assessment (CHIA) practiced in rural Nova Scotia, Canada since 1997. Experience suggests that informal learning in these processes is often transformative; ordinary citizens learn to identify factors that influence their health, to think beyond the illness

problems of individuals, and to consider how programs and policies can weaken or support community health. They learn that that they can identify directions for future action that will safeguard the health of their community.

Gauvin,FP. "Developing a Citizen-Participation Strategy for Health Impact Assessment". Montréal: National Collaborating Centre for Healthy Public Policy;2013.

## **INTRODUCTION**

Health Impact Assessment (HIA) is a practice that has generated much interest since its emergence in the 1990s. HIA can be defined as "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" (European Centre for Health Policy, 1999, p. 4). The goal of HIA is to project, with the help of scientific and contextual information, the potential impacts of policies on population health, so as to minimize the negative and maximize the positive effects.

The founding documents of HIA, and in particular the Gothenburg Consensus paper (European Centre for Health Policy, 1999), identify citizen participation as one of its cornerstones. In fact, some practitioners and researchers maintain that an HIA remains incomplete without the effective and concrete participation of the community (Dannenberg et al., 2006, p. 266). However, there seems to exist a significant gap between rhetoric and practice. In fact, not only are participatory HIA practices still limited in scope and number (Gagnon, St-Pierre & Daignault-Simard, 2010), but the very idea of citizen participation in HIA also seems poorly articulated and is sometimes called into question (Mahoney, Potter & Marsh, 2007; Wright, Parry & Mathers, 2005).

Some HIA researchers and practitioners attribute these problems, in part, to the absence of a theoretical framework or guidelines that can help orient them with respect to citizen participation (Bauer & Thomas, 2006, p. 512). Similarly, the absence of a proven method for its inclusion seems to feed criticism of citizen participation, which some view as an intangible practice and an unattainable goal (Elliott & Williams, 2008, p. 1112).

This guide is intended as a response to some of these problems. In it, we propose a framework for reflection to assist HIA practitioners who are trying to determine whether it is relevant for them to develop a citizen-participation strategy and, if so, what form this should take. Our framework for reflection is based on a review of the literature on HIA and on key documents examining citizen participation. More specifically, it will allow practitioners to:

1. Analyze the context within which an HIA is being carried out.

2. Determine the following elements:

- the objectives of the citizen-participation strategy;
- which citizens should be involved;
- the step(s) during which citizens should be involved;
- the degree of influence that citizens should exercise.

Thus, the idea is not to propose a single model of citizen participation, but rather to equip practitioners to reflect on which approach would be the most appropriate given a particular context and set of objectives. Finally, we propose a framework for evaluating the success of a citizen-participation strategy.

Gauvin FP, Ross MC. "Citizen participation in health impact assessment: overview of issues". Montréal: National Collaborating Centre for Healthy Public Policy;2012.

### ***INTRODUCTION***

During the winter of 2005, some 175 citizens and close to twenty experts participated in a wideranging dialogue aimed at generating ideas in support of a healthy Québec. These deliberations, organized by the Institut du Nouveau Monde (INM), brought to light the desire among citizens for the creation of a Bureau d'audiences publiques en santé (BAPS). Modelled on the Bureau d'audiences publiques sur l'environnement (BAPE – office of public hearings on the environment) created in 1978 in Québec, this new agency would provide citizens with a forum dedicated to assessing the potential health effects of any large scale project to be developed in the province. The citizens demanded: "That the government carry out a systematic prior assessment of the health impact of public policies and that it modify these policies to reduce their harmful effects" (Venne & Famhy, 2005, p.83) [Translation]. Such concerns have also been expressed in other Canadian provinces. On April 23, 2009, the Chair of the Capital Health Population Health Committee (Halifax region, Nova Scotia) expressed concern, in an open letter to the Chronicle Herald, about the decision to introduce new video lottery machines in Nova Scotia. The author, Dr. E. Kinley (2009), maintained that this decision had been made without sufficient public consultation and without an independent assessment of its potential impacts on population health. He urged the Nova Scotia government to institute an impact assessment that would actively involve the community prior to the adoption of any new initiative with potential health risks. According to Kinley, such an approach offers many advantages both health-related and economic: "[Such an approach] would allow decision-makers to identify the potential harmful effects

of new products, programs or policies prior to implementation, thereby preventing health issues that may result in the need for costly treatment or intervention further down the road.” (p. A13) Although these proposals did not produce the changes they recommended, they aptly illustrate two things: First, there is growing recognition that the policies of various government sectors can affect population health. Whether public policies originate from the area of lotteries or from the transportation, environment, revenue, education, daycare, or social housing sectors, they can have consequences for health and its determinants. It is thus desirable to assess their potential impacts before they are implemented. Secondly, these two events also demonstrate that both citizens and health professionals would like citizens to be able to participate in such assessments. The application of Health Impact Assessment (HIA) is a practice that has generated much interest since its emergence in the 1990s. HIA can be defined as “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” (European Centre for Health Policy, 1999). The goal of HIA is to estimate, with the help of scientific and contextual information, the potential impacts of policies on population health so as to minimize the negative and maximize the positive effects. The founding documents of HIA, and in particular the Gothenburg consensus paper (European Centre for Health Policy, 1999), identify citizen participation as one of the cornerstones of HIA. In fact, some practitioners and researchers maintain that an HIA remains incomplete without the effective and concrete participation of the community (Dannenberg, Bhatia et al., 2006, p.266). However, there seems to exist a significant gap between rhetoric and practice. In fact, not only are participatory practices in HIA still limited in scope and number (Gagnon, St-Pierre et al., 2010), but also the very idea of citizen participation in HIA seems poorly articulated and is sometimes called into question (Mahoney, Potter et al., 2007; Wright, Parry et al., 2005). The aim of this report is to introduce public health actors to the issues surrounding citizen participation in HIA. Citizen participation refers to all of the means that are used to involve, whether actively or passively, citizens or their representatives in an HIA process. Basing our discussion on a review of the literature on HIA<sup>1</sup> carried out using predetermined terms,<sup>2</sup> we will first examine the principal arguments in favour of citizen participation. We will then put these arguments into perspective, by also addressing some of the obstacles and risks associated with citizen participation in HIA.

