

CITIZEN SCIENCE:

THEORY AND PRACTICE

Representing Neighborhood Health: Exploring Citizen Science as a Democratic Force

RESEARCH PAPER

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ABSTRACT

In discussions about citizen science (CS), scholars have considered CS as not only a tool to produce better science, but also a democratizing practice allowing for new definitions of public problems. Inspired by science and technology studies, we present an analysis of a CS collaboration on public health—University with the Neighborhood—in low-income neighborhoods. We show how this CS project results in three representations of neighborhood health. 1. Health is not defined in terms of individual lifestyle but rather in terms of public space. 2. Citizens' work is not participation, but maintenance and repair. 3. Neighborhood work is not about "the community" but about diverse publics. We conclude that the democratic potential of CS in public health and health promotion lies not in the mirroring-of-reality capability of citizens but in the transformation of objects of concern and the representation of problems in public health.

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INTRODUCTION

Citizen science (CS) is a new approach to research that has become increasingly popular (Hecker et al. 2018; Kasperowski and Kullenberg 2019; Tauginienė et al. 2020). In the life sciences, the ability of CS to cover large spatial and temporal scales is heralded as an important contribution to the understanding of complex ecological systems (Theobald et al. 2015). In the (bio)medical sciences, CS provides citizens privileged access to their own (health) data (PGP-UK Consortium 2018). Citizens are also expected to benefit from participation in science because it allows them to learn about specific topics, provide new meaning to hobbies (Bonney et al. 2016), or improve local communities.

Although scholars see the benefits of CS differently, there is a widely shared idea and hope that CS is a democratizing force that helps to address "unprecedented social, environmental, and economic challenges" (Moedas 2018, p. V). The CS literature distinguishes between different forms of democratizing citizen involvement. Authors have categorized CS as ranging from crowdsourcing, in which citizens provide resources to researchers, to more direct forms of engagement, in which participants take part in data collection, to "extreme" CS, in which citizens take part in problem definition, analysis, and interpretation (Haklay 2013). Strasser et al. (2019) have, however, argued that while active participation brings citizens inside the knowledge production process, their transformation into scientists does not necessarily indicate a fundamental change in science-society relations. In other words, by applying traditional scientific methods and by considering CS an advanced form of scientific literacy, CS is an example of scientization, strengthening the traditional understanding of science-society relations, in which less standardized ways of knowing are disqualified as nonscientific. In contrast, the democratization of science would imply challenging the strict separation of lay public and lay knowledge from privileged forms of knowledge production (Latour 2012; Strasser et al. 2019). As a transformation of sciencesociety relations, democratization requires creating space for new and different social epistemologies (Kasperowski and Kullenberg 2019). In other words, democratization is equally about influencing how and what scientific research is, affecting concepts and methods as well as its objects.

To enhance our understanding of the democratic potential of CS, we studied how CS can contribute to the conceptualization of research objects. Recently, there has been increased interest in CS in the field of public health, especially as a way to understand and address health disparities (Rosas et al. 2022). Public health addresses topics that are of great importance to the public, and the way health is defined has a major impact on research

and policies. Here, we present a study in which citizens in low-income neighborhoods shared their understanding of health and healthy neighborhoods by actively forming "matters of concern." We present a unique approach to public health research in which citizen participation serves not only to acquire data, but also, more fundamentally, as a way to redirect research through new conceptualizations of neighborhood health.

In the following section, we first discuss the literature on CS as a democratic force. Next, we introduce our case and methodology. After presenting the results of our analysis of CS in low-income neighborhoods, we discuss how CS may transform objects of research within public health.

CITIZEN SCIENCE AS A DEMOCRATIC FORCE

CS is part of a long history of different forms of lay involvement in science, while it also indicates a new step in the participatory turn involving citizens in the production of science itself (Strasser et al. 2019). The introduction of the term "citizen science" is usually ascribed to the work of Rick Bonney or Alan Irwin, both in the mid 1990s. Bonney's work concerns CS projects initiated by scientists in ornithology, inviting citizens to contribute as data collectors, with bird counting as a paradigmatic example. Bonney's work has been influential in celebrating not only the potential of CS for collecting large quantities of data and thereby advancing scientific knowledge, but also as a model for enhancing scientific literacy (Bonney et al. 2009; Bonney et al. 2016). Irwin, on the other hand, analyzes CS as a response to scientific experts by citizens affected by science. Paradigmatic examples include nuclear power and gene technology. Irwin's work builds on the ideas of science and technology studies about deliberative governance, in which citizen perspectives oppose dominant expert understandings of technologies as part of scientific governance (Irwin 2002). Irwin considers gaps between privileged expert knowledge and citizens or lay knowledge as a problem of democracy. How this gap is mediated when citizens become scientific knowledge producers themselves is an important question of citizen science (Kasperowski and Kullenberg 2019).

The identification of CS as a form of democratizing science is not self-evident. The language of democratization can be very illusive, especially in the realms of policymaking and commerce. In recent years, CS has become a buzzword and rhetorical device for recruiting research subjects (Woolley et al. 2016). According to some critics, the CS language of democratization hides the logic of platform capitalism, in which citizens, under the banner of CS, perform cheap labor

(Mirowski 2018). Moreover, scientization often implies that citizens are pressured to frame their arguments in terms of scientific data and technical reasoning, which does not necessarily do justice to the concerns that sparked CS in the first place (Kimura and Kinchy 2016). Therefore, the question arises of how citizens and researchers can work together to shape the research objects that matter to the citizens involved.

