Ethics guidelines in Citizen Science

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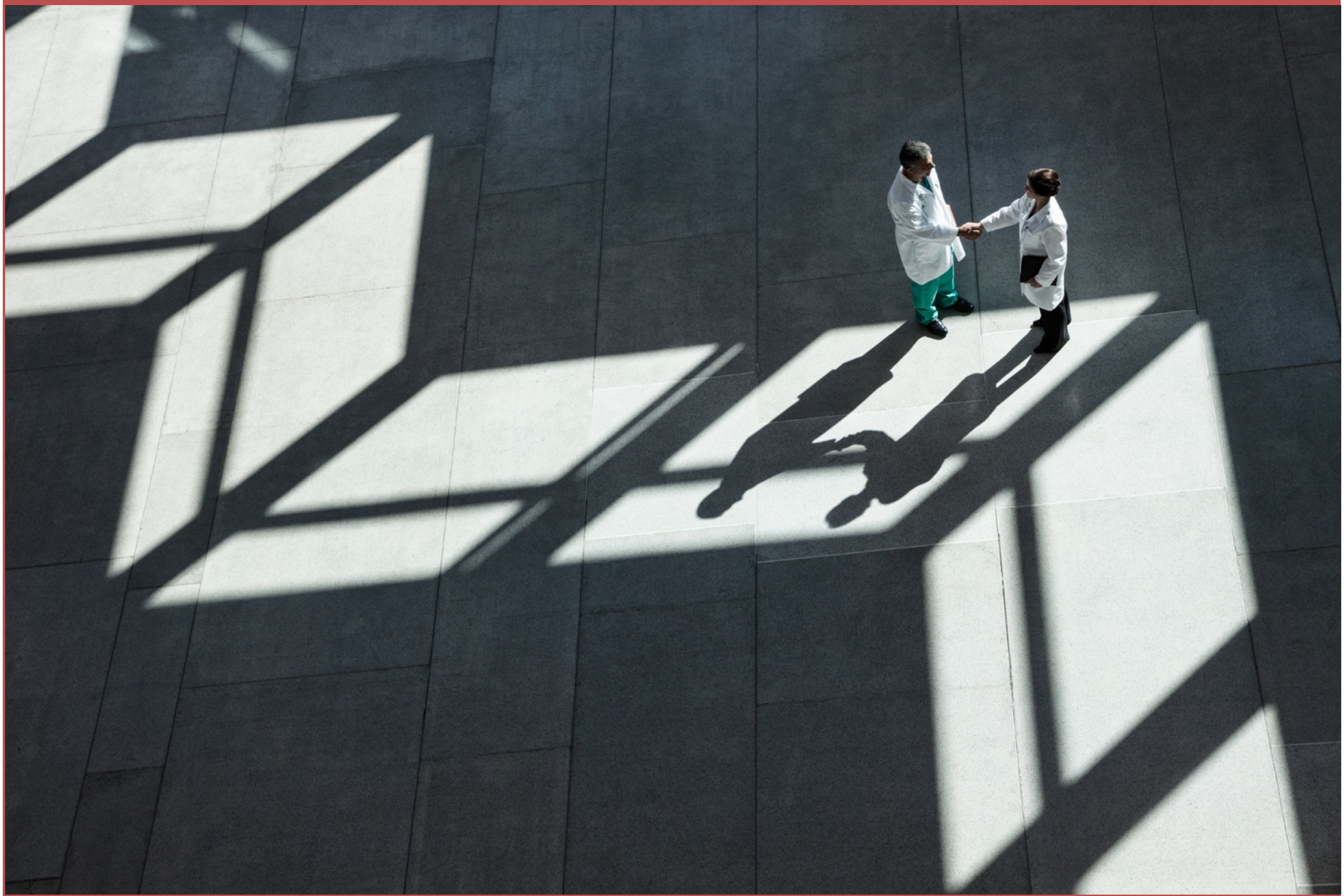

EXECUTIVE SUMMARY

The aim of this report is to support the Competence Center Citizen Science Zurich (CCCS). Starting out from the point of research oversight in the Swiss context, it gives an overview of existing ethics guidelines in citizen science as promoted by the Citizen Science Association (CSA), the European Citizen Science Association (ECSA) and similar organizations. It highlights the relative lack of attention to ethical governance and processes in current citizen science guidelines and recommends to set up an intra-institutional process to deal with ambiguities in the future.

