

Chapter 20

Ethical Challenges and Dynamic Informed Consent



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Abstract This chapter uses informed consent as a point of departure for the description of multiple ethical facets in citizen science. It sets out an overview of general ethical challenges in citizen science, from conceptual issues around social imbalances and power relations, to practical issues, such as how to deal with privacy for participants as well as data protection, intellectual property rights and other emergent issues. The chapter goes on to describe the different types of informed consent, particularly focusing on dynamic informed consent as the solution to the challenges described. Finally, practice-oriented recommendations about how to tackle some of the ethical issues raised in the chapter are set out.

Keywords Research ethics · Research integrity · Informed consent · EU GDPR · Inclusiveness

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Introduction

New forms of data and participant-led research are challenging traditional oversight mechanisms and raising concerns over the ethics of collaboration and partnership between researchers and *research participants* (or *citizens* – both terms will be used interchangeably). Such developments require a critical examination of the challenges that may arise when individuals become partners in research, and a thorough discussion of the requirements that have to be met for citizen science to be considered ethical. Relationships that are complicated by imbalances of power can be observed in almost everything around us. In citizen science, these issues come to the fore, particularly because of the ways in which citizen science opens up the research process for active volunteer participation in different stages of undertaking research. Making citizens more central in the science-policy process is also inevitably constrained by pre-existing uneven power relationships between politicians and citizens, scientists and citizens, and scientists and politicians (Kythreotis et al. 2019). Also, the context in which a citizen science project or initiative is set up, and therefore who is driving the project, who has access to resources, and other specific responsibilities within a project, all contribute to the ways in which the dynamics of relationships between actors play out.

The new roles, boundaries, and relationships between researchers and research participants that citizen science entails currently lack sufficient ethical and regulatory coverage (Rasmussen and Cooper 2019a; Fiske et al. 2018; Rothstein et al. 2015). While the protection of human subjects in research has traditionally been guided by *informed consent* or Institutional Review Board (IRB) mechanisms, the widely distributed nature of citizen science challenges a one-size-fits-all set of ethical requirements for the broad variety of practices and collaborative formats that it embraces (Fiske et al. 2018). Also, many citizen science projects count on the collaboration of research participants who are not the primary subjects of research.

Citizen science poses ethical challenges since research participants become both subjects and objects of research (Resnik 2019; Wiggins and Wilbanks 2019) and may interact with researchers as equals in the research process. Yet, existing regulatory mechanisms in human subject research focus on the protection of the rights and welfare of ‘passive’ research subjects. Also, existing regulatory mechanisms in human subject research build on the paternalistic assumption that research participants may not be able to correctly assess the harms and benefits involved in the research process (Rothstein et al. 2015). Finally, the vast amounts of data collected, aggregated, and repurposed in citizen science projects imply a degree of uncertainty about the outcomes, which could evolve over time. This means that a one-to-one model of informed consent does not fit the networked structure of citizen science collaborations; new models of consent are needed. Yet, these models of consent require understanding of complex information and concomitant privacy risks, and thus a high level of information literacy which, in turn, calls for new and more inclusive consent procedures (Cheung 2018; Eleta et al. 2019) such as the model of *dynamic informed consent*. Dynamic informed consent is a strategy to

involve participants, support the principle of informed consent, and solve the ‘stationary’ aspect of consent, via a technological construct such as a communication platform that establishes a continuous two-way communication between researchers and participants.

Before delving into more detail about dynamic informed consent, we highlight the ways in which citizen science gives rise to complex ethical issues that are not easily resolved. We explain the issues around unethical citizen science and why a high standard of ethical practice in citizen science is crucial to its success. As Rasmussen and Cooper (2019a) suggest, it is not sufficient to simply react to ethical issues; what is needed is to proactively and prospectively address problems. Furthermore, many citizen science projects exist outside of institutions where regulations apply, and there is no central authority or governing body that oversees the field of citizen science. Our key argument in this chapter is that it is not only the principle of *ethical citizen science* that is important, but that, done well and to an ethically high standard, its practice will allow for better experiences for participants and potentially more sustainable projects. Citizen science practitioners can diminish the ethical doubts of the research community by setting an example with their projects (e.g. regarding quality and integrity of data). As Eleta et al. (2019) claim, ‘most importantly, to fulfil the promise of citizen science empowering people and gaining trust in science, we need to design citizen science projects with ethics at their core’ (p. 7). The solution that we offer to these ethical challenges is to focus attention on developing dynamic informed consent, namely, consent that is both supported by the necessary information for participants to actively consent to participate, and consent that is dynamic, and frequently revisited, not static and negotiated only once. Hence, we see dynamic informed consent as a potent solution to shifts in the ways in which ethical research is practiced and within the current constraints related to data protection in Europe.

Ethical Challenges in Citizen Science

In this section, we consider a series of contemporary issues in undertaking state-of-the-art citizen science and the ethical issues that arise when engaging the public in research. This list constitutes a starting point for discussion – it is important to state here that it is not exhaustive and that the different dimensions are very much interrelated and intertwined. The list is the result of the collective deliberations of the authors, and, therefore, in many ways, it reflects our own perspectives and principles and values. The list starts with the more conceptual issues and goes through to the more practical issues.

Instrumentalisation

Some see citizen science not primarily as scientific approach but as a useful instrument with which to reach specific targets, for instance, in areas such as science education. There is an increasing number of school programmes being developed which support participants' learning about STEM (science, technology, engineering, and mathematics), and the scientific process itself, with sometimes limited added scientific value (see Kloetzer et al., this volume, Chap. 15).

For some, citizen scientists are perceived to be a useful resource with which to pursue a neoliberal agenda. In particular, the promise of open data and access hides disparities in remuneration (Kansa 2014). For politicians, citizen science can also be an instrument to reach policy targets, such as the mobilisation of citizens for science, in order to increase the innovative power of Europe, or to mainstream concepts such as *responsible research and innovation* (Vohland and Göbel 2017). Citizen science is also seen as an instrument to support *sustainable development*; however, sustainable development can be seen to be broadly positive and normative. As a result, the question of how to judge the *instrumentalisation* of citizen science in this area is therefore more complex than simply examining how it is undertaken.