In our study, we drew on the field of science and technology studies (STS). A central assumption of STS work on hybrid fora or other "democratic machineries" is that the ways in which citizens are assembled matter for the kind of knowledge produced. An important insight from the work of STS scholars, such as Irwin (2002), among others, is that democratically opening up academic and policy issues to citizens requires more than a recognition of a knowledge equivalence: It requires a recognition that citizen involvement will most likely alter the ways in which issues at stake are defined and which knowledge is produced. Similarly, scholars such as Weibel and Latour (2005) and Marres (2007) have argued that democracy is not about given public problems of given groups, but problems have to be made public by new groups that become assembled through their concerns about these problems. In other words, new political actors and new objects of concern are co-created.

The idea that scientific methods and procedures represent and construct objects of public concern and publics in a particular way contrasts with public health scholars' assumption that scientific methods will guarantee an objective, apolitical representation of a public health problem of a specific population. Hence, public health problems, such as the "unhealthy lifestyle of people with low social economic positions," are not the result of objective methods that allow revealing reality, but rather scientific-political constructions of problematic populations (Dijkstra and Horstman 2021). To understand how representation processes construct problems and publics, Latour introduced the concepts of translation and displacement. Against a naïve assumption of science and society as separate worlds, Latour shows how knowledge claims travel between different actors and through diverse networks and, meanwhile, undergo different translations. Latour (1993) has shown that while Pasteur succeeded in negotiating a laboratory context in which microbes could be tamed, he had to renegotiate his ideas with farmers and veterinarians to develop a vaccine. It was through these negotiations that the option of vaccination was adapted and translated into curative therapy, which would allow the veterinarians to still earn a good income. In other words, knowledge claims need to be translated to make knowledge claims true and bring them into reality. Inspired by this approach to STS, we aim to shed light on democratizing knowledge through CS: How can the knowledge claims of citizens as new scientific-political actors constitute new objects of science and democracy?

In our study, we trace how neighborhood health developed as a research object through the experiments of citizens and researchers within the University with the Neighborhood (UwtN) project, and demonstrate how neighborhood health as an object became represented beyond the research setting. Below, we first introduce the collaboration developed under UwtN; subsequently, we present our analysis of this CS collaboration—not as data collection or as input for scientists—but as a way of shaping research objects. In the discussion, we return to the question of what the analysis of this CS practice can teach us about the democratizing potential of CS.

RESEARCH CONTEXT AND METHODS

In this article, we analyze the collaboration between researchers and residents of three low-income neighborhoods in Maastricht, the Netherlands. Public health statistics have shown that many residents in these neighborhoods struggle with health problems and loneliness (GGD 2018), and the municipality has observed that these neighborhoods have very few participatory initiatives. To study the neighborhood health dimension, we did not apply classical epidemiological methods, but developed a reflective research practice drawing from a broad social science humanities background, including STS, political philosophy, and community-based research. Methodologically, we were especially inspired by participatory research methodologies that aligned with this background (Lezaun, Marres, and Tironi 2017) and enabled us to combine university-neighborhood collaborations with various qualitative methods of data collection such as participant observation, (walking) interviews, and Photovoice (Denzin and Lincoln 2017).

In 2017, we initiated the UwtN as an experimental platform for participation and collaboration and as a research object (Lezaun et al. 2017). This initiative was built on university and neighborhood contacts that were made during the organization of a neighborhood citizen summit in 2015 about the quality of health and well-being in the neighborhoods. The most pressing neighborhood concern that came to the fore in different wordings was a lack of social contact, a concern that was related to the built infrastructure and poverty. Under the banner of the UwtN, residents and researchers started collaborations on these topics.

Activities, which are ongoing, started in 2017 and consisted of a monthly philosophy café, a series of local lectures, a "SocialGreen" neighborhood park working group, and several ad hoc initiatives, such as a spring festival and a festival of grief. The ethnographic component consisted

of fieldwork (participant observations) between 2017 and 2021 at sites such as parks and cafés, neighborhood network meetings, and meetings of professional teams and social clubs. In addition to conducting countless informal conversations with residents, the first author conducted walking interviews with individual residents (14) and several group interviews (5). To understand how UwtN gave rise to new representations of neighborhood health, we analyzed fieldwork pertaining to UwtN as well as its uptake by local professionals and policymakers. Additionally, we analyzed papers and a book published in the past three years, taking its subject matter from UwtN's activities.

UwtN produced a diversification of citizen roles: philosopher (reflecting on changes in policies and neighborhood), moderator (between researchers and other citizens), co-organizer (of activities), teacher (of students participating in the UwtN), and data collector (diaries of a park). The researchers' roles developed in different directions as well. In addition to being philosophers and ethnographers, we functioned as moderators (the philosophy café and local lectures), facilitators (SocialGreen), mediators between neighborhood and professional care (the ambulance case) and between neighborhood and municipality (redesigning the park), hosts (of a talk show or a lecture), and volunteers (cleaning the park). These roles made academics active stakeholders in more than the research itself.

The ethical framing of the project was guided by the ideas of the American Anthropological Association (AAA) (American Anthropological Association 2012). Whereas informed consent in health research about participation in a research protocol is commonly organized in specific formalized moments and procedures, collaborations developed in ethnographic and participatory research are less protocolled, and informed consent is better approached, such as in the AAA, as an ongoing process. This implies that in all collaborations, we were transparent about our position as university researchers and our research work. On several occasions, we made flyers that included references to our website and email addresses. All interviewees provided written or oral consent for the recording and for the anonymous use of the interviews. In several meetings, we discussed our anonymized findings and insights with residents to obtain feedback. Sometimes, we asked residents for feedback on a Dutch text, and two times, residents accompanied us at a national conference.

SHAPING RESEARCH OBJECTS

To trace how CS can shape research objects, we first analyze how UwtN opened up a new space for knowledge exchange. Next, we analyze how UwtN assembled new actors and

matters of concern. Finally, we analyzed how UwtN as CS resulted in new *r*epresentations of neighborhood health beyond the effects of UwtN.

BRINGING THE UNIVERSITY TO THE NEIGHBORHOOD

As an experiment in CS, UwtN relied on two strategies: reversing the paradigm of reach and creating space for local knowledge. These strategies set the stage for the formation of matters of concern, providing direction for the research.

