

# ETHICAL BOUNDARY WORK IN CITIZEN SCIENCE:

#### Themes of insufficiency

by Dick Kasperowski, Niclas Hagen & Frauke Rohden

The concept of boundary work (Gieryn 1983, 1999) has been developed to capture the ways in which scientists collectively defend and demarcate their intellectual territories. This article applies the concept of boundary work to the ethical realm and investigates the ethical boundary work performed by researchers in the field of citizen science (CS) through a literature review and by analysing accounts of ethics presented in CS literature.

Results show that ethical boundary work in the CS literature is, to a large extent, a matter of managing ambiguities and paradoxes without any clear boundaries drawn between the unethical and ethical. Scientists are negotiating ethical positions, which might, occasionally, enhance the ethical authority of 'non-science' and non-scientists, as well as maintain already established research ethics. The main ethical boundary work in CS displays variations towards perceived insufficiencies of conventional research ethics to accommodate "outsiders", addressing issues of distribution, relevance, and expulsion as science include volunteer contributors in the scientific process.

Keywords:	Citizen science, review, ethics, boundary work, autonomy, content analysis
Author:	Dick Kasperowski, Department of Philosophy, Linguistics & Theory of Science, University of Gothenburg, Sweden
	Niclas Hagen, Department of Philosophy, Linguistics & Theory of Science, University of Gothenburg, Sweden
	Frauke Rohden, TIK Centre for Technology, Innovation and Culture, University of Oslo, Norway
Licensing:	All content in NJSTS is published under a <u>Creative Commons Attribution 4.0 license</u> . This means that anyone is free to share (copy and redistribute the material in any medium or format) or adapt (remix, transform, and build upon the material) the material as they like, provided they give appropriate credit, provide a link to the license, and indicate if changes were made.

### Introduction & background

The participation of non-professional contributors in the production of scientific knowledge has been undergoing a process of institutionalisation during the last decade (Macq et al, 2020). Under the banner of citizen science (CS), this includes recognition and expectations from national and international policy makers; evaluation and standardisation of methods and technology; the launching of a specialised journal; establishment of national and international associations, conferences, courses; and specified calls for CS from national and international funders.

In fact, this development resembles many of the aspects Kuhn (1962) associated with the development of normal science. Individual projects have been showcased as exemplars that successfully mobilise volunteer contributors, make large-scale observations, and explore empirical materials beyond earlier possibilities of science (Follett & Strezov, 2015; Kullenberg & Kasperowski, 2016). CS has also been recognised by national and international institutions such as the United Nations (UN) as important for complementing and improving data for monitoring the sustainable development goals (Fritz et al., 2019; Fraisl et al., 2020).

This process inevitably involves discussions and controversies over what can be regarded as CS in struggles over credibility, resources, participation, and truth (Riesch, 2010, p. 454; Prainsack, 2014, p. 147). Some argue that CS is "redefining or even disassembling boundaries", but also that "a baseline of mutual understanding of what is meant by the term 'citizen science'" is necessary for the development of the field (Hecker et al., 2019, p. 1). While CS is held to dissolve boundaries between professional scientists and volunteer contributors, the structuring of participation in CS has also been shown to limit inclusion, recreating borders between scientists and volunteer contributors (Hagen, 2020).

The ethical issues of CS are an important part of discussions and controversies in the field of CS. There is little controversy over issues, such as securing anonymity of participants (Woods et al., 2015, p. 25; cf. Cinderby, 2010, p. 249; Blatt, 2015, p. 102). However, there is less consensus on whether existing ethical frameworks are sufficient, as "data collection [left] to citizen scientists involves a risk that ethical requirements may not be taken care of" (Svendsen, 2018, p. 155). Many organisations, platforms, and national portals initiate discussions on ethics, including the journal Citizen Science: Theory & Practice with a special issue in 2019 (Citizen Science: Theory and Practice, 4:1, 2019), and there is a growing exploratory body of academic literature on ethical issues of CS (cf. Resnik & Kennedy, 2010; Riesch & Potter, 2014; Resnik, Elliott & Miller, 2015; Purdam, 2014; Chesser et al., 2019; Tanginiene, 2019; Fiske et al., 2019; Rasmusen, 2019; Vohland et al., 2021). The European Citizen Science Association (ECSA) provides ten guidelines for CS, and when ethics is specifically addressed, "leaders" of projects are pointed out as ethically responsible:

10. The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing, confidentiality, attribution, and the environmental impact of any activities. (https://ecsa.citizen-science.net/wp-content/uploads/2020/02/ecsa\_ten\_principles\_of\_citizen\_science.pdf Accessed 20201229).

### Purpose and research questions

Against this background, utilising a review of research on CS, the purpose of this paper is to discern how ethical boundary work occurs in CS (Gieryn, 1999; Wainwright et al., 2009, 2006). Following Gieryn (1983, 1999), Wainwright et al. (2009, 2006), Hobson-West (2012), and Frith et al. (2011), we argue that ethical guidelines are socially and culturally enacted. There is no essence to ethical standpoints, only ongoing ethical boundary work, which strives for demarcation lines in CS, where actors and practices are constructed as ethical or unethical. Ethical boundary work creates controversies between scientists. What are the ethical issues in CS, and how are these to be managed? To attain our aim, we will turn to peer-reviewed publications in the field of CS with three questions:

• What ethical issues are identified and debated in the scientific

literature on CS?

- How are these ethical issues proposed to be managed?
- What ethical boundary work can be identified in the citizen science literature?

The paper starts with an introduction to the concept and the different strategies of ethical boundary work, followed by a brief description of the field of CS, and the specific form of CS that is the focus of the paper. Thereafter, we explain the method used to search for relevant publications for the review and subsequent qualitative content analysis. This is followed by a presentation of our findings in accordance with our research questions, and a concluding discussion of ethical boundary work performed in the CS literature.



## Theoretical perspective: Boundary work and ethical boundary work

Thomas Gieryn (1983, 1999) introduced the concept of boundary work in Science and Technology Studies (STS) to understand the ways in which scientists collectively defend and demarcate their intellectual territories. According to Gieryn (1999), boundary work entails

[...] the discursive attribution of selected qualities to scientists, scientific methods and scientific claims for the purpose of drawing a rhetorical boundary between science and some less authoritative residual 'non-science' (Gieryn, 1999, pp. 4–5).

The view expressed by Gieryn is that there is no essential definition of "science", only an ongoing debate and rhetorical standpoints among actors to create boundaries that include certain practices or actors, while excluding others. This includes different strategies: *expulsion, expansion,* and *autonomy* to create boundaries separating science from non-science to maintain the authority and credibility of scientists (Gieryn, 1999, p. 16-17).

The first of these, *expulsion*, revolves around demarcations of "real" science from other knowledge-producing activities judged as non-scientific (pseudoscience, amateur science, deviant or fraudulent science, etc.). Here, boundary work becomes a means of social control, denying epistemic authority to those actors who are seen as not belonging to the established cultural boundaries of science (Gieryn, 1999, p. 16). Boundary work also takes place when scientists try to *expand* their epistemic authority over an ontological domain that is also under influence from rival authorities (for example, lay or local knowledge), who might try to deny science an exclusive right to interpret and to act within this contested domain (Gieryn, 1999, pp. 16–17).

