

Chapter 17

Science as a Lever: The Roles and Power of Civil Society Organisations in Citizen Science



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Abstract Citizen science has become an umbrella term that encompasses a growing range of activities, actors, and issues. This chapter examines the potential of citizen science to generate transformative knowledge and argues that civil society organisations (CSOs) are key actors in this regard. However, the roles of CSOs are neglected in the literature on citizen science. We turn to the traditions of community-based research and participatory action research to learn more. With two case studies on health and safety, we show how transformative knowledge enables concerned communities to claim their rights and enriches scientific knowledge generation. Through a socio-historical analysis, we find three main roles grassroots CSOs take on in participatory research: (1) a technical role in the production of data and knowledge; (2) a governance role in the deliberation on research activities and risk assessment; and (3) an advocacy role by campaigning for transformative knowledge. These roles determine the ability of grassroots CSOs to generate legitimacy and rely on CSO members belonging to different spheres of society, scientific skills, and access to marginalised communities. Finally, we discuss the conceptual and practical challenges of accounting for CSOs' roles in order to build a more just and transformative future through citizen science.

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CSOs as Key Agents of Transformative Research

This chapter contributes a reflective social science perspective on the organisational context of *transformative knowledge production* in citizen science. It focuses on *civil society organisations* (CSOs) that belong to neither the state nor the market but the so-called third sector of civil society, for example, associations of amateur naturalists or climate justice movements. It builds on a recent article by Strasser et al. (2019) that traces the rise of the citizen science concept in relation to historical and political contexts. The authors argue that the current popularity of citizen science is linked to changes in science policy, in which the understanding and promotion of participation have shifted from a focus on deliberation to one on knowledge production. They show how the rise of citizen science is grounded in experiences from *community-based research* and *participatory action research* carried out in the context of social movements in the fields of health, environmental activism, and development studies since the 1960s. However, proponents of citizen science today who refer more often to amateur naturalists do not commonly evoke this legacy. From this perspective, several promises of citizen science, such as the democratisation of science, scientific literacy, and enhanced knowledge generation, can be critically interrogated.

In this chapter, we are particularly interested in the promise of producing ‘better science’, which is a leading argument to explain the value of citizen science. Strasser et al. (2019) highlight that fundamental transformations of scientific knowledge have been achieved in the past through work by and with ‘concerned’ persons and communities who directly, often physically, experience harmful or precarious conditions. It is by drawing on these experiences that they can substantiate knowledge claims on the phenomena in question and make available to research alternative perspectives on these issues:

It is no historical accident that many of the successful challenges from lay people to scientific orthodoxy emerged from knowledge grounded in their own body or its immediate environment. The credibility of the knowledge claims made by women health activists in the 1970s, by AIDS patients in the 1980s, or by residents of toxic neighborhoods in the 1990s was based on their intimate experience of their own bodies and physical environments. ... Seen in this light, the contribution of participatory research could be far more significant than simply adding an army of unpaid volunteers to help in solving current scientific problems at a lower price. It could result in a different kind of science and a different kind of knowledge. If participatory research can transform how knowledge is being produced, at a deep epistemological level, then it could hold important potential for transforming who can produce legitimate knowledge and what we know about the natural world. (Strasser et al. 2019, p. 65)

Strasser et al. thus locate the promise of innovation and improvement of science through citizen science – which is fuelling the growth of citizen science agendas today – in the epistemic authority hard-won by concerned individuals and groups

over the last century. Against this background, they call for more emphasis on community-based research and participatory action research, approaches focused on work with concerned groups, as well as the historical and sociological studies of the latter.

This chapter builds on these suggestions. We begin by examining the organisational settings and dynamics of participatory research processes. In particular, we consider how citizen science needs to be organised to generate transformative research. We argue that CSOs are key actors in this regard. They bring together those who are typically excluded from research processes, advocate for their perspectives, do research, and establish links to institutions. Prominent examples are the cases of AIDS treatment activists and movement organisations (Epstein 1995), patients' associations (Callon and Rabearisoa 2008), and environmental justice movement organisations (Ottinger 2010).

Thus, CSOs can act as catalysts to enrich scientific data and knowledge by brokering knowledge between institutionalised research and social movements.¹ The idea of knowledge brokerage relies heavily on knowledge transformation: 'knowledge brokers can be understood as persons or organisations that facilitate the creation, sharing, and use of knowledge' (Meyer 2010, p. 119, following Sverrisson 2001). In this chapter, we focus on the generation of transformative knowledge through participatory research with an emphasis on the active roles of CSOs.

