

ESSAY

The Promise of Participation and Decision-Making Power in Citizen Science

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Citizen science is challenging professional researchers and their organizations to rethink the way they do science and connect with society. In any citizen science project, professional researchers are “making a promise” to the public about the level of participation and power in decision making that they are willing to provide to citizen scientists. Researchers should set expectations explicitly to ensure informed participation, trust, and motivation. Also, the design of tools for informed consent, information sharing, recognition, and privacy has to be adapted to the new power relations and distributed knowledge production.

Based on fieldwork experiences and literature review about environmental and biomedical citizen science, this article examines the challenges and proposes solutions for: 1) setting expectations for informed participation; 2) addressing privacy concerns and adapting informed consent to evolving interests and networked environments; and 3) promoting citizen governance of research data.

Citizen science has the potential to both increase scientific literacy and counteract mistrust and skepticism about scientific evidence of global problems (such as climate change) that need to be addressed. However, there are still many challenges to fulfilling the promise of citizen science – for example, empowering people and gaining trust. A few inspiring initiatives help us reflect on a facilitation model for engagement and informed participation; privacy by design; and new governance models for research data provided by citizen scientists.

Keywords: informed participation; privacy by design; informed consent; data governance; collective governance

Introduction: The Promise to the Public

Every public participation program results in a promise to the public regarding the level of their potential influence on the outcome of the project and what they can expect ... [program developers should] make this promise clear and explicit so as to create common expectations among all stakeholders (EPA 2018).

Citizen science is a powerful approach for creating new scientific knowledge (Kullenberg and Kasperowski 2016). At the same time, it can be leveraged for science education, social engagement with science and the subject of study (Bonney et al. 2009), and raising awareness about environmental problems (Johnson et al. 2014). Also, if strategically designed and conducted, citizen science might empower participants to improve the stewardship of their communities' natural resources (Vitos et al. 2013)

and engage in policy processes for local improvements (Overdeest et al. 2004). However, the academic research community has expressed concerns about data quality, integrity, and confidentiality; recognition of intellectual property and authorship for volunteers; and doubts about conflicts of interest in citizen science (Nature Editorial 2015; Resnik et al. 2015).

As a democratizing approach in research, citizen science inevitably will encounter some resistance for recognition: The *status quo* of science governance is being challenged, while science processes and methods are adapted in innovative ways (Newman et al. 2012). However, identifying and addressing weaknesses in citizen science is important to ensure that its full potential can be realized.

Traditional academic research is not without its flaws, similarly facing challenges with integrity, conflicts of interest, and a crisis of trust (Saltelli and Funtowicz 2017). Citizen science provides research institutions with opportunities to rethink the ways they do science and connect with society to improve their positive social and ecological impact and increase trust in science.

The International Association for Public Participation (IAP2) provides a set of core values and a code of ethics to enhance any public participation process, notably, “We will carefully consider and accurately portray the public's role in the decision-making process” (IAP2 n.d.a). During

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the design of a citizen science project, the degree and quality of public participation should be established in relation to desired outcomes and impacts. In some cases, involving the public in the early stages of design might be appropriate (Shirk et al. 2012).

Many classifications of citizen science projects exist to orient the type of design and the public's role in the project, e.g., the spectrum of public participation by IAP2 (n.d.b), a ladder of citizen participation (Arnstein 1969), Haklay's typology of participation (Haklay 2013), and models for public participation in scientific research (Shirk et al. 2012). These different sources coincide in some levels of the spectrum, for example, they identify: (1) contributory or distributed intelligence projects, where citizens are involved in data collection or analysis tasks; (2) participatory research projects, where citizens partner or collaborate with scientists in a wider range of the research process; and (3) co-creation projects, or "extreme" citizen science, where citizens are empowered, initiate, and control the project.

Taking into account the design of a project and the role of the public within it, project leaders can establish the promise made to the public. At the least, project leaders should commit to providing feedback on how project outcomes were influenced by the volunteers' input (IAP2 n.d.a). If a project is of a more participatory nature, project leaders should commit to incorporating advice and recommendations from participants into the decisions, including designing how they participate, and should be transparent in recognizing and communicating the needs and interests of all participants (IAP2 n.d.a).