The last of Gieryn's strategies, *autonomy*, concerns strategies to defend science against efforts from outside actors to exploit the epistemic authority of science in such a way that it compromises the material and symbolic resources of scientists inside the cultural boundaries of science. Here, scientists create boundaries in order to retain sovereignty and autonomy over the selection of scientific problems or the standards used to evaluate research and knowledge-production (Gieryn, 1999, p. 7). To Gieryn (1983), scientists are central to performing and being affected by boundary work. Consequently, as CS is not performed by scientists alone and envisioned to include citizens in several aspects of the research process (Hetland, 2020), this might question the analytical reach of strategies.

The empirical foundation for Gieryn's original formulation of the concept, boundary work among British scientists in the 19th century, differs greatly from the current context of CS. The inclusion of non-scientists in the research process implies that boundary work might occur in new ways. Cultural borders of science, including demarcations of science from other types of knowledge, the extension of the authority of science, and scientific autonomy might be redrawn as CS distributes the work between scientists and non-scientists and on occasion also enhance the ethical authority of 'non-science' and non-scientists (Wainwright et al., 2009). We might need to treat the dimensions of boundary work as a phenomenon that is more fluid and flexible as scientific practices and ethical issues become more distributed and extended beyond the professional realm of science (cf. Prainsack 2014, p. 151).

Wainwright et al. (2009) have refined Gieryn's concept in relation to ethical implications of biomedical research, as they explore how biomedical researchers draw the boundaries between ethically scientific activity within stem-cell research. This kind of boundary work differs from Gieryn's original strategies, as ethical boundary work does not necessarily expel non-science (ethics) from science but rather assimilates or even privileges non-science as part of maintaining the image of science (Wainwright et al., 2009, p. 735). Inspired by Wainwright et al. (2009), Hobson-West (2012) have also used the concept of ethical boundary work when exploring the use of animals in scientific experiments, defining ethical boundary work as an activity that makes a distinction between what is, and what is not, ethically legitimate research. Similar to Wainwright et al. (2009), Hobson-West (2012) also found that scientists were both active and adept at constructing boundaries that preserved their research as ethically sound, for example, the use of animals and embryos for research is discursively justified through ethical boundary work (p. 660). The notion of ethical boundary work is also employed by Frith et al. (2011), who uses the concept to investigate how infertility clinicians construct boundaries between ethical and non-ethical issues in their everyday practice. A similar picture emerges from this study, namely that ethics is an area that is "managed" through the construction of boundaries that differentiate between ethical and non-ethical (Frith et al., 2011).

In the present study, we intend to build upon the implications from these previous studies that have applied the notion of ethical boundary work, specifically how CS and scientists active in this field make distinctions of what counts as ethical issues or not, as well as how these issues are to be resolved (cf. Hobson-West, 2012, p. 661). The field of CS allows us to extend or modulate the perspectives given by these previous studies further.

First, the field of CS is still in its constitutive phase, especially in relation to the presence of formal ethical frameworks that regulate the field. This situation enables us to apply the notion of ethical boundary work on a context, an emerging scientific practice/field, which differs from the previous studies accounted

for above, where debates and controversies around ethics are more established. Second, by its methods and empirical material (see below), the present study differs from the studies mentioned above, which have all utilised interviews in collecting their empirical material. By combining a literature review with qualitative content analysis, this study intends to take a more general view than previous research that have applied ethical boundary work on various contexts. Consequently, by combining the notion of ethical boundary work with our chosen methodology, this study explores the emergence of what is, and what is not, considered ethically legitimate research within a scientific practice that is in a formative phase.

### Forms of citizen science

Citizen science (CS), in the form of projects in which scientists recruit members of the public, has recently been creating very visible imaginaries and expectations for an array of such topdown participatory research initiatives (Bonney, 1996; Irwin, 1995; Kasperowski & Kullenberg, 2019; Strasser et al., 2019). However, CS is not one thing, and STS researchers have extensively described and analysed community and activist-based initiatives seeking epistemic justice or representation also being critical towards top down CS (cf. Brown, 1992; Corburn, 2005; Kimura, 2016; Ottinger, 2010; Wylie et al., 2017; Kuchinskaya, 2019; Kenny et al., 2019). Many of these deal with health or environmental issues by creating data and observations, questioning conventional protocols and research designs (Epstein, 1996; Allen, 2018; Prainsack, 2014) that will not represent the needs and problems of local communities (Kimura, 2016; Ottinger, 2010; Kullenberg, 2015; Kenny et al., 2019). Important studies of CS (Wynne, 1992; Irwin, 1995, 2001) also include opening up the processes of science policy for a more legitimate decisionmaking, involving science and technology and representative stakeholders in science and policy (Stirling, 2008; Felt & Wynne, 2007; Maasen & Weingart, 2005).

These latter forms differ from the science initiated, top-down models of CS (Franzoni & Sauermann, 2014; Kullenberg & Kasperowski, 2016; Hagen, 2020), which are the focus of this paper. To a large extent, activist-based initiatives are undertaken outside the reach of, possibly also in opposition to, institutional ethical frameworks that are in place for scientific research. Thus, they might coincide with some of the difficulties recognised by proponents of top-down initiatives.

### Methods and material

This study departs from a search of published, peer-reviewed, papers in the field of CS, motivated by the importance of scientific publications in the formation of a field, and the ability to identify the range of ethical issues that are discussed. It relies on accounts of ethics as they are present in the CS literature. It is therefore largely the realm of professional scientists and usually presupposes top-down initiatives, where citizens are mobilised to perform well-defined tasks in the research process of science. This is a limitation, as discussions and boundary work might also be found elsewhere.

Academic literature is often published following a long process of research, peer review, and revisions. More recent and rapid developments are often described in grey literature and online sources. The methodology of a literature search then has obvious limits, including also the choice of literature databases for performing the search, as there might be journals of interest not indexed by them. However, as a tool for obtaining data for a study (cf. Pullin & Stewart, 2004) on how ethical issues are accounted for and boundaries negotiated in the field, we believe it is justified despite its limitations.

The search for literature made use of a search string developed by Kullenberg and Kasperowski (2016). The search term "ethic\*" was added to the existing string for the search to capture variations such as ethics or ethical.<sup>1</sup> A search was performed in the Web of Science (WoS) core collection on 17 April 2020, resulting in 232 papers. From an initial reading of abstracts, many of these papers did not address ethical issues but were papers in popular epidemiology, discussing public engagement more generally. A new search was performed removing "popular epidemiology" and "public engagement" from the original search terms but also adding "citizen social science". This resulted in N=84 papers to be checked manually.

The same search string was then used in the Scopus database, yielding 139 results. Sixty-five papers were duplicates, so another N=74 papers were added to the list of papers to be checked manually.