Definitions of CSOs are as numerous as definitions of civil society (cf. Evers 2020). On a general level, CSOs are understood as social networks with (in)formal social relations between different actors (individuals, groups, organisations, etc.) as well as the patterns, which are formed by these relations. In the context of the United Nations, for instance, CSOs are defined as 'non-State, not-for-profit, voluntary entities formed by people in the social sphere that are separate from the State and the market. CSOs represent a wide range of interests and ties. They can include community-based organisations as well as non-governmental organisations (NGOs)' (HRRAFI 2019). In the context of the European Union, a similar definition can be found, referring to CSOs as 'any legal entity that is non-governmental, not-for-profit, not representing commercial interests, and pursuing a common purpose in the public interest' (Gall et al. 2009, p. 33). The latter shows that there is an important normative dimension: what belongs to 'the public interest' is wide-ranging and often contested. From a sociological perspective, CSOs are constituted by informal networks and individuals, bound together by shared values and solidarity mechanisms, and mobilised on conflictual issues. These varying perspectives need to be taken into account in order to properly characterise CSOs. Other important aspects for the analysis of CSOs include organisational history; forms of organisation, such

¹Moreover, these processes can be characterised as an exchange of perspectives and perceptions that lead to 'alignment, co-creation, and entanglement' (Sedlačko 2016, p. 6) as well as revealing contradictory data and scientific uncertainty. Gaining knowledge and knowing need to be understood as social interactions that are embedded in hierarchies.

as legal status; and forms of action, such as protest, evidence collection, and advocacy. On this basis, it is possible to distinguish NGOs, community-based organisations, and registered associations on different societal levels with their respective objectives and structures. In this chapter, we will focus on small grassroots CSOs that are part of new social movements.

In order to mobilise the analytical potential of social science research for our study, we adopt the differentiation by Strasser et al. (2019) between the concepts of *citizen science* and *participatory research*. Participatory research is broadly understood to refer ‘to the many ways in which members of the public have engaged and continue to engage in the production of scientific knowledge, and how they make sense of this engagement’ (Strasser et al. 2019, p. 67). There are many varieties of participatory research performed by and advocated for by different communities of practice. Their common trait is that the generation of scientific knowledge happens in a participatory way, with an emphasis on including people and communities who are not usually part of these processes. In this space of participatory research, citizen science is ‘a recent and increasingly fashionable label’ (Strasser et al. 2019, p. 55). We aim to disentangle this interpretation along with the conceptions of particular forms of participation and doing research. This distinction makes it possible for us to analyse and put into perspective the discursive level at which citizen science is established in current debates among practitioners as well as in research policy.

Against this background, we argue that to learn more about transformative participatory research, it is necessary to examine the characteristics and roles of CSOs in citizen science and participatory research. For this purpose, we will first review literature on citizen science regarding how CSOs are addressed. Since, as we will show, citizen science literature has a lacuna with respect to CSOs, we then proceed to mobilise additional sources. We will analyse two historical case studies situated within the traditions of participatory research and ask what we can learn in order to undertake innovative citizen science today in terms of generating transformative knowledge. Our first case study concerns the Nord-Cotentin Radioecology Group as a *pluralist* expert group on environmental health and nuclear risk in France in the late 1990s. The second case explores the association Arbeit & Gesundheit e.V. that has worked between academia, new social movements, and the state to improve occupational health and safety in Germany since the 1980s. Based on the points raised by these cases and by synthesising findings from grey literature on stakeholder workshops, we then discuss conceptual and practical challenges for the participatory generation and the application of transformative scientific knowledge. Finally, it is our hope that this will provide a basis to strengthen citizen science by leveraging the power of CSOs.

CSOs in Citizen Science

This section explores literature published explicitly on citizen science, the variant of participatory research that currently receives considerable attention from the media and decision-makers across Europe (see Vohland et al., this volume, Chaps. 1 and 3).

It asks how citizen science is organised and how CSOs are involved. Painting with a broad brush, one can observe that, beyond case studies of single citizen science activities, the literature on citizen science approaches these questions in three ways: *participation typologies*, *managerial logics of knowledge production*, and *good practice repositories*. The first key strand of scholarly work on the organisation of citizen science systematises the diversity of participatory research activities with the help of participation typologies. Such classifications of project types are based on models of governance, a key feature of project organisation, for example, if and how deeply volunteers or collaborators outside academia are involved in research and project management tasks (for an overview, see Ceccaroni et al. 2016). A second strand looks at the managerial logics of knowledge production in citizen science from a procedural perspective and examines the challenges. For instance, Franzoni and Sauermann (2014) identify the matching of projects and people, division of labour, integration of contributions, project leadership, and motivational aspects, as organisational challenges. A third strand of literature on the organisation of citizen science comprises guidelines for undertaking citizen science activities (see Sanz et al., this volume, Chap. 21). They are written either by practitioners or for them. Such good practice repositories often stem from capacity building activities and are both a product and the basis of the ongoing standardisation of citizen science.