Reversing the paradigm of reach

In the field of public health, the question of involving research participants is usually understood as a "problem of reach" (Bonevski et al. 2014). Professionals present certain "risk groups" as hard to reach because of a certain (chronic) condition, ethnicity, social economic status, age, or another trait. The dominant approach to addressing the problem of hard-to-reach groups is to attune as best as possible to the specific risk characteristics of this group, but this approach entails many assumptions about the identities of people. The following example, from a workshop at a national public health conference about improving reach, illustrates this:

We sat in a circle and were asked to pick a photo from a stash that had to symbolize a diversity of citizens. Pictures included women with headscarves and people in wheelchairs. A second step involved a role play in which you had to ask the respective citizen to participate in a CS project measuring air pollution, taking into consideration the citizen's supposed characteristics, such as having a disability or belonging to a specific cultural group. (Fieldnotes)

The workshop's message was that tailored strategies were required to successfully reach and include different citizens. From a democratic perspective, however, this way of dealing with "problems of reach" can be criticized because it makes stereotypical assumptions about the identity, concerns, and values of potential participants. Claiming to know (part of) the participant's identities before entering into a conversation limits the possibilities for citizens to define and express themselves in relation to the researcher and the topic at hand. This is particularly problematic in the field of public health, where, through classifications of vulnerability and socioeconomic status, identities are reified and placed within a hierarchy of healthy behavior (Dijkstra and Horstman 2021) and where many assumptions are operative with respect to the meaning of health (Knibbe et al. 2016). As a first point of departure, UwtN aimed to resist the sort of translations that much public health research

has made: defining health as an individual trait and groups as vulnerable or at risk.

This stance was supported by residents who became involved in UwtN. Some residents introduced the option of a philosophy café, as they were "fed up with the assumption of others that residents of these neighborhoods were only interested in playing bingo." When the name "philosophy café" was questioned by local professionals who argued that inhabitants' needs were better met by calling it a "support group," the initiators strongly resisted this, as they wanted to create "something different" (Raap et al. 2022). First, they felt uncomfortable with how professionals defined their needs. Professionals thought that "philosophy" was too difficult for the neighborhood, while inhabitants were interested in reflection and were determined to adhere to the name "philosophy café." Second, by naming the monthly meetings "philosophy café," the residents also aspired to a change in their neighborhood's identity as backward. The philosophy café hereby became the first example of breaking with an epidemiologically inspired public health perspective of a vulnerable neighborhood with certain (already understood) needs. Discussing philosophy in relation to their own lives enabled citizens to (re)define themselves, the way they related to each other, and what a healthy neighborhood meant.

The UwtN revealed another potential blind spot in public health research. During fieldwork, it became clear that neighborhood residents struggled with "problems of reach" themselves. A recurrent concern of citizens who were active in neighborhood networks was difficulty cooperating with other citizens, professionals, and the municipality.

We used to sit around the table with everybody, now everything is fragmented. (Fieldnotes neighborhood network member)

"Fragmented" here refers to residents having a hard time reaching professionals, authorities, and other parties, mostly hidden behind institutional websites and buildings that have administrative opening hours and are not easily accessible for outsiders. Although finding citizens to cooperate with is not necessarily easy for institutional parties, including the university, institutional actors are also difficult to reach. In the UwtN, neighborhood gatherings were relatively informal and open to outsiders, which cannot be said of most academic meetings. Bringing the university to the neighborhood itself, organizing a multiplicity of informal meetings between professionals, researchers, and citizens allowed, to place it in Latour's words, for translations that would otherwise not have taken place, displacing and changing typical public health understandings of neighborhood health.

Creating informal spaces for knowledge exchange

UwtN made university professors, researchers, and public health professionals relatively "easy to reach" by making their presence known through word of mouth and flyers announcing different events and meetings as well as through their practical volunteer work. However, to approach the neighborhood as a site of knowledge production rather than simply a source of data, it is necessary to create occasions for local knowledge exchange that are open, informal, and dialogical. Meetings' locations and times were chosen together with residents and took place at sites that were familiar to participants, such as the neighborhood library or community center, where the barriers to attending were considered low. Moreover, the time for informal mixing during drinks before and after meetings was highly valued by researchers, students, and other residents. On a basic level, UwtN was accessible in the sense that all events were free of charge, everybody was welcome, and there was no need to preregister or share any (personal) data.

UwtN was not developed to educate citizens about health risks and healthy behaviors, but to foster reflection and dialogue by triggering curiosity and formulating new questions. These questions dealt with a variety of topics, such as the meaning of nature, neighborhood diversity, intergenerational relations, friendship, solidarity, arthrosis, and dementia, among others. The dialogical aim of UwtN was expressed in the conversational character of meetings, with formats that were not overly standardized and attuned to the ideas and input of participants. For example, during a workshop by an epidemiologist for members of neighborhood networks who were interested in making valid questionnaires about neighborhood issues, it became clear that residents were already quite knowledgeable about the "dos" and "don'ts" of developing questionnaires, so the exchange continued by discussing what stimulated people to participate in local forms of research, a common challenge of epidemiologists and neighborhood network members alike. In these informal spaces for knowledge exchange, residents participated as epistemic agents by determining the setting and frame in which they interacted. Within the philosophy café, it was agreed that philosophy was introduced but not taught, and there were no listed readings or homework because people were interested in stories and ideas of other participants that came up in relation to the philosophy introduction.

[What I like is] that the personal is always connected to the topic, right. ... it is not the case that we simply tell our individual story and leave it at that. I think these (our stories) are, in fact, connected to a broader experience. (Philosophy café participant, focus group)

The participants pointed out how they learned not through instruction or information but through the connections between personal stories and overarching more or less abstract themes. This approach to knowledge formation is radically different from much public health research and intervention. Instead of counting loneliness or discussing the extent to which loneliness correlated with individual neighborhood characteristics, the residents translated individual experiences of loneliness into an understanding of loneliness as embedded in (the lack of) everyday encounters and local social infrastructures.