<sup>1</sup> Search string: TITLE-ABS-KEY ( ethic<sup>®</sup> ) AND ( TITLE-ABS-KEY ( "citizen social science" OR "citizen science" OR "Community-based monitor<sup>®</sup> OR "Community-based envir<sup>®</sup> OR "civic science" OR "crowd science" OR "civic technoscience" OR "community based auditing" OR "community environmental policing" OR "citizen observatories" OR "participatory science" OR "volunteer monitoring" OR "volunteered geographic information" OR "volun<sup>®</sup> GIS" OR "neogeography" OR "participatory GIS" OR "street science" OR ("participatory monitoring" AND "science") OR ("participatory sensing" AND "science") OR "public participation in scientific research" OR "locally based monitoring" OR "volunteer based monitoring" ))

The nature of discussions on ethics in CS is a rather recent phenomenon, displaying a measure of uncertainty among researchers in the field, which makes literature searches a somewhat 'messy' indicator in this case.

In light of this "messiness", we combined our identification of papers with a triangulation approach. Hence, papers were distributed among three readers (authors of this paper) who independently read the abstracts and reference lists of the identified papers and performed a basic concordance search for "ethic", "ethics", and "ethical" in all papers, observing if any publications should be removed from the analysis, and noting ethical boundary work that occurred commonly across several publications for further content analysis.

This resulted in the removal of 18 papers from the WoS dataset of 84 papers on the grounds of being concerned with general research ethics, not discussing specific ethical issues in relation to CS, or only

recognising the need for studies of CS ethics. This process resulted in 66 papers from the WoS dataset. For the Scopus dataset, the same procedure resulted in the removal of 10 papers, resulting in 64 papers.

Thereafter, 11 papers were added to this dataset from a recent special issue on ethics in the peer-reviewed journal Citizen Science: Theory and Practice (2019), as the journal is not indexed in the databases of WoS and Scopus. Furthermore, a chapter on ethics in a recently edited publication on the "science of citizen science" was also included (Tauginienė et al., 2021). This resulted in a dataset for a qualitative content analysis of 142 publications. The content analysis followed the triangulation approach and was performed by the three authors, independently analysing each article in full, with the aim of identifying issues that arose across publications. This yielded an identification and preliminary coding of debated ethical issues. These were then compared and grouped together by the three authors, resulting in three themes of ethical boundary work.

### Ethical boundary work in the citizen science literature

From the content analysis of the academic literature on CS, three reoccurring themes could be defined: (1) *distribution*, (2) *relevance*, and (3) *expulsion*. These themes, in their own ways, display variations of perceived *insufficiencies* of conventional research ethics in relation to CS.

#### Distribution

The main ethical boundary work performed in our empirical material departs from opinions that ethical frameworks in science are insufficient and need to be broadened or renewed for CS (Ehlers et al., 2014, p. 13; Rothstein et al., 2015, p. 902; Winickoff et al., 2016, p. 170). A recurrent narrative is that CS is different from conventional science and cannot be contained in existing institutional frameworks to control and decide on ethical issues (cf. Canosa et al., 2018, p. 400; Tauginiené et al., 2021, p. 408). The main difference is believed to be that of the highly distributed and inclusive character of CS:

[...] embraces people from a wide variety of backgrounds, with a diversity of values and goals, and uses inexpensive, shared, and/ or open-access technology to enable broader participation. But a lack of gates also might mean a dearth of gatekeeping, the traditional approach to quality assurance. Therefore, as citizen science creates new approaches to scientific discovery, it also must consider new approaches to ensuring research integrity (Rasmussen, 2019, p. 2).

It is maintained that conventional research ethics, influenced by the medical sciences, focuses on the protection of subjects of research and researcher's integrity. Such a research ethics cannot be easily upheld in CS (Cooper et al., 2019, p. 2), as citizens are involved in "study design, data quality and integrity, reporting misconduct, authorship, or publication[s]" (Resnik, 2019 (a), p. 1; cf. Keune, 2019, p. 49).

To interact with scientists as "equals" in the "research process" (Rothstein, 2015, p. 900), being part of the "research team", doing research together with scientists, the volunteer participant's "role [is] mostly closely aligned with that of a research assistant or team member" (Oberle et al., 2019, p. 5). This makes existing ethical frameworks insufficient or less relevant for assessing the ethics of CS-projects, "where those who would formerly have been considered subjects are increasingly becoming partners" (Oberle et al., 2019, p. 8). As CS is not a usual way of conceptualising and practising science, not widely accepted in the current culture of science (Resnik, 2019 (b); Haklay, 2013, p. 14), placed outside the mainstream of scientific epistemology and ethics (Wiggins & Wilbanks, 2019, p. 2), it therefore needs to develop

[...] the understanding of ethics beyond consent, fairness, and data protection to what is arguably at the core of the rise of citizen science: citizens as active in the making and shaping of the data [...] (Ruppert et al., 2018, p. 177).

And also extend ethical responsibility beyond the professional researcher

[...] within a broader perspective of a research network. This research network can be regarded as a network of responsibilities in which every stakeholder involved has to jointly meet the ethical challenges posed to research (Brall et al., 2017, p. 27).

However, if there is a consensus that CS is different, and conventional ethics insufficient, then there is further disagreement

on how the broadening and distribution of ethics should be resolved, resulting in further boundary work on how ethical responsibility can be distributed also to volunteer participants (Augar & Fluker, 2014, p. 2).

For authors arguing for the increased distribution of ethical responsibility in CS, the strategy is to educate, increasingly communicate with, or train the volunteer contributor to the high ethical standards of science.

The data gathered would be used as part of published research and part of an open and transparent process and subject to the same ethical standards as any other social science research project. It is vital that volunteer observers are guided and trained in line with the highest standards of social science research practice (Purdam, 2014, p. 384).

Or, to carefully control or oversee the work of volunteers:

To promote ethical research, scientists should develop guidelines for involvement of citizens in research, communicate effectively with participants and local communities at the outset of their involvement in research projects, carefully oversee their work, develop appropriate publication practices, take steps to address conflicts of interest, and provide lay-volunteers with education and training on the responsible conduct of research (Resnik et al., 2015, p. 480).

In conjunction with arguments for training and control, authors also produce an image of CS as being more ethically sensitive towards the wrong-doings on behalf of both professional researchers and volunteer contributors:

Traditional research can be at risk of fraud and abuse in the same kinds of ways, but precisely because it *is* at risk, regulations have been established to guard against and confront instances of misconduct. Citizen science may lack an institutional framework for addressing research integrity, however, which exposes the field to reputational risk [...] As the field grows and its research findings contribute increasingly to the scientific literature and to policymaking, it is critical for citizen scientists to think deliberately about fostering trust in the results of citizen science (Rasmussen, 2019 3).

However, other authors stress that extensive training in ethics presents dangers of unethical exploitation of volunteer participants. Thus, arguments pointing to the insufficiency of science end up in the paradox of turning participants into *ethical scientists*, as they "are trained to make ethical determinations related to the collection of, access to and use of information" (Lynn et al., 2009, p. 1). This is met by the counter-argument that such a conventional research-centric perspective will produce unethical CS (cf. Rothstein et al., 2015: Resnik, 2019 (b), p. 1).

Citizens cannot be educated, instructed, and tutored extensively before being able to contribute to CS-projects, as it creates unethically excessive demands of time and effort from volunteer contributors. In some exceptional cases, there is concern about the increased requirement of citizens to be more engaged in the process; however, this is seen as an inevitable remission since the ethical issues of CS are complicated (Tauginienė et al., 2021, p. 408). For some authors, this borders on exploitation, and will eventually be regulated by participants themselves, who will refrain from involvement and thus abandon projects.