Beyond these three stands, scarce systematic and comparative research has been carried out on the organisation of citizen science to date. A stakeholder analysis of 16 citizen science projects from various disciplines found 6 groups of stakeholders (Gobel et al. 2017): (1) CSOs, informal groups, and community members; (2) academic and research organisations; (3) government agencies and departments; (4) participants of citizen science initiatives; (5) formal learning institutions such as schools; and (6) business or industry. These provide diverse contributions to citizen science projects and are involved to varying degrees across different governance models. Along those lines, a review of projects on the German and Austrian citizen science platforms (Pettibone et al. 2017) found that project initiation and coordination lie with a heterogeneous group of actors. Most projects in their sample are initiated by scientific organisations, while actors from civil society represent the second largest group of project initiators, and government and media organisations are responsible for a smaller fraction of projects. Pettibone et al. point out that little is known about the concrete roles of these actors and their rationale for engaging in citizen science. They find a diverse range of third sector organisations involved in citizen science: ‘These groups include non-profit organizations (i.e. NGOs) focused on political or social issue engagement (such as environmental groups), some of which have professional research components (such as BUND or NABU) or are structured as research organizations (such as UfU). In addition, we consider independent groups interested in scientific research outside the academic context (*Fachgesellschaften* in German), which we group with engaged individuals and small groups of individuals’ (Pettibone et al. 2017, p. 6).

European and national meta-organisations concerned with the establishment of citizen science networks for practitioners, professional organisations, and science-policy mediators are another type of CSO in the field of citizen science (Göbel et al.

2016). Roles of CSOs in citizen science thus emerge as significant but understudied in the literature on citizen science. The first two strands of literature on participation typologies and managerial logics do not scrutinise CSOs, while the third stream on good practice mentions CSOs as potential partners but remains practice oriented and unsystematic. Arguments from capacity building work on improving CSO involvement will be covered in the section on challenges.

This general lack of scrutiny of CSOs is related to common implicit assumptions in citizen science literature. First, much of the scholarly work seems based on a model that portrays citizen science as a relationship between two parties – *researchers* and *volunteers* (cf. Eitzel et al. 2017). This neglects the diverse range of other actors involved, including CSOs as representatives of organised civil society. Second, the prototypical format of citizen science activity usually discussed is that of temporally limited research and engagement projects. Organisations running these projects and marketing them to the public and the networks which support them are largely absent from the research landscape. For instance, Tancoigne (2019) shows that CSOs are invisible in citizen science communication on Twitter and that, generally, there is a lack of attention to the brokers of citizen science. A third aspect that is neglected in the literature on citizen science – without a direct link to the scrutiny of CSOs, but important for studying them – is that the governance of citizen science activities, such as the distribution of decision-making power and tasks, changes over time. While such considerations are sometimes mentioned (e.g. Franzoni and Sauermann 2014), deeper empirical research on such linkages and project dynamics is currently missing.

In this light, we hypothesise that the lacuna regarding the involvement and roles of CSOs is a systematic one. Dominant framings of how participatory research is undertaken in the citizen science discourse mostly paint pictures of stable two-party relationships between researchers and lay individuals in temporally limited projects. This narrow model, however, only partially corresponds to empirical findings that show diverse CSO engagement in participatory research activities labelled as citizen science. Participatory research by and with CSOs is thus not only a neglected aspect of the past, as Strasser et al. (2019) have shown, but continues to be overlooked today. In order to learn more about the organisation of transformative participatory research and to enrich discussions on citizen science, we now turn to mobilising additional sources.

The Roles and Power of CSOs in Participatory Research: Two Case Studies

This section draws on two paradigmatic case studies to explore how the generation of transformative knowledge has been organised, especially how CSOs have been involved in participatory research in new social movements since the 1960s. It focuses on the creation of legitimacy – a central challenge for collaborations that

cross the boundaries of scientific institutions (Tratschin 2016).² Both cases are bottom-up initiatives in which grassroots and non-formal organisations have affected changes in work and living conditions.

Mindful of the shortcomings identified in the citizen science literature above, we present two case studies on multiple and evolving forms of collaboration with various partners. In addition, the case studies have been chosen to broaden the knowledge base of citizen science in three ways. First, the case studies provide a historical perspective that helps to consider contemporary citizen science initiatives as rooted in the heritage of earlier forms, rather than as innovations. Second, the case studies provide examples from the fields of social sciences and health that figure marginally in the citizen science discourse compared to experimental and environmental sciences. Third, our focus is on scientific knowledge generated in or close to contexts of application – public expertise in risk governance involving state agencies and occupational health knowledge relevant to workers, industry, and workers' unions.