Exploitation

In citizen science, little attention has been paid to concerns about knowledge extraction, namely, the collection and circulation of (sensitive) data without explicit individual and/or community consent, and the subsequent potential traumatising of such extraction processes. Research participants could have varying, even conflicting, stakes in the research process, which are at odds with researchers' interests, with the latter potentially only sticking with the research for the duration of a funding cycle.

Further concerns are raised in relation to exploitation where data ownership is not properly defined, and participants' data are valued not only for the information they provide but also for the increasing commercial or research value they may entail (see Lupton 2014 and the subsection on collaboration with private partners below). This points to the need for individual input to, and community-level considerations for, research ethics reviews and consent practices (Dickert and Sugarman 2005; Box 20.1).

Box 20.1: Civil Laboratory for Environmental Action Research

Researchers at the Civic Laboratory for Environmental Action Research (CLEAR) in Canada have implemented *community peer review* processes. These combine consent, community self-determination, and peer review for

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Box 20.1 (continued)

environmental research in such a way that consent is agreed at the community level at the beginning of the research cycle. The aim of this is to mitigate unexpected and unintended harms, as well as to increase benefits to communities and their ownership over the process (Liboiron et al. 2018). This gives the research participants involved the ability to determine whether the research may cause them harm and to be part of determining how knowledge should best circulate to reduce or eliminate that harm.

Inclusiveness

There is a paucity of literature that exhaustively describes equity-driven involvement in citizen science using dynamic informed consent (Prictor et al. 2018). In some fields of scientific research, the involvement of certain citizens in research prevails. For example, in health research, Indigenous and socially, culturally, and linguistically disadvantaged people are quite often disregarded (Prictor et al. 2018), and their potential contribution, in terms of know-how, is missed or overlooked. Furthermore, the findings of research that excludes certain citizens are necessarily incomplete since they lack the ability to be extrapolated fully. Some platforms seek to reduce this constraint (Box 20.2).

Consideration of the timing and scheduling of citizen science activities is of crucial importance to ensure as wide and diverse a group of people as possible can participate in such activities. For example, being attentive to the days of the week when participation is required, as well as varying the times of day at which activities are scheduled, plays an important part in ensuring the inclusiveness of citizen science. Another way in which to increase the potential for diverse groups to participate includes reflecting on the location of activities, projects, and initiatives. Whilst some may feel comfortable attending events or citizen science activities in, for example, university or institutional buildings, or grounds, this may be off-putting and exclusive for others. Attention needs to be paid to the specific details of how citizen science activities are organised to address some of these issues (see Paleco et al., this volume, Chap. 14).

Box 20.2: Sapelli: A Tool to Translate Icons and Language in Order to Enhance Inclusiveness

The Extreme Citizen Science (ExCiteS) research group based at University College London works to develop tools specifically for undertaking more bottom-up, extreme citizen science. The particular tool they are developing is called Sapelli, an open-source project that facilitates data collection across language or literacy barriers through highly configurable icon-driven user

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Box 20.2 (continued)

interfaces. Sapelli is frequently used with communities with low levels of literacy or in some instances with nonliterate people. Whilst ExCiteS works extensively with different groups to implement the use of Sapelli in a wide variety of different contexts and countries, and to adhere to a values-based approach to implementing the use of the tool, focusing on a bottom-up practice that takes into account local needs, practices, and culture; there are unavoidable power dynamics that come into play in each instance in which the tool is used. To address potential issues surrounding imbalances of power in particular contexts, and to ensure inclusivity in the research process as much as possible, the ExCiteS group starts any project by following the steps of the free, prior, and informed consent (FPIC) process, thereby allowing for frequent discussions with all those involved in a project, to understand the local context and to subsequently address the potential issues and imbalances of power relationships that might arise.

Research Malpractice

Concern over data quality in citizen science is a long-standing issue (Guerrini et al. 2018; Balász et al., this volume, Chap. 8). Owing to the characteristics and activities of citizen science, the tasks that citizen scientists undertake are not necessarily subject to institutional or regulatory oversight (Resnik et al. 2015a). This means that whilst professional researchers are bound to methodological rigour and research integrity and are held accountable for the quality of their work, citizen scientists might not be susceptible to such formal mechanisms and pressures (Guerrini et al. 2018; Resnik et al. 2015b). This could, in turn, challenge the implications of research malpractice in citizen science projects. For instance, in archaeology, lay people may destroy places of recovery and take away valuable artefacts for science (Davydov et al. 2017). Also, conflicts of interest may stem from research participants' affiliations to private, public, or political organisations or from their individual perceptions of the harm or benefit of the research (Guerrini et al. 2018). Evidence has indeed shown that the collection of non-representative data has been used to obtain relief resources, support lawsuits, gain media attention, and support erroneous scientific conclusions (Roy and Edwards 2019). Although professional scientists themselves are not exempt from bias, conflicts of interests, and research misconduct, it is important to develop strategies that promote integrity in research collaborations among professional and non-professional scientists.

Collaboration with Private Partners

Some of the new forms of collaboration in citizen science relate to the linkage of citizen science projects with either small- or medium-sized enterprises and even larger industrial companies. The primary issue with these types of collaboration is the monetary valuation of the research results. Whilst this might be an issue that is planned for before the research takes place, it may also develop during the research process itself. A discussion at the Citizen Science Forum 2017, in Germany, demonstrated that the community is split (Ziegler et al. 2018). Other forms of collaboration, such as in the provision of services for technology and design, do not have such issues attached and can strongly benefit from the quality of citizen science tools and public dissemination.

Box 20.3: Case of the German Butterfly Monitoring Scheme

A complex case arose when a private company used and interpreted data from citizen scientists in a way that contradicted their intentions. In the case of the German Butterfly Monitoring Scheme (TMD) of the Helmholtz Centre for Environmental Research – UFZ, Monsanto wanted to use the scheme’s data to demonstrate that genetically modified organism (GMO) maize does not harm butterflies. The TMD scheme delivered viable data that was useful for research (Kuehn et al. 2008), but the participants wanted to support nature conservation (Richter et al. 2018). The intended ‘cooperation’ between the private company and the TMD scheme did not take place, mainly because the monitoring scheme was not suited to answering the question of how harmful GMOs are for butterflies. However, the case also opened up questions of data ownership, different ways of interpreting data, and the issues surrounding properly funding independent environmental monitoring schemes.

