

MIND THE RELATIONSHIP: A MULTI-LAYERED ETHICAL FRAMEWORK FOR CITIZEN SCIENCE IN HEALTH

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ABSTRACT

There is a heated debate about what citizen science is and is not. We argue that instead of aiming at a definition of citizen science, we should reflect upon its ethical starting points. Based on our practical experiences with citizen science initiatives, we come up with an ethical framework that consists of two core values (respect and justice), five ethical desiderata (relationship between equals; recognition of each other's capacities, knowledge, and agency; reciprocity; openness for different goals; and openness for different research methods and paradigms) and two fundamental qualities (symmetry and transparency). The desiderata reflect ethically problematic practices, such as the use of citizens by academic scientists as mere sensors, and biases in the existing literature, such as labelling the projects that are initiated and led by citizens as "extreme". The desiderata are supported by two ethical theories: care ethics and the capabilities approach. The aim of our ethical framework is to stimulate and facilitate reflection upon what needs to be considered when co-creating or assessing a citizen science initiative. Fundamentally, citizen science ought to be a humanizing endeavour unlocking the investigative capacities of humans. The ethical framework is meant to help reflect on this endeavour.

KEYWORDS

Capabilities approach; care ethics; citizen science; health; justice; participation; respect

1. INTRODUCTION

Over the past years, numerous overviews have been produced that define and explore the breadth and width of citizen science (Vohland et al., 2021) The *European Citizen Science Association* (ECSA) describes citizen science as a concept which is flexible and could be adapted and applied within diverse situations and disciplines (Robinson et al., 2018). The flexibility is reflected in descriptions of citizen science, such as “any form of active and non-professional participation in science that goes beyond human subject research conducted by professional researchers” (Vayena & Tasioulas, 2015). Eitzel et al. (2017) assert that citizen science is intended to broaden participation in science, and the inclusion of the public in different aspects of research. A common denominator of citizen science is the involvement of researchers and citizens who join efforts to produce knowledge.

To provide some guidance for citizen science projects, ECSA published ten principles of citizen science, which express key principles that underlie good practice in citizen science (Robinson et al., 2018). In the context of the rising popularity of citizen science, the potential misuse of the term and the need of funders and policy makers for more clarity concerning citizen science’ conceptual boundaries, Heigl et al. (2019) came up with a set of more precise criteria. Their effort was immediately counteracted by the citizen science community, which claimed that any effort to provide a precise definition of citizen science would do injustice to the inherent heterogeneity of citizen science practice (Auerbach et al., 2020). Strasser et al. (2019) propose to understand citizen science as a collection of epistemic practices, thereby giving space to the diversity of ways in which knowledge may be produced and the world may be explored and understood, while at the same time avoiding hierarchical classifications of citizen science as in more or less participation of citizens.

Given the diversity of citizen science activities, the debate will no doubt continue to evolve. Hence, we agree with Eitzel et al. (2017) that “the boundaries of citizen science are ethical boundaries”, which need to be explored. Ficorilli (2020) argues that “we are witnessing the transition from an ethics of protection of ‘research subjects’ to an ethics of empowerment of the ‘citizen scientists’”. This transition took place in reaction to the Bioethics Revolution, in which the concept research participant replaced that of research subject (Baker, 2019, p.77). Empowerment of citizen scientists requires researchers to be transparent during the entire project, and specifically about the reason for collaboration between professional scientists and citizens. One such reason is that citizens are thought to have types of knowledge that professional scientists lack, e.g., experiential’ knowledge, which is knowledge gained through lived experience, for instance through coping with a health

condition or disability. In this paper we propose an ethical framework to facilitate reflection on what needs to be considered, from an ethical point of view, when co-creating or assessing a citizen science initiative. We hope that the ethical framework makes it easier to form equal, respectful, and collaborative relationships between professional and citizen scientists, allowing for a diversity of valuable citizen science projects to emerge.

It is difficult to formulate labels for the key-players in citizen science that cover all meanings; Eitzel et al. (2017) have provided a profound account of the complex and sometimes conflicting connotations of each label. For this paper, we chose to use the labels 'professional scientist' and 'citizen scientist' as the main denominators, with the intent to encompass notions such as formal and informal scientists, paid and volunteer scientists, expert and amateur scientists, experts and lay persons.

The proposed framework is built on the ethical concerns of citizens and patients engaging in health research, in particular those connected to the Dutch patient driven ZelfOnderzoek Netwerk Nederland (ZONN, translated 'Self Research Network Netherlands') for citizen science on health, and finds support in two ethical theories. The heart of our ethical framework consists of five desiderata. We understand desiderata as general guidelines that connect values to specific issues. In our framework, the values respect and justice are connected to issues like differences between persons, capacities, methods, goals, and benefits. We chose to use the term desiderata rather than norms and principles to stress that our concern is with what is desirable rather than what is mandatory or required.

The first draft of the ethical desiderata emerged from the experiences of the patients in the ZONN-network. These were described and this draft was discussed with the researchers from the TOPFIT Citizenlab and the members of the ZONN-network. These discussions initially helped to demarcate the desiderata from the fundamental qualities. In later stages, the authors of the paper recognized that the desiderata responded to two core values. This gradual process of reflection and interaction gave rise to the conceptualization of the ethical framework we present in this paper.

In section 2, we lay out why there is a need for such an ethical framework by providing a brief literature review on ethics in citizen science and a description of the hands-on experiences of the authors in the design and delivery of citizen science projects in health. Subsequently, in section 3, the framework is presented. In section 4, we summarise the main points, reflect on limitations of our framework, and make suggestions for further research.