Human Impact Partners & Group Health Research Institute. Community participation in health impact assessments: a national evaluation. Seattle, WA: Center for Community Health and Evaluation and Human Impact Partners;2016.

To date, there has been limited evaluation of the extent to which impacted communities are incorporated into U.S.-based HIA practice. There are three reasons why community participation is important to consider.

- Inherent in the values of HIA are democracy and decreasing health inequities. Participation of those most impacted by the policies and programs that affect systemic racism and poverty is key to decreasing health inequities.
- Practitioners report that success of an HIA is dependent in part upon how well impacted community and other stakeholders are engaged in the HIA.
- Resources used to engage community members in HIA differ greatly.

This evaluation offers new data related to community participation in the United States-based practice of Health Impact Assessment (HIA). The findings are intended to inform the work of HIA practitioners, but are relevant to all researchers and organizations intending to authentically engage community members in addressing policy, program, or planning solutions, as well as funders of HIA or similar types of community-based participatory research. This evaluation is the first study of its kind to assess:

#### ***OUTCOMES***

- Impact of community participation on HIA values of democracy and health equity, as measured through civic agency (see definition below)
- Impact of community participation on the success of an HIA

#### ***PROCESS***

- How HIA practitioners differ in implementation of community participation in HIAs
- Barriers and facilitating factors for meaningful community participation

Findings illustrate that there are compelling benefits of community participation in HIA, including increased civic agency in communities and increased success of HIA.

Iroz-Elardo N. Participation, Information, Values, and Community Interests Within Health Impact Assessments. Portland, OR: Portland State University;2016.

Health impact assessment (HIA) has emerged in the U.S. as one promising process to increase social and environmental justice through addressing health equity issues within planning. HIA practice is guided by values such as democracy and equity and grounded in broad social determinants of health. The most readily applied definition of democracy is problematic because it implies an element of direct, participatory engagement with the public. This is at odds with HIA practice that largely relies on stakeholder engagement

strategies. This dissertation critically examines the engagement strategies of three transportation planning HIA cases to more fully understand how the HIA process may or may not promote democratic values and protect community health interests. It employs a multi-case study design that uses qualitative content analysis to trace community health interests through the HIA process, HIA document, and target plan. It finds that while the field is overstating the participatory nature of HIA, commitments to health equity and broad determinants of health protect community health interests with and without robust engagement of community stakeholders.

Stakeholder Participation Working Group of the 2010 HIA of the Americas Workshop. *Guidance and Best Practices for Stakeholder Participation in Health Impact Assessment*. Oakland: Stakeholder Participation Working Group of the 2010 HIA in the Americas Workshop;2011.

### **PREFACE**

*Guidance and Best Practices for Stakeholder Participation in Health Impact Assessments* primarily targets health impact assessment (HIA) practitioners who are working to improve stakeholder participation and leadership in the practice of HIA. It may also appeal to community groups and stakeholders who want to more effectively participate in, lead, or influence an HIA. This guide is a collective product of the Stakeholder Participation Working Group, which emerged from the second HIA in the Americas Workshop that convened in Oakland, California, in March 2010. The working group was one of several formed around a variety of issues, and its goal was to increase the effectiveness of stakeholder participation in HIAs<sup>1</sup>. This guide distills stakeholder participation techniques, case studies, and guiding principles from various fields of expertise, including HIA, environmental and social impact assessment, land use and transportation planning, community-based participatory research, and public health. It was informed by a host of materials that can be found in Appendix C. This document also draws on the expertise and experiences of the members of the Stakeholder Participation Working Group. This is a living document that will be updated as new information becomes available.

Welsh Health Impact Assessment Support Unit. *Community Led HIA Case Study*. Cardiff: Welsh Health Impact Assessment Support Unit;2005.

The comprehensive health impact assessment examined the impact of the proposed extension to the Margam Opencast mine, located in South Wales. Residents of the villages bordering the existing opencast operations, which have been operation for many years, believe that the existing opencast working in the area had already had a

negative impact on their health, and that the proposed extension would exacerbate this further. In addition residents were concerned about the cumulative effects of exposure to pollutants from other industries within the locality including a local steelworks. The HIA arose from an approach made to WHIASU in early 2005 by a community member representing local residents who had formed an action group, PACT, to protest against the proposed extension. The HIA the planning application was being considered by two local authorities (Bridgend and Neath Port Talbot County Borough Councils). At the time of the HIA there was no statutory requirement for HIA to be undertaken on opencast proposals in Wales. The HIA was undertaken by WHIASU and the National Public Health Service for Wales (NPHS) on behalf of the Margam Opencast and Health Steering Group in December 2005.