Furthermore, when choosing the recruitment strategy for a citizen science project, diverse channels can be used to involve citizens in research. However, advertisements using the logos of business enterprises are not always recommended by the IRB, usually responsible for the ethical review of a research project. In Southern Alberta, researchers of citizen scientist radon testing survey were recommended to remove the university logo from the industry partner’s website and to restrict recruitment channels and to solely use the university’s website (Oberle et al. 2019). This was required to avoid a potential conflict of interest around the financial independence of researchers from the industry partner. On the other hand, citizen scientists may complain if companies which follow different interests use their data (Box 20.3).

Payment and Free Labour

Recruitment of citizens is another issue that needs to be more comprehensively discussed (Resnik et al. 2015a; Riesch and Potter 2014; Rothstein et al. 2015; Tauginienė 2019). Most often, citizens are volunteers, with the assumption that they should not be paid for their contribution. However, payment in this context needs to be understood properly; it relates to the reimbursement of citizens' costs (such as travel to an instruction meeting with researchers), not to a profit that citizens might gain from taking part in citizen science. In this sense, there can be an imbalance between researcher and citizen, where a researcher is paid for his/her time on a research project, but not necessarily for undertaking citizen science, whereas a citizen is not paid at all (Riesch and Potter 2014). In some European projects (e.g. LandSense), and also in some German projects (following a call from the German Ministry), scientists are paid to run citizen science projects. Participant recruitment strategies should be carefully chosen to avoid issues of inequity, exploitation, voice buying (in political terms, getting the agreement of lay people by paying for their contribution), and voice manipulation (Oberle et al. 2019; Resnik et al. 2015b; Rothstein et al. 2015).

The question of payment, however, also refers to another dimension of society, namely, the increasing economisation of our lives, the internalised judgement, and the framing of daily activities around their economic benefit (Brown 2015). This is especially visible in the area of environmental sciences (Lave 2017), which focuses on smaller scales, contributing activities which support institutional researchers and administrations, rather than groundbreaking exploratory research. Citizen science is therefore in an ambivalent situation (Vohland et al. 2019). On the one hand, as described above, a feeling of injustice may arise if citizens are not paid for undertaking the activities that researchers are paid for. On the other hand, citizen science can provide a space free of economic considerations where key motivations are learning, contributing subtly to sustainable development, and having fun.

Ownership and Acknowledgement

Authorship credit and/or data citation constitute practices aimed at formally recognising citizen scientists' contributions to a project (ECSA 2015; Resnik et al. 2015a). However, citizen science participants are rarely included as authors of peer-reviewed publications (Dickinson et al. 2012). The reasons are varied: there are no consistent credit assignment practices for collaborative work from one field to the next, and those that do exist mainly rely on standards around what one must contribute to be considered an author (Cozzarelli 2004; ICMJE 2019). The data produced in citizen science projects may be generated by large online communities, with participant numbers that are constantly changing and expanding, which makes it difficult to acknowledge potentially thousands of named contributions (Theobald

et al. 2015). Formal acknowledgement of citizen scientists' contributions may also raise issues of data quality (Burgess et al. 2017). In addition, it might be that the results of citizen science projects are published via alternative dissemination platforms to reach the general public, rather than peer-reviewed scientific journals (Gadermaier et al. 2018). Although gaining citizen scientists' permission to be listed as co-authors can be challenging, research participants may have an active stake in the production of data, their engagement might be time and effort intensive, and their contribution might be quite substantial (Riesch and Potter 2014). Also, formal acknowledgements and attribution are crucial motivational factors (Rotman et al. 2012) that can potentially help attract and retain volunteers (Piwowar and Vision 2013), as well as improve research accountability. It is therefore important to discuss potential co-authorship or formal acknowledgment directly with participants as early as possible in the research process.

Licensing of data and other research materials constitutes a further practice that formally defines ownership and re-use conditions. In terms of the data set, a license specifies how the data can be used by the involved partners or even the public under an open license. A common license for *open data* is the Open Database Licence or ODbL,¹ which allows the use of the data without needing to cite every contributor individually.

In terms of content elements, like photographs or written text by users, intellectual property laws apply. In a European context, the authorship of a unique content item is owned by the author automatically. The author can only grant usage rights to the project, or the public, by applying a license. In most cases, this is done automatically at the point of user registration via accepting the terms of use with a checkbox in the registration form. The license, under which 'unique creative works' are published by a user, can vary from specified rights to use just by the project to more open licenses, like the various forms of Creative Commons (CC) licenses which allow sharing, define the needs of author citation, and specify how the creative work can be used. With the different forms of the CC BY license, the author must always be cited when content is used within the project or, for example, on a website or in social media.² At the opposite end of the available spectrum, the CC0 license, also known as Public Domain, allows anyone the free use of content without citations or restrictions.³ In addition to the aforementioned licenses, there are many others available for use by projects from the outset. However, licenses are not restricted to pre-existing ones; everyone can create a new type of license and apply it to the data or content elements within a citizen science project, but normally

¹Open Data Commons Open Database License (ODbL): <https://opendatacommons.org/licenses/odbl/index.html>

²See further CC licenses and examples: <https://creativecommons.org/share-your-work/licensing-types-examples/>

³See further on public domain licensing: <https://creativecommons.org/share-your-work/public-domain/>

it is advised to use licenses already in use, not only because of efficiency, but also be sure that the significant legal aspects are covered.