2. WHY THIS ETHICAL FRAMEWORK?

Several authors have explored ethics in relation to citizen science. Kasperowski et al. (2021) explored the concept of ethical boundary work in relation to citizen science. Boundary work is a concept introduced by Gieryn (1999) to understand the ways in which researchers collectively defend and demarcate their intellectual territories. It 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). Kasperowski et al. (2021) conclude that ethical boundary work in citizen science considers management of ambiguities without drawn boundaries between the unethical and ethical. This leads towards difficult to resolve paradoxes. This confirms the statement by Eitzel et al. (2017) that the boundaries of citizen science are ethical, hard to draw and enacted and negotiated in the interaction between stakeholders.

Other authors have identified different domains in which ethical issues in citizen science emerge and should be dealt with, e.g., in the special issue on citizen science ethics in the SCTP journal (Rasmussen & Cooper, 2019). Resnik et al. (2015) distinguish four domains: dilemmas of data quality and integrity, data sharing and intellectual property, conflict of interest, and exploitation. Vayena (2016) explored issues relating to ethical oversight in the context of patient-led research. Goodwin and Roberts (2019) discuss the relevance of developing ethics within communities of citizen scientists and suggest ‘conversation as a procedure’ to come to agreements with formal bodies of oversight. Cooper et al. (2019) suggest different modes of ethical oversight for citizen science.

Banks and colleagues (ICPHR, 2022) take an approach in pursuit of generic ethical principles from the perspective of participatory health research. They generate the following principles: (1) mutual respect; (2) equality and inclusion; (3) democratic participation; (4) active learning; (5) making a difference; (6) collective action; (7) personal integrity. The ICPHR principles are valid and grounded primarily in the experiences with participatory health research. They do reflect less the experiences of patients in the biomedical realm, notably their ambition to also be included in the heart of methodological and ontological discussions.

Groot and Abma (2022) argue that “despite the guidance of principles, researchers must work daily on ethical tensions to deal with the particular issue at that moment, in that specific context, taking into account the moral responsibilities to continue the research project from a commitment to epistemic justice”. Epistemic justice is understood as ‘the active inclusion of the voices of those whose issues are at stake, and who have formerly been wronged in their capacity of knowing (...), and whose voice did not count as relevant in a certain context’

(Fricker, 2007). Consequently, they develop an ethical framework for researchers, which builds on the concept of ethics work, defined by Banks et al. (2016, p. 36) as “the effort people (...) put into seeing ethically salient aspects of situations, developing themselves as good practitioners, working out the right course of action and justifying who they are and what they have done”. They are using the term ‘work’ as a description of the psychological and bodily processes to perform research tasks which ask for noticing, attending, thinking, interacting and performing (Banks et al. 2016, p. 36).

Hence, literature provides us with inventories of ethical issues, generic ethical principles, and a framework to guide everyday ethical practice. The ethical framework we present in this paper does not intend to replace them. However, the current literature on ethics and citizen science can be more strongly connected to the wider ethical literature. The framework proposed in this article is supported by two ethical theories: care ethics and the capabilities approach. Additionally, based on our practical experiences, there is a need for a simpler overview of the core issues at stake when constructing a relationship between a professional and a citizen scientist, in which the efforts required not only bear on the professional, but also on the citizen. This is not to downplay the relevance of power asymmetries often implicit in those relationships, but instead emphasizes citizen scientists as responsible and accountable human beings at the same level as professional scientists. What matters in the end is the capacity of all actors involved to reflect on their relationship and each other's position in it. This has led us to take the practical experiences of both professional and citizen scientists as a point of departure for our framework.

The proposed framework is based on experiences of researchers and citizens in two projects/networks: the professional-driven TOPFIT Citizenlab and the patient-driven ZONN network for Citizen Science on Health. TOPFIT Citizenlab is situated in the Twente region, a part of the province of Overijssel in the Netherlands. It started in January 2020, and intends to mature into a regional hub for citizen science. It has involved a great diversity of stakeholders in a top-down attempt to improve the development and implementation of technologies with the help of citizens. The citizen science perspective forced it to question the set-up of the different projects and the role of co-creation and research. It provoked significant uncertainty and self-questioning among the researchers involved, while at the same time there seemed to be nothing wrong with the willingness and the intentions to engage with citizens in innovative ways. The researchers connected to TOPFIT Citizenlab recognized the need for an instrument that valued both the researcher's intentions and interests, while at the same time paving the way for sincere interaction with citizens, in a way that would cater for the emergence of a diversity of citizen science projects. To that extent, a series of workshops was held,

in which a draft of the five desiderata was discussed with the members of TOPFIT Citizenlab. They approved the desiderata, which they perceived as capturing the ethical core of citizen science collaborations and as providing a useful tool for setting up such collaborations in an ethical manner.