Based on our experiences with the projects CITI-SENSE, Mapping for Change, Making Sense, SalusCoop, and others—as well as literature about environmental and biomedical citizen science—we detected various challenges to appropriately developing and committing to a formal promise to the public. We also envisioned promising solutions. In particular, this article examines the challenges and proposes solutions regarding:

- setting expectations for informed participation;
- addressing privacy concerns and adapting informed consent to evolving interests and networked environments; and
- investigating procedures for data governance.

We limit the scope of the promise to the public to levels of participation of volunteers and their decision-making power. Other facets of the promise, such as overstating scientific outcomes (e.g., promises about finding a cure or advancing science), or overstating policy outcomes (e.g., forcing the government to take measures to improve air quality), deserve their own article.

Great Expectations: How to Avoid Deceiving Participants?

An example of the challenge

Reflecting on the experience of project CITI-SENSE (<https://social.citi-sense.eu/>), which involved volunteers evaluating air quality with low-cost sensors, a facilitator of the project expressed that:

[Citizens] wanted to receive the air quality data directly. However, only the researchers were receiving the sensor data. The format of the data was only understandable for specialized technicians. On top of that, the data were not reliable nor comparable with the official values. For these reasons, we could not provide air quality information to volunteers and, later, we had to manage their high expectations (Personal communication in Spanish, 15th of February, 2018).

The role of the public in CITI-SENSE should have been adequately defined in relation to planned outcomes (Shirk et al. 2012). In this case, albeit in good faith on behalf of the project leaders, the outcomes were not clear because they changed during the project's life. This situation is not uncommon in scientific projects and that is why Shirk et al. (2012) propose to conduct a continuous evaluation of evolving interests that might not be known or recognized at the onset of the project. For example, as CITI-SENSE progressed, researchers' interests changed from wanting to gather data for generating a detailed map of air quality in a city to needing to gather data for testing the actual utility of the sensor pods. This change in outcomes and interests was not adequately transmitted to the volunteers; researchers should have explained that they were evaluating the sensor pods before embarking upon actual air quality evaluation.

Alternatively, they could have invited public participation at the early stages of the project for designing the tools for air quality evaluation, as the Technical Advisory Group noted: "Not enough citizen focus in the development of tools, it's coming late." (See supplemental material for notes from CITI-SENSE annual consortium meeting, March 2015).

Solution 1: Evaluating and balancing expectations

Shirk et al. (2012) proposed a framework to design citizen science projects in which one of the first questions asked is "whose interests are being served?" They add that the hopes, desires, goals, and expectations of the public and the scientific community should be taken into account and "balanced." Wiggins and Crowston (2012) conducted an analysis of the goals identified in citizen science projects to develop a typology; i.e., a scientific goal, education and outreach, action, monitoring, and conservation are some of the goals they included. However, the critical question of how to balance diverse interests and goals can be addressed only after evaluating the expectations of stakeholders and their needs (supplemental materials 2015: 7).

For example, in project CITI-SENSE we found a mix of goals and concerns. Project facilitators and teachers involving school students had an education and outreach goal, but the schools were concerned about their own image if they would find a pollution problem (supplemental materials 2015: 3). Meanwhile, other research institutions involved in the project had a public health goal. This example serves to illustrate the need for establishing an engagement plan before the onset of the project, involving stakeholders in the evaluation of their needs and expectations and in the design of the project, and creating a two-way feedback

channel between project leaders and participants that can help in the continuous evaluation of dynamic interests (Serrano Sanz et al. 2015; Shirk et al. 2012).

Solution 2: A strong facilitation model for participatory projects

Shirk et al. reflect on the “the rhetoric of participation”: “simply invoking the language and ideals of participation is insufficient.” Instead, they call for “careful, intentional, and transparent employment of participation strategies to achieve targeted outcomes” (Shirk et al. 2012: 3), which they then classify in outcomes for science, for individual participants, and for social-ecological systems. In the case of participatory and co-creation projects, leaders and professional scientists should go beyond the idea of volunteer participation and establish a collaboration or partnership relationship with citizen scientists, balancing power relations. The role of the facilitator is critical in establishing, balancing, and maintaining this collaboration relationship.