Local lectures made it clear that residents were also interested in expert talks and were able to connect expert discourses to their own knowledge. Although the lectures followed a classic format, adjustments were made to support the expression of residents' knowledge and concerns, such as a café setting and a playful quiz about the topic at hand. The quiz usually showed that the public was already quite knowledgeable, encouraging speakers and the public to explore the topic in more depth. The speakers were instructed to open up a conversation rather than tell their audience how to be (come) good (healthy) citizens, and there was much time for interaction. The participants responded to each other as well as to the speaker. At one of the first meetings, two doctors and a nurse in orthopedics performed a lecture on arthrosis and how joints "work." The specialists in orthopedics brought models and provided many mechanical metaphors to make the workings of joints insightful. The public investigated the models attentively and raised many questions:

"What kind of movement is recommendable?"
Before one of the speakers replies, a different
participant answered: "rest rusts" (a saying in Dutch)
and the speakers nod in agreement. Audience
member: "Why is that so hard for people to
understand [that exercise is important]?", Someone
else explains: "Well for people who are alone, they
tell themselves: it is (too) cold, that's the way it is."
(Fieldnotes)

Through curiosity, metaphors, sayings, and anecdotes, the public made translations between their own knowledge and the knowledge of expert speakers. The meeting proved a revelation for the specialist speakers, both in terms of form and content:

It was truly interesting to experience which questions people have, that sometimes contained connections that I would not have made or would not have thought of (...). ... we could explain what

the public wanted to know, instead of, and I think this is most important, what we planned on telling. (Evaluation form)

When successful, bringing experts to the neighborhood enabled the translation of clinical knowledge to the daily lives of residents and vice versa. In contrast, at a different local lecture, an expert gave a more classic "lay" talk about dementia that simplified the subject and did not address the complexities of research and everyday care. The meeting was less appreciated; the participants thought it lacked depth.

Returning to the example of the arthrosis lecture, a homemaker participant made medical experts rethink the social dimension of arthrosis.

"Can you get arthroses from cleaning (a lot)?"
The speakers take a moment to think about the question, "Well yes, not the water but the wringing and squeezing, yes." A bit later, "Can you get it from stress?" "Well, (thinking out loud) when you are stressed, you may start to move differently, tax your muscles in the wrong way, which may damage the cartilage." (Fieldnotes)

This example shows some of the frictions that exist between clinical knowledge and citizens' knowledge. The role of tough cleaning tasks—of homemakers or of cleaners—and of stress in causing or worsening health problems is selfevident for many residents of the neighborhood, but not necessarily for medical specialists who usually see patients only inside of the hospital. While conversations in clinical settings tend to focus on individual lifestyle advice, this dialogue within a neighborhood setting enabled citizens' translation of arthrosis as a socially embedded illness. At its core, UwtN interactions led residents, professionals, and researchers to reconsider their conception of health. Translations between residents' and experts' knowledge showed health to be less tied to individual bodies and lifestyle choices and more embedded in the wearing and tearing of everyday lives and the support or lack of social infrastructures.

CREATING MATTERS OF CONCERN

As a CS experiment, the UwtN enabled the co-production of several problem definitions. Here, we focus on two issues: the low quality of neighborhood green spaces and the low quality of community care. We analyze how these problems, via different translations, became new matters of concern. These translations express a learning process brought about through the assembly of new parties and the reformulation of issues.

A neighborhood park as a matter of neighborhood health

Ethnographic fieldwork has brought forward many green space–related worries. The parks did not stimulate social life: Residents mentioned a lack of maintenance, a need for benches, and the illegal dumping of rubbish, among others. Residents did share many memories of social gatherings that used to take place in the green space, and nature was a popular topic of conversation within UwtN.

The participants shared their special relationships with nature. One participant described his relationship with a tree in his garden: "I greet it every morning." (Fieldnotes philosophy café)

By bringing people together in the philosophy café and in the working group SocialGreen, UwtN provided an infrastructure to share memories and knowledge about parks and city-nature. These contributions, ranging from childhood memories to new experiments making the park more attractive, often served as counterfactuals to the actual neighborhood green space, describing what green spaces could mean: adventure, beauty, play. This enabled translations from a situation of absence, lack of maintenance, safety, and interaction to a situation in which the park itself could become a mediator for interaction. For example, smaller and larger tree trunks, placed by the working group, were used by kids to climb and sit on or to drag around with parents often watching. Their observation of this experiment, in turn, led the working group to realize a nature playground. Slowly, the park transformed from a green but empty space into a space that allowed for neighborhood liveliness.

Making neighborhood green spaces into a shared matter of concern required bringing different parties together, which appeared to be a process of trial and error. For example, in response to residents' observations about a lack of liveliness and the wish to meet other residents, students who worked in the UwtN came up with the idea of creating a kitchen garden in the park. The idea did not come out of thin air, but was found in the literature to be a promising strategy to improve community health. As a recent abstract of a review article on community gardening puts it:

Vulnerable communities (...) represent the most at-risk populations facing inequities and negative health, economic, and social outcomes. (...) Community gardening has emerged as a community-based solution to address these inequities (...). (Tracey et al. 2023, p1)

To address this issue, the students contacted the local kitchen garden association, which is located at the other end of the

neighborhood. To their surprise, the response was angry. How dare they compete with the existing club that struggled to find users themselves. The incident provided an important lesson for the students in the formation of matters of concern. What at first appeared to be a perfect blueprint to address residents' health needs turned out to be a divisive proposal. A more modest approach—the organization of temporary occasions for play and gathering in the park—appeared to be more effective in assembling the neighborhood. Students brought improvisation theater and games to the park. The organization of a spring festival with music and an exhibition of future park scenarios, among others, attracted a rather large crowd. These actions were more successful in sketching the contours of a healthy park, fostering a translation from a "poor quality park" to a place to meet and watch other people, enabling fleeting contact with strangers.