The second source is the hands-on experience of several patient-driven communities engaged in a diversity of self-research practices on health, united in the Dutch ZONN network ¹ (Remmers & Spijker, 2020). ZONN operates as a patient-driven national platform for citizen science on health of about 15 communities of patients and citizens organizing and conducting some form of health research by themselves. They represent a wide range of diseases (like cardiac failures, cancer, migraine, rare disease, diabetes, kidney failure), and about 10.000 individuals engaged in self-observations. There are bimonthly meetings, in which early drafts of the ethical framework and its desiderata were discussed and approved by the participants. The ZONN-network emerged out of the personal experiences of those involved in the network. They accumulate experiential knowledge of what it means to be a ‘citizen scientist’ and have acquired a clear view on the difficulties that emerge when, as a patient, one wants to contribute to one’s own recovery. The realm of possible interventions a patient explores and considers is often different from protocols of the medical professionals. They often sense a fundamental denial of their capacity to co-create their own health. The members of the ZONN network realize that they build on a large tradition in the health domain of patients claiming their identity as humans and as potent collaborators to their own and other’s health (Remen, 1980; Smit & De Knecht, 2015; van den Bovenkamp et al., 2020; Borkman, 1976; Abma & Broerse, 2007; Frank, 2013; Emanuel & Emanuel, 1992; Elwyn et al., 2012). This tradition has long battled its way to gain a stronger patients’ voice in the definition of research issues and the health care process in general. Since 2015, the concept of citizen science has been embraced in The Netherlands to accommodate a diversity of patient-driven research.

3. A MULTI-LAYERED ETHICAL FRAMEWORK FOR CITIZEN SCIENCE IN HEALTH

Our ethical framework is grounded in two ethical theories (care ethics and capabilities approach). It has three components: two core values (respect and justice), five ethical desiderata (relationship between equals; recognition of each other's capacities, knowledge, and agency; reciprocity; openness for different goals; and openness for different research methods and paradigms), and two fundamental

¹ <https://mdog.nl/wat-is-burgerwetenschap/zelfonderzoek-netwerk-nederland/>

qualities (symmetry and transparency) to support the desiderata when they are used in practice, see figure 1.

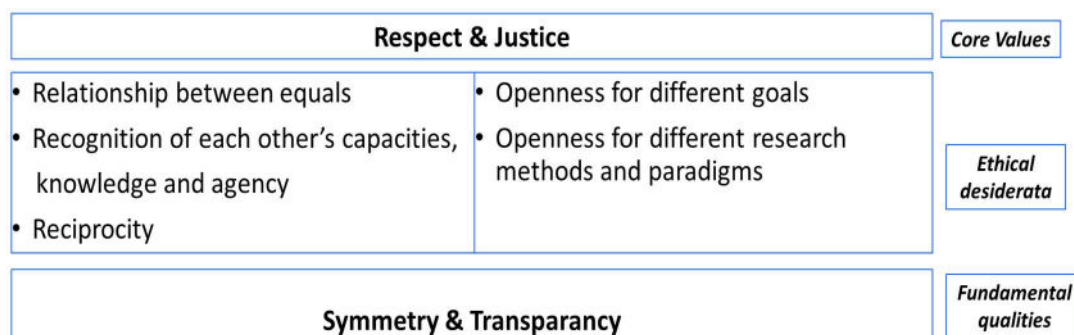


Figure 1 Ethical Framework for Citizen Science in Health

3.1. Grounding the ethical framework

Our ethical desiderata find support in the traditions of care ethics and the capabilities approach. Care ethicists emphasise the interdependence and vulnerability of human beings. In contrast to the idea of the autonomous rational agent, which is at the centre of the two most prominent ethical theories in the Western tradition (deontology and utilitarianism), care ethics sees human agents as vulnerable beings who stand in multiple relationships and are in need of care.² While some care ethicists conceive of care as specifically related to women or the mother-child relationship (Noddings 1984; Ruddick 1989), others, such as Joan Tronto (1993), emphasise that care is an essential element of human life as such: all human beings depend on others and need care: ‘An ethic of care is an approach to personal, social, moral, and political life that starts from the reality that all human beings need and receive care and give care to others. The care relationships among humans are part of what mark us as human beings. We are always interdependent beings’ (Tronto, 2009). This interdependence is not limited to humans. It is an

² Utilitarianism focuses on the consequences of actions. Whether an action is morally right or wrong depends on the quality of its consequences. The classical Utilitarians Jeremy Bentham and John Stuart Mill held that one ought to bring about “the greatest amount of good for the greatest number” (Driver 2022). Moral agents should aim at maximising happiness, whereby it is allowed to violate the rights of some people. Utilitarians apply a cost-benefit analysis to determine which action would be the right one to take. Deontology, by contrast, puts emphasis on the rights and duties of individuals and on moral rules. The moral quality of an action is not determined by its consequences, but by the intention of the agent. The most famous deontologist in the Western history of philosophy is the German philosopher Immanuel Kant (Larry & Moore 2021).

“interdependence between the human, non-human, and more-than-human worlds” (Moriggi et al., 2020). Caring practices include “everything we do to maintain, continue, and repair our world so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web” (Tronto, 2013, p. 19).

The ethical framework proposed in this paper has the relationship between professional and citizen scientist at its core. Like so many of the relationships that humans find themselves in, this relationship is asymmetrical. It is characterised by differences in power, stemming from the institutional embeddedness of the scientist and their formal education. From the perspective of care ethics, ethicists concerned with citizen science should pay close attention to the relationships between the participants of citizen science projects. They should ask questions like “What is the quality of these relationships?”, “Are the needs of the participants recognised?”, “Is care being given where needed, and is the care that is given good care?”