## CHAPTER 5

### Appendix 1: Code book (final version)

<b>Code family: Definitions of health (research question a and b)</b>	
Physical condition (health defined by physiological status) (1,2)	Mental condition (health defined by (perceived) psychological status) (1,2)
Social condition (health defined by (perceived) amount of social interaction and sense of social isolation and feeling of loneliness) (1,2)	Sense of wellbeing( health defined by (perceived) general feeling regarding one's life and existence) (1)
Environmental interaction (health defined by (perceived) ability to function within one's environment to satisfy wants and needs) (1)	Spiritual wellbeing (health defined by spiritual fulfilment and a sense of purpose) (1)
Autonomy (health defined by (perceived) ability to make decisions on changes related to one's life and environment) (9)	
Free of diseases and risk exposure (health defined explicitly as (caused by) the lack of diseases and health risk exposures) (9)	Health is subjective (health defined as a subjective experience and different for each individual even with similar contextual factors)(9)
Health is totality (health defined as a complete and/or integrated state of being with a combination of different components or aspects)(9)	Other health defining elements (not confirming to the definition of other elements)(9)
<b>Code family: Elements defining a healthy living environment (research question a and b)</b>	
Social and cultural (vibrant, harmonious and inclusive communities) (3)	Governance (effective and inclusive participation, representation and leadership) (3)
Environmental (providing places for people to live in an environmentally friendly way) (3)	Housing and the built environment (a quality built and natural environment) (3)
Transport and connectivity (good transport services and communication linking people to jobs, schools, health and other services) (3)	Economy (a flourishing and diverse local economy) (3)
Services (a full range of appropriate, accessible public, private, community and voluntary services) (3)	Other elements of a healthy living environment (9)
Healthy living environment is totality (a combination of various aspects)(9)	
<b>Code family: Perceived level of similarity on relevant aspects of healthy living environment (research question c)</b>	
Perceived general level of similarities on relevant aspects of healthy living environment by participants (9)	
<b>Code family: Perceived similarities on relevant aspects of healthy living environment (research question c)</b>	
Perceived similarity social and cultural (3)	Perceived similarity housing and the built environment (3)
Perceived similarity environmental (3)	Perceived similarity economy (3)

## Appendix 1: (continued)

<b>Code family: Perceived similarities on relevant aspects of healthy living environment (research question c)</b>	
Perceived similarity public and commercial service (3)	Perceived similarity transport and connectivity (3)
Perceived similarity governance (3)	Perceived similarity other elements of healthy living environments (2)
<b>Code family: Perceived differences on relevant aspects of healthy living environment (research question c)</b>	
Perceived difference social and cultural (3)	Perceived difference housing and the built environment (3)
Perceived difference environmental (3)	Perceived difference economy (3)
Perceived difference public and commercial service (3)	Perceived difference transport and connectivity (3)
Perceived difference governance (3)	Perceived difference on other elements of healthy living environments (2)
<b>Code family: Contributing factors for consensus building on health and healthy living environment (research question c)</b>	
Compatible mental models such as culture, religions, social function and role (4, 5,8)	Compatible personalities and emotions, and behaviours (8)
Compatible interests (4,6)	Compatible information access and interpretation (4,5,7)
Compatible decision making mechanisms (6,7)	Compatible strategies to cope with power (6,7)
Significant amount of trust and insignificant amount of distrust (7,8)	Other contributing factors (9)
<b>Code family: Hindering factors for consensus building on health and healthy living environment (research question c)</b>	
Incompatible mental models such as culture, religions, social function and role (4,5,8)	Incompatible personalities and emotions, and behaviours (8)
Incompatible interests(4,6)	Incompatible information access and interpretation (4,5,7)
Incompatible decision making mechanisms(6,7)	Incompatible strategies to cope with power (6,7)
Insignificant amount of trust and significant amount of distrust (7,8)	Other contributing factors (9)
<b>Code family: Recommendations on stakeholder gatherings</b>	
Recommendations on GBB workshops (9) <i>Referring to problems and advantages that should be maintained or improved in future implementation</i>	
<b>Code family: Other assisting codes</b>	

Interesting quotes (9)

*Remarks made about the evaluation itself*

## SOURCES

- (1) **Based on:** Huber, M., et al. Towards operationalisation of the new dynamic concept of health, leading to 'positive health'. Towards a new, dynamic concept of Health. Its operationalisation and use in public health and healthcare, and in evaluating health effects of food. Driebergen, Louis Bolk Instituut; 2014: 55-82.
- (2) **Based on:** World Health Organization. Constitution of the World Health Organization. Geneva: World Health Organization; 1948.
- (3) Egan, J. Skills for sustainable communities. London: Office of the Deputy Prime Minister; 2004.
- (4) Briggs, R. O., et al. Toward a theoretical model of consensus building. Omaha, Nebraska: AMCIS; 2005.
- (5) **Based on:** Susskind, L. E., et al. The consensus building handbook: A comprehensive guide to reaching agreement. Thousand Oaks, California: Sage Publications; 1999.
- (6) **Based on:** Bingham, G. Resolving environmental disputes: A decade of experience. Washington DC: Conservation Foundation; 1986.
- (7) **Based on:** Reed, M. S. "Stakeholder participation for environmental management: A literature review." *Biological Conservation*. 2008; 141(10): 2417-2431.
- (8) **Based on:** Ducker, D. J. and T. K. K. B. Morgan "A Psychosocial Approach to Stakeholder Participation in Environmental Problem Solving. The Case of the Contaminated Site Cleanup at Mapua, New Zealand." *Environmental Management and Sustainable Development*. 2012; 1(2): 163-186
- (9) **Based on data content (open coding).**

## CHAPTER 6

### Additional files

**Table 1a.** Generic and combination search terms used in English and Dutch

Generic terms (English)	Combination terms (English)	Generic terms (Dutch)	Combination terms (Dutch)
App	Community asset mapping	Applicatie wijkschouw	Actief in kaart brengen
Audit tool	Community-based	App wijkschouw	Bewonersparticipatie
Physical streetscape	Citizen observation	Audit tools	Burgerparticipatie
Site survey	Resident observation	Fysiek straatbeeld onderzoek	Bewonersobservatie
Visually surveying neighborhood	Citizen participation	Instrumenten wijkschouw	Burger observatie
Visually surveying neighbourhood	Resident participation	Locatieonderzoek	Empowerment
	Empowerment	Onderzoeksinstrument	Eigenschappen gebouwde omgeving
	Population health	Visueel buurtonderzoek	Eigenschappen sociale omgeving
	Neighborhood health	Wijkschouw	Gezondheid bevolking
	Neighborhood characteristics	Wijkaudit	Gezondheid wijk
	Neighbourhood characteristics		Leefbaarheid buurt
	Neighborhood features		Leefbaarheid wijk
	Neighbourhood features		Leefbaarheid omgeving
	Liveability		Meting buurtkenmerken
	Neighborhood liveability		Meting buurtkarakteristieken
	Neighbourhood liveability		Meting buurteigenschappen
	Measuring		Eigenschappen meten
	Built or social environment		Kwaliteiten meten
	Systematic social observations		Systematische sociale observaties
	Visually surveying		Visueel buurtonderzoek
	Neighbourhood health		
	Walkability		