Types of Informed Consent

There is currently access to more information than ever before, and many people express the desire to participate in the scientific process, either passively by providing (personal) information or actively by, for instance, participating in a citizen science project. What in former times was some kind of *implicit* consent, meaning consent that was not expressly granted by someone, now becomes increasingly *explicit*. With the rise of Web 2.0 user-oriented technologies and the big data era, *research ethics 1.0* has been revisited and subsequently has been replaced with *research ethics 2.0* where appropriate (Tauginienė 2019; Fig. 20.1). This shift mostly affected the role of informed consent. In research ethics 1.0, informed consent referred to regularly informing participants about the purpose of research, the risks and benefits of being involved, and the right of a citizen to withdraw from the research at any time (Brall et al. 2017). As such, informed consent was paper based and reflected conventional models of involving human subjects used in ‘Engagement 1.0’ (Teare et al. 2015). In this instance, a citizen was a passive subject. However, in research ethics 2.0, the balance between a researcher and a citizen in

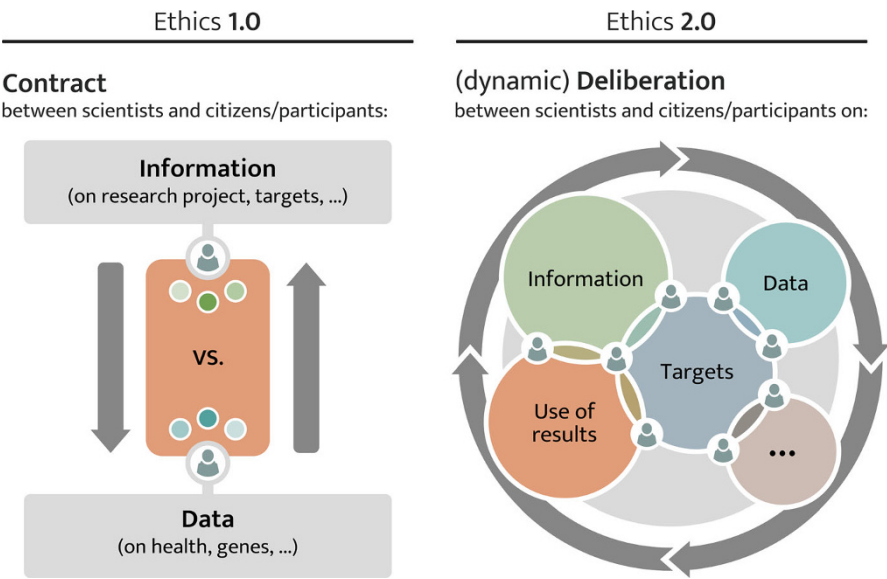


Fig. 20.1 The difference between informed consent in research ethics 1.0 and 2.0. Whilst, traditionally, informed consent is understood as a kind of contract, in ethics 2.0, there is a continuous – dynamic – interdependence between initiating researchers and participating citizens

informed consent has been reconsidered, giving more attention to greater transparency between actors, and giving citizens more control over their own data, as well as continuous updates on the reuse of his/her data in specific research projects (Kaye et al. 2015; Woolley et al. 2016). In this sense, in research ethics 2.0, a citizen is an active subject who interacts with a researcher (who is the keeper of the citizen's data) (see, e.g. Fig. 20.1).

Given the effects of different types of ethical stances on research, it is important to describe what consent is and what types of consent have been used so far. In general, consent is characterised as FPIC. FPIC is a process that allows for a deeper understanding of the power relationships at play in particular contexts and for frequent discussions with all those involved in a project, to understand the local context and to subsequently address the potential issues that might arise. FPIC focuses on harmonising and equalising relationships between groups of different power and means (Lewis 2012). To achieve this, the following facets should be carefully taken into consideration: transparency, access to expertise, data access and control, the right to withdraw, relevance, beneficence, responsibility, flexibility, and inclusivity (see more in Grant et al. 2019).

Whilst we focus on the benefits of dynamic informed consent in more detail in the next section of the chapter, it is useful to briefly introduce five types of informed consent here, by stating their core characteristics: broad, blanket, open, portable legal, and meta. It is also crucial to iterate that this typology is not exhaustive; in the scientific literature, other types of consent are also described (see more in, e.g. Hofmann 2009).

Broad consent is used for a single research project; in other words, it is not designed to be repurposed or reused in a different way in another research project (Cheung 2018). Usually a research participant is passive when broad consent is used in research, meaning that the assurance of the participant being properly 'informed' is questionable (Cheung 2018). Broad consent also fails to explicitly detail the use (and potential reuse) of collected data (Steinsbekk et al. 2013); it is, therefore, hard to apply this type of consent for data of multiple use (Budin-Ljøsne et al. 2017). Also, broad consent lacks flexibility when legal regulations are revised (e.g. EU GDPR 2016) and cause unanticipated concerns (Budin-Ljøsne et al. 2017).

Blanket consent has an indefinite range of options and mostly respects the autonomy of a research participant (Hansson et al. 2006). However, it is 'impractical to renew [blanket] consent' (Hofmann 2009, p. 126) as it contains future unspecified data use (Ploug and Holm 2015).

Open consent requires an entire disclosure of privacy from research participants who, in doing so, should 'demonstrate comprehension of the nature of the research and the risks involved prior to enrolment' (Ball et al. 2014 as cited in Cheung 2018, p. 26). It excludes recontact and withdrawal and has other limitations (Caulfield et al. 2003). This type of consent seems the least realistic to use in some fields of science, such as the biomedical sciences.

Portable legal consent refers to the right of a research participant to decide what kind of data (e.g. genetic sequences, medical records, patient reported outcomes) to

donate to and share for research purposes (Cheung 2018). This type of consent is detached from any specific scientific research.

Meta consent allows a research participant to choose which type of consent they are willing to give for which type of data, as well as how, and when, they wish to give consent (Budin-Ljøsne et al. 2017; Cheung 2018). Such specifications can also be applied across diverse stakeholders (e.g. doctors, industries, researchers) (Ploug and Holm 2015). This type of consent facilitates the articulation of types of informed consent and data, as well as context-driven communication.

Dynamic Informed Consent

In health research (viz., in *biobanking*, or the collection of health and biological data), the processes needed to reach informed consent are now called dynamic informed consent (Kaye et al. 2015). The need to revise regular-informed consent comes from demands to update and customise preferences of consent and to have more actively engaged citizens in biobanking, as well as to provoke ‘system-wide behaviour change’ (Teare et al. 2015, p. 9). This is achieved through dynamic informed consent, all parties – citizen scientists and researchers – acknowledge interdependence and social identity, or what can be understood as their belongingness to society (Christensen 2012; Johnsson and Eriksson 2016). After only a short space of time, dynamic informed consent has become a determinant of social innovation in citizen science and research ethics that requires these changes in the behaviour of the community of researchers, as well as of citizens.