Citizen Science

citizen science *n.* scientific work undertaken by members of the general public, often in collaboration with or under the direction of professional scientists and scientific institutions.

- Oxford English Dictionary

Human research

Various factors influence which category a human research project is assigned to. The category determines which authorisation procedure a project must undergo and which official conditions must be fulfilled.

- Federal Office of Public Health

CS volunteers and non-human subject projects

Because [these] projects are highly varied in design and activities, and raise different ethical and related issues from projects with research participants (human subjects), we do not recommend a one-size-fits-all approach of institutional oversight. Dialogue on this matter is urgently needed.

- Cooper, Shanley, Scassa & Vayena (2019)

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1 - INTRODUCTION

This report starts out at the current situation of research oversight in Switzerland and highlights the challenges for citizen science. It then gives an overview of existing ethics guidelines in citizen science as promoted by the Citizen Science Association (CSA), the European Citizen Science Association (ECSA) and similar platforms. It highlights the relative lack of attention to ethical governance and processes and provides recommendations to the Competence Center Citizen Science Zurich (CCCS) regarding ethical oversight.

Civil Society and academic research have always been intrinsically entangled, but the terms and circumstances of their engagement has been greatly transformed by digitalization. New technologies and phenomena such as the widespread use of the Internet and connected devices have greatly facilitated the opportunities of an ongoing direct engagement between citizens and scholars. However, new op-opportunities come with new challenges. Specifically, the reconfiguration of modes of engagement influences the stakes for all parties involved in the research process, yet existing ethics frameworks for research are outpaced by such reconfigurations. It is therefore necessary to identify and address ethical issues that arise from the new forms of engagement summarized as Citizen Science.

For the purpose of our report we conducted a discovery and review of existing policy documents about ethical principles and ethics guidelines in and for citizen science stemming from citizen science associations or related communities. We embedded our analysis in the legal context of research oversight in Switzerland as well as in existing scholarly literature on research ethics and ethical issues in citizen science.

2 - RESEARCH OVERSIGHT IN SWITZERLAND

In order to determine formal oversight guidance of research projects in the Swiss context, there are two main distinctions being made. The first is whether a research project involves human research or not. The second is whether a human research project requires authorisation or not.

Historically, evaluative processes and institutions for review and oversight of human subject researcher were established throughout the Western world in the second half of the 20th century. The aim of such external or institutional review boards (IRBs) was to protect research participants from potentially unethical researcher behaviour by preventing unethical research and providing guidance on ethical research. Today still, medical research is subjected to specific laws and oversight processes which, despite certain national variances, generally serve the same purpose: to ensure that research is not exploitative by happening in a context where participants are able to act autonomously and are provided with sufficient and accurate information to make an informed choice about their potential participation.

In Switzerland, there are two pieces of Federal legislation which may be relevant to the conduct of citizen science research involving humans. These pieces of legislation are the *Human Research Act 2011* (HRA) and the *Federal Act on Data Processing 1992* (FDAP). These instruments are supported by the *Human Research Ordinance* 2013 (HRO) and the Ordinance to the Federal Act on Data Processing (OFADP). Outside of this legislation, there are cantonal data protection acts that may apply to data processing conducted by cantonal instruments universities. However, many replicate the operate of the federal legislation, and are therefore outside the scope of this report.

Of the four Federal instruments described above, the HRA and HRO have a significantly narrower focus and only apply to persons (living or deceased), biological data or health related personal data (Art. 2 Para. 1, HRA). The HRA and HRO do not apply to research that involves the use of anonymised biological material or anonymously collected health related data (Art. 2 Para 2, HRA). In the HRA, anonymised genetic data is described as data that cannot be used to reidentify a person without disproportionate further effort (Art. 3 Lit. i, HRA). In particular, anonymisation requires deleting identifiers such as name, address, date of birth and any unique identifiers (Art. 25 Para. 2, HRO). However, the HRA and HRO still apply to research involving the use of coded data, which is synonymous with pseudonymised data (Art. 3 Lit. h, HRA). To meet the standards of coding, the code linked to the data must be stored in a secure location so that for a person without the code, the data would appear anonymised (Art. 26 Para. 1, HRO).