**Table 1b.** Used search strings (English and Dutch) to search (SCOPUS database and Google)

The following search string was used: ((TITLE(App OR Audit tool OR Physical streetscape OR Site survey OR Visually surveying neighborhood)) AND ((TITLE-ABS-KEY(Community asset mapping OR Community-based OR Citizen observation OR Resident observation OR Citizen participation OR Resident participation OR Empowerment OR Population health OR Neighborhood health OR Neighbourhood characteristics OR Neighbourhood characteristics OR Neighborhood features OR Neighbourhood features OR Neighborhood liveability OR Neighbourhood liveability OR Measuring OR Built social environment OR Systematic social observations OR Visually surveying OR Walkability)) AND LANGUAGE (english) AND PUBYEAR AFT 2010.

The following search string was used: ((TITLE(Applicatie wijkschouw OR App wijkschouw OR Audit tools OR Fysiek straatbeeld onderzoek OR Instrumenten wijkschouw OR Locatieonderzoek OR Onderzoeksinstrument OR Visueel buurtonderzoek OR Wijkschouw OR Wijkaudit)) AND ((TITLE-ABS-KEY(Actief in kaart brengen OR Bewonersparticipatie OR Burgerparticipatie OR Bewonersobservatie OR Burger observatie OR Empowerment OR Eigenschappen gebouwde omgeving OR Eigenschappen sociale omgeving OR Gezondheid bevolking OR Gezondheid wijk OR Leefbaarheid buurt OR Leefbaarheid wijk OR Leefbaarheid omgeving OR Meting buurtkenmerken OR Meting buurtkarakteristieken OR Eigenschappen meten OR Kwaliteiten meten OR Systematische sociale observaties OR Visueel buurtonderzoek) AND LANGUAGE(dutch) AND PUBYEAR AFT 2010.

**Table 2.** Overview of excluded 'non-participative' instruments

	Author, Year [ref]	Instrument name	Country of origin*
1.	Andresen et al., (2008)	African American Health (AAH) Neighborhood Assessment Scale	1
2.	Bader et al., (2015)	CANVAS	1
3.	Badland et al., (2010)	Can Virtual Streetscape Audits Reliably Replace Physical Streetscape Audits? (using NZ Spaces)	2
4.	Badland et al., (2010)	Examining Public Open Spaces by Neighborhood-Level Walkability and Deprivation (using the NZ-Public Open Space Tool)	2
5.	Boarnet et al., (2006)	Irvine-Minnesota Inventory	1
6.	Cain et al., (2014)	Contribution of streetscape audits to explanation of physical activity (using MAPS)	1
7.	Caughy et al., 2001	Neighborhood Brief Observation Tool	1
8.	Charreire et al., (2014)	Using remote sensing to define environmental characteristics	n/a (review paper)
9.	Clarke et al., (2010)	Remote sensing CCAHS	1
10.	Cunningham et al., (2005)	SWEAT	1
11.	De Vries et al., (2013)	Streetscape greenery and health audit tool	4
12.	Evenson et al., (2009)	PIN3	1
13.	Ewing et al., (2006)	Field Manual Urban design measures for NYC	1
14.	Foltete and Piombini, (2007)	N/A	3
15.	Franzini et al., (2008)	N/A	1
16.	Franzini et al., (2009)	Healthy Passages	1
17.	Furr-Holden et al., (2010)	NifETY	1
18.	GGD Amsterdam (2012)	Inventarisatie Gebruik Openbare Ruimte (IGOR)	4
19.	Gustafson et al., (2011)	Perceived and objective measures of the food store environment	1
20.	Hoedl et al.,(2010)	The Bikeability and Walkability Evaluation Table Reliability and Application	5
21.	Hoehner et al., (2007)	Active Neighborhood Checklist	1
22.	Hoyt et al., (2014)	Neighborhood Influences on Girls' Obesity Risk	1
23.	Kamphuis et al., (2008)	VicLANES	5
24.	Kelly et al., (2013)	Using Google Street View to Audit the Built Environment: Inter-rater Reliability Results	1

**Table 2.** (continued)

	Author, Year [ref]	Instrument name	Country of origin*
25.	King, (2008)	NASH	1
26.	Laraia et al., (2006)	Neighborhood Attributes Inventory	1
27.	Leonard et al., (2011)	Systematic Neighborhood Observations at High Spatial Resolution	1
28.	Leung et al., (2010)	CYGNET	1
29.	Loukaitou-Sideris et al., (2001)	N/A	1
30.	McMillan, (2007)	SR2S	1
31.	Millstein et al., (2013)	MAPS instrument	1
32.	Minnery and Lim, (2005)	CPTED Scale	1
33.	Mitchell et al., (2014)	The Healthy Neighborhood Audit Instrument	6
34.	NISB (2012)	De Bewegvriendelijke Omgeving Scan (BVO Scan)	4
35.	Perkins et al., (1992)	Block Environment Inventory	1
36.	Phillips et al., (2012)	A cluster randomized trial of community engagement for improving health behaviors and mental wellbeing	7
37.	Pitts et al., (2013)	Formative Evaluation for a Healthy Corner Store	1
38.	Quintas et al., (2014)	The COURAGE Built Environment Outdoor Checklist	n/a (multiple countries engaged in international project)
39.	Settle et al., (2014)	Voorkomen van buitenreclame over voeding	6
40.	Schaefer-McDaniel, (2009)	N/A	9
41.	Seymour et al., (2010)	SPACES for Alleys	1
42.	Suminski et al., (2007)	BWM	1
43.	Taylor et al., (2014)	Features of the Built Environment	1
44.	Van Cauwenberg et al., (2014)	Using Manipulated Photographs to Identify Features of Streetscapes	10
45.	Watts et al., (2013)	Physical Activity in Deprived Communities in London	7
46.	Wright and Kloos, (2007)	HERS-NQ	1
47.	Zhu and Lee, (2008)	N/A	1