Environmental Health and Nuclear Risk: Pluralist Expert Groups

This first case study examines the involvement of CSOs in the field of risk evaluation by describing a key moment in the recent history of regulatory agencies in France: the opening up of public expertise to CSOs by setting up a *pluralist* expert group – the Nord-Cotentin Radioecology Group (GRNC).³

Regulatory agencies are part of the state apparatus (Jasanoff 1990; Joly 2009) – they provide knowledge for the government and public administration that serves as an input for drafting public policies, acting on crisis issues, monitoring compliance, and controlling risks (Demortain 2017).⁴ To perform risk evaluation, a central task of regulatory agencies is to convene expert committees to elaborate so-called public expertise to resolve controversial issues. Public expertise consists of a report or study elaborated on the contemporary state of scientific knowledge in order to answer to a pragmatic issue or question (Roqueplo 1997). Over the last 10 years, several French regulatory agencies have established a policy of *openness to society*, which aims to better include civil society in public expertise.

²From a communication science perspective, (dis)empowerment can be understood as the ability of individuals and CSOs to consolidate protest by gaining legitimacy from the political as well as the societal sphere.

³The case study is based on published literature, current research, as well as unpublished interviews.

⁴As scientific bodies, the scientific work of regulatory agencies is meant to be independent from the political work of the administrations that they are linked to. At the same time, their scientific work happens in close relationship with administrative work and consequently follows different standards to research undertaken at universities or other research institutes. These particular conditions are expressed in the concept of *regulatory science*.

One of the first experiences that led to openness policies was in the late 1990s on the issue of sanitary effects of nuclear contaminations. In 1997, an epidemiological study attested the nuclear waste reprocessing plant of La Hague, Nord-Cotentin, which caused environmental contamination that was responsible for an increased rate in child leukaemia. The mothers of the region's sick children mobilised to close the plant, calling themselves Angry Mothers. Environmental activists, CSOs, and independent radiologists, who were already mobilised in the local anti-nuclear movement, joined them in their protests. The accused company and several epidemiologists working on the subject disputed that the results of the study provided evidence of environmental or health contamination. The controversy became public and a subject of intense media interest.

In order to respond to the controversy and to determine the credibility of the study, the Institute of Protection and Nuclear Safety (IPSN)⁵ convened a first group of experts. After an initial expert report, based only on data gathered by the accused company, did not convince protesters, the environmental minister asked for a second expert report on the controversy. The new scientific director, Annie Sugier, played a key role here as she was highly regarded by all of the parties involved in the controversy due to her professional record in three different fields (the nuclear industry, CSOs, and public expertise). She proposed replicating the controversial original study by conducting a pluralist expert study which actively involved local CSOs in the expertise process (Miserey and Pellegrini 2006).

Two parallel working groups were created. The first group was to replicate the epidemiology study to investigate the rates of child leukaemia in the area; this group was composed of scientists from different public institutes. A second group was to lead a radioecological study to investigate possible radioactive contamination around the plant; this group included some of the protesting associations as well as plant representatives and scientific experts from different public institutes. Once the pluralist group was composed, every party was involved in every stage of the expert work: identification of questions and problems, corpus building, data analysis and interpretations, synthesis reduction, as well as public communication (Miserey and Pellegrini 2006; Topçu 2013).

The final report indicated an increased rate of child leukaemia in the area but did not manage to establish any environmental contamination causality. However, several other possible causes were identified in the conclusions, leading to the formation of a second pluralist radioecological group. The uncertainty maintained in the scientific results is an important characteristic of the GRNC's work. It underlines the potential of such an organisation to be used as pluralist expertise to calm down a controversy even in the absence of a scientific consensus (Barbier 2019). These findings also highlight how such a scientific device also changes the knowledge produced. GRNC opened the doors of the technical and administrative spaces of technology assessment to CSOs. By being 'invited' to take place in the

⁵Until 2001, the IPSN was a department of the public administration of the Commissariat for Atomic Energy.

pluralist group, CSOs moved from positions of outside witnesses and protesters to inside contributors to the scientific work. It was the first experience of an institutional turn in the way IPSN cooperates with CSOs. Multiple institutional, social, and technical changes followed (Ottolini [forthcoming](#)).