Wee et al. (2013) distil the key elements of informed consent to the following: (1) communication between a researcher and a research participant, (2) adequately informing a research participant, and (3) a deliberate choice by a research participant to decide on their level of involvement in research. All these elements are also inherent in dynamic informed consent. However, whilst all these elements are reached at the initial stage of research using broad consent, with dynamic informed consent, additional elements occur – such as continuity in relationship maintenance and high levels of interaction through multiple contacts and ongoing communication (Wee et al. 2013). Therefore, we suggest adopting dynamic informed consent not only in health research but also in citizen science in general, to reflect the real-world iterative research process. This is to say that dynamic informed consent requires live iteration, by returning to participants to obtain consent throughout the research process as it develops, or as more information becomes available, or as needs emerge. As a result, such consent requires citizens to be more engaged in the process.

In general terms, informed consent is one of the key elements to ensure ethical research practice, as well as being ‘part of a framework of research governance’ (Steinsbekk et al. 2013, p. 899). To obtain informed consent from a citizen before the start of research is a fundamental ethical research principle, as stated in the *Declaration of Helsinki* (World Medical Association 1964). However, this social contract evolved when citizen science became immersed in other disciplines. In addition to

this, *General Data Protection Regulation* (EU GDPR 2016, Art. 17), which refers to the right to erasure ('right to be forgotten'), means that data can no longer be stored without a clear purpose for an unlimited period of time. It seems that regular-informed consent is no longer sufficient to deal with such issues, whereas dynamic informed consent might be a sensible solution in the twenty-first century.

Though dynamic informed consent has been foremost in the debates in the biomedical sciences, the discussion of its potential in the context of citizen science is best encapsulated in the framing of the Ensuring Consent and Revocation (EnCoRe) project. The EnCoRe project sets out to give individuals more control over their personal information, by improving the ease, reliability, and rigour with which individuals can grant and, more importantly, revoke their consent to the use, storage, and sharing of their personal information by others. In this way, dynamic informed consent may reconcile a few types of consent at once (Budin-Ljøsne et al. 2017; Kaye et al. 2015). More specifically, dynamic informed consent refers to the deliberative decision-making process about citizen-generated data using a web-based platform that allows citizens (research participants) to interact with the keeper of their data. The essential points here are that this entails the proper informing (provision of detailed and specified information) and a personalised interaction, which reduces the risk of instrumentalisation. These are achieved through the sustained recontacting of citizens in order to provide them with the latest relevant information about a project and, in turn, to receive their consent/dissent. As such, a bidirectional interaction between participants and researchers allows for the *autonomy* of citizens to be encapsulated, that is, citizens can decide in which research, and to what extent, their data can be reused or not (Steinsbekk et al. 2013). Furthermore, citizens can have more control over the use of their data (Wee et al. 2013); in this way, keepers of citizen-generated/shared data testify their respect for those who have generated the data. This control can be expressed using a variety of types of informed consent, so as to fulfil citizens' preferences. Also, citizens receive more detailed and specific information about the research; therefore, *integrity* is better maintained (Johnsson and Eriksson 2016), and payment becomes less of an issue.

The core benefit of dynamic informed consent for researchers relates to its sustainability – including less costly recruitment of participants, enhanced communication with participants, and reduced paperwork, which is ultimately less time-consuming (Kaye et al. 2015; Stoeklé et al. 2017). Budin-Ljøsne et al. (2017) clarify these benefits in more detail: being around electronically stored records and their updates (reliable track record), instant confirmation of the consent status, as well as the potential for an audit and review of standard operating procedures. Among the benefits of dynamic informed consent for research participants are the potential to be re-contracted when they are in a potentially less stressful frame of mind (e.g. after surgery) and their increased scientific literacy due to being better informed about the issues at stake (Kaye et al. 2015; Teare et al. 2015).

Challenges for Practical Ethical Citizen Science

Dynamic informed consent will clearly require a great shift in both the culture of research ethics and the culture of academia itself. These will result in the updating of research ethics policies, as well as the refining of existing standard operating procedures and their operationalisation (e.g. IT solutions, customised training, etc.). However, this shift will also bring with it additional challenges. The first challenge is around how to strike a balance between the risk of a greater burden on research participants and their willingness to be cognisant about the use of their data. In developing dynamic informed consent, contact with research participants becomes easier. However, there is also a risk of consultation fatigue amongst research participants as a result of multiple and frequent contact from researchers, which might result in lower levels of successful recruitment to a project. Another issue related to the frequent contact of participants using dynamic informed consent is that the ties with the citizen, as the owner of personal data and other data held by them, should be established over a longer period. The need for such ties might conflict with standard purposes of safeguarding data, as described by the European personal data regulation (according to the EU GDPR). To fulfil this need will require the redefinition of the purposes of safeguarding data for a longer period if dynamic informed consent is used (Cheung 2018). Meanwhile, the need to have control over their own data might motivate citizens to become more engaged in research, but, conversely, demotivate them from continued participation.

The second challenge relates to the reuse of citizens' open data. Open data is often promoted at the European level, not only to give wider society access to data but also for research integrity. However, it remains unclear whether open data should be reused without (dynamic) informed consent. It goes without saying that there is a clear tension between the ideals of openness and accessibility that citizen science promotes and participants' interests related to data protection (Suman and Pierce 2018). This is something that will continue to be negotiated and worked out as the field develops further.

The third challenge relates to democratic maturity. It is assumed that societies with deliberative democracy can entrust research ethics in citizen science to citizens. However, there is a complex maze of issues that might become manifest, particularly when considering the uneven distribution of citizens in deliberations (Parvin 2018), and citizens' unevenly distributed knowledge about science. Furthermore, such complexities continue when considering participants' skills in making informed decisions, as well as the role of research ethics committees/IRBs in such contexts. It is still difficult to define how responsibilities in ensuring research ethics will be managed, perhaps by evenly sharing such responsibilities amongst all parties, or by reducing one party's role (Kaye et al. 2015; Steinsbekk et al. 2013; Wee et al. 2013), or indeed by altering the focus of research ethics committees/IRBs from the type of consent to the functionalities of tools (e.g. apps) (Budin-Ljøsne et al. 2017).