Additionally, the institutions involved should have a commitment to their citizen collaborators; provide them with timely, frequent, actionable feedback; and communicate how their input affected decisions and outcomes (IAP2 n.d.a). Here, the facilitator can act as a two-way feedback channel between professionals in research institutions and citizen scientists.

Furthermore, the institutional economic and logistical support to the facilitator, and providing decision-making power to the facilitator, are fundamental to ensure long-term trust relationships, motivation, and engagement (Serrano Sanz et al. 2015).

A good facilitation model is Mapping for Change (<http://mappingforchange.org.uk/>) in London. This social enterprise, partly owned by University College London, was created in 2010 with the objective of providing a suite of mapping tools to help communities engage with local issues such as noise or air pollution (UCL News 2010). Since then, Mapping for Change has facilitated many citizen science projects, helping local communities to partner with UCL researchers and providing tools and training (City of London 2017).

The example of Mapping for Change becoming a social enterprise contrasts with funded academic research projects, like CITI-SENSE, where the facilitator’s contract is terminated once funding has finished. In such cases, the research institution loses a “community champion” (Balestrini et al. 2017; Balestrini et al. 2015) who is perceived as trustworthy by the local community and citizen collaborators, as well as the social capital that this person has generated. The latter is a lost opportunity for having a positive social impact.

Solution 3: Transparency and accountability

In addition to Solutions 1 and 2, we also propose to make the promise to the public explicit and in writing, and to disseminate it for transparency. Transparency is the first step for informed participation, which we examine below.

In particular, this promise should include the expected outcomes whether or not they come from a participatory process. We also recommend making the expectations of

different stakeholders explicit. In this manner, project leaders will be transparent about potential conflicts of interest. Furthermore, an explicit promise could help in settling conflicting interests.

Very importantly, the role of the public in the project should be clearly stated, as should a commitment to inform participants about how their input influenced outcomes. Additionally, the timeline of the project and the period of the institutional commitment should be clearly communicated, to avoid deception when a facilitator disengages and communications stop. Ideally, a sustainability plan should seek to prevent this situation (Taylor et al. 2013).

Finally, the stakeholders should be invited to evaluate the project’s commitment to the promise for accountability. The stakeholders include professional researchers, participants, and organizations involved in the citizen science project and directly affected by it.

Our proposed steps for designing a citizen science project with ethics at its core, preparing the promise to the public, and ensuring commitment to the promise, are summarized in **Figure 1**.

Privacy, Trust, and Informed Consent in Networked Environments for Citizen Science

An example of the challenge

Citizen science projects often require the collection of personal data or data that could lead to re-identification. For instance, geolocalized data are important for environmental monitoring and epidemiology. Even when direct identifiers such as names and addresses are avoided, geolocalized data or metadata contained in pictures and other digital pieces of information could pose data protection and privacy risks.

The project Making Sense (<http://making-sense.eu/>) empowers communities with methods and tools for environmental monitoring. It enables citizens to capture data, make sense of those data, and work towards positive change. The pilot carried out in Barcelona involved a group of neighbors asked to measure how high noise levels are and what can be done to improve the situation in a specific area (a public square). The Smart Citizen Kit was used by neighbors to collect data about the noise levels coming from the square, which were publicly shown as live feeds in the online platform, smartcitizen.me. The platform showed the level of noise of each individual sensor, some of which were positioned inside the houses of participants, in their bedrooms or living rooms. This led some participants to raise concerns about privacy issues, reporting that they were not always comfortable about sharing their data and would rather disconnect their sensor at times. To address this concern, co-creation workshops were held with participants and designers to discuss data governance tensions and envision new features that would empower them to have better control over their data.

This example illustrates how addressing privacy concerns is crucial, not only to ensure legality and data protection compliance, but also to ensure the willingness of participants to contribute data to citizen science projects, and to trust their proponents and results.



Figure 1: Summary of recommended steps for designing a citizen science project with ethics at its core. Stakeholders are researchers, participants, and organizations involved in the project and directly affected by the project.

Table 1: Privacy and data protection problems and solutions identified by Galdon Clavell.