For Tronto, care should be understood as a practice as opposed to a virtue or attitude. While virtues, attitudes, skills and activities are a part of care, they do not exhaust it. Tronto (1993, pp. 105-137) distinguishes four phases of caring and four corresponding moral elements. In the first phase (“caring about”), those who give care recognise that others are in need and what their needs are (attentiveness). In the second phase (“taking care of”), those giving care take responsibility for meeting those needs (responsibility). In the third phase (“caregiving”), they perform an action to fulfil those needs (competence). In the fourth phase (“care-receiving”), those giving care recognise that the care-receivers respond to the care given (responsiveness). Tronto (2013) adds a fifth phase (“caring with”). This phase concerns the distribution of care in society and here the corresponding moral elements are solidarity and trust. Our framework, if applied, could lead to citizen science projects involving practices of caring.

Another ethical theory that supports our ethical framework is the capabilities approach, which has been introduced by Amartya Sen in the 1980s (Sen 1985a, 1985b) and further developed by Martha Nussbaum (2000; 2011). It has been used in a variety of fields, including welfare economics, political philosophy, and ethics of technology. The core question of this approach is “What is a person able to do and be?” From the perspective of this approach, it is not sufficient to look at the available resources, since people might not actually be able to make use of these resources. For instance, in a society where girls are not allowed to go to school, the existence of schools does not by itself enable them to go to school and receive education. Similarly, a person who has a broken leg is not able to ride a bike, even if they are in the possession of a bike. Capabilities, which are ‘the real opportunities for a person to do and be what he/she has reason to value’ (Oosterlaken, 2013, p. 80), are distinguished from functioning, which are realised capabilities. For instance,

the functioning that corresponds to the capability to have good health is actually being in good health. According to Nussbaum (2011), states have the task to secure for their citizens a threshold of what she takes to be the ten central capabilities. It is not the state's task to secure people's functioning, as that would restrict their freedom illegitimately. The capabilities approach is a liberal theory with the value of freedom at its core. Its notion of freedom is that of effective freedom, as opposed to mere formal freedom. Whether a particular capability can be turned into a functioning depends on what are called conversion factors. There are personal conversion factors such as genetic diseases or character traits, environmental conversion factors such as features of the built environment, and social conversion factors, such as social conventions, and widely shared prejudices.

One of Nussbaum's central capabilities is health. Other capabilities from her list that seem clearly relevant for citizen science are "senses, imagination and thought", "control over one's material and political environment", and "social affiliations that are meaningful and respectful" (Nussbaum, 2009, p. 33). Citizen science activities can potentially help enhance these capabilities. From the perspective of the capabilities approach, citizen science projects should be set up in a way that enhances relevant capabilities not only of those who participate in these projects but ideally also of other citizens. When assessing a citizen science initiative, we should ask questions like 'Does this collaboration enhance the participating citizens' ability to use their senses, imagination and thought?', 'Does the project potentially contribute to a society in which people's capability for living in good health can be realised?', or 'Does participation in this project enhance citizens' ability to have control over their political environment?' When setting up a citizen science project we should, e.g., reflect upon how the activities that will be carried out by the participants could strengthen the capability "senses, imagination and thought", thereby considering the more concrete capabilities that fall under this general capability, such as abilities for critical and analytic thinking, for systematic analysis, and for the interpretation of data.

3.2. Two core values

Our first-hand experience with citizen science initiatives and the concerns voiced by citizen scientists as pointed out in section 2, confirmed that citizen science is not just about generating knowledge but is also a social practice. In this social practise, different stakeholders have differences in social background, profession, motivations and relation with the problem. These differences allude to tensions that need to be addressed and were hence expressed in five desiderata. They were voiced by the participants in the ZONN-network and recognized by the researchers in the TOPFIT Citizenlab.

Congruent with the idea of citizen science as a social practice is that all desiderata concern the relationships between stakeholders. Our first-hand experience teaches us that the willingness to live up to the desiderata is of paramount importance. We recognized that this willingness builds on two fundamental values: justice and respect. It means that the desiderata do not constitute a practical checklist, but appeal to a moral position to bridge differences.

The first core value is respect and concerns the relationship between professional and citizen scientists and what this means in social practice. In this context the value respect comes close to what Feinberg (1975) calls “observantia”: respect gives moral consideration towards citizens in their own right, regardless of their abilities and social positions. This means not considering citizens as less valuable in virtue of not being professional scientists or lacking specific knowledge.

The second core value, justice, concerns how efforts, endeavours and benefits are divided between professional and citizen scientists. It is a matter of injustice when labour or effort are unequally shared or when benefits, outcomes or credits are disproportionate with the effort or labour. Another aspect that we regard as unjust is a bias in valuing outcomes only for certain groups, such as professional scientists. We elaborate this point as openness for different goals and in a critical reflection on indirect effects on society.

Next to intrinsic value, a social practise based on respect and justice also has instrumental or practical value. If citizen science is a fair practise for all stakeholders, there is, amongst others, fairness in knowledge distribution or a system of reciprocity, the motivation of citizens will be higher and citizens are more likely to stay involved for the full duration of the research project in contrast, if the relationships are not based on these values, this might result in less successful citizen science initiatives and premature termination.

3.3 Desiderata

The desiderata (see figure 1) we propose are general guidelines that connect respect and justice to specific issues in citizen science. In this section, we present the five ethical desiderata and argue subsequently that they should respond to two fundamental qualities. While the first three desiderata that we discuss concern the quality of the relationship between the participants in citizen science projects, the fourth and fifth desideratum concern a desirable openness of the participants. All five desiderata are interrelated, and though it is useful to distinguish them analytically, their interrelatedness in practice should be acknowledged.