#### Relevance

NORDIC IOURNAL

This theme revolves around what kind of relevance, scientific or social, should guide and drive CS. Here, issues of empowerment, research integrity, marginalised groups, funding, and translating scientific results into community relevant knowledge, and promises of change, come to the surface (cf. Chesser et al., 2019, p. 2). These kinds of issues are driven to the foreground, particularly in relation to CS-projects that are directed towards and involve local communities. The main ethical issue for authors concerned with top-down CS extending into local communities is that such projects usually have as its main goals to contribute to science, i.e. to achieve a scientific rather than a social relevance for the local communities. For that to be realised (producing scientific publications), such initiatives must rely on institutionalised ethical frameworks of science (cf. Vayena & Tsaioulas, 2015). Some authors, displaying a strong science centred position, argue for an expansion of research ethics to also include CS initiated outside scientific institutions. In their view, citizen scientists

operating outside of standard institutional contexts [need] mechanisms of oversight to ensure compliance with relevant scientific and ethical standards. Only in this way can CS responsibly achieve the goal of making a socially recognized contribution to scientific knowledge (Vayena & Tsaioulas, 2015, pp. 482–83; see also Oberle et al., 2019, p. 6).

Thus, through arguments which claim that ethical review boards must guide and protect participants in CS and that most scientific journals require ethics approval (Resnik, 2019 (a), p. 22), this reasoning presupposes that community-driven projects should emulate institutional CS.

From an ethical point of view, this is seen as highly problematic by other authors as it undermines and affects the knowledge gained and its relevance for the local community (Wiggins & Wilbanks, 2019, p. 10; Morello-Frosch et al., 2009, p. 1). This is of particular concern for CS that mobilises members from marginalised groups, with respect to cultural diversity, traditions, and beliefs. Some CS approaches do not benefit local communities, creating or reinforcing tensions and polarisation among members that are underrepresented in power and more privileged actors (Hulbert, 2019, p. E9).

Ethically sound research in applied ethnobiology should benefit local communities by giving them the possibility "to actively participate in all phases of research and related activities from inception to completion, as well as in application of research results" (Grasser et al., 2016, p. 2).

NORDIC JOURNAL of Science and Technology Studies

This argument extends to conventions on research applications and funding. Short time spans of project funding, and the demands of citizens' time and efforts might be wasted if scientists are not able to translate findings into socially relevant knowledge for the community (Smith et al., 2019, p. 2). Structural conditions of top-down CS initiated by professional scientists might thus create unethical conditions, as the goals of such projects cannot be translated into social goals, which results in exploitation of participants (Sorensen et al., 2019). The risk of not being funded might also be a source of loss of trust from volunteer participants. These circumstances limit the possibilities for fulfilling socially relevant goals, as the competitive grants for research only allow for "minimal capacity to generate a research project in partnership with community members that align with community and scientific research goals" (Sorensen et al., 2019, p. 6).

Scientific relevance, usually the main concerns of researchers and funders, thus overrides social relevance for a local community in an unethical way. Science does not have the resources to keep close ethical attention on stakeholders' interaction, which includes capturing of local context, strengthening local identity, as well as generating empowerment through knowledge that is relevant to local people's needs (Verplancke et al., 2016, p. 311). Science therefore needs to create more proactive steps for the inclusion of various people and publics, which will vary with the goals, needs, settings, and historical precedents of individual projects. Knowledge of indigenous people must be protected, which is in danger of being treated as a 'free-for-all' resource for open exploitation by science (McKall & Dunn 2009, p. 86). This is particularly important for projects that involve the sharing of traditional or sacred knowledge, for groups who have experienced historical trauma, or being exploited within the context of scientific research.

Citizen science must avoid exclusion and disempowerment by adhering to ethics, values, and principles among community members in "the elicitation of knowledge, dissemination of analysis, and observation" (Verplancke et al., 2016, p. 311; cf. Eggleson et al., 2011) and develop "democratic methodologies that aim to represent the values of stakeholders, their land ethics, and senses of place" (Glover et al., 2008, p. 397). If members of a local community are engaged, local benefits must be provided. "Expertdriven research within resource-poor communities that does not provide some local benefits is unethical to conduct" (Quigley, 2016, pp. 731–732; cf. Chesser et al., 2019), and will eventually be regulated by participants themselves, who will refrain from being involved or refuse to be mobilised. For CS, this means that in order for various local communities to be engaged ethically, a finer granulated and context sensitive ethics than what conventional research ethics can offer is needed (cf. McGowan, 2017, p. 513; see also Tauginienė et al., 2021). A general framework for all forms of CS, and for all tasks undertaken by volunteer contributors in projects, might therefore be difficult to develop.

Coalitions of convenience may emerge out of expediency and affinity for specific issues, but shared ethics may not be central; coalitions of conscience are more likely to emerge out of necessity, commitment, and personal or collective identity, and ethics is central to the formation and critical praxis of a participatory coalition (Aungst et al., 2017, p. 362).

"Micro-ethics" is referred to in this context, illustrating the ethical decision-making required in a CS project negotiating the "fluidity" of research (Rashid, 2015, p. 525). This creates demands for a "dynamic" ethic (Tauginiené et al., 2021, p. 409), which is pitted against a research centred "macro-ethics" (Simialka & Samways, 2018, p. 637; Verplancke et al., 2016, p. 310). Multiple modes of ethical engagement and strategies that are tailored to a given situation are called for. Given the growing diversity of CS approaches changing the research landscape (Wiggins & Wilbanks, 2019, p. 11–12), each project should address the concerns most relevant to volunteer collaborators (Fiske et al., 2019, p. 621).

Members of local communities have important local knowledge about the ethical issues associated with particular practices, places, or communities. Thus, they may be able to collect data or conduct experiments more ethically than professional scientists (Duxbury, 2018, p. 436; Elliott & Rosenberg, 2019, pp. 50–51; cf. McConchie, 2015; cf. Guerrini et al., 2018, p. 136), as

local people are often the best placed to take action on local issues, they can complement, extend, refine, monitor, or initiate conventional science and do so with an ethic of care (Carr, 2004, p. 841).

Similarly, frequent use of terms like "participant-driven", "democratisation", or even the term "citizen science" itself, is problematised in discussions of the relationship between citizen science research and local communities as they are

[...] increasingly being used to encourage the public to become involved in research ventures as both subjects and scientists. Originally, these labels were invoked by volunteer research efforts propelled by amateurs outside of traditional research institutions and aimed at appealing to those looking for more "democratic," "patient-centric," or "lay" alternatives to the professional science establishment (Woolley et al., 2016, p. 10).