\* 1= US, 2= New Zealand, 3= France, 4= The Netherlands, 5= Austria, 6 = Australia, 7=UK, 8= Italy, 9= Canada, 10= Belgium

**Table 3.** Overview of excluded instruments categorized ‘unknown’

	Author, Year [ref]	Instrument name	Country of origin*
1.	Bakker et al., (2014)	Speelscan	1
2.	Brownson et al., (2004)	St. Louis Audit Tool – Analytic Version	2
3.	Clifton et al., (2007)	PEDS	2
4.	Dannenberg et al., (2011)	Walkability Audit Tool	3
5.	Michael et al., (2009)	SWEAT-R	2
6.	Morgan et al.,(2013)	Wisconsin Resource Kit	2
7.	Pikora et al., (2002)	SPACES	3
8.	Rundle et al., (2011)	Using Google Street View to Audit Neighborhood Environments	2

\* 1 = The Netherlands, 2= US, 3= Australia

**Table 4.** Top 3 most measured sub domains

Domains	Most measured sub domains
Amenities for public space	<ul style="list-style-type: none"> <li>• Bus stops/transit stops (8)</li> <li>• Playground, sports equipment (6)</li> <li>• Street furniture (6)</li> </ul>
Landscaping/nature features	<ul style="list-style-type: none"> <li>• Street trees (9)</li> <li>• Landscape features (7)</li> <li>• Landscaped open space (7)</li> </ul>
Recreational uses/ public spaces	<ul style="list-style-type: none"> <li>• Park/playground (8)</li> <li>• Facilities for handicap accessibility (7)</li> <li>• Availability of recreational facilities /public spaces (6), playing/sports field (6)</li> </ul>
Sidewalks	<ul style="list-style-type: none"> <li>• Sidewalks (9)</li> <li>• Sidewalk continuity (8)</li> <li>• Completeness of sidewalks (6), lighting covering the sidewalk (6), sidewalk material/decorative paving (6), sidewalk obstacles/obstructions (6), sidewalk under construction/being repaired (6)</li> </ul>
Land uses	<ul style="list-style-type: none"> <li>• Predominant type of residential housing (6)</li> <li>• Transportation facilities (6)</li> <li>• Residential land uses (5)</li> </ul>
Parking and driveways	<ul style="list-style-type: none"> <li>• Parking lots/structures (7)</li> <li>• On-street parking (4)</li> <li>• Parking spaces (3)</li> </ul>
Safety	<ul style="list-style-type: none"> <li>• Outdoor lighting (7)</li> <li>• Dogs, stray animals (4)</li> <li>• Perceived safety (4)</li> </ul>
Streets/traffic	<ul style="list-style-type: none"> <li>• Vehicles (8)</li> <li>• Street traffic (7)</li> <li>• Shoulders or wide outside lanes (6)</li> </ul>

**Table 4.** (continued)

Domains	Most measured sub domains
Local business and economy	<ul style="list-style-type: none"> <li>• Presence of commercial destinations (7)</li> <li>• Presence of public destinations (7)</li> <li>• Distance to commercial destinations (2), distance to public destinations (2)</li> </ul>
Architecture/building characteristics	<ul style="list-style-type: none"> <li>• Buildings (3)</li> <li>• Historic buildings (2)</li> <li>• Interesting.varied architecture/design (2)</li> </ul>
Cycling environment	<ul style="list-style-type: none"> <li>• Bicycle parking facilities (6)</li> <li>• Bicycle lanes (5)</li> <li>• Continuity of bicycle route (4)</li> </ul>
Maintenance/appearance	<ul style="list-style-type: none"> <li>• Maintenance of buildings, lots (4)</li> <li>• Condition of public recreational spaces (3)</li> <li>• Condition of grounds (2), condition of residential buildings (2)</li> </ul>
Pedestrian environment	<ul style="list-style-type: none"> <li>• Crossing aids for pedestrians, non-specified (7)</li> <li>• Crosswalks (6), pedestrian-friendly traffic sign (6), perceived safety while walking (6), traffic/pedestrian signal system (6)</li> <li>• Pedestrian street buffers (5), street markings for pedestrian crossings (5)</li> </ul>
Physical disorder	<ul style="list-style-type: none"> <li>• Litter (7)</li> <li>• Piles of garbage or dumped materials on street (6)</li> <li>• Graffiti (5)</li> </ul>
Signs	<ul style="list-style-type: none"> <li>• Cultural messages/events (3)</li> <li>• Neighbourhood/social message/event (3)</li> <li>• Physical activity messages, events/billboard (3)</li> </ul>
People and behaviours	<ul style="list-style-type: none"> <li>• Presence of people who are talking or greeting each other (3)</li> <li>• Visible people (3)</li> <li>• Active behaviours of adults (2), active behaviours of children (2), active behaviour of older adults (2), active behaviours of teenagers (2), presence of people who are fighting or acting in hostile or threatening manner (2)</li> </ul>
Smell/noise/pollution	<ul style="list-style-type: none"> <li>• Air pollution (3)</li> <li>• Noise levels (3)</li> <li>• Unpleasant smell (3)</li> </ul>
Views/enclosure	<ul style="list-style-type: none"> <li>• Open views/long sight lines (3)</li> <li>• Views (3)</li> <li>• Attractiveness of views (1), views (1)</li> </ul>
Barriers	<ul style="list-style-type: none"> <li>• Barriers (general) (2)</li> <li>• Highway (elevated or below grounds) (2)</li> <li>• River (2)</li> </ul>
Steepness	<ul style="list-style-type: none"> <li>• Grade/steepness/slope (3)</li> </ul>
Neighbourhood identification/legibility	<ul style="list-style-type: none"> <li>• Neighbourhood monuments/markers/banners (1)</li> </ul>
Ethnic identification	<ul style="list-style-type: none"> <li>• <i>One included instrument measured all sub domains</i></li> </ul>