3.3.1 Relationship between equals

The first desideratum holds that citizen scientists and professional scientists must recognise each other as equal collaboration partners. As Fiske et al. (2019, p. 618) point out, “[p]articipatory processes are fraught with power imbalances between researchers and participants”. This holds for instance for “medical research projects that uncritically promote public or patient ‘engagement’” (Fiske et al., 2019). According to the authors, these projects have “failed to create reciprocal and mutually beneficial relationships” (Fiske et al., 2019). Failures of this kind give rise to our first ethical desideratum. This desideratum gains support from the care ethics tradition, which emphasises the asymmetrical nature of many relationships.

The citizens involved in citizen science are not an object or instrument of study, but subjects with whom professional researchers enter a relationship, in which all participants should respect each other. In the context of citizen science, we must go beyond ethical codes for research with human subjects, in which respect for persons is one of the main ethical principles (Belmont Report). In citizen science, participants are not subjects of research, but partners with equal standing. Therefore, in addition to respecting them as a person, scientists should treat them as equally capable of carrying out research. Following the premise of symmetry, citizens should not instrumentalize scientists either, e.g., for proving their opinions. This is particularly relevant when research outcomes are not confirming expectations. Just like industries, citizens should not interfere with the integrity of scientists and refrain from influencing possibly unwelcome study results. The balance, however, is delicate. A critical dialogue must remain possible, especially given the power imbalances present. A claim on independence and integrity by researchers should not mean that they may avoid debate about, e.g., adequate methodology. It is precisely this area that is one of great concern for citizens, which is the reason why we included desideratum 4.

A relationship between equals requires that citizens and scientists trust one another. Trust, however, needs to be built up through repeated interactions, in which everyone involved shows to be trustworthy. Neither trust nor a relationship between equals is prior to the interactions between scientists and citizens.

‘More human, less patient’

To be seen as a human person first and then as a patient, is a matter of great concern to patients (Remen, 1980). The Dutch Federation of Patient Organisations adopted the slogan ‘Meer mens, minder patient’ (more human, less patient) (Patientenfederatie, 2018) as a leading motto for their activities. Patients

want to be seen as more than an interesting biophysiological system that should be ‘fixed’. Citizens are no instruments to address shortages of research means or used as sensors. The adoption of a human approach demands more time in the medical realm, and this is the same in citizen science. While the interest is rising in so-called Real-World Data and Citizen Generated Data, in order to facilitate Big Data analysis and new forms of health service provision, there is a risk that citizens and patients are again considered as mere data-providers, handed over to the benevolence of industry and academia. An equal relationship in those cases cannot be reached only by improved communication and a humanistic worldview but needs to be addressed at a systemic level, too, involving the strengthening of citizen-centered data governance models and legal arrangements (Lancet, 2021; Remmers et al., 2021).

3.3.2 Recognition of each other’s capacities, knowledge, and agency

The second desideratum is closely related to the first and says that citizen scientists and professional scientists contribute different insight and abilities, which are of equal worth and complement one another. This recognition enables a relationship between equals, in which everyone respects everybody else, recognising their capacities, knowledge and agency.

Why should academic scientists seek collaboration with lay people? Part of the answer is that lay people have different knowledge/insights and other sorts of capacities than professional researchers. In the area of health, patients have insights into their own condition that nobody else can have, simply because they experience their body in a way that cannot be replaced by any kind of knowledge others have about it. Moreover, patients can integrate experiments in their daily life, for instance related to nutrition, which can lead to useful insights. As Petersen et al. (2019, p. 4) point out, in citizen science endeavours, “everyone comes to the table with different abilities and perspectives”. Citizen science aims to integrate all valuable abilities and perspectives.

The second desideratum must be seen in the context of the process of professionalisation of research in the 19th century, where the kitchen table was once the forerunner of what would become the laboratory (Strasser et al., 2019). As with the emergence of the laboratory people came to be excluded from the production of knowledge about the world, we could interpret the citizen science movement as a way of reversing this development to some extent: of cautiously opening the scientific ivory tower and allowing citizens to play a role again in the production of knowledge. The citizen science movement might transform the current scientific

hierarchy in knowledge production and bears the potential of more democratic and inclusive research (Fiske et al., 2019, p. 617).

From the perspective of the capabilities approach, the citizen science movement moreover provides the opportunity to further develop certain capabilities in the first place. Participation in a citizen science project can, depending on the way the project is designed, not only enable citizens to use the abilities and skills they already have, but also to further develop those skills or develop new ones.

Different people, different roles

Within TOPFIT Citizenlab, we collaborated with informal caregivers, people with a migration background, rheumatoid patients, older adults, and diabetes patients. Recognition of capacities, knowledge, and agency does not merely involve utilizing the knowledge, skills, and attitudes these people have. On several occasions, collaboration was also about deciding together which role each preferred in research projects and what knowledge or skills they would like to use to contribute. In one case, we used clustering and association methods. This resulted in fruitful conversations, new starting points for further collaboration and new roles, activities and tasks.

3.3.3 Reciprocity

The relationships in citizen science projects should be reciprocal, which is our third desideratum. As mentioned above (first desideratum), many medical research projects “failed to create reciprocal and mutually beneficial relationships” (Fiske et al., 2019, p. 618). Therefore, we must ask ourselves: What do the people involved (citizen scientists as well as professional scientists) gain from this collaborative endeavour? We can conceive of the relationships between professional researchers and citizen researchers as relationships of care. For such relationships, reciprocity is important. There should be a “mutually beneficial relationship made possible by an attitude of attentiveness, respect, and solidarity” (Moriggi et al., 2021, p. 4). Care receivers should be recognised as “active agents in the caring process” (ibid.), who can communicate to those who give care if their needs have been interpreted correctly and if they have been met adequately. In the context of citizen science projects, this means that everyone involved in the collaboration should play an active role and signal to the others what their needs are and if they are being met. A critical reflection on needs begins with a conceptualization of the power differentials (Fiske et al., 2019, p. 618). Understanding the disparities in position,

access, experiences or resources helps to arrive at explicit codes of conduct on which stakeholders can agree. To assist the professional scientists, citizens should receive training (Petersen et al., 2019, p. 5). We can also imagine trainings for scientists provided by citizens. Furthermore, effort is needed to create an environment in which citizen scientists find their professional scientist partners (Petersen et al., 2019).