These appropriated concepts, which have been turned into "populist rhetoric[s]" and recruitment strategies used by scientists to create and encourage wider public participation (cf. Ezran et

al., 2017) in scientific work, are afflicted with ethical implications. One example is capitalising on CS ideologies, drawing on an idea of a social contract and greater societal good, but in fact exploiting volunteer contributors' efforts to collect and classify data, which is then stored without reach of citizens (Riesch & Potter, 2014, p. 117). Thus, neither individual autonomy nor greater societal good are automatically realised by current ethical frameworks of science applied to CS (Woolley et al., 2016, p. 14), and ethical issues are raised in confusion over the meanings of CS (Goodwin & Roberts, 2019, pp. 36–39), in ways that do not

[...] make visible and clear the full spectrum of meanings of "citizen science," [...] Noting the significant confusion that already exists over the ways the terms "participation," "involvement" and "engagement" are used, [...] citizen science rhetoric poses even a greater risk for confusion [on the ways] "citizen science" is used and the ethical significance of differences in its uses. This enables us to better see what vison of societal good is being advanced by the research, and what other visions are, perhaps, being sidelined by it (Woolley et al., 2016, pp. 13–14).

#### Expulsion

In accounts of the historical development of the field of CS, ethical issues of invisibility and displacement of outsiders are a longlasting legacy, usually resulting from the preoccupation with the dangers of bad data, low quality research, and bias (Haklay, 2013; Cooper et al., 2014).

While outsiders are not barred from taking part, or being defined as rivals, but in fact recruited and mobilised, they are expelled and made invisible *after* their contributions to science, taking unethical advantage of public engagement (Tauginiene, 2019, pp. 122–123). This is in accordance with historical accounts which demonstrate that the visibility of actors in scientific work is not a given, but subject to cultural values. Shapin's (1989) notion of "invisible technicians" denotes the vital scientific worker as being part of the invisible infrastructure of science. The reliance on outsiders has been found to decrease during the professionalisation of the sciences during the 20th century (Star & Griesemer, 1989; Goodchild, 2007; Miller-Rushing, 2012).

However, this account is questioned as the history of CS is now beginning to be written. Did the practises of relying on outsiders actually decrease? Or were outsiders, volunteering for service in the sciences, made invisible and not acknowledged for their contributions, and if so, why? Cooper et al. (2014) show that observations and data on avian migratory patterns and climate change still make contributing citizens invisible, despite advances in securing data quality.

The use of citizen science data in an active field of ecological research, such as migration phenology, is strong evidence that any stigma associated with the use of data collected by volunteers is unwarranted. Yet, the contributions of citizen science were not readily detectable in most cases. Thus, the stigma may persist unless researchers begin to draw attention to the citizen-science elements in their research papers (Cooper et al., 2014, p. 3).

It is difficult to answer the extent to which the practice of invisibility has ensued (Cooper et al., 2014). Some authors argue that "hundreds of scientific papers" in bird migration studies would not have been possible without volunteer contributions, yet without acknowledging these efforts (Haklay, 2013, p. 113).

Several explanations have been offered for making volunteers invisible in CS, as well as why this has not previously been considered being an ethical problem. General ethical frameworks for science, such as informed consent, exploitation, and the benefit of projects for participants, did not formally exist as guiding principles, even in medicine, until the mid-2oth century (Reiheld & Gay, 2019, p. 2). Furthermore, discussions on ethical frameworks that apply specifically to CS, in comparison with the long history of recruiting volunteer contributors in science, are few and mainly occur from 2015 onwards. The main argument, however, is that "outside" contributors have been managed both as an *asset* and as a *problem* for science.

Whether outsiders could violate scientific standards has been, and still is, a continuous issue in participatory practices of science. The danger of bad data, affecting the possibilities of CS contributing to science, is foremost associated with the "citizens", as they are more (than professional scientists) prone to becoming activists or falling into advocacy as they are included in scientific work. However, according to some authors, CS cannot be regarded as being of a lesser quality than any other form of science. It has to be based on "the details of [the] specific research context", as with any evaluation of scientific work. To waste scarce resources on research of low standards is as problematic as it is to dismiss research of high value, regardless of who performs it (Elliott & Rosenberg, 2019, p. 9).

### Concluding remarks: Paradoxes of ethical boundary work

The purpose of this study has been to investigate the ethical boundary work in publications in the field of CS. Returning to our initial questions, firstly, what ethical issues are identified and debated in the scientific literature on CS? We can conclude that CS researchers are concerned with three overlapping themes of ethical issues: (1) *distribution*, (2) *relevance*, and (3) *expulsion*. The boundary work, occuring in these themes, results from controversies over how existing and established

ethical frameworks and methods can be applied to CS, as they are regarded as *insufficient* in accommodating the "outsiders" to be ethically enrolled in scientific work. These insufficiencies stress structural features or conventions of science as problematic for the realisation of ethical CS. This becomes explicit in ethical boundary work by authors giving a historical account of CS. Here, the "outside" contributor is regarded both as an asset and a problem, called upon as a contributor to science, but made invisible and expelled as a way to live up to conventions of scientific standards.

Secondly, how are insufficiencies managed? For some authors, ethical CS can be attained by training, supervision, and control of volunteer contributors in accordance with already present ethical frameworks in science. If the aim is to have scientific contribution, then it is difficult to call upon ethical autonomy for CS, as already established and institutionalised ethical frameworks for science must be adhered to for scientific publications. For others, this is not an option since it will open up for exploitation and producing research with little or no social relevance for participants, as the reproduction of ethically "stringent" research ethics will affect the knowledge gained and the relevance for local communities. Citizen Science might benefit those who are resourceful and contribute to social injustice. Unethical demands placed upon volunteers will eventually be resolved by participants themselves, deflecting or refusing to be mobilised. More context sensitive ethical alternatives are requested; however, coherent options are presented. To develop a universal code of ethics seems unattainable for some, stressing the diversity of CS. For instance, CS-projects carried out by concerned communities outside the realm of institutional science are largely out of reach for research ethics.

Finally, what ethical boundary work can be defined in the CS literature? Our empirical material cannot, in its majority, be subsumed under the concepts of boundary work suggested by Gieryn (*expulsion, expansion*, and *autonomy*). This is a result that is largely consistent with earlier studies of ethical boundary work in bio-medical research (see Wainwright et al., 2006; Hobson-West, 2012) and medical practices (Frith et al., 2011). Our view, therefore, is that the conceptual resources for studying ethical boundary work would likely be best regarded as a heuristic device, under which more fine granulated analytical work is still required. In particular, this concerns how actors, and not only scientists, deal with current ethical dilemmas and boundary work in their day-to-day practice of the distributed work that is taking place in CS.

On the basis of our limited data, we suggest that ethical boundary work in CS is, to a large extent, a matter of managing ambiguities without any clear boundaries drawn between the unethical and ethical, ending up in paradoxes that seem very difficult to resolve. It is in these judgments and managing of paradoxes that ethics "happen" in the field.

Ethical boundary work gives an insight into the complex role of ethics in the field of CS, which is important to bring forward and further explore, as CS is currently undergoing a process of institutionalisation, including also evoking positive visions and high expectations of democratisation, trust, and scientific literacy raised as societal benefits of CS. As Gieryn notes, "the boundaries of science are ambiguous, flexible, historically changing, contextually variable, internally inconsistent and sometimes disputed" (1983, p. 792). This also seems to hold for ethics in CS.

### Declarations

#### Funding:

This research was funded by Sweden's innovation agency, Vinnova, DNR 2017-03527 for the project Arenas for building relations for co-operation through citizen science (ARCS).