Problems	Solutions
Privacy policies do not always reflect data practices.	Create transparency, accountability, and audit mechanisms , allowing others to verify that the stated policies are a clear reflection of actual data policies.
Privacy risks of metadata and third party sharing are not taken into account.	Determine what data can be released and under which conditions (anonymization).
Basic privacy precautions such as data minimization are not implemented consistently.	Require only minimal personal information about project participants, give sufficient notice of privacy options, provide users the option to hide some of their data, and allow citizen users the possibility to modify and delete their data.

Identified problems and solutions

Galdon Clavell assessed the privacy and data protection aspects of three different citizen science projects. In a conference presentation cited by Wiggins (2016), Galdon Clavell identified a series of problems and provided a set of recommendations for promoters and developers of citizen science projects, shown in **Table 1**.

The model of Privacy by Design

To incorporate privacy and data protection precautions in citizen science projects, developers of technological innovations should not only consider co-designing privacy with citizen collaborators, but also should consider Privacy by Design (PbD) principles and configure them based on the Privacy by Default parameters. PbD puts the privacy of users first, promoting its integration into the

design of technologies (in a broad sense: Hardware, software, network designs). It implies proposing by default the most restrictive privacy options in a way that reinforces the active choice of the user when it comes to sharing data.

The 7 foundational principles of PbD (Cavoukian 2009) are useful to achieve this in practical terms:

1. *Proactive, not Reactive; Preventive, not Corrective.*
The PbD approach is characterized by proactive rather than reactive measures, meaning that it anticipates and works to prevent privacy infringements before they occur. PbD does not wait for risks to materialize, nor does it offer remedies to resolve privacy breaches once they have occurred; its purpose is to prevent them from occurring.

2. *Privacy as the Default Setting.* PbD seeks to deliver the highest degree of privacy by ensuring that personal data are automatically protected in any computer system or data process. In the absence of intervention, the level of privacy remains intact. No action on the part of the individual is required to protect privacy as it is integrated into the system as a default setting.
3. *Privacy Embedded in Design.* PbD is embedded in the design and architecture of computer systems and data processes. It is not added as a complement, *a posteriori*. The result is that privacy becomes an essential component of core functionality—an integral part of the system—without diminishing its functionality.
4. *Total Functionality: Positive Addition Versus Zero Sum Play.* PbD seeks to accommodate all legitimate interests and objectives, without the benefits in one setting implying concessions on the part of another. PbD avoids false dualities, such as privacy versus security, showing that having both at the same time is possible.
5. *End-to-End Security: Full Life Cycle Protection.* Having been embedded in the system before any data have been collected, PbD maintains security conditions throughout the entire lifecycle of the data involved. Robust security measures are essential for privacy, from start to finish. This ensures that all data are retained and deleted safely at the end of the process, without delay. Therefore, PbD ensures secure end-to-end management of the information lifecycle.
6. *Visibility and Transparency: Keep it Open.* PbD seeks to ensure that all relevant parties, regardless of the technology involved, are operating in accordance with the stated promises and objectives and subject to independent verification. Components and operations remain visible and transparent to users and suppliers.
7. *Respect for Users' Privacy: User-Centered Approach.* Above all, PbD requires that architecture managers and operators uphold the interests of the citizens and users, offering measures such as robust default security, proper notification, and user-friendly options that increase control.

Education and tools for informed consent in biomedical citizen science

Cheung (2017) describes the main challenges of informed consent in biomedical citizen science: The vast amounts of data collected, aggregated, or repurposed imply a degree of uncertainty about the outcomes, which could evolve over time. In addition, the one-to-one model of informed consent does not fit the networked structure of citizen science collaborations. New models of informed consent have been proposed to overcome these challenges: Open consent, which openly excludes privacy (Angrist 2009; Cheung 2017); dynamic consent, where each participant selects through an online platform which data she wants to donate and under what conditions (see next section);

portable legal consent, which is not linked to a particular institution but to the participant and her data; and meta-consent, where participants can choose from a set of types of research and types of data to share (Cheung 2017).

However, all these new models of informed consent require a high level of information literacy (Cheung 2017). The process of understanding this complex information and concomitant privacy risks could be addressed with innovative educational materials, the use of new media, and giving participants time for their own personal research on the Internet (Henry et al. 2009). Also, Welch et al. (2016) propose the use of “teleconsent,” where the researcher uses remote video conferencing for informing participants and answering their questions. Very importantly, a risk visualization tool might facilitate the comprehension of risks for privacy or unforeseen consequences (Arthur et al. 2015). Finally, Bowser and Wiggins (2015) propose to design citizen science data platforms that support evolving choices of participants that might change with context or location. We will examine further the idea of dynamic consent with the lens of data governance below.