For the work of the pluralist expert group on radioecology, legitimacy has been a central issue. For instance, the inclusion of CSOs, in general, as well as which ones were included, in particular, was justified by *technical legitimacy*. Therefore, not all the protesting groups were invited; only the ones that produced data and were able to take part in technical deliberation could get involved. Legitimacy was also an output of the process. The associations involved were recognised for their technical legitimacy. Not all NGOs involved in the protests and collecting data joined the group; some refused to become part of a state-led technology assessment process, fearing participation would decrease their ability to be critical. This could have also affected the NGOs legitimacy in the eyes of their supporters. The fact that CSOs held different positions in the GRNC matters to be remembered. In addition, it should be highlighted that the legitimacy of the radioecology group and its work was questioned regarding its entire membership, not just the NGO representatives. Company representatives and scientific experts also had to prove their legitimacy to the other parties involved. For instance, scientific experts had to demonstrate their independence from the nuclear industry. At the time, such pressure on experts' legitimacy was unusual (Callon et al. 2009). Finally, at the centre of the argument for more openness of the French risk evaluation institutes was the hypothesis that improving relationships with NGOs would counter a perceived lack of legitimacy. The GRNC experience has been a crucial episode in establishing this question as a matter of concern for regulatory agencies in France.

Occupational Health and Safety: Between Academia and New Social Movements

This second case study examines processes in the field of occupational health and safety in Germany regarding how (scientific) knowledge is gained by including a variety of perspectives on workers' experience, academic perceptions, and political considerations. The case study describes relevant moments in the history of a part of the German health shop movement located in Hamburg, fighting against authoritarian structures within the German health system that led to the foundation of a registered association called Arbeit & Gesundheit e.V. (Work & Health association).⁶

In the 1970s and 1980s, parts of Western Europe mobilised around new concepts of occupational health and safety within a broader health movement; this had ties to

⁶The case study is based on expert interviews with former activists within the health shop movement as well as people committed to Arbeit & Gesundheit. e.V.

the anti-nuclear, peace, environmental, and feminist movements. In West Germany, tensions arose between established university physicians and medical students regarding scientific approaches, data, analytical results, and recommendations to industry and politics. One salient topic was confrontation with the national socialist past. A focus was on the role of medicine in selecting productive bodies while neglecting a holistic approach that embraces human beings in their psychosocial and physical constitutions as well as the environment surrounding them. Also contested were the established power relations of the old, elite governing universities, hospitals, and occupational health institutions. Another salient topic was the critique of industrial hazards. Examples included exposure to polyvinyl chloride (PVC), used in the mechanical engineering industry, which leads to angiosarcoma of the liver, and isocyanates used to produce foams, in the automotive and timber industries, which lead to obstructive airway diseases (Schulze et al. 2018, pp. 258–259).

In European countries like the Netherlands, the United Kingdom, Denmark, and West Germany, university staff as well as students discussed how to make scientific knowledge available and comprehensible to ‘lay people’ (EWHN 2016). They also claimed that people not working in academia should have the option to co-decide research topics and projects. These discussions led to the establishment of *science shops*⁷ at universities and of working groups, for example, on occupational health, to which trade union members, students, and academic staff were committed (EWHN 2016). These developments were accompanied by the founding of independent advice centres on healthy working and living conditions.⁸ Members came from labour unions, health and technical professions, academia, and community activism (regarding the role of traditional actors and their relation to new forms of engagement, see Schulze et al. 2018; Jenkins and Marsden 2019).

In this context, the concept of so-called health shops was born, referring to community-based, self-determined approaches of health care, moving science shops from the university to the community (see also EWHN 2016). Stemming from the health shop movement and inspired by the Italian workers’ movement,⁹ the NGO Arbeit & Gesundheit e.V. was founded, in 1987, by some of the people involved in the working group Workers’ Medicine from the health shop in Hamburg. Its aim was to enhance and institutionalise two approaches: (1) focus on workers as experts of their health and their working environment and (2) utilise workers’

⁷Science shops are scientific research spaces in which information and education are carried out for and with citizens (Wals et al. 2016, p. 35; see Senabre Hidalgo et al., this volume, Chap. 11). They started with issues and hazards at the shop floor level (EWHN 2016).

⁸Prominent examples include the London Hazards Centre, founded in 1984, in the United Kingdom, and the Committees/Coalitions on Occupational Safety and Health (COSH-groups) in the USA, where the first one was established in 1972.

⁹The Italian workers’ movement declared in the mid-1960s that ‘Health is not for sale!’ (Calavita 1986, p. 199), founding working groups at shop floor level and establishing the principle of non-delegation. This meant that neither union representatives nor occupational physicians had to decide which claims were to be negotiated with employers. Instead the workers themselves collected data on health issues and working conditions to use for improvements in the workplace.

knowledge of occupational illnesses. These perspectives were used as the basis for research and scientific consultation, as well as setting the scene for new relationships with experts from other domains, such as occupational physicians, politicians on local and national levels, and toxicologists.