Therefore, the HRA and HRO apply to citizen science studies involving the use of identifying or coded health-related personal data. For example, a study in which patients are requested to collect and submit fitness data from wearables would be considered human research under the HRA and HRO. If the data were coded, the research team would need to take steps to ensure identifying details (such as names, addresses, date of birth and other unique identifiers) were removed. To meet the standards of coding under the HRA and HRO, these identifiers must be removed or replaced with codes, which are then stored on a safe server. Further, the research team would also need to consider the requirement to obtain for consent from participants to use their data for research. The HRA and HRO require researchers to inform participants about the nature of the research, expected risks and benefits, data protection measures and participant rights (Art. 16 Para. 2, HRA). In addition, both acts create a differing standard of consent required for the further processing of health-related data without consent depending on the type of data. For identifiable health-related data, informed consent for the further data must be sought at the time when data is collected (Art. 33 Para. 1, HRA). However, for coded health-related data, there must only be no dissent to the further use of data (Art. 33 Para. 2, HRA). Therefore, ensuring that coded data is used instead of identifiable data might increase the flexibility of data collected from citizen science projects.

Furthermore, even if a citizen science project does not use health-related personal data, researchers should consider the impact of the FADP. In addition to defining personal data as data relating to an identified or identifiable person (Art. 3 Lit. a, FADP), the FADP creates a separate category of sensitive personal data. These sensitive personal data include religious, political or ideological data, social security measures, administrative or criminal proceedings and health related data (Art. 3 Lit. c, FADP). Crucially, these sensitive personal data can only be processed with the express consent of the data subject (Art. 4 Para. 5, FADP). Therefore, in the case of a citizen science project, the research team should take care to ensure that consent has been sought to process these categories of data. Returning to the example above, if sensitive data about a person's lifestyle can be gathered or inferred from their smart devices, the research team should seek consent to collect this data.

Under the FADP, personal data can only be collected from the research subject for purposes stated at the time of collection (Art. 4 Para. 3, FADP). Further, personal data cannot be disclosed without a licit ground for doing so, such as a statutory basis or consent (Art. 19 Para. 1, FADP). To this end, the FADP does create an exception for further use and disclosure of data for scientific research purposes, provided data subjects cannot be reidentified (Art. 22 Para. 1, FADP).

Nevertheless, compliance with legal requirements is not enough to guarantee the ethical nature of a citizen science project. The next section considers the ethical factors that must be considered beyond legal factors.

3 - ETHICAL ISSUES IN CITIZEN SCIENCE

Citizen science is an umbrella term for a varied range of projects and practices which have in common that they actively include citizens[1] in the research process. Although some of these projects and practices raise new challenges, not all modes of engagement present the same degree of ambiguity. As the previous description of the Swiss human research oversight contexts shows, there are processes in place for projects that can clearly be situated in an existing category. The current section therefore focuses on projects that are more ambiguous as to their categorization, and to the ethical issues that arise.

This section draws heavily on the groundwork laid by Cooper et al. (2019) on categories for citizen science projects led by scientists. Their framework provides a useful account of the nuances introduced by citizen science of a novel combination between the two categories "human subject research" and "personally identifiable information" ("PII"). Indeed, these two categories present a challenge for common citizen science projects that are carried out through modern information technology. That is, although their subject matter are not humans, and participants are not subjects but, rather, volunteers, they are often collecting traceable personal data.

Cooper et al. (2019) suggest to distinguish citizen science projects according to three dimensions: whether it is institutional or non-institutional research; what the subject matter is; whether PPI is collected or not and, if yes, how this PPI is handled (cf. FIGURE 1 below). Although their categorization relies on the current legal situation in the US, its ramifications can

[1] We are aware of the semantic baggage such terms bring with them. We have settled on the labels that are widely in use in the citizen science community but recognize the need for a thorough engagement with appellations in and the implications of their use (cf. Eitzel et al., 2017).

readily be transferred to the Swiss context as long as the underlying legal definitions for "human subject matter" and "PII" are translated accordingly. (For the specifications regarding these matters cf. previous chapter.)

FIGURE 1: Figure 1 from Cooper et al. (2019) entitled "Categories of citizen science projects"

	Institutional Research				Non-Institutional Research
Subject Matter	Humans	Humans	Not Humans	Not Humans	All subjects
PII	Private	Open	No	Yes	Yes/No
Type	1	2	3	4	5

For project types 1-3 and 5, the question of ethical oversight is either already addressed in the existing legal framework or outside of the scope of this report. Projects falling into type 1 include apps and online surveys that aim at supporting individuals in learning about themselves. Type 2 projects are similar in many regards but include (self-) disclosure of the collected data or samples. Translated to the Swiss context, and according to Swiss regulation, both these project types clearly fall under human research with non-anonymized data and are therefore subject to formal authorisation as stipulated by the Federal Office of Public Health (cf. previous chapter). In contrast, type 3 and type 5 projects are typically not governed by the Federal Act on Research involving Human Beings, as type 3 is not concerned with human subject matter at all and does not collect PII, and type 5 is non-institutional research (which raises other ethical issues but none of which are of immediate concern for the CCCS).