For projects that involve fewer participants, it is viable to use focus groups for education about the topic and for building a trusting and collaborative relationship between participants and researchers (Skinner et al. 2015). However, in co-creation or “extreme” citizen science projects, the boundaries between professional researchers and citizen collaborators become blurry (Banks et al. 2013). In such cases, establishing a research collaboration agreement might be more appropriate than an informed consent process.

Data Governance

The challenges of data governance in biomedical citizen science

New initiatives are pushing the frontiers of participation in citizen science forward by opening up a new dimension of participation that relates to the governance of research data. This is particularly relevant for the biomedical sector, where a large amount of personal data is needed to make advances in research. This need has fostered the creation of a wide range of initiatives from private, public, and academic sectors which aim to encourage citizens to make their health data available by praising their involvement in research for the public good. However, the way in which citizen participation is conceptualized varies significantly, as do the roles that citizens could play in the value chain of research (e.g., data collection and sharing, or instigation of the research agenda).

On one hand, many initiatives promoted by private companies focus on providing citizens with products or services that generate new data. Such data are being used in research studies aimed at creating new patents, products, or drugs from which the company derives a financial profit. This occurs, for instance, on patient platforms such as PatientsLikeMe, or genomic analysis services such as 23andMe, where user-generated data are shared with pharmaceutical companies

to conduct research studies. Although these initiatives provide services of value for patients that have proactively consented to donate their data for research, the lack of transparency about the researchers' and company's intentions to commercialize and patent the results achieved through users' participation have stirred up controversies (Sterckx et al. 2012).

On the other hand, governmental research programs (e.g., Care.data in UK, Visc+ in Catalonia) tend to leverage the civic duty of citizens to participate in public research (Woolley et al. 2016). The lack of transparency (e.g., who can gain access to citizens' data) and the fact that these programs often are based on opt-out models of participation, have led to a cessation of such programs. Strong concerns were raised about the lack of compliance with the conditions of social license for research (i.e., voluntary participation, governance by values of reciprocity, non-exploitation, and service to the public good) (Carter et al. 2015).

Whether by leveraging a rhetoric of altruism or the appeal of benefits offered through services or products, citizen participation in medical research initiatives often is limited to data donation. The whole value chain remains under the control of professional scientists, and no opportunities are given to citizens to set research priorities and agendas or to have a voice about how research outcomes are exploited. Citizen control of such matters is especially crucial in the health domain, where both personal risks and collective benefits are high, and where competing interests must be aligned.

Collective governance: A framework for new solutions

To tackle such ethical issues, new initiatives are looking at data governance as a means to enable citizen participation in the governance of science. The aim is to flip the traditional partnership relationship of citizen science from looking at citizens as collaborators in research projects (mainly written and run by professional researchers) to looking at them as the real instigators of the studies, as they supply the capital assets (in the form of data) to support research that they endorse (Evans 2016).

In the era of big data, where huge datasets are processed, groups of citizens can have greater control over their data than individuals acting alone. That is why collective governance models are strongly advocated and proposed as a way to overcome the pitfalls of individual solutions and the one-to-one model of informed consent. An example of collective governance is the EPPI model (Buyx et al. 2017). Conceived for the epidemiology field (and not yet implemented), EPPI citizens are envisioned as being part of the governing bodies of research, and they collectively exercise control over the data, as well as propose and deliberate on research questions and concerns. Other initiatives have chosen the cooperative model as a legal form to enact such collective governance. Healthbank, MiData.coop (Hafen 2014), and SalusCoop (SalusCoop 2016) are examples of data cooperatives. Their aim is to aggregate health data from cooperative members and to put these data at the service of research projects on which they have deliberated. Moreover, members of HealthBank can exercise the right to an economic reward from researchers who access their data.

Such models of citizen direct governance are still in their infancy, and have not yet been fully deployed. There is need to understand better how a model of this type could be enacted practically and at scale, and what challenges it might face.