The Future

To foster the ethical engagement of citizens in science as well as to ethically accomplish citizen science, we conclude with a set of practical and specific recommendations about how to tackle some of the ethical issues related to dynamic informed consent. These serve as practice guidelines about how to deal with ensuring that participants are both informed and consenting. Hence, the recommendations will help to understand how to create a culture of research integrity and thereby improve the ‘dynamic’ aspects of dynamic informed consent in citizen science (Fig. 20.2).

We recommend using and exploring dynamic informed consent further whilst acknowledging that it is not a new phenomenon. However, we perceive its renaissance, particularly due to the EU GDPR applied in all EU countries, and as the best solution in the current context to avoid the stigmatisation of citizen science, and science in a general sense. To achieve this, an overall *increase in ethical literacy* is needed, by encouraging public reflections on ethical concerns in citizen science (Rasmussen 2019). This could be done by discussing with citizens what knowledge and information dissemination, as well as acknowledgments, they prefer (Kaye et al. 2015; Resnik 2019; Teare et al. 2015; Wiggins and Wilbanks 2019). Such interactions allow for an increase in the responsibility and accountability of a researcher, as well as avoiding any potential conflicts of interest (so upholding transparency of research) and questionable research practices from the outset.

The *efficiency of communication* in citizen science can be improved by providing hyperlinks to various alternative forms of presenting project and ethical information. This is particularly useful for vulnerable groups of potential participants, such as children, and others (Kaye et al. 2015), and has the potential to assist with increasing the transparency of research.

Furthermore, *issues of data protection* in citizen science need to be addressed from a praxis standpoint. For example, identity protection must be upheld at all times with particular consideration given to the potential for re-identification of participants in the research process (Cheung 2018). Written permission to use photos where citizen scientists can be identified (e.g. from discussions, meetings) in a research report/scientific paper must be obtained (Resnik 2019). User privacy should be taken seriously, and the necessary tools of the EU GDPR should be provided,

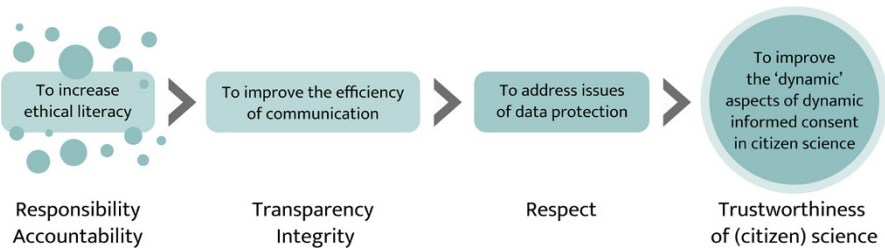


Fig. 20.2 The core ‘dynamic’ aspects of dynamic informed consent in citizen science

such as consent boxes and account deletion options – these will all help to properly respect privacy.

Such factors help promote the veracity and truthfulness of (citizen) science through responsibility, accountability, transparency, respect, and integrity, not only when drafting dynamic informed consent but also through the entire citizen science research process.

Further Reading

- International Institute for Environment and Development. (2012). Biodiversity and culture: Exploring community protocols, rights and consent [Special issue]. *Participatory Learning and Action*, 65.
- Rasmussen, L.M., & Cooper, C. (Eds.) (2019b). Ethical issues in citizen science [special collection]. *Citizen Science: Theory and Practice*, 4(1).
- Resnik, D. B., Elliott, K. C., & Miller, A. K. (2015). A framework for addressing ethical issues in citizen science. *Environmental Science & Policy*, 54, 475–481.
- Vayena, E., & Tasioulas, J. (2015). We the scientists?: A human right to citizen science. *Philosophy & Technology*, 28, 479–485.

References

- Ball, M., Bobe, J., Chou, M., Clegg, T., Estep, P., Lunshof, J., et al. (2014). Harvard personal genome project: Lessons from participatory public research. *Genome Medicine*, 6(2), 10. <https://doi.org/10.1186/gm527>.
- Brall, C., Maeckelbergh, E., Porz, R., Makhoul, J., & Schröder-Bäck, P. (2017). Research ethics 2.0: New perspectives on norms, values, and integrity in genomic research in times of even scarcer resources. *Public Health Genomics*, 20, 27–35. <https://doi.org/10.1159/000462960>.
- Brown, W. (2015). *Undoing the demos: Neoliberalism's stealth revolution*. Cambridge, MA: MIT Press.
- Budin-Ljønsne, I., Teare, H. J., Kaye, J., Beck, S., Bentzen, H. B., Caenazzo, L., et al. (2017). Dynamic consent: A potential solution to some of the challenges of modern biomedical research. *BMC Medical Ethics*, 18, 4. <https://doi.org/10.1186/s12910-016-0162-9>.
- Burgess, H. K., DeBey, L. B., Froehlich, H. E., Schmidt, N., Theobald, E. J., Ettinger, A. K., et al. (2017). The science of citizen science: Exploring barriers to use as a primary research tool. *Biological Conservation*, 208, 113–120. <https://doi.org/10.1016/j.biocon.2016.05.014>.
- Caulfield, T., Upshur, R., & Daar, A. (2003). DNA databanks and consent: A suggested policy option involving an authorization model. *BMC Medical Ethics*, 4, E1. <https://doi.org/10.1186/1472-6939-4-1>.
- Cheung, A. S. (2018). Moving beyond consent for citizen science in big data health and medical research. *Northwestern Journal of Technology and Intellectual Property*, 16(1), 15–40.
- Christensen, E. (2012). The re-emergence of the liberal-communitarian debate in bioethics: Exercising self-determination and participation in biomedical research. *Journal of Medicine and Philosophy*, 37(3), 255–276. <https://doi.org/10.1093/jmp/jhs012>.
- Cozzarelli, N. R. (2004). Responsible authorship of papers in PNAS. *Proceedings of the National Academy of Sciences*, 101(29), 10495. <https://doi.org/10.1073/pnas.0404563101>.