The most salient category of projects is type 4, which includes projects that are not interested in researching human subject matters but nonetheless are -- or may be -- collecting PII. In the Swiss legal context, it is important to point out that two types of data and data uses are to be considered. On the one hand, the Federal Act on Research involving Human Beings centers, for its definitions, on the category of "health-related" data, offering special protection to “genetic data”. On the other hand, current legislations differentiate between anonymized and non-anonymized data use (cf. previous chapter).

Cooper et al. (2019) notice that the current situation regarding type 4 projects is ambiguous, because some type 4 projects have been reviewed by institutional review boards (IRBs) whereas others have not. They demonstrate that projects of type 4 "often fall through the regulatory cracks due to a gray area of interpretation" and attribute this gray are to the lack specific guidelines for institutional oversight regarding citizen science projects. Even a consistent application of current oversight for human subject research would not fill that gap, because citizen science project present different risks and different ethical issues than traditional human subject research (Cooper et al. 2019).

Citizen science project of type 4 present ethical issues that can be construed around the five foundational ethical principles of respecting autonomy, non-maleficence, beneficence, justice, and fidelity (Beauchamp et al., 2001, in Cooper et al. 2019). They are, however, reconfigured in light of the nuanced new relation between professional scientists and volunteers. Examples mentioned in Cooper et al. (2019) include provision of training and acknowledgement of volunteer contributions as beneficence, and protection of data privacy as non-maleficence.

Advising against a one-size-fits-all approach of institutional oversight, the authors also point to the existence of novel ethical issues, for instance the sharing intellectual property rights as an issue of justice and autonomy that needs to be adequately balanced with the management of confidentiality and privacy risks. Beyond this one example, they argue that the "popularity, interdisciplinarity, and novelty involved in Type 4 projects calls for broad discussion among stakeholders" about benefits and risks, which should include options for institutional oversight.

Because ethical oversight of citizen science projects must consider very different contexts and stakes from existing ethical oversight processes that are informed by traditional human research. For this report, we have therefore analyzed existing citizen science guidelines with regard to the ethical issues they identify or address, and the oversight processes they mention.

4 - ANALYSIS OF CS GUIDELINES

The current report has analyzed existing citizen science guidelines regarding their guidance on ethical issues. As acknowledged in the introduction, the field of citizen science is broad and encompasses a broad range of actors and projects. We have therefore chosen to focus our analysis on documents and guidelines about ethical issued that were published or recommended by selected associations and organizations most relevant for the Competence Center Citizen Science in Zurich. These guidelines include those published by the Citizen Science Association CSA, the European Citizen Science Association ECSA, both the German and the Austrian Citizen Science platform[2], and the DIYbio community. Our analysis includes the statements and recommendations on ethics by these organizations as well as the documents and guidelines recommended on their website in dedicated "ethics" sections. A full list of the relevant documents is attached in Appendix 2. Below, each organization is presented briefly with regard to how they present, or refer to, ethics in citizen science.

- ### CITIZEN SCIENCE ASSOCIATION (CSA)[3]

CSA is US-based but acting globally. In their own words: "The Citizen Science Association (CSA) is a member-driven organization that connects people from a wide range of experiences around one shared purpose: advancing knowledge through research and monitoring done by, for, and with members of the public."

In 2016, it launched a new Citizen Science Journal *Citizen Science: Theory and Practice*, which features a special collection about ethical issues (2019). Furthermore, it has Ethics Working

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[2] The Swiss organizations Science & Cité and Schweiz Forscht have not been included because they do not provide any guidance on ethical issues on their websites.
[3] https://citizensciene.org/

Group (EWG), one out of currently nine CSA working groups. The objectives of the EWG, as stated on the website, are the following:

1. Chart the landscape of ethical issues across the spectrum of citizen science.
2. Increase the capacity of CSA to provide resources and training in ethics to practitioners and participants.
3. Develop mechanisms for CSA to support research ethics review.
4. Raise awareness among the greater research community about unique ethical challenges of citizen science and the need for training in ethics.