#### Acknowledgement

The authors would like to thank one anonymous reviewer for extensive comments, which improved the paper significantly.

#### Conflicts of interest:

No conflicts of or competing interest are declared by the authors.

### References

Atchison, J., Gibbs, L., & Taylor, E. M. (2017). Killing Carp (Cyprinus carpio) as a Volunteer Practice: implications for community involvement in invasive species management and policy. *Australian Geographer*, *48*(3), 333–348.

https://doi.org/10.1080/00049182.2016.1265229

Aungst, H., Fishman, J. R., & McGowan, M. L. (2017). Participatory

Genomic Research: Ethical Issues from the Bottom Up to the Top Down. Annual Review of Genomics and Human Genetics, 18, 357–367. https://doi.org/10.1146/annurev-genom-091416-035230

Augar, N., & Fluker, M. (2014). Developing Social Media for Community Based Environmental Monitoring. 25th Australasian Conference on Information Systems Developing Social Media for CBEM. 8th -10th Dec 2014, Auckland, New Zealand. pp. 1–10.

Blatt, A. J. (2015). The Benefits and Risks of Volunteered Geographic Information. *Journal of Map & Geography Libraries*, 11(1), 99–104. https://doi.org/10.1080/15420353.2015.1009609

Bonney, R. (1996). Citizen science: A lab tradition. *Living Bird*, 15(4), 7–15.

- Brall, C., Maeckelberghe, E., Porz, R., Makhoul, J., & Schröder-Bäck, P. (2017). Research Ethics 2.0: New Perspectives on Norms, Values, and Integrity in Genomic Research in Times of Even Scarcer Resources. *Public Health Genomics*, 20(1), 27–35. doi: 10.1159/000462960
- Callaghan, C. W. (2019). Critical perspectives on international pharmaceutical innovation Malthus, Foucault and resistance. *Critical Perspectives on International Business*, 15(1), 68–86. doi: 10.1108/cpoib-11-2017-0078
- Canosa A., Graham A., & Wilson E. (2018). Reflexivity and ethical mindfulness in participatory research with children: What does it really look like? *Childhood*, *2*5(3), 400–415. https://doi.org/10.1177/0907568218769342
- Carr, A. J. L. (2004). Why do we all need community science? Society and Natural Resources, 17(9), 841–849.

<u>https://doi.org/10.1080/08941920490493846</u>

- Chesser, S., Porter, M. M., & Tuckett, A. G. (2019). Cultivating citizen science for all: ethical considerations for research projects involving diverse and marginalized populations. *International Journal of Social Research Methodology*. doi: 10.1080/13645579.2019.1704355
- Cinderby, S. (2010). How to reach the 'hard-to-reach': The development of Participatory Geographic Information Systems (P-GIS) for inclusive urban design in UK cities. *Area*, 42(2), 239–251. doi: 10.1111/j.1475-4762.2009.00912.x
- Citizen Science Ethics. Citizen Science: Theory and Practice, 4(1), 5. doi: http://doi.org/10.5334/cstp.235
- Cooper, C., Shanley, L., Scassa, T. & Vayena, E. (2019). Project Categories to Guide Institutional Oversight of Responsible Conduct of Scientists Leading Citizen Science in the United States. Citizen Science: Theory and Practice. doi: <u>http://doi.org/10.5334/cstp.202</u>
- Cooper, C. B., Shirk, J., & Zuckerberg, B. (2014). The invisible prevalence of citizen science in global research: migratory birds and climate change. *PloS ONE*, 9(9).

https://doi.org/10.1371/journal.pone.0106508

Duxbury, S. W. (2018). Information creation on online drug forums: How drug use becomes moral on the margins of science. *Current Sociology*, 66(3), 431–448.

https://doi.org/10.1177/0011392115596055

- Ehlers, M., Woodgate, P., Annoni, A., & Schade, S. (2014). Advancing Digital Earth: beyond the next generation. *International Journal of Digital Earth*, 7(1), 3–16. doi: 10.1080/17538947.2013.814449
- Elliott, K. C., & Rosenberg, J. (2019). Philosophical Foundations for Citizen Science. Citizen Science: Theory and Practice. doi: <u>https://doi.org/10.5334/cstp.155</u>
- Ezran, C., Karanewsky, C. J., Pendleton, J. L., Sholtz, A., Krasnow, M. R., Willick, J., Razafindrakoto, A., Zohdy, S., Albertelli, M. A., & Krasnow, M. A. (2017). The Mouse Lemur, a Genetic Model Organism for

Primate Biology, Behavior, and Health. *Genetics*, 206(2), 651–664. https://doi.org/10.1534/genetics.116.199448

- Fiske, A., Prainsack, B., & Buyx, A. (2019). Meeting the needs of underserved populations: setting the agenda for more inclusive citizen science of medicine. *Journal of Medical Ethics*, 45, 617–622. http://dx.doi.org/10.1136/medethics-2018-105253
- Follett, R., & Vladimir, S. (2015). An Analysis of Citizen Science Based Research: Usage and Publication Patterns. *PLoS ONE*, 10(11), e0143687.

https://doi.org/10.1371/journal.pone.0143687

NORDIC IOURNAL

- Fraisl, D., Campbell, J., See, L., Wehn, U., Wardlaw, J., Gold, M., Moorthy, I., Arias, R., Piera, J., Oliver, J. L., Maso, J., Penker, M., & Fritz, S. (2020). Mapping citizen science contributions to the UN sustainable development goals. *Sustainabilty Science*, 15, 1735–1751. https://doi.org/10.1007/s11625-020-00833-7
- Frith, L., Jacoby, A., & Gabbay, M. (2011). Ethical boundary-work in the infertility clinic. *Sociology of Health & Illness*, 33(4), 570–85. doi: 10.1111/j.1467-9566.2010.01308.x
- Fritz, S., See, L., Carlson, T., Haklay, M., Oliver, J. L., Fraisl, D., Mondardini, R., Brocklehurst, M., Shanley, L. A., Schade, S., Wehn, U., Abrate, T., Anstee, J., Arnold, S., Billot, M., Campbell, J., Espey, J., Gold, M., Hager, G., He, S., Hepburn, L., Hsu, A., Long, D., Masó, J., McCallum, I., Muniafu, M., Moorthy, I., Obersteiner, M., Parker, A. J., Weisspflug, M., & West, S. (2019). Citizen science and the United Nations Sustainable Development Goals. *Nature Sustainability*, *2*, 922–930. https://doi.org/10.1038/s41893-019-0390-3
- Gimbert, C., & Lapointe, F. J. (2015). Self-tracking the microbiome: where do we go from here? *Microbiome*. doi:10.1186/s40168-015-0138-x
- Gieryn, T. F. (1983). Boundary-Work and the Demarcation of Science from Non-science: Strains and Interests in Professional Ideologies of Scientists. *American Sociological Review*, *48* (6), 781–795. https://doi.org/10.2307/2095325
- Gieryn, T. F. (1999). Cultural boundaries of science: credibility on the line. Chicago: University of Chicago Press.
- Glover, T. D., Stewart, W. P., & Gladdys, K. (2008). Social ethics of landscape change: Toward community-based land-use planning. *Qualitative Inquiry*, 14(3), 384–401. doi: 10.1177/1077800407309409
- Grasser, S., Schunko, C., & Vogl, C. R. (2016). Children as ethnobotanists: Methods and local impact of a participatory research project with children on wild plant gathering in the Grosses Walsertal Biosphere Reserve, Austria. *Journal of Ethnobiology and Ethnomedicine*, 12(1), 46, 1–16. https://doi.org/10.1186/S13002-016-0119-6
- Guerrini, C. J., Majumder, M. A., Lewellyn, M. J., & McGuire, A. L. (2018). Citizen science, public policy. *Science*, 361(6398), 134–136. doi: 10.1126/science.aar8379
- Hagen, N. (2020). Scaling up and rolling out through the web: The "platformisation" of citizen science and scientific citizenship. Nordic Journal of Science and Technology Studies, 8(1), 4–17. doi:10.5324/njsts.v8i1.3320
- Haklay, M. (2013). Citizen Science and Volunteered Geographic Information – overview and typology of participation in *Crowdsourcing Geographic Knowledge: Volunteered Geographic*