**Table 5. neighbourhood domains and sub domains (in brackets: numbers of instruments measuring each (sub)domain)**

Domains and sub domains based on Nickelson (2013), amended by additional domains. Note that the table concerns only the participative instruments

Amenities for outdoor public space (10)	Architecture/ building characteristics (7)	Barriers (3)
Bench and/or covered shelter at transit stop (3)	Average height of borders (e.g. fence) *	Ability to overcome the specified barrier *
Bus headway (timing between buses) *	Building accent colors *	Barriers (2)
Bus stop/transit stop signage (1)	Building access*	Bridge (1)
Bus stops/transit stops (8)	Building height (1)	Drainage ditches *
Equipment rental stand (2)	Building setbacks *	Highway (elevated or below ground) (2)
Heat lamps *	Buildings (3)	Impassable land use (e.g. gated community, major industrial complex, etc.) *
Newspaper dispenser *	Buildings that have garage doors facing the street *	Railroad track (1)
Outdoor dining areas (2)	Buildings with identifiers *	River (2)
Playground, sports equipment (6)	Buildings with windows facing the street *	Road with 6 or more lanes *
Public restrooms (4)	Buildings/residential units with front porches (1)	Tunnel *
Public telephones (3)	Buildings/residential units with front yard (1)	
Sports stands/seating (1)	Buildings/residential units with some form of decoration (1)	
Street furniture (6)	Fire escapes *	
Trash bins (4)	Historic buildings (2)	
Vending machines (1)	Interesting, varied architecture/design (2)	
Water fountains (for drinking) (4)	Prominence of garage doors when viewing front of building *	
	Properties/residential units with a border (e.g. fence) (1)	
	Vertical-mixed use (different land uses on different floors of the building) *	
	Windows/blank walls at street level *	

**Table 5.** (continued)

<b>Cycling environment (7)</b>	<b>Ethnic identification (1)</b>	<b>Land uses (9)</b>
Attractiveness for cycling (1)	Business featuring an explicit display of colors, murals, or symbols oriented toward African Americans (1)	Agricultural land/ranch/farming (2)
Bicycle lanes (6)	Business or institution featuring an explicit display of colors, murals, or symbols oriented toward Latinos (1)	Commercial/retail uses (3)
Bicycle parking facilities (5)	Business or institution with "African," "Caribbean," or "African American" in the name (1)	Educational uses *
Continuity of bicycle route (4)	Business or institution with a "Mexican," "Latino," "Cuban," or a Spanish name or surname in the name or a name in Spanish (1)	Industrial/manufacturing uses (3)
Crossing aids for bicyclists, non-specified (3)	Business or institution with a sign or advertisement in Spanish on the building or property (1)	Institutional buildings (3)
Demarcation of bicycle lanes (1)	Business or with a sign or advertisement indicating that they sell African or Caribbean goods or provide services specifically for African Americans (1)	Integration of land use (1)
Difficulty for cycling (1)	Business or institution with a sign or advertisement indicating that they sell Latino or Mexican goods or provide services specifically for Latinos (1)	Non-residential land uses (general) (2)
Obstructions in bicycle lanes (1)	Sayings/symbols/murals of African American identity or pride (1)	Predominant land use (2)
Other bicyclist friendly traffic sign (1)	Sayings/symbols/murals of Mexican or Latino identity or pride (1)	Predominant type of residential housing (6)
Perceived safety while biking (3)		Public recreational spaces (2)
"Share the road" sign (2)		Public/civic buildings (2)
		Residential land uses (5)
		Transportation facilities (6)
		Undeveloped land (2)
<b>Landscaping/ nature features (10)</b>	<b>Maintenance/ appearance (7)</b>	<b>Neighborhood identification/ legibility (1)</b>
Desert *	Buildings under renovation (1)	Indication of neighborhood/ block uniformity (1)

**Table 5.** (continued)

<b>Landscaping/ nature features (10)</b>	<b>Maintenance/ appearance (7)</b>	<b>Neighborhood identification/ legibility (1)</b>
Forest/woods (3)	Chipped exterior paint or broken fixtures *	Neighborhood monuments/ markers/ banners *
Fountain/reflecting pool *	Clothes drying *	
Height of trees (2)	Condition of commercial buildings (1)	
Lake/ pond (2)	Condition of grounds (2)	
Landscaping features (7)	Condition of industrial buildings (1)	
Landscaped open space	Condition of institutional buildings (1)	
Mountains/ hills (3)	Condition of public recreational spaces (3)	
Nature features (5)	Condition of residential buildings (2)	
Ocean (2)	Condition of undeveloped property (1)	
Open field/ open space (3)	Maintenance of buildings, lots (4)	
Private yard/ garden (1)	Municipal maintenance-related facilities (1)	
Public art (2)	Newly built buildings *	
Small planters (5)		
Stream/ river/ canal/ creek (4)		
Street trees (9)		
Waterfront (4)		
<b>Parking and driveways (9)</b>	<b>Pedestrian environment (7)</b>	<b>Physical disorder (7)</b>
Driveways (2)	Attractiveness for walking (3)	Abandoned building(s) (3)
Need to walk through parking lots to enter buildings (1)	Crossing aids for pedestrians, non-specified (7)	Abandoned car(s) (2)
No parking/stopping sign (2)	Crosswalks (6)	Blood *
Off-street parking *	Difficulty for walking (2)	Boarded-up buildings *
On-street parking (4)	Length of crosswalks (4)	Boarded-up windows *
Parking lots/structures (7)	Pedestrian cut through (3)	Broken glass (3)
Parking restrictions (1)	Pedestrian friendly traffic sign (6)	Buildings with broken windows (1)
Parking spaces (3)	Pedestrian street buffers (5)	Burned buildings (1)
Parking violations *	Pedestrian street distance from curb (3)	Cigarette butts, tobacco paraphernalia (3)