Common concerns among citizens who do research include a lack of recognition of their knowledge and capacities (second desideratum) and a scepticism on the part of the professional scientists towards less rigorous research methods. Scientists seek collaboration with citizens because they expect this to enrich their research, but often they do not give them full recognition for their contributions, for instance by not mentioning them in their academic publications or by not compensating them appropriately for their efforts. Careful reflection is required to understand how each stakeholder could benefit from the collaboration. A relationship between equals (first desideratum) does not by itself ensure the realisation of reciprocity. Some forms of reciprocity may even induce reverse effects. Prainsack and Forgó (2022) argue that paying people for their data might exacerbate inequities and enlarge dependencies. It might also reduce altruism since people who expect to get paid are unlikely to give their data away for free.

Valuable outcomes

TOPFIT Citizenlab projects used vouchers as a token of gratitude. This was often appreciated, but not all participants saw it as a necessary condition for participation. More important were other forms of benefits and outcomes experienced by citizens. We found both indirect and direct benefits and outcomes. The most frequently mentioned long-term and indirect outcomes were a desired change, expected societal impact, improvement of their own health and that of others.

Participants also mentioned direct benefits that are more intrinsic and related to positive health like being appreciated, having a purpose, doing something meaningful, and being part of a community. These benefits exist regardless of the outcome of the citizen science project. One participant declared that he experienced joy and that his participation in the project provided a new purpose in his life.

3.3.4 Openness for different goals

The fourth desideratum holds that there should be an openness towards different kinds of goals that participants might be pursuing. Arriving at generalisable knowledge is not the only legitimate goal of such an enterprise. Ficorilli (2019, p. 125) describes the collaboration between researchers and citizens as a “bi-directional interaction, in the course of which researchers and citizens actively contribute to defining the goals of a research”.

The second principle of citizen science states that citizen science projects “have a genuine science outcome” (Robinson et al., 2018). The following examples are then given to answer a research question or inform conservation actions, manage decision-making or environmental policy (ibid.). It is not clear from this principle what counts as a genuine science outcome. Does a genuine science outcome necessarily involve generalisable knowledge? Our take, as authors, is that in the context of citizen science, the generation of knowledge at an individual level is valuable and that citizen science projects do not have to strive for generalisable knowledge, at least not in the first instance. Research projects that aim at knowledge relevant for one individual are worthwhile, provided that the knowledge gained can be used to generate knowledge that is relevant for others as well. In times of personalised medicine, it is important to take research at the individual level seriously (Suman et al, 2023). Here, new labels such as Personal Science (Wolf & Groot, 2020) and Personal Health Science (Heyen & Dickel, 2019) emerge. Acquiring general knowledge and translating it into practice occurs through acknowledging the worthiness of results at the individual level. In health care settings, for example, knowing the difference in outcome of a certain treatment could eventually change the advice professionals give to individuals.

Beyond the production of knowledge, there are many other goals that citizens and scientists might pursue with a research project. For a citizen this is often solving a certain problem regarding health, safety or environmental conditions. Not only knowledge, but also education, political influence, or a social network are goals that a participant pursues. Both parties should be transparent about their goals, as it will influence the set-up of the project, and might prevent disappointments or conflicts.

Jointly defining research goals

On several occasions, researchers of TOPFIT Citizenlab worked with a group of people with diabetes type 2 and a group of people with rheumatoid arthritis. We used several co-creation sessions to define research goals, topics, and questions. All expressed the goals to solve specific problems they experience in their daily lives. They argued that these problems are personal as well as general for people

with similar conditions. More specifically, a goal for patients with diabetes type 2 was to make technology broadly accepted, and for patients with rheumatoid arthritis to cope with fatigue.

Pursuing these goals resulted in relevant research, since these people knew from experience what questions they deemed relevant. We noticed a strong attachment towards research goals when these goals are defined in collaboration between citizens and researchers. There are some limits to what the research goals can be though. For example, in the project on rheumatoid arthritis, researchers set boundaries regarding feasibility and safety. For instance, no research was conducted to change medicine dosages, since without supervision and cooperation of attending physicians, this would be ethically irresponsible.

3.3.5 Openness for different research methods and paradigms

The fifth desideratum pleads for an openness for the use of different methods and for different paradigms. We believe in methodological pluralism. There is a wide range of methods that can lead to valuable insights and knowledge, including methods used by citizens that stand in sharp contrast with more traditional scientific methods.