Information (VGI) in Theory and Practice (Eds.), Daniel Sui, Sarah Elwood and Michael Goodchild, pp. 105–122. Berlin: Springer. doi: 10.1007/978-94-007-4587-2

Hecker, S., Wicke, N., Haklay, M., & Bonn, A. (2019). How Does Policy Conceptualise Citizen Science? A Qualitative Content Analysis of International Policy Documents. *Citizen Science: Theory and Practice*, 4(1), 1–16.

http://doi.org/10.5334/cstp.230

- Hetland, P. (2020). Citizen science: Co-constructing access, interaction, and participation. *Nordic Journal of Science and Technology Studies*, 8(2), 5–17. doi: 10.5324/njsts.v8i2.3547
- Hobson-West, P. (2012). Ethical Boundary-work in the Animal Research Laboratory. *Sociology*, 46(4), 649–663. doi:10.1177/0038038511435058
- Irwin, A. (1995). Citizen Science: A Study of People, Expertise and Sustainable Development. London: Routledge.
- Kasperowski, D., & Hillman, T. (2018). The epistemic culture in an online citizen science project: Programs, antiprograms and epistemic subjects, *Social Studies of Science*, First Published 23 May 2018, 1–25 (p.13). doi.org/10.1177/0306312718778806

Kelty, C., & Panofsky, A. (2014). Disentangling Public Participation in Science and Biomedicine. Genome Medicine, 6(8). https://doi.org/10.1186/gm525

- Keune, J. D. (2019). Considering Power Relations in Citizen Science, The American Journal of Bioethics, 19(8), 48–49. doi: 10.1080/15265161.2019.1619863
- Kullenberg, C., & Kasperowski, D. (2016). What Is Citizen Science? A Scientometric Meta-Analysis. PLoS ONE, 11(1), e0147152. https://doi.org/10.1371/journal.pone.0147152
- Labude, M., & Xafis, V. (2019). Ethically Justified Restrictions on Citizen Science: A Perspective from Singapore. *The American Journal of Bioethics*, 19(8), 38–40. doi: 10.1080/15265161.2019.1619872
- Lynn, S., J., Kaplan, N., Newman, S., Scarpino, R., & Newman, G. (2019). Designing a Platform for Ethical Citizen Science: A Case Study of CitSci.org. Citizen Science: Theory and Practice, 4(1), 14, 1–15. https://doi.org/10.5334/cstp.227

Macq, H.,Tancoigne, È., & Strasser, B. J. (2020). From Deliberation to Production: Public Participation in Science and Technology Policies of the European Commission (1998–2019). Minerva. https://doi.org/10.1007/S11024-020-09405-6

McKall, K., M., & Christine E. D. (2009). Geo-information tools for participatory spatial planning: Fulfilling the criteria for 'good' governance? *Geoforum*, 43(1), January, 81–94. doi: 10.1016/j. geoforum.2011.07.007

McConchie, A. (2015). Hacker Cartography: Crowdsourced Geography, OpenStreetMap, and the Hacker Political Imaginary. ACME: An International Journal for Critical Geographies, 14(3), 874–98.

https://www.acmejournal.org/index.php/acme/article/view/1237 Miah, A. (2017). Nanoethics, Science Communication, and a Fourth Model for Public Engagement. *Nanoethics*, 11, 139–152. https://doi.org/10.1007/s11569-017-0302-9

Milek, K. (2018). Transdisciplinary Archaeology and the Future of Archaeological Practice: Citizen Science, Portable Science, Ethical Science. *Norwegian Archaeological Review*, 51(1-2), 36–47. doi: 10.1080/00293652.2018.1552312

NORDIC IOURNAL

Morello-Frosch, R., Brody, J. G., Brown, P., Altman, R. G., Rudel, R. A., & Pérez, C. (2009). Toxic ignorance and right-to-know in biomonitoring results communication: a survey of scientists and study participants. *Environmental Health*.

https://doi.org/10.1186/1476-069X-8-6

Miller-Rushing, A., Primack, R., & Bonney, R. (2012). The history of public participation in ecological research. *Frontiers in Ecology and the Environment*, 10(6), 285–290. https://doi.org/10.1890/110278

Oberle, K. M., Page, S. A., Stanley, F. K., & Goodarzi, A. A. (2019). A reflection on research ethics and citizen science. *Research Ethics*. https://doi.org/10.1177/1747016119868900

O'Leary, H. (2018). Pluralizing Science for Inclusive Water Governance: An Engaged Ethnographic Approach to WaSH Data Collection in Delhi, India. *Case Studies in the Environment*. doi: https://doi.org/10.1525/cse.2017.000810

Patrick-Lake, B., & Goldsack, J. C. (2019). Mind the Gap: The Ethics Void Created by the Rise of Citizen Science in Health and Biomedical Researcher. *Bioethics.net* 

(https://www.bioethics.net/2019/07/mind-the-gap-the-ethics-voidcreated-by-the-rise-of-citizen-science-in-health-and-biomedicalresearch/)

Porter, D. (2017). Ontological assumptions, a biopsychosocial approach, and patient participation: Moving toward an ethically legitimate science of psychiatric nosology. *Philosophy, Psychiatry, & Psychology.* 

https://doi.org/10.1353/ppp.2017.0030

- Prainsack, B. (2014). Understanding Participation: The 'Citizen Science' of Genetics', Ch. 9. In Barbara Prainsack, Silke Schicktanz, and Gabriele Werner-Felmayer (Eds.), Genetics as Social Practice. Transdisciplinary Views on Science and Culture (pp.147-164). London: Routledge.
- Pullin, A., & Stewart, G. B. (2007). Guidelines for Systematic Review in Environmental Management. Conservation biology. *The Journal* of the Society for Conservation Biology.

https://doi.org/10.1111/j.1523-1739.2006.00485.x

Purdam, K. (2014). Citizen social science and citizen data? Methodological and ethical challenges for social research. *Current Sociology*, 62(3), 374–392.