- Davydov, D., Grünewald, C., Morscheiser, J., Tutlies, P., Vollmer-König, M., & Zeiler, M. (2017). *Sondengänger und archäologie*. LWL/LVR: Die rechtslage in NRW. http://www.roemisch-germanisches-museum.de/download/Sondengaenger_u_Arch.pdf.
- Dickert, N., & Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health*, 95(7), 1123–1127. <https://dx.doi.org/10.2105%2FAJPH.2004.058933>.
- Dickinson, J. L., Shirk, J., Bonter, D., Bonney, R., Crain, R. L., Martin, J., et al. (2012). The current state of citizen science as a tool for ecological research and public engagement. *Frontiers in Ecology and the Environment*, 10(6), 291–297. <https://doi.org/10.1890/110236>.
- ECSA. (2015). *Ten principles of citizen science*. https://ecsa.citizen-science.net/sites/default/files/ecsa_ten_principles_of_citizen_science.pdf
- Eleta, I., Clavell, G. G., Righi, V., & Balestrini, M. (2019). The promise of participation and decision-making power in citizen science. *Citizen Science: Theory and Practice*, 4(1), 8. <https://doi.org/10.5334/cstp.171>.
- EU GDPR. (2016, April 27). Regulation (EU) 2016/679 of the European Parliament and of the Council on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation). <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679>
- Fiske, A., del Savio, L., Prainsack, B., & Buyx, A. (2018). Conceptual and ethical considerations for citizen science in biomedicine. In N. B. Heyen, S. Dickel, & A. Brüninghaus (Eds.), *Personal health science* (pp. 195–217). Wiesbaden: Springer. https://doi.org/10.1007/978-3-658-16428-7_10.
- Gadermaier, G., Dörler, D., Heigl, F., Mayr, S., Rüdiger, J., Brodschneider, R., & Marizzi, C. (2018). Peer-reviewed publishing of results from citizen science projects. *Journal of Science Communication*, 17(3), L01. <https://doi.org/10.22323/2.17030101>.
- Grant, A. D., Wolf, G. I., & Nebeker, C. (2019). Approaches to governance of participant-led research: A qualitative case study. *BMJ Open*, 9, e025633. <https://doi.org/10.1136/bmjopen-2018-025633>.
- Guerrini, C. J., Majumder, M. A., Lewellyn, M. J., & McGuire, A. L. (2018). Citizen science, public policy. *Science*, 361(6398), 134–136. <https://doi.org/10.1126/science.aar8379>.
- Hansson, M., Dillner, J., Bartram, C., Carlson, J., & Helgesson, G. (2006). Should donors be allowed to give broad consent to future biobank research? *The Lancet Oncology*, 7(3), 266–269. [https://doi.org/10.1016/S1470-2045\(06\)70618-0](https://doi.org/10.1016/S1470-2045(06)70618-0).
- Hofmann, B. (2009). Broadening consent – And diluting ethics? *Journal of Medical Ethics*, 35(2), 125–129. <https://doi.org/10.1136/jme.2008.024851>.
- ICMJE. (2019). *Defining the roles of authors and contributors*. <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>
- Johnsson, L., & Eriksson, S. (2016). Autonomy is a right, not a feat: How theoretical misconceptions have muddled the debate on dynamic consent to biobank research. *Bioethics*, 30(7), 471–478. <https://doi.org/10.1111/bioe.12254>.
- Kansa, E. (2014, 27 January). *It's the neoliberalism, stupid: Why instrumentalist arguments for open access, open data, and open science are not enough [Blog]*. LSE Impact Blog. <https://blogs.lse.ac.uk/impactofsocialsciences/2014/01/27/its-the-neoliberalism-stupid-kansa/>
- Kaye, J., Whitley, E. A., Lund, D., Morrison, M., Teare, H., & Melham, K. (2015). Dynamic consent: A patient interface for twenty-first century research networks. *European Journal of Human Genetics*, 23, 141–146. <https://doi.org/10.1038/ejhg.2014.71>.
- Kuehn, E., Feldmann, R., Harpke, A., Hirneisen, N., Musche, M., Leopold, P., & Settele, S. (2008). Getting the public involved in butterfly conservation: Lessons learned from a new monitoring scheme in Germany. *Israel Journal of Ecology & Evolution*, 54(1), 89–103. <https://doi.org/10.1560/IJEE.54.1.89>.
- Kythreotis, A. P., Mantyka-Pringle, C., Mercer, T. G., Whitmarsh, L. E., Corner, A., Paavola, J., et al. (2019). Citizen social science for more integrative and effective climate action: A science-policy perspective. *Frontiers in Environmental Science*, 7, 10. <https://doi.org/10.3389/fenvs.2019.00010>.