Finally, as the biodiversity of grass fields is almost zero, the working group attempted to breathe new life into the park. Collaboration with local nature organizations stimulated the integration of biodiversity and city ecology into ideas about high-quality parks. During the spring festival, a local folksinger who lived in the neighborhood and a local philosopher sang a song together. They wrote new lyrics on the melody of the folksinger's well-known hit song, describing the park as a place for humans and nonhumans:

(...) being codependent makes life wonderful and great (...) Together with plants, sparrows, blackbirds, owls, bees, next door boys (..) the water the air. (Lyrics of spring-festival song)

This song set the tone for including biodiversity as an aim of the park transition. During meetings, working group members shared stories of the diversity of plants that used to grow in and around the neighborhood when they were young. Collaborations with an organization for nature education gave the theme of biodiversity even more priority. The initial aim, which was to connect people in the park, broadened by including animals and plants. This led to a change in the working group's understanding of the park not only as a designated meeting place for humans and dogs, but also as a part of the city's ecological and social infrastructure.

Emergency services as a matter of collective care

As a CS project, the UwtN facilitated new problem definitions by mediating between neighborhood knowledge and professional knowledge infrastructures. Local knowledge infrastructures were, however, also already in place; in monthly neighborhood network meetings, residents discussed concerns that formed larger issues by pooling them together. One such issue was composed of stories surrounding the failure of ambulances to arrive in a timely

manner at local addresses—a problem that, at some point, could have fatal consequences. A group was formed to investigate "the missing ambulances," and it became clear that problems occurred at locations that had been the object of neighborhood restructuring.

Yes, the situation has changed. This used to be [part of] the square. However, since the new housing development ten years ago (...), it has become [part of] the avenue. The first aid system of the police, fire brigades, and ambulances has apparently never changed correctly. (Group interview neighborhood network members)

The neighborhood network transformed isolated incidents into a shared matter related to a change in the built environment.

Although the network initially planned to address the issue itself by placing improved street signs, members soon realized that ambulances based their routes on virtual navigation systems. As such, the issue needed to be discussed with the municipal authorities responsible for emergency care. The municipality advised the network to file complaints on the municipal website. The web format required inserting information about the ambulance's number plates, date, and time of arrival, and so forth, which did not align with the knowledge and experiences of the neighborhood, disabling a more fruitful understanding of the problem. Through her fieldwork, the first author became familiar with the "missing ambulances" case, and her academic networks enabled her to contact emergency medical services (EMS) directly. The researcher sat together with the neighborhood working group to help them record all information about missing ambulances and to present the case to the EMS in a meeting in the neighborhood center.

Initially, the interpretations of residents and EMS professionals regarding the problem with public health services were directly opposed. The residents suggested that ambulance drivers used their own GPS or Google Maps instead of the official navigation system of emergency services, while the EMS professionals suggested that residents most likely did not provide the right information to EMS services. The assumption about the citizen's role within the emergency infrastructure—as not knowledgeable was also reflected in how the EMS professionals prepared the meeting: They started off with an often-held lay talk on the citizen role in EMS, which describes calling the alarm number, providing a clear explanation of the situation and location, and eventually providing first aid before an ambulance's arrival. However, the residents considered their role broader, namely, including signaling structural problems in the EMS. Therefore, in the second part of the meeting, they invited three EMS professionals to a neighborhood walking tour. By sharing their stories and pointing to locations where ambulances were known to arrive late, a pattern emerged that could no longer be disregarded by EMS professionals as "incidents." This led the EMS coordinator to check the EMS system's coordinates the following day, and on that basis, he rephrased the problem of the missing ambulances as one of the "inaccurate coordinates within the GPS system." The right coordinates were entered into the system, after which residents reported that ambulances now drove directly to the right address and entrances.

This analysis shows that through the translation of individual knowledge into a shared issue by the neighborhood network and the subsequent translation of neighborhood knowledge claims into professional knowledge by the UwtN, an understanding of the ambulance case emerged that enabled a solution. Although no new cooperative framework between professionals and citizens has been developed, the case shows that the assumption of a strict separation between systems and citizens as beneficiaries is inadequate. Serving neighborhood health requires the epistemic involvement of citizens at the level of professional infrastructure.

REPRESENTING WORK ON NEIGHBORHOOD HEALTH BEYOND THE NEIGHBORHOOD

Inspired by STS, we analyzed how UwtN, as a CS collaboration, allowed—through newly assembled actors and translations—to construct matters of concern. In this section, we analyze how these processes enabled the representation of neighborhood health beyond the setting of this CS experiment.

First, in all publications about this CS project, improvements in health in the neighborhood were represented in terms of improvements in the social and spatial environment. This presents health as a shared collective phenomenon, not as a sum of individual behaviors (e.g., Horstman and Knibbe 2022). Neighborhood health should not be promoted through behavioral interventions, but by improving the quality and accessibility of public space. This representation of neighborhood health as an issue of public space found fertile ground in municipal governance oriented at "health in all policies" (HiaP). Policymakers were exploring how to cross boundaries between policy domains of health, spatial planning, social welfare, and sustainability, and the CS translations of health concerns helped to represent health to all policy fields. Through this representation, local concerns raised in CS became part of a broader movement of HiaP.