Citizen science is a paradigm example of transdisciplinary research. More specifically, citizen science projects exemplify “participative transdisciplinary”, which “is aimed at collaboration between the real world with experiential knowledge of citizens and other stakeholders, and researchers from academic disciplines” (van der Bijl-Brouwer, 2022, p. 6). The contextualised and experiential knowledge necessary for transdisciplinary work is at odds with “the generalising, decontextualising and reductionist tendencies of disciplinary inquiry” (Horlick-Jones & Sime, 2004, p. 445). This does not mean that these forms of disciplinary inquiry cannot be used within citizen science; it only means they cannot claim dominance over other ways of inquiry, like forms of narrative inquiry (Bovenkamp et al., 2020). It is for this reason that Strasser et al. (2019) discuss epistemic practices, which can be regarded as various styles of knowledge acquisition. There is a multitude of forms of research and knowledge gathering. All forms are of potential value for citizen science; even forms of knowledge acquisition that are not so high on the methodological ladder should be taken seriously.

A typical way of going about for patients who want to find out more about their disease and what can help them is to adjust several things at the same time within a dynamic and complex life. For instance, a patient who wants to find out how to change behaviour or lifestyle in order to suffer less from a certain illness might

decide to try out several things at the same time (adjusting diet, going to bed earlier, taking a certain supplement). This contrasts with the scientific approach of changing only one thing at a time in an experimental setting in order to isolate the effects of a particular intervention. Within citizen science we need to strive for methods that are sufficiently flexible so that citizens are able to fit them into their daily routines and at the same time sufficiently robust to qualify as a scientific method (in the broad sense). Ficorilli (2019, p. 124) ascribes a “*bottom-up*, non-academic and non-institutional approach” to citizen science. The citizen scientist and professional scientist ought to collaborate and decide on the most suitable method to answer their research questions.

The differences in perspective on what good research is and what not, may differ wildly. Scientists are often flabbergasted about the way their patients tend to draw conclusions about the efficacy of a self-employed treatment. Often there is no placebo involved, and there is an apparent lack of relevant data; confounding and changing contextual aspects are not factored in. Yet, the solution to this cannot be, as is often the reflex, that patients conduct mini randomized controlled trials on themselves, including a formalized placebo condition and preferably with a wash-out period. Instead, it would be more valuable to check with patients for the existence of natural placebo conditions. A case in point are people who suffer from a chronic condition, like fatigue. These patients have often tried numerous things in a trial-and-error mode. When these have provided no result, and the next thing they try out does prove beneficial, there is at least a likeliness that there is an effect. So, these patients provide a hypothesis, which can be further tested. Likewise, from the patient’s point of view, it is unethical to demand to include a wash-out period and hence to stop a certain treatment to check whether the effect withers, while it has proven beneficial. Instead, a more open attitude of scientists could be to acknowledge the result and develop additional research, possibly with other patients, to confirm the hypothesis. This is no easy terrain (see textbox).

Battling over methods

The Dutch MyOwnResearch project was a 2.6 million Euro award winning project, with a dual lead of a medical academic institution (Amsterdam UMC) and a patient organisation (Foundation Mijn Data Onze Gezondheid). Together with nine other partners they developed an approach honouring both research demands and possibilities of patients and researchers. They co-created a novel research flow connecting n-of-1 research of patients with chronic fatigue and intestinal problems, with pattern analysis on accumulated data to identify homogeneous subgroups, to conclude with a formal randomized controlled trial (RCT) to confirm the results on one of the identified subgroups. One of the

innovations was to limit the number of products patients would choose from to conduct their n-of-1 research. The main aim of this innovation was to increase the likeliness that a product might work, while decreasing the possibility of adverse effects and thereby enhancing safety. The final choice was made by the patients. At its inception in 2018, MyOwnResearch was heralded by both reviewing patient organizations, researchers, and funders. The proposal, however, was not granted permission by the Medical Ethical Review board, on the grounds that the methodology employed would not lead to knowledge that would be of value to other patients. The alternative offered was to either opt for a fully observational study, allowing patients to choose from all products on the market, or a RCT, testing only two products on a very heterogenous population. The research consortium considered this impossible to reconcile with its objective and unethical vis-a-vis participating self-researching patients, and the project was aborted early 2020 (Iske & Ruysenaars, 2022; Remmers, 2022).

Likewise, diverging views on what is considered to contribute to health exist between professional scientist and citizen scientists. Citizens, and especially patients, may pursue research on topics or issues that are completely out of scope of the dominant medical paradigm. Their urge to find a solution to what matters to them drives them to explore health paradigms that are unorthodox, like bacteriophage therapy, electromagnetic hypersensitivity or a vegan diet to control auto-immune disease. For patients, it is not so much the health paradigm that matters, but the results it produces. They are open to different ontologies of health. Their views contribute to epistemic justice (Fricker, 2007), and may accelerate research and good health practices. This desideratum demands that we should remain open to the possibility that people benefit from certain unusual approaches. The simple act of documenting these cases, and assisting patient-researchers in making adequate observations, might accelerate the discovery of valuable and eventually generalizable options for treatments or promising innovations.

3.4. Two fundamental qualities

Desiderata govern the quality of citizen science. Making these desiderata work is not a matter of checking a box. It is a joint practice of professional scientists and citizens scientists alike, in which efforts and benefits are distributed equally and in full disclosure. They all carry responsibility. We argue that the use of the desiderata should respond to two fundamental qualities: transparency and symmetry. Therefore, these qualities function on a meta-level, meaning that the fundamental qualities do not govern the quality of citizen science itself but rather the quality of how the desiderata are applied in practise.

Both these qualities should therefore also be understood as moral principles when applying the desiderata. Stakeholders in a citizen science project are open and show integrity to their ethical position and actions they undertake. Being transparent about the ins and outs of a citizen science project, and especially about the desiderata, is primordial for the desiderata to be used in any way; transparency, so to say, enables or by lack of transparency impairs the desiderata to function (cf Turilli & Floridi, 2009). At the same time, it demands that our desiderata can be made transparent. It should be possible to give words and meaning to the desiderata.