- Lave, R. (2017). Neoliberalism and the production of environmental knowledge. *Environment and Society*, 8, 19–38. <https://doi.org/10.3167/ares.2012.030103>.
- Lewis, J. (2012). How to implement free, prior informed consent (FPIC). *Participatory Learning and Action*, 65, 175–178.
- Liboiron, M., Zahara, A., & Schoot, I. (2018). Community peer review: A method to bring consent and self-determination into the sciences. *Preprint*, 2018060104. <https://doi.org/10.20944/preprints201806.0104.v1>.
- Lupton, D. (2014). The commodification of patient opinion: The digital patient experience economy in the age of big data. *Sociology of Health & Illness*, 36(6), 856–869. <https://doi.org/10.1111/1467-9566.12109>.
- Oberle, K. M., Page, S. A., Stanley, F. K. T., & Goodarzi, A. A. (2019). A reflection on research ethics in citizen science. *Research Ethics*, 15(3–4). <https://doi.org/10.1177/1747016119868900>.
- Parvin, P. (2018). Democracy without participation: A new politics for a disengaged era. *Res Publica*, 24, 31–52. <https://doi.org/10.1007/s11158-017-9382-1>.
- Piwowar, H. A., & Vision, T. J. (2013). Data reuse and the open data citation advantage. *PeerJ*, 1, e175. <https://doi.org/10.7717/peerj.175>.
- Ploug, T., & Holm, S. (2015). Going beyond the false dichotomy of broad or specific consent: A meta-perspective on participant choice in research using human tissue. *American Journal of Bioethics*, 15(9), 44–46. <https://doi.org/10.1080/15265161.2015.1062178>.
- Prior, M., Teare, H. J. A., & Kaye, J. (2018). Equitable participation in biobanks: The risks and benefits of a ‘dynamic consent’ approach. *Frontiers in Public Health*, 6, 253. <https://doi.org/10.3389/fpubh.2018.00253>.
- Rasmussen, L. M. (2019). Confronting research misconduct in citizen science. *Citizen Science: Theory and Practice*, 4(1), 10. <https://doi.org/10.5334/cstp.207>.
- Rasmussen, L. M., & Cooper, C. (2019a). Citizen science ethics. *Citizen Science: Theory and Practice*, 4(1), 5. <https://doi.org/10.5334/cstp.235>.
- Resnik, D. B. (2019). Citizen scientists as human subjects: Ethical issues. *Citizen Science: Theory and Practice*, 4(1), 11. <https://doi.org/10.5334/cstp.150>.
- Resnik, D. B., Elliott, K. C., & Miller, A. K. (2015a). A framework for addressing ethical issues in citizen science. *Environmental Science & Policy*, 54, 475–481. <https://doi.org/10.1016/j.envsci.2015.05.008>.
- Resnik, D. B., Miller, A., Kwok, R., Engle, L., & Sandler, D. (2015b). Ethical issues in environmental health research related to public health emergencies: Reflections in the GuLF study. *Environmental Health Perspectives*, 123(9), A227–A231. <https://doi.org/10.1289/ehp.1509889>.
- Richter, A., Hauck, J., Feldmann, R., Kühn, E., Harpke, A., Hirneisen, N., et al. (2018). The social fabric of citizen science – Drivers for long-term engagement in the German butterfly monitoring scheme. *Journal of Insect Conservation*, 22, 731–743. <https://doi.org/10.1007/s10841-018-0097-1>.
- Riesch, H., & Potter, C. (2014). Citizen science as seen by scientists: Methodological, epistemological and ethical dimensions. *Public Understanding of Science*, 23(1), 107–120. <https://doi.org/10.1177/0963662513497324>.
- Rothstein, M. A., Wilbanks, J. T., & Brothers, K. B. (2015). Citizen science on your smartphone: An ELSI research agenda. *Journal of Law, Medicine and Ethics*, 43(4), 897–903.
- Rotman, D., Preece, J., Hammock, J., Procita, K., Hansen, D., Parr, C., et al. (2012). Dynamic changes in motivation in collaborative citizen-science projects. In *Proceedings of the ACM 2012 conference on computer supported cooperative work, Seattle, Washington, USA, February 11–15* (pp. 217–226). New York: ACM. <https://doi.org/10.1145/2145204.2145238>.
- Roy, S., & Edwards, M. (2019). Citizen science during the Flint, Michigan federal water emergency: Ethical dilemmas and lessons learned. *Citizen Science: Theory and Practice*, 4(1), 12. <https://doi.org/10.5334/cstp.154>.
- Steinsbekk, K. S., Myskja, B. K., & Solberg, B. (2013). Broad consent versus dynamic consent in biobank research: Is passive participation an ethical problem? *European Journal of Human Genetics*, 21, 897–902. <https://doi.org/10.1038/ejhg.2012.282>.

- Stoeklé, H.-C., Deleuze, J.-F., Vogt, G., & Hervé, C. (2017). Vers un consentement éclairé dynamique. *Médecine/Sciences*, 33(2), 188–192. <https://doi.org/10.1051/medsci/20173302015>.
- Suman, A. B., & Pierce, R. (2018). Challenges for citizen science and the EU Open Science agenda under the GDPR. *European Data Protection Law Review*, 4(3), 284–295. <https://doi.org/10.21552/edpl/2018/3/7>.
- Tauginienė, L. (2019). Ethical concerns in citizen science projects and public engagement related research projects. *Ethical Perspectives*, 26(1), 119–134. <https://doi.org/10.2143/EP.26.1.3286291>.
- Teare, H. J., Morrison, M., Whitley, E. A., & Kaye, J. (2015). Towards ‘engagement 2.0’: Insights from a study of dynamic consent with biobank participants. *Digital Health*, 1, 1–13. <https://doi.org/10.1177/2055207615605644>.
- Theobald, E. J., Ettinger, A. K., Burgess, H. K., DeBey, L. B., Schmidt, N. R., Froehlich, H. E., et al. (2015). Global change and local solutions: Tapping the unrealized potential of citizen science for biodiversity research. *Biological Conservation*, 181, 236–244. <https://doi.org/10.1016/j.biocon.2014.10.021>.
- Vohland, K., & Göbel, C. (2017). Open Science und Citizen Science als symbiotische Beziehung? Eine Gegenüberstellung von Konzepten TATuP. *Zeitschrift für Technikfolgenabschätzung in Theorie und Praxis*, 26(1–2), 18–24. <https://doi.org/10.14512/tatup.26.1-2.18>.
- Vohland, K., Weißpflug, M., & Pettibone, L. (2019). Citizen science and the neoliberal transformation of science – An ambivalent relationship. *Citizen Science: Theory and Practice*, 4(1), 25. <https://doi.org/10.5334/cstp.186>.
- Wee, R., Henaghan, M., & Winship, I. (2013). Dynamic consent in the digital age of biology: Online initiatives and regulatory considerations. *Journal of Primary Health Care*, 5(4), 341–347.
- Wiggins, A., & Wilbanks, J. (2019). The rise of citizen science in health and biomedical research. *American Journal of Bioethics*, 19(8), 3–14. <https://doi.org/10.1080/15265161.2019.1619859>.
- Woolley, J. P., McGowan, M. L., Teare, H. J. A., Coathup, V., Fishman, J. R., Settersten, R. A., Jr., et al. (2016). Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. *BMC Medical Ethics*, 17(33), 1–17. <https://doi.org/10.1186/s12910-016-0117-1>.
- World Medical Association. (1964). *Declaration of Helsinki – Ethical principles for medical research involving human subjects*. <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
- Ziegler, D., Knapp, V., Weißkopf, M., Rahemipour, P., & Vohland, K. (2018). *Forum Citizen Science 2017*. https://www.buergerschaffenwissen.de/sites/default/files/grid/2019/03/18/180821_forum%20citizen%20science%202017_dokumentation_final.pdf

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