Participatory research was fundamental here: the health shop movement provided interaction between people coming from different (institutional) backgrounds. Medical students shared their knowledge about questionnaires with the workers who conducted research inside the factory; both aimed to correct hazardous conditions. Here, the participatory research initiative was bottom-up in two ways: in the mobilisation of students within the university environment with its hierarchical structures and in the mobilisation of workers within the industry vis-à-vis its occupational health physicians. Both groups become actors leading research processes. The founding principle of Workers' Medicine was 'non-delegata', referring to gaining control over working conditions, especially in improving health and safety issues at work (Calavita 1986, p. 201). This is especially important in the context of participatory research because it relates to at least two aspects that enable knowledge production that widens the scope of the scientific discourse and medical practice. These are monitoring of the workplace by workers and having an internal exchange of information and experience, for example, of symptoms, through questionnaires and group discussions. This helped to 'identify previously unknown occupational risk factors, indicate the presence of known factors, and provide indications for solutions' (Reich and Goldman 1984, p. 1034, with regard to Berrino and Morosini 1977).

However, this way of producing knowledge was controversial: due to the subjectivity of the individual experiences, the collection of data was considered biased, and the lack of expertise to take into account hazards not experienced first-hand, like 'non-odorous toxic gases', was also considered problematic (Reich and Goldman 1984, p. 1033). In this context, legitimacy was achieved in three main ways. The first was cooperating with academia in the construction of questionnaires, gathering data collectively, and analysing data comparatively.¹⁰ Bargaining with employers in a science-based way was the second way to achieve legitimacy. This involved using the collected data and its analysis, as well as mobilising expertise outside the factory. It became an important part of the strategy of the workers group to co-determine work processes and to co-regulate and by doing so to gain power in protecting their health. As one of the interviewees put it: the data became 'a rational basis for a constant debate about health issues at work' (member of the working group and of Arbeit & Gesundheit e.V. 11 July 2017). The third way to gain legitimacy was

¹⁰The reports of workers were compared regarding the symptoms, looking for similarities and differences. That was done by forming homogenous groups by bringing together workers who were assumed to experience the same exposure (Calavita 1986, p. 202). Here, the predecessor of Arbeit & Gesundheit e.V., the working group Workers' Medicine, played a central role: as members of this working group were also members of work councils and medical students specialising in occupational medicine, bringing people together to plan research activities as well as facilitate negotiations with the employer and within the work council.

through legal recognition by becoming a registered association and receiving public funding from the Senate of Hamburg. Through this, the institutionalisation process of the demands in the health shop movement began. The financial support represented stability and seriousness. This made Arbeit & Gesundheit e.V. an actor relevant to trade unions and politicians. By creating credibility in the scientific expertise of the actors (work councils representing workers' interests and activists from the health shops), these zones of plausibility opened the path to negotiations on legislation and regulations like the Technical Rules for Hazardous Substances, for example, on carcinogenic hazardous materials.

Evolving Roles and Relations

In this section we examine the two case studies in relation to each other. For this purpose, we discuss the roles of the leading CSOs, the relations of CSOs to other actors, and the evolution of those relations. These constellations, we argue, lay the fundamentals for the transformation of the creation and use of scientific knowledge by including hitherto excluded perspectives to which both case studies testify. For both community-based organisations discussed, participatory research was used as a lever to elaborate and justify their positions. While different factors led to the emergence of collaborations in each case, it was especially the connection to science that enabled activists and engaged citizens to pave the ground for being recognised as legitimate negotiators. That differentiated them from 'mere' protesters and people being mainly committed to parliamentary activities in their pursuit of social and political change.

The presentation of the two case studies challenges the idea that successful participatory research always has its starting point in academic research. To the contrary, in these two case studies, it involved an interplay of diverse actors who worked on social and cognitive injustices and used science to gain legitimacy as well as to enrich the knowledge base. CSOs have taken on central activities and leading positions in the collaborations that can be summarised in three different roles:

1. A *technical role* in the production of knowledge, such as gathering data or choosing methodologies of data interpretation
2. A *governance role* in the organisation of research activities, such as choosing or bringing up new topics of research
3. An *advocacy role* that includes campaigning for transformative knowledge and translating or brokering knowledge between contexts of research and application.