Second, this CS project enabled the *re*presentation of work in a healthy neighborhood as various types of "infrawork" (Lancione and Macfarlane 2016) oriented at the repair and maintenance of material and social assemblages and infrastructures. In recent decades, austerity has

led to the dismantling of many social and institutional infrastructures while underscoring the responsibilities of individual citizens. These policies predicated that citizen participation in neighborhood care would flourish upon the retreat of institutional care. In contrast, our representation of neighborhood care showed that citizens, social workers, and other professionals were continuously investing in the repair and maintenance of damaged social, institutional, and infrastructural relationships to build knowledge about neighborhood needs and to enable collective care (Raap et al. 2022a). Professional work was not replaced by volunteer engagement; instead, both citizens and professionals worked on rebuilding connections in their neighborhood care. Cases such as the lost ambulance and the work of the SocialGreen can be seen as examples of infrawork.

Third, the practice of CS inspired us to represent work on a healthy neighborhood as practices of communing as publics rather than as communities. This representation highlighted specific challenges of neighborhoods, namely, developing good ways of sharing public space in a very diverse neighborhood (Huron 2015; Kornberger and Borg 2015). In SocialGreen, citizens experimented with ways of overcoming "the tragedy of urban commons," thereby realizing the health potential of a park that was considered empty, boring, and unsafe. Although the tragedy of the commons refers to the overuse of resources, urban commons, such as a park in a low-income neighborhood, can also suffer from underuse because of diverse and temporary publics that are not attached to the neighborhood or park and have difficulties in building informal arrangements (Knibbe and Horstman 2022). The philosophy café also constituted a new public rather than a "community." The participants expressed "the desire of neighborhood inhabitants to meet strangers and exchange ideas, rather than to form close attachments to a neighborhood community" (Raap et al. 2022, p. 1). The philosophy café formed an epistemic public, and deliberations did not aim for consensus but for the exchange and exploration of difference.

In short, collaborations with citizen groups resulted in different translations of health and allowed us to represent neighborhood health in academic, professional, and policy discourses beyond the neighborhood in a new way. As a CS collaboration, the UwtN enabled a shift in focus from health behaviors to public space, from citizen participation to infrawork, and from communities to publics.

DISCUSSION

Our study aimed to develop a deeper understanding of the democratizing character of CS. In the various strands of CS, citizens have been positioned in different ways, varying from data collectors to promoters of scientific literacy (Bonney et al. 2009) and activists (Irwin 2002), and their knowledge is valued differently accordingly. By analyzing science–society platforms and participatory procedures, STS scholars have shown how citizens construct new objects of concern (Weibel and Latour 2005; Marres 2007). In such hybrid platforms, stakeholders and objects of concern develop together. Toomey et al. (2020) have provided an interesting example of how CS fostered shared concerns in a project that monitored oysters along the New York waterfronts. In this study, citizen–scientists not only collected oyster data, but also transformed the project into a process of making ecological places that connected oysters, citizens, and the wider society.

We aimed to further conceptualize the democratic potential of CS based on collaborations at the UwtN, where scientists and citizens work together to understand and promote neighborhood health. The various collaborations in actions (philosophy café, Together Greener, neighborhood lectures, etc.) and participatory ethnographic research created conditions for democratic knowledge production that is characterized by fostering dialogue and plurality. This diverged in two ways from common forms of health promotion and research. First, it turned the problem of "reach" around: Residents of lowincome neighborhoods are not hard to reach, as is often stated in health research, but public institutions, including academia, are hard for residents to reach. One of the benefits of the UwtN was that residents had new access to authorities and professionals to address neighborhood concerns, such as lost ambulances. Second, the UwtN created informal spaces for knowledge exchange to foster dialogue and collective learning about healthrelated issues in the neighborhood. The participants did not have to follow procedures, adjust to specific methods, comply with academic time/place schedules, or conform to specific health concepts, but they could speak in their own voices. Both conditions challenge common power relations and enable new forms of inclusion, supporting translations of issues into shared health concerns. Through CS, neighborhood issues such as low-quality green spaces and missing ambulances translated into shared matters of concern and initiatives developed to create a lively and biodiverse park and to improve connections (physical, digital, and social) between neighborhood and emergency infrastructures. In interactions with broader publics beyond the neighborhood, neighborhood health was conceptualized by shifting the focus from individual health behaviors to public space, from formats for citizen participation to the infrastructural work of repair and maintenance, and from community to public communing. In this way, concerns about low-income neighborhoods

were represented to policymakers and researchers in health, spatial planning, social work, and other fields.

Health promotion research has shown increasing interest in participatory approaches and CS (Den Broeder et al. 2018; De Weger et al. 2022; Grootjans et al. 2022). In the field of health promotion research, with a strong emphasis on individual health behaviors and evidencebased interventions, many participatory projects only enable participation within strictly regulated procedures. Leask et al. (2019), for example, outlined a framework for the co-creation of health interventions to reduce sedentary behavior and promote physical activity in a systematic and reproducible way that can be scaled up to populations at large. In the CS study of Grootjans (2022), 13 citizens were trained to collect data on six dimensions of positive health provided by the researchers, and the data were analyzed qualitatively and statistically by the researchers in line with conventional methods. This type of citizen participatory approach combines citizen engagement with conventional norms for good evidence (Halvorsrud et al. 2021).

Taking a different perspective, interest in participatory approaches can be connected to the rise of a "Mode 2" philosophy of science (Nowotny et al. 2003). In contrast to Mode 1 science, driven by universities and characterized by a technocratic accountability culture and standardized norms for "good knowledge," Mode-2 science is socially distributed and subject to multiple norms of good knowledge (Nowotny et al. 2003). Our analysis of the processes of translation and representation in this CS project contributes to this development. Representation is a matter of both science and democracy. Science—through making new issues of public concern—is constructing new actors and realities. Although the representation of matters of concern does not produce generalizable knowledge in the classic sense (Mode 1), UwtN did produce knowledge that, through translations, becomes relevant beyond the particular and material research context. The democratic potential of CS now revolves around the question of whether it is able to make new objects of public concern and mobilize new actors. This democratic potential can be realized if a citizen's science is not considered instrumentally the assistant of science and performed according to given methods, formats, and spaces but rather if it develops on its own terms in temporal-spatial configurations of everyday life.