**Table 5.** (continued)

Parking and driveways (9)	Pedestrian environment (7)	Physical disorder (7)
Predominant form of parking *	Pedestrian street material (3)	Condoms (2)
Predominant use of parking structure on ground floor *	Pedestrian street obstructions (4)	Empty beer, liquor bottles (3)
Resident parking sign (1)	Pedestrianized street (2)	Eviction notice *
	Perceived convenience for pedestrian crossing (3)	Evidence of graffiti that has been painted over (1)
	Perceived safety while walking (6)	Graffiti (5)
	Street markings for pedestrian crossings (5)	Litter (7)
	Traffic/pedestrian signal system (6)	No dumping sign (1)
	Traffic/pedestrian signal system length of time (4)	Old, beat-up vehicles *
		Piles of garbage or dumped materials on street (6)
		Police tape/outlines *
		Shell cases *
		Syringes, drug paraphernalia (1)
		Vacant lots (2)
		Vandalism (2)
Recreational uses/ public spaces (10)	Safety (9)	Sidewalks (10)
Accessibility of recreational facilities/public spaces (4)	Bars on windows (1)	Alternative path buffers (2)
Availability of recreational facilities/public spaces (6)	Security bars/gratings (1)	Alternative path distance from curb (1)
Beach (2)	Pull-down metal security blinds (1)	Alternative path material *
Facilities for handicap accessibility (7)	Gate on property *	Alternative path obstructions *
Golf course (3)	Security fencing (1)	Alternative paths (2)
Harbor/ marina (2)	High mesh fencing with barbed wire or spiked tops (1)	Completeness of sidewalks (6)
Institutional yard *	Low (<6 ft) security fencing (1)	Continuity of alternative path (1)
Outdoor pool (3)	Surveillance cameras *	Curb cuts (4)
Park/ playground (8)	Security devices *	Distance from curb (1)
Playing/ sports field (6)	Presence of neighborhood watch/neighborhood block club signs (3)	Features that provide protection from sun/rain/snow (1)

**Table 5.** (continued)

Recreational uses/ public spaces (10)	Safety (9)	Sidewalks (10)
Plaza/ square/ courtyard (2)	Block Home or Safe Haven signs (1)	Items in sidewalk buffer zone (2)
Public garden (3)	Security warning signs (2)	Length of alternative path *
Sports track (3)	No trespassing sign (3)	Lighting covering the sidewalk (6)
	Beware of dog sign (2)	Marking for multi-use on/near alternative path (1)
	Visibility from surrounding buildings (1)	Sidewalk buffers (4)
	Visibility of street and outside lot from 1st floor windows (1)	Sidewalk continuity (8)
	Police cars (1)	Sidewalk material/decorative paving (6)
	Illegal/unlicensed taxis *	Sidewalk obstacles/obstructions (6)
	Chemical storage barrels *	Sidewalk shading (e.g. shade from trees) (3)
	Hazardous liquids *	Sidewalk under construction/ being repaired (6)
	Outdoor lighting (7)	Sidewalk width (3)
	Dogs, stray animals (4)	Sidewalks (9)
	Animals (other than dogs, stray animals) (1)	Width of alternative path *
	Hiding places in street *	Width of sidewalk buffer zone (2)
	Perceived safety (4)	
Signs (6)	Smell/ noise/ pollution (4)	Steepness (3)
Alcohol billboards/signs advertising (2)	Air pollution (3)	Grade/steepness/slope (3)
Billboards *	Noise levels (3)	
Cultural messages/events (3)	Unpleasant smell (3)	
Drug-free zone sign (2)		
Empty sign posts *		
Fast food billboards/signs advertising (2)		
For sale' and/or 'for rent' signs (1)		
Help wanted sign *		
Home-based business sign *		
Inspirational/educational sayings *		

**Table 5.** (continued)

<b>Signs (6)</b>	<b>Smell/ noise/ pollution (4)</b>	<b>Steepness (3)</b>
Neighborhood/social message/ event (3)		
Other entertainment/event sign (1)		
Physical activity messages, events/billboard (3)		
Place to post personal notices/ signs *		
Political message/event (1)		
Presence of athletic event sign *		
Religious messages/events (2)		
Sign with a health message (1)		
Signs (2)		
Tobacco billboards/signs advertising (2)		
Unreadable sign/billboard (1)		
<b>Streets/ traffic (9)</b>	<b>Views/ enclosure (4)</b>	<b>Local business and economy (9)</b>
Alley *	Attractiveness of views (1)	Presence of commercial destinations (7)
Alternative routes *	Degree of enclosure (1)	Presence of public destinations (7)
Availability of alternative transportation modes (2)	Open views/long sight lines (3)	Distance to commercial destinations (2)
Curb (3)	Views (3)	Distance to public destinations (2)
Curb extension *		Located on (street with) commercial destinations (1)
Curb height *		Located on (street with) public destinations (1)
Expressway*		
Freeway over/underpass (1)		
Intersection (5)		
Length of street segment (1)		
Marked lanes (2)		
Median (1)		
No commercial vehicles' sign (1)		
Noise level of street (2)		
Obstructions in the shoulder (2)		
Posted speed limit (5)		

**Table 5.** (continued)

Streets/ traffic (9)	Views/ enclosure (4)	Local business and economy (9)
Potholes (2)		
Road connectivity (3)		
Road curve warning sign (1)		
Road material (2)		
Road obstructions (1)		
Road under construction/being repaired (3)		
Semis (1)		
Shoulder continuity (5)		
Shoulder width (3)		
Shoulders or wide outside lanes (6)		
Special speed zone (5)		
Street cleaning sign *		
Street segments (1)		
Street traffic (7)		
Traffic calming measures (5)		
Turn lane*		
Vehicle travel lanes (5)		
Vehicles (8)		
Way-finding aids *		
Width of street segment (4)		
People and behaviors (5)		
Active behaviors of children (2)		
Active behaviors of teenagers		
Active behaviors of adults (2)		
Active behaviors of older adults (2)		
Availability of a social committee (1)		
Availability of public meeting places (1)		
Inactive behaviors of teenagers (1)		
Inactive behaviors of adults (1)		