The solutions of the SalusCoop model

To contribute towards filling this gap, and to support the implementation of SalusCoop in Catalonia (Spain), we have conducted desk research and interviews with key actors in the healthcare sector in Barcelona. A snowball sampling approach was followed to determine the sample group of interviewees. The selected sample was composed of 24 people, including the public; members of patients' associations; professionals from private and public hospitals and research institutions; bioethics researchers; and companies working in the field of open data and bioinformatics. The study has been published as a public report (SalusCoop 2016). Here we summarize the main results as an example of potential solutions for the identified challenge of citizen data governance.

The results of that study highlighted four fundamental governance principles that we propose as driving values for the implementation of "citizen governance models for health data science":

1. *Conditional donation and data literacy.* Citizens should have the right to decide under which conditions they want to donate their health data. Sharing data requires that people weigh many risks, including privacy and security as well as the potential improper use of the data. Only individuals can make these decisions, in line with their beliefs, fears, and incentives. The more knowledge they have about the nature of the data (e.g., what are potential benefits and risks of sharing, how value is extracted from the data, or how data are used throughout the value chain), the more capable they will be to make decisions that minimize the risks and increase collective benefit—e.g., contributing to scientific discoveries.
2. *Collective benefits.* The use of data by any agents should generate a clear and unequivocal benefit to society. There is need to design new models for policy and research that can safeguard, guarantee, and monitor the collective benefits produced from the analysis of data.
3. *Motivational incentives.* The rhetoric of altruism might not be sufficient to reach a critical mass of people. Incentives should be given to individuals to motivate them to participate and share their data. However, incentives to individuals should not be put ahead of the common good. Our results suggest that incentives in the form of services or new knowledge are preferred to economic rewards.
4. *Flexible and transparent collective governance.* Collective governance means ensuring transparency in decision-making processes. Transparency

fosters trust, which is key to encouraging people to participate. This could be enabled by a flexible infrastructure for participation that allows for informed decisions and a delegative or liquid democracy, a form of collective decision making where voters can either vote directly on issues or give their voting power to delegates who vote on their behalf.

Conclusions and Future Work

We argue that any citizen science project should start with a formal and well-disseminated promise to the public to enhance the public participation process and ensure transparency, accountability, and trust. We identify the challenges and propose solutions to appropriately develop and commit to this promise. First, we recommend evaluating and balancing stakeholders' expectations while defining the outcomes of the project. Second, the project leaders should plan a continuous evaluation process to inform participants about evolving interests and adapt participation strategies to it. Third, the promise to the public should clarify the role of the public and stakeholders in the project. Fourth, to ensure accountability, we strongly recommend communicating how participant input affects outcomes and decisions. Fifth, we suggest that the promise to the public also could address privacy concerns and include a data governance model.

Citizen science projects often require the collection of personal data or data that could lead to re-identification. To safeguard participants' privacy, we recommend requiring only minimal personal information about project participants, determining what data can be released and under which conditions (anonymization), and creating transparency, accountability, and audit mechanisms. In line with these recommendations, we propose following the principles of Privacy by Design.

The process of understanding complex biomedical information and risks for privacy constitutes a challenge for informed consent. To overcome this challenge, we suggest some novel approaches and tools to educate citizens and explain the risks of participation. Also, we explain the concept of dynamic consent, both with the lens of privacy and with the lens of data governance.

Finally, we propose solutions for data governance in citizen science, such as conditional donation of data and flexible and transparent collective governance. In future work, we would like to examine the obstacles that citizen science projects encounter when trying to implement these recommendations, for example, small staff devoted to citizen science projects, technical challenges, and unforeseen conflicts.

Citizen science practitioners have the opportunity to diminish the ethical doubts of the academic research community by setting an example with their projects. Most importantly, to fulfill the promise of citizen science empowering people and gaining trust in science, we need to design citizen science projects with ethics at their core. We hope that the ideas we propose in this article will help in this endeavor.

Supplementary Files

The supplementary file for this article can be found as follows:

- **CITI-SENSE consortium annual meeting notes (2015)**. CITI-SENSE consortium annual meeting (March 2015). DOI: <https://doi.org/10.5334/cstp.171.s1>

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Competing Interests

The authors have no competing interests to declare.

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