For CSOs to fulfil these roles, three factors were important. First, the members of the CSOs belonged to multiple organisations, for example, social movements, universities, trade unions, and work councils. This enabled the actors to meet in different spaces, exchange information, and develop ideas for change. Second, for generating transformative knowledge, CSOs had access to academic skills. Third, CSOs also had access to otherwise excluded communities, for instance, in the

workplace. On this basis, CSOs were able to shift their position from being objects of research or outside protestors to becoming co-developers of research. In this position they were empowered to make claims and to observe, collect, interpret, and, finally, negotiate scientific knowledge. This meant gaining legitimacy,¹¹ that is, representing justified authority for communities, scientific institutions, as well as politicians (see, e.g. King 2003, p. 25).

In addition to the focus on the generation of knowledge, our cases show the importance of contexts of knowledge application for this type of participatory research.¹² Both the cases are in scientific domains that rely on the embodied expertise of concerned groups to (re)claim epistemic authority – occupational medicine and social sciences (health shop) and epidemiology (pluralist expertise). We argue that the nature of such participatory research is closely tied to it taking place as applied research. Without the contexts of occupational health regulation or risk governance, the work of Arbeit & Gesundheit e.V. and the pluralist radioecology group cannot be understood.

Challenges for CSOs in Citizen Science

In this section, we link what we have learned from the case studies to broader debates on the involvement of CSOs in participatory research, particularly citizen science. We do this by focusing on five core issues that represent conceptual and practical challenges associated with understanding and analysing roles of CSOs in participatory research. For a discussion on the roles of technologies in citizen science, see Butkeviciene et al. (this volume, Chap. 16):

1. *Taking mistrust and controversies into account.* Both case studies challenge our understanding of what is nowadays called citizen science on fundamental, conceptual, and political levels. At the heart of both case studies, we find suspicion towards scientists, experts, and company authorities, who are assumed to act in favour of industrial interests. This approach taken by the CSOs actually represents a form of mistrust, which today's politicians seek to minimise by funding citizen science. However, such an approach disregards that it was mistrust that acted as a catalyst for civil society groups to engage in research themselves and become legitimate parties in the processes of scientific knowledge generation and application in contexts that directly affect their lives and bodies (cf. Wynne 2006). The role of CSOs is therefore not only to participate in research activities

¹¹'An account of legitimacy involves assumptions, principles, and arguments in terms of which authority is justified' (King 2003, p. 25). See Ruokonen (2013) regarding the relation between trust, trustworthiness, and responsibility from a philosophical perspective.

¹²Although this characteristic has been prominently highlighted in the strand of science and technology studies work on technical democracy pioneered by Callon et al. (2009), it is largely absent from current discussions on citizen science.

but also to achieve transformative goals, that is, to change specific living and working conditions, which endanger their own and other people's health. Moreover, CSO action aims to claim a right to know (see EWHN 2016), thereby democratising knowledge (see Derickson 2016 for an example of workplace health hazard information access). This tension of approaches to science, participation, and (mis)trust highlights the productivity of both sociotechnical controversies and including critics in scientific processes to question technical roles and responsibilities in scientific work (cf. Callon et al. 2009). Making visible and exploring controversy and critique in our analysis of citizen science offer the opportunity not only to change our understanding of participatory research but also to enable deliberation on scientific governance (see also the concluding section).

2. *Considering values as drivers.* The role of CSOs is closely linked to values which motivate participation in and commitment to collective action. Therefore, it would be interesting to ask what values motivate involvement in science, producing one's own data and using these for demanding change, as well as which values provide the basis for legitimacy. A historical perspective reminds us that different actors can mobilise different (registers of) values at different times and thus may change our perception of the roles of values in (participatory) science.¹³ Moreover, we should also gain insight into the socio-economic conditions the (non)participating individuals and communities live in, which may affect motivations and strategies to pursue goals as well as the choice of collaboration partners. Additionally, a systematic approach of researching citizen science has to analyse how these actors mobilise for change and produce collaboratively scientific results. New communication technologies and more sophisticated techniques of participation can widen the repertoire of scientific and political participation, which will bring challenges to methodological approaches.
3. *Inclusiveness.* This brings us to the question of who can take part in collaborative research (see also Paleco et al., this volume, Chap. 14). As far as the cited literature and the two case studies indicate, it is usually necessary to speak the language of science and administration as well as the language of law. This requires analysing the settings in which CSOs and their members are able to act as researchers and acknowledged as experts outside scientific institutions. Therefore, the question of who is marginalised needs to be scrutinised. One can hypothesise that those who have not obtained expert knowledge or who are not able to collect data or to interpret data will be excluded from citizen science. The two case studies show how this question of inclusion and exclusion has been crucial in the history of participatory research – a topic scholars and practitioners of citizen science should address more thoroughly. However, it is important to ensure that CSO involvement is not merely limited to providing access to volunteers. Although this can represent a valuable contribution, we have argued

¹³Understanding the roles of values in the 'moral economy' of science is a fundamental subject in the sociology and history of science (cf. Daston 1995).

that, in general, the potential of CSOs for transformative research can be best captured through drawing on their expertise and leadership to partner with them for co-creation.