The charting referred to in point one is achieved through a collection of resources. Indeed, the CSA Ethics Working Group does not feature their own ethics guidelines or principles but highlights (and links to) other resources. They are charted into the following categories: Codes of Ethics, Reusable Consent Forms, CSA Ethics webinars, Other training, Guides, Related websites and Related blogs.

Having examined all linked content, only the Codes of Ethics were included in this report due to its scope. Hence, our analysis included the Belleville Committee Ethical Principles, the CCPH Guiding Principles of Partnership, and the Beyond Sabor Code of Ethics.

- ## EUROPEAN CITIZEN SCIENCE ASSOCIATION (ECSA)[4]

In their own words: "The European Citizen Science Association (ECSA) is a non-profit association set up to encourage the growth of the Citizen Science movement in Europe in order to enhance the participation of the general public in scientific processes, mainly by initiating and supporting citizen science projects as well as performing research on citizen science."

[4] https://citizen-sciene.net/

Like CSA, ECSA has working groups, though none explicitly devoted to ethics. ECSA has, however, integrated RRI ("Responsible Research and Innovation") into its structure by appointing an RRI liaison/focus point in its organizing body.

The *Documents* section of ECSA's website contains is structured into the following sections: Citizen Science Guidelines and Publications, ECSA Policy Papers, ECSA General Documents, ECSA General Assembly Documentation, Reports from Workshops and Events and DITOs Policy Briefs. It also prominently features ECSA's 10 Principles of Citizen Science in 29 languages, as well as a link to The Australian Citizen Science Association's adaptation of the 10 principles.

In addition to the 10 ECSA principles, the present report also takes into consideration the three ECSA policy papers. However, the documents within the collection of Citizen Science guidelines and publications have not been scoped for the current analysis.

• OTHER SELECTED ORGANIZATIONS AND PLATFORMS

Bürger schaffen Wissen (GEWISS)

The online plattform *Bürger schaffen Wissen*, funded by the German Ministry for Education and Research, is the central platform for citizen science in Germany. Its main purpose, in their own words, "is to give an overview of citizen science projects to illustrate the concept of citizen science and so increasing its visibility within the German public and discourse." Among the many publications and documents available on their website, Bürger schaffen Wissen explicitly refers to a handful of specific resources on their page "Definitionen, Standards und

Qualitätskriterien"[5]: the 10 ECSA principles, the quality criteria of Österreich forscht, and their own Green Paper. We included relevant sections from the GEWISS Guidance document as well as from the GEWISS Green paper in our analysis.

Österreich forscht

In their own words: "The platform Österreich forscht (www.citizen-science.at) was founded in 2014 with the objectives of (1) connecting citizen science actors in Austria, (2) providing the broadest possible overview of citizen science projects in Austria, and (3) scientifically advancing citizen science as a method." Österreicht forscht established a catalogue of quality criteria. They were established during a multi-stage process, building on the knowledge of the working group members, on feedback by external research domain experts and, through a public consultation, also integrating the opinions and attitudes of general public. The final version, which we included in our analysis, was presented, and came into effect, in February 2018.

DIYbio community

In their own words: " DIYbio.org was founded in 2008 with the mission of establishing a vibrant, productive and safe community of DIY biologists. Central to our mission is the belief that biotechnology and greater public understanding about it has the potential to benefit everyone." Draft codes of ethics originating in both North America and Europe are published on their website. Both were included in our analysis.

[5] https://www.buergerschaffenwissen.de/citizen-science/definitionen-standards-qualitaetskriterien

5 - RESULTS & DISCUSSION

Overview

Overall, twelve current citizen science principles, policy statements and guidance documents were analyzed through selective coding in Nvivo (see also Appendix 1). Considering the heterogenous corpus of documents analyzed it is unsurprising to find a wide range of ethical issues mentioned in various ways and depths. We will discuss some of them below.

Although the documents analyzed mention a range of ethical issues, it is what they *lack* to address that may be most noteworthy: overall, the documents crucially lack references to ethical oversight or ethical governance. With one notable exception, which will be highlighted below, our analysis could not identify any call for establishing processes to deal with uncertainties or ambiguities that may arise out of ethical considerations. Further, our analysis did not identify references to oversight in any form, compliance with existing laws notwithstanding. Therefore, the current report