https://doi.org/10.1177/0011392114527997

- Quigley, D. (2016). Building Cultural Competence in Environmental Studies and Natural Resource Sciences. *Society and Natural Resources*, 29(6), 725–737. 10.1080/08941920.2015.1080338
- Rasmussen, L. M., & Cooper, C. (2019). Citizen Science Ethics. Citizen Science: Theory and Practice, 4(1), 5. DOI: http://doi.org/10.5334/cstp.235

Rasmussen, L. M. (2019). Confronting Research Misconduct in Citizen Science. Citizen Science: Theory and Practice. doi: https://doi.org/10.5334/cstp.207

Reiheld, A., & Gay, P. L. (2019). Coercion, Consent, and Participation in Citizen Science.

https://arxiv.org/abs/1907.13061

Riesch, H., & Potter, C. (2014). Citizen science as seen by scientists:

Methodological, epistemological and ethical dimensions. Public Understanding of Science, 23(1), 107–12. https://doi.org/10.1177/0963662513497324

- Riesch, H. (2010). Theorizing Boundary Work as Representation and Identity. Journal for the Theory of Social Behaviour, 40(4), 452–473. https://doi.org/10.1111/j.1468-5914.2010.00441.x
- Resnik, D. B. (2019) (a). Citizen Scientists as Human Subjects: Ethical Issues. Citizen Science: Theory and Practice, 4(1), 11, 1–7.
- Resnik, D. B. (2019) (b). Institutional Review Board Oversight of Citizen Science Research Involving Human Subjects. *The American Journal of Bioethics*, 19(8), 21–23. doi: http://doi.org/10.5334/cstp.150
- Resnik, D. B., Elliott, K., & Miller, A. (2015). A Framework for Addressing Ethical Issues in Citizen Science. *Environmental Science and Policy*, 54, 475–481.

http://dx.doi.org/10.1016/j.envsci.2015.05.008

- Resnik, D. B., & Kennedy, C. E. (2010). Balancing scientific and community interests in community-based participatory research. *Accountability in Research*, 17(4), 198–210. doi: 10.1080/08989621.2010.493095
- Rothstein, M. A., Wilbanks, J. T., & Brothers, K. B. (2015). Citizen Science on Your Smartphone: An ELSI Research Agenda. *The Journal of Law, Medicine and Ethics*, 43(4), 897–903. doi: 10.1111/ jlme.12327
- Roy, S., & Edwards, M. (2019). Citizen Science During the Flint, Michigan Federal Water Emergency: Ethical Dilemmas and Lessons Learned. Citizen Science: Theory and Practice, 4(1), 12, 1–28. http://doi.org/10.5334/cstp.264
- Ruppert, E. S., Gromme, F., Ustek Spilda, F., & Cakici, B. (2018). Citizen data and trust in official statistics. *Economie et Statistique*, 505–506, 179–193.

https://doi.org/10.24187/ecostat.2018.505d.1971

- Svendsen, B. A. (2018). The dynamics of citizen sociolinguistics. Journal of Sociolinguistics, 22(2), 137–160. https://doi.org/10.1111/josl.12276
- Smith, E., Bélisle-Pipon, J. C., & Resnik, D. B. (2019). Patients as Research Partners; How to Value their Perceptions, Contribution and Labor? *Citizen Science: Theory and Practice*, 4(1), 15, 1–13. doi: <u>http://doi.org/10.5334/cstp.184</u>
- Sorensen, A. E., Jordan, R. C., LaDeau, S. L., Biehler, D., Wilson, S., Pitas, J.-H., & Leisenham, P. T. (2019). Reflecting on Efforts to Design an Inclusive Citizen Science Project in West Baltimore. *Citizen Science: Theory and Practice*, 4(1), 13, 1–12. <u>http://doi.org/10.5334/cstp.170</u>
- Tauginienė, L., Hummer, P., Albert, A., Cigarini A., & Vohland K. (2021).
  Chapter 20: Ethical Challenges and Dynamic Informed Consent.
  In Katrin Vohland, Anne Land-Zandstra, Luigi Ceccaroni,
  Rob Lemmens, Josep Perelló, Marisa Ponti, Roeland Samson,
  Katherin Wagenknecht (Eds.), *The Science of Citizen Science* (pp. 397–418). Springer.

Tauginiene, L. (2019). Ethical Concerns in Citizen Science Projects and Public Engagement Related Research Projects. *Ethical Perspectives*, 26(1), 119–134. doi: 10.2143/EP.26.1.3286291

NORDIC IOURNAL

Vallejos, E. P. (2015). Insights From The Workshop On Social Media Analysis And Mental Health: Putting People At The Centre Of Human Data. *Proceedings Of The 2nd European Conference On Social Media* (ECSM). 22 January 2015

https://casma.wp.horizon.ac.uk/2015/01/22/insights-from-the-workshopon-social-media-analysis-and-mental-health-putting-people-at-thecentre-of-human-data/

Vayena, E., & Tasioulas, J. (2015). "We the Scientists": a Human Right to Citizen Science. Philosophy & Technology, 28, 479–485. https://doi.org/10.1007/513347-015-0204-0

- Wainwright, S., Williams, C., Michael, M., & Cribb, A. (2009). Stem cells, translational research and the sociology of science. In: Paul Atkinson; Peter Glaser and Margaret Lock, (Eds.), *The Handbook* of Genetics & Society: Mapping the New Genomic Era. Abingdon and New York: Routledge: (pp. 41–58). ISBN 978-0-415-41080-9
- Wainwright, S. P., Williams, C., Michael, M., Farsides, B., & Cribb, A. (2006). Ethical boundary-work in the embryonic stem cell laboratory. *Sociology of Health & Illness*, *28*(6)732–748. doi: 10.1111/j.1467-9566.2006.00465
- Wehn, U., Collins, K., Anema, K., Basco-Carrera, L., & Lerebours, A. (2018). Stakeholder engagement in water governance as social learning: lessons from practice. *Water International*, *43*(1), 34–59. https://doi.org/10.1080/02508060.2018.1403083
- White, L. (2019). A Neglected Ethical Issue in Citizen Science and DIY Biology. *The American Journal of Bioethics*, 19(8), 46–48. doi: 10.1080/15265161.2019.1619876
- Wiggins, A., & Wilbanks, J. (2019). The Rise of Citizen Science in Health and Biomedical Research. *The American Journal of Bioethics*, 19(8): 3–14. https://doi.org/10.1080/15265161.2019.1619859
- Winickoff, D. E., Jamal, L., & Anderson, N. R. (2016). New modes of engagement for big data research. *Journal of Responsible Innovation*, 3(2), 169–177.

https://doi.org/10.1080/23299460.2016.1190443

Woolley, J. P., McGowan, M. L., & Teare, H. J. A. (2016). Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. *BMC Medical Ethics*, 17(1), 2–17.

https://doi.org/10.1186/s12910-016-0117-1

Woods, A. T., Velasco, C., Levitan, C. A., Wan, X., & Spence, C. (2015). Conducting perception research over the internet: a tutorial review. *Peer Journal*, *3*, e1058.

https://doi.org/10.7717/peerj.1058

Zilliox, S., & Smith, J. M. (2018). Colorado's Fracking Debates: Citizen Science, Conflict and Collaboration. *Science as Culture*, 27(2), 221–241. https://doi.org/10.1080/09505431.2018.1425384