4. *Ambiguity of terminology.* There is a conceptual tension in the framing of citizen science, to which we referred at the beginning of this chapter. On the one hand, the label citizen science is typically used for a subset of participatory research activities, usually involving large-scale data gathering or analysis, and closely linked to crowdsourcing (cf. Strasser et al. 2019). However, on the other hand, citizen science is also being established as an umbrella term (Rip and Voß 2013) in research and environmental policy. So, it becomes clear how citizen science claims to unite various streams of participatory research under one joint concept, including community-based research. Such umbrella terms allow scientific research agendas, societal concerns, and policy issues to be linked. We argue that more research is needed on the tension between these two usages, such as the unifying and hegemonic qualities of the concept.
5. *Funding.* Finally, on a practical level, funding conditions are a key challenge for expanding the roles of CSOs in citizen science.¹⁴ A central argument is that the decline of public investment in academic research and universities since the early 2000s corresponded with an increase in investment in private research and innovation (Larédo 2015). Citizen science, if understood as outsourcing of research work to unpaid volunteers, might be seen as the latter (cf. Mirowski 2017). However, by taking the roles of CSOs more seriously and systematically into account, participatory research can also be understood (and further established) as a third kind of research – following a civic logic and complementing public government and private market research (cf. ALLISS 2017).

The Power of Transformative Research: Future Perspectives

This chapter started with the assumption that CSOs are key actors for generating better science, that is, knowledge that changes both understanding as well as how people live and act. We have argued that discourses on citizen science between practitioners and policymakers do not consider CSOs systematically. Through the presentation of two case studies, we demonstrated how different forms of collaboration between organised civil society and scientific institutions have a long-term history that the recent trend of promoting citizen science can draw on. The CSOs we examined took over technical, governance, and advocacy roles in the production of knowledge, closely linked to contexts of application. These cases challenge the dominant view of citizen science as a stable two-party relationship between

¹⁴Discussing more practical challenges of improving relations between CSOs and scientific institutions is beyond the scope of this chapter (for results of capacity building work at the European level, see Göbel et al. 2019).

academic researchers and lay individuals who collect or analyse data in temporally limited projects. Important aspects of those forms of collaborations are scientific skills and access to marginalised communities, handling power imbalances between academic institutions and CSOs and generating legitimacy. Addressing these analytically, as well as in practice, gives rise to a web of interconnected challenges that we have discussed above.

Based on these findings, how can the involvement of CSOs be taken seriously in the definition of citizen science and the shaping of this field of research and engagement practice? Here citizen science is understood as a variety of existing participatory research approaches, linked together by a joint label (not merely associated with a specific methodology for participation in research, like crowdsourcing). This is important, because through that linkage what counts as participation and what counts as research are configured. In this sense, there is a danger of generalising a citizen science model of participatory research, which neglects the contributions of CSOs and eclipses other forms of participatory research along with their associated methodologies, communities, and trusted relations. In our case studies, we have shown how CSOs have adopted multiple roles in participatory research processes, transforming the generation and use of scientific knowledge. This transformative potential is deeply rooted in the configuration of self-organised engagement with socio-techno-scientific issues, which is why CSOs play a critical role. We argue that they should be key agents in shaping the future of participatory research and need more consideration – both in research as well as in practice – in the context of citizen science.

Engaging with self-organised civil society groups and organisations also means engaging with controversial issues. These can be issues for which scientific and political consensus might not yet have been reached (as in our first case study) or maybe controversies not even yet recognised (as in the second case study). In this sense, more engagement with CSOs as part of citizen science also signifies increased politicisation of both the field and the practice. This could mean, for instance, that more citizen science projects and practitioner organisations would take positions on controversial issues and get involved in the messiness of shaping them. Another expression of taking this ambition seriously would be to ask – not only why CSOs are important for citizen science, as we did in this chapter, but notably – what role citizen science can play for CSOs.

Finally, to facilitate more work in such a direction, we need to focus on the values binding together our own heterogeneous communities of practice. It is key to examine to what degree the structures and processes we use to act together support these values, so we can improve them to ensure that they address mutual respect, equity, and inclusiveness in adequate ways. It might then be possible to nurture communities of mutual support and care, which are key to unlocking the transformational potential of making and using scientific knowledge.

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