CONCLUSION

The democratic potential of CS in public health and health promotion lies not in the mirroring-of-reality capability of

citizens, but in the transformation of objects of concern and the representation of problems in public health.

DATA ACCESSIBILITY STATEMENT

This study is part of a PhD. After completion of the PhD data will be stored at Maastricht Data Repository. Metadata: De Maastricht Data Repository employs the DataCite metadata scheme.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

SR conducted the empirical fieldwork and the initial data analysis and developed the initial interpretation of the results. In dialogue with MK and KH, the analyses and initial interpretation were refined. All authors contributed to the conceptualization of the study, to the interpretation and discussion of the findings, and to the revision of the manuscript. All authors approved the final manuscript.

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REFERENCES

- American Anthropological Association (2012) Principles of professional responsibility. Available at https://ethics. americananthro.org/category/statement/ Accessed 17 April 2024.
- Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L.,
 Bryant, J., Brozek, I., and Hughes, C. (2014) Reaching the
 hard-to-reach: A systematic review of strategies for improving
 health and medical research with socially disadvantaged
 groups. BMC Medical Research Methodology, 14(1), pp. 1–29.
 DOI: https://doi.org/10.1186/1471-2288-14-42
- Bonney, R., Cooper, C.B., Dickinson, J., Kelling, S., Phillips, T., Rosenberg, K.V., and Shirk, J. (2009) Citizen science: a developing tool for expanding science knowledge and scientific literacy. *BioScience*, 59(11), pp. 977–984. DOI: https://doi.org/10.1525/bio.2009.59.11.9
- Bonney, R., Phillips, T.B., Ballard, H.L., and Enck, J.W. (2016) Can citizen science enhance public understanding of science? Public Understanding of Science, 25(1), pp. 2–16. DOI: https://doi.org/10.1177/0963662515607406
- De Weger, E., Drewes, H.W., Van Vooren, N.J., Luijkx, K.G., and Baan, C.A. (2022) Engaging citizens in local health policymaking. A realist explorative case-study. *Plos One*, 17(3), p. e0265404. DOI: https://doi.org/10.1371/journal.pone.0265404
- Den Broeder, L., Devilee, J., Van Oers, H., Schuit, A.J., and
 Wagemakers, A. (2018) Citizen Science for public health. *Health*Promotion International, 33(3), pp. 505–514. Advance online
 publication. DOI: https://doi.org/10.1093/heapro/daw086
- **Denzin, N. Lincoln Y.** (eds.) (2017) The SAGE Handbook of Qualitative Research 5th edn. New York: SAGE.
- Dijkstra, I., and Horstman, K. (2021) 'Known to be unhealthy': Exploring how social epidemiological research constructs the category of low socioeconomic status. Social Science and Medicine, 285, p. 114263. DOI: https://doi.org/10.1016/j. socscimed.2021.114263
- GGD Zuid-Limburg. *Gezondheidsatlas Zuid-Limburg*. 2018. https://www.gezondheidsatlaszl.nl/. Accessed 17 April 2024.
- Grootjans, S.J.M., Stijnen, M.M.N., Kroese, M.E.A.L., Ruwaard, D., and Jansen, I.M.W.J. (2022) Citizen science in the community: Gaining insight in community and participant health in four deprived neighborhoods in the Netherlands. Health and Place, 75, Article 102798. DOI: https://doi.org/10.1016/j.healthplace.2022.102798
- Haklay, M. (2013) 'Citizen science and volunteered geographic information: Overview and typology of participation'. In: Sui, D., Elwood, S. & Goodchild, M. (eds.) Crowdsourcing Geographic Knowledge, pp. 105–122. DOI: https://doi.org/10.1007/978-94-007-4587-2
- Halvorsrud, K., Kucharska, J., Adlington, K., Rüdell, K., Brown Hajdukova, E., Nazroo, J., Haarmans, M., Rhodes, J., and Bhui, K. (2021) Identifying evidence of effectiveness in the

- co-creation of research: A systematic review and metaanalysis of the international healthcare literature. *Journal* of *Public Health*, 43(1), pp. 197–208. DOI: https://doi. org/10.1093/pubmed/fdz126
- Hecker, S., Bonney, R., Haklay, M., Hölker, F., Hofer, H., Goebel, C., Gold, M., Makuch, Z., Ponti, M., and Richter, A. (2018) Innovation in citizen science–perspectives on science-policy advances. Citizen Science: Theory and Practice, 3(1). DOI: https://doi.org/10.5334/cstp.114
- **Huron, A.** (2015) Working with strangers in saturated space: Reclaiming and maintaining the urban commons. *Antipode*, 47(4), pp. 963–979. DOI: https://doi.org/10.1111/anti.12141
- **Horstman, K.,** and **Knibbe, M.** (2022) *Gezonde stad. Uitsluiting en ontmoeting in de publieke ruimte.* Utrecht: Uitgeverij de Graaff.
- **Irwin, A.** (2002) Citizen Science: A Study Of People, Expertise and Sustainable Development. Oxfordshire: Routledge. DOI: https://doi.org/10.4324/9780203202395
- **Kasperowski, D.,** and **Kullenberg, C.** (2019) The many modes of citizen science. *Science and Technology Studies*, 32(2), pp. 2–7. DOI: https://doi.org/10.23987/sts.74404
- **Kimura, A.H.,** and **Kinchy, A.** (2016) Citizen science: Probing the virtues and contexts of participatory research. *Engaging Science, Technology, and Society,* 2, pp. 331–361. DOI: https://doi.org/10.17351/ests2016.99
- **Kornberger, M.,** and **Borch, C.** (2015) Introduction: urban commons. In *Urban Commons*. Oxfordshire: Routledge. pp. 11–31.
- Knibbe, M., de Vries, M., and Horstman, K. (2016). Bianca in the neighborhood: moving beyond the 'reach paradigm' in public mental health. *Critical Public Health*, 26(4), 434–445. DOI: https://doi.org/10.1080/09581596.2016.1142067
- Knibbe, M., and Horstman, K. (2022) Overcoming the tragedy of urban commons. Collective practices for a healthy city ecology in disadvantaged neighborhoods. Health Place, 75, 102777. DOI: https://doi.org/10.1016/j. healthplace.2022.102777
- Lancione, M., and McFarlane, C. (2016) Life at the urban margins: Sanitation infra-making and the potential of experimental comparison. *Environment and Planning A: Economy and Space*, 48(12), pp. 2402–2421. DOI: https://doi.org/10.1177/0308518X16659772
- **Latour, B.** (1993) *The pasteurization of France*. Harvard University Press.
- **Latour, B.** (2012) We Have Never Been Modern. Harvard University Press.
- Leask, C.F., Sandlund, M., Skelton, D.A., Altenburg, T.M., Cardon, G., Chinapaw, M.J.M., De Bourdeaudhuij, I., Verloigne, M., Chastin, S.F.M., GrandStand, Safe Step and Teenage Girls on the Move Research Groups (2019) Framework, principles and recommendations for utilizing participatory methodologies in the cocreation and evaluation of public health interventions. Research Involvement and Engagement,