**Table 5.** (continued)

Streets/ traffic (9)	Views/ enclosure (4)	Local business and economy (9)
Presence of people who are fighting, or acting in hostile or threatening manner (2)		
Presence of people who are talking or greeting each other (3)		
Being looked at by other people (1)		
Unsafe drivers behaviors (1)		
Visible people (3)		

## CHAPTER 7

### Additional file 1: Code book

Code families and codes	Code description
<b>Family: Health</b>	
Health definition	Quotes about the definition of health and of health determinants
Health status	Quotes about residents' health status
Health behaviour	Quotes about health behaviour of residents, including care services utilisation
Action for health	Quotes about collective activities of residents to protect, promote or improve community health
<b>Family: Egan dimensions (source: Egan, 2004)</b>	
Environmental	<p>Quotes about the environment:</p> <ul style="list-style-type: none"> <li>Efficient use of resources now and in the future in the built environment and service provision</li> <li>Living in a way that minimises the negative environmental impact and enhances the positive impact</li> <li>Protecting and improving natural resources and biodiversity</li> <li>Having due regard for the needs of future generations in current decisions and actions</li> </ul>
Economy	<p>Quotes about the local economy:</p> <ul style="list-style-type: none"> <li>A wide range of jobs and training opportunities</li> <li>Sufficient land and buildings to support economic prosperity and change</li> <li>Dynamic job and business creation</li> <li>A strong business community with links into the wider economy</li> </ul>
Housing and built environment	<p>Quotes about housing and the built environment:</p> <ul style="list-style-type: none"> <li>Creating a sense of place</li> <li>Well-maintained, local, user-friendly public and green spaces with facilities for everyone including children and older people</li> <li>Sufficient range, diversity and affordability of housing within a balanced housing market</li> <li>A high quality, well-designed built environment of appropriate size, scale, density, design and layout that complements the distinctive local character of the community</li> <li>High quality, mixed-use, durable, flexible and adaptable buildings</li> </ul>
Social en cultural	<p>Quotes about the social environment:</p> <ul style="list-style-type: none"> <li>A sense of community identity and belonging</li> <li>Tolerance, respect and engagement with people from different cultures, background and beliefs</li> <li>Friendly, co-operative and helpful behaviour in neighbourhoods</li> <li>Opportunities for cultural, leisure, community, sport and other activities</li> <li>Low levels of crime and anti-social behaviour with visible, effective and community-friendly policing</li> <li>All people are socially included and have similar life opportunities</li> </ul>

**Additional file 1: (continued)**

<b>Code families and codes</b>	<b>Code description</b>
Governance	Quotes about local governance: Strategic, visionary, representative, accountable governance systems that enable inclusive, active and effective participation by individuals and organisations Strong, informed and effective leadership and partnerships that lead by example Strong, inclusive, community and voluntary sector A sense of civic values, responsibility and pride Continuous improvement through effective delivery, monitoring and feedback at all levels
Transport and connectivity	Quotes about local transport and connectivity: Transport facilities, including public transport, that help people travel within and between communities Facilities to encourage safe local walking and cycling Accessible and appropriate local parking facilities Widely available and effective telecommunications and Internet access
Services	Quotes about services locally offered: Well-educated people from well-performing local schools, further and higher education and training for lifelong learning High quality, local health care and social services Provision of range of accessible, affordable public, community, voluntary and private services Service providers who think and act long term and beyond their own immediate geographical and interest boundaries
<b>Family: Health literacy (source: Nutbeam, 2008)</b>	
Finding knowledge	Quotes about people's abilities to find knowledge relevant to their health
Understanding knowledge	Quotes about people's abilities to understand knowledge relevant to their health
Applying knowledge	Quotes about people's abilities to apply knowledge to improve or sustain their health
<b>Family: Asset based approach</b>	
Asset	Quotes about aspects that help people to remain healthy and live healthy lives
Deficit	Quotes about barriers for people to remain healthy and live healthy lives
<b>Family: Additional codes</b>	
Interesting/important quotes	Quotes that are either highly illustrative for a code or code family or that provide new insights





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## **ABOUT THE AUTHOR**

Lea den Broeder (1958) was born in Amsterdam as the youngest of three sisters. She grew up in Amsterdam Nieuw-West, where part of the research carried out for this thesis was located. After secondary school Lea studied Educational Sciences at the University of Amsterdam (UVA) where she obtained her Master's degree in 1998, with women's studies as an additional subject. After a short time in which she worked as a researcher in historical sociology for the University of Utrecht, she left the Netherlands to live and work in Zimbabwe (Mberengwa district, Midlands) between 1990 and 1994. During her stay, she carried out a small research project in HIV/STD prevention. After returning to the Netherlands she worked as a researcher and policy adviser in women's health, occupational health and public health and she obtained her Master of Public Health degree in 2003.

Since 2003 Lea works at the National Institute for Public Health and the Environment. In addition, she works at the Faculty of Sports and Nutrition of the Amsterdam University of Applied Sciences where she develops her professorate in Environment and Health. She is engaged in Health in All Policies (HiAP), both on a national and an international level cooperating with, amongst others, the World Health Organisation and the International Union for Health Promotion and Education. Specific fields of interest are qualitative research methods, citizen engagement, Health Impact Assessment (HIA) and urban health. She has combined work in research, advice, teaching and instrument and guideline development. Lea is a long standing member of the International Association for Impact Assessment (IAIA) where she has contributed in different ways, including as a Director on the IAIA Board.

Lea den Broeder is married to Frans van der Velde. They have three children and a daughter-in-law.



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