The concept of symmetry demands that the ethical desiderata should be able to be approached and viewed both from the perspective of a researcher and from a citizen in similar terms. In other words: the employment of the desiderata should be neutral to either researcher or citizen. The principle of symmetry was first formulated by Bloor (1976). It was later introduced an important notion within Actor-Network Theory (Callon, 1986; Law, 1993; Latour, 1996). It is used within the so-called SCOT-approach (Social Construction of Technology) and has gained firm ground within Science and Technology Studies (STS) worldwide (Law & Lin, 2017). In this paper, we won't delve into the sociological-theoretical aspects of the concept of symmetry but use it to provide a context within which the ethical desiderata can be explored in ways that do justice to the perspectives of both the 'citizen' and the 'scientist' in citizen science projects.

We argue that symmetry in recognition of capabilities entails citizen scientists recognizing capabilities of professional scientists and vice versa. In the literature on citizen science, projects are often initiated and led by professional scientists. Research activities initiated and led by citizens have been labelled "extreme" (Haklay, 2012). These labels are problematic because they convey the impression that professional scientists should lead a citizen science project. There is no reason why a citizen science project should not be led by citizen scientists. The initiative to investigate a particular issue in the form of a cooperation between citizens and professional scientists can as well come from citizens. Some authors use the term 'passive citizen science', to describe research activities that analyse photos and observations of e.g.wildlife, uploaded by citizens on the internet, without interference of any intentional citizen science campaign. (Edwards et al, 2021). While the term 'passive' is understandable from the point of view of the professional researcher, it does not honour the curiosity and observational qualities of the individuals collecting the data.

On the other end, while the desideratum of 'openness to different methods and paradigms' demands that scientists are open to other methods and paradigms than those they are used to, the principle of symmetry demands that citizen scientists appreciate that to draw conclusions, specific procedures need to be put in place.

Citizens should be willing to reflect on the processes and methodology that is needed to arrive at solid observations and conclusions. The symmetry concept is in no way meant to re-invoke the 'science wars' reminiscent of the heated debates in the 80-90 ties and cannot be understood as a freeway for post-modern relativism and 'anything goes'. The concept is essentially an invitation to respect the intricacy and complexities involved in processes of knowledge generation (Sismondo, 2017), be it knowledge upholding a claim for generalizability or only valid in individual or very specific circumstances. When taken seriously, the concept of symmetry has the potential to connect perspectives of professional and citizen scientists in what Harambam (2021) calls 'deliberative citizen knowledge platforms'.

4. CONCLUSION

At the onset of this paper, we observed that definitions of citizen science are inherently problematic, and that its boundaries are ultimately ethical. Based on field experiences of both researchers and citizens engaged in citizen science in the healthcare domain, we have developed an ethical framework to enable a multitude of citizen science projects that honour demands of professional researchers and citizens. The framework consists of two core values (respect and justice), five ethical desiderata (relationship between equals; recognition of each other's capacities, knowledge, and agency; reciprocity; openness for different goals; and openness for different research methods and paradigms) and two fundamental qualities (symmetry and transparency). It is meant to complement existing frameworks, such as the ICPHR framework for participatory health research, addressing concerns of citizen scientists active in the field of bio-medical research. We posit that when taking these desiderata seriously, citizen science can claim to be, at its core, a humanizing endeavour unlocking the investigative capacities in people.

A theoretical framework does not by itself ensure ethical practice. There must be provisions in place to make ethical concerns practical and actionable. The formulation of these provisions is beyond the scope of this paper, and is something that should be explored in future research.

The ethical framework discussed in this paper does not cover all ethical issues related to citizen science. For instance, a government could decide to make medical treatment and care dependent on participation in health-related citizen science projects. Participation could thus become quasi-mandatory. Such a development would be highly problematic, as not everyone has the capacities and means to participate in such research activities, and as there can be good reasons to refuse participation even if one has the capacities and means for participating. Considerations of justice require that access to treatment and care not be dependent

on participation in citizen science projects. We believe that possible indirect effects on society should be explored further.

We have formulated our framework using first-hand experience in the healthcare domain. However, both desiderata and fundamental qualities are formulated in a generic way such that we see no reason why the framework would not apply beyond the domain of health. We would welcome it if other practitioners were to apply and test the framework in other domains.

Further research could moreover aim at developing an ethical code for citizen science, akin to ethical codes for research with human subjects. Our ethical framework could function as a basis for such a code. Like this framework, such a code should be based on the concerns of practitioners in the field.

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AUTHOR CONTRIBUTIONS

All authors contributed to the design and preparation of the study. GR provided input based on his experience as a patient and citizen scientist and came up with a preliminary list and text of desiderata. He wrote the first draft of sections 2, 3.4, and the conclusion, and the text box in section 3.3.5. JH wrote the first draft of sections 1, 3.1 and 3.3, excluding the text boxes. She contributed significantly to the conclusion. CvL and ES provided input on the basis of their involvement in TOPFIT Citizenlab. CvL contributed significantly to section 1 and made sure that all sections were aligned and coherent. ES wrote the first draft of section 3.2 and the text boxes with examples from TOPFIT

Citizenlab. He contributed significantly to section 3.4. All authors approved the latest version of the manuscript.

CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

DATA AVAILABILITY

All relevant data are in the manuscript.

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