- 5(2). PMID: 30652027; PMCID: PMC6327557. DOI: https://doi.org/10.1186/s40900-018-0136-9
- **Lezaun, J., Marres, N.,** and **Tironi, M.** (2017) Experiments in participation. *The Handbook of Science and Technology Studies*, 4, pp. 195–221.
- **Marres, N.** (2007) The issues deserve more credit: Pragmatist contributions to the study of public involvement in controversy. *Social Studies of Science*, 37(5), pp. 759–780. DOI: https://doi.org/10.1177/0306312706077367
- **Mirowski, P.** (2018) The future (s) of open science. *Social Studies of Science*, 48(2), pp. 171–203. DOI: https://doi.org/10.1177/0306312718772086
- **Moedas, C.** (2018) Citizen Science: Innovation in Open Science, Society and Policy. London: UCL Press.
- Nowotny, H., Scott, P., and Gibbons, M. (2003) Introduction: 'Mode 2' revisited: The new production of knowledge. Minerva, 41(3), pp. 179–194. DOI: https://doi.org/10.1023/A:1025505528250
- **PGP-UK Consortium** (2018) Personal Genome Project UK (PGP-UK): a research and citizen science hybrid project in support of personalized medicine. *BMC medical genomics*, 11, pp. 1–12. DOI: https://doi.org/10.1186/s12920-018-0423-1
- Raap, S., Knibbe, M., and Horstman, K. (2022) Making health public: a philosophy café in a disadvantaged neighborhood. Health Promotion International, 38(4), pp.1–11. DOI: https://doi.org/10.1093/heapro/daab206
- Raap, S., Knibbe, M., and Horstman, K. (2022a) Caring neighborhoods: Maintaining collective care under neoliberal care reforms. *European Journal of Social Work*, 25(5), pp. 867–879. DOI: https://doi.org/10.1080/13691457.2021.199 7928
- Rosas, L.G., Espinosa, P.R., Jimenez, F.M., and King, A C. (2022)

 The role of citizen science in promoting health equity. *Annual Review of Public Health*, 43. DOI: https://doi.org/10.1146/annurev-publhealth-090419-102856

- **Strasser, B., Baudry, J., Mahr, D., Sanchez, G.,** and **Tancoigne, E.** (2019) "Citizen science"? Rethinking science and public participation. *Science and Technology Studies*, 32(ARTICLE), pp. 52–76. DOI: https://doi.org/10.23987/sts.60425
- Tauginienė, L., Butkevičienė, E., Vohland, K., Heinisch, B.,
 Daskolia, M., Suškevičs, M., Portela, M., Balázs, B., and
 Prūse, B. (2020) Citizen science in the social sciences
 and humanities: the power of interdisciplinarity. *Palgrave Communications*, 6(1), pp. 1–11. DOI: https://doi.
 org/10.1057/s41599-020-0471-y
- Theobald, E.J., Ettinger, A.K., Burgess, H.K., DeBey, L.B., Schmidt, N.R., Froehlich, H.E., Wagner, C., HilleRisLambers, J., Tewksbury, J., and Harsch, M.A. (2015) Global change and local solutions: Tapping the unrealized potential of citizen science for biodiversity research. *Biological Conservation*, 181, pp. 236–244. DOI: https://doi.org/10.1016/j.biocon.2014.10.021
- Toomey, A.H., Strehlau-Howay, L., Manzolillo, B., and Thomas, C. (2020) The place-making potential of citizen science:

 Creating social-ecological connections in an urbanized world.

 Landscape and Urban Planning, 200, p. 103824. DOI: https://doi.org/10.1016/j.landurbplan.2020.103824
- Tracey, D., Gray, T., Manohar, N., Kingsley, J., Bailey, A., and Pettitt, P. (2023) Identifying key benefits and characteristics of community gardening for vulnerable populations: A systematic review. *Health and Social Care in the Community*, vol. 2023, pp1–23. DOI: https://doi.org/10.1155/2023/5570089
- **Weibel, P.,** and **Latour, B.** (2005) *Making Things Public:* Atmospheres of Democracy.
- Woolley, J.P., McGowan, M.L., Teare, H.J., Coathup, V., Fishman, J.R., Settersten, R.A., Sterckx, S., Kaye, J., and Juengst, E.T. (2016) Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. *BMC Medical Ethics*, 17(1), pp. 1–17. DOI: https://doi.org/10.1186/s12910-016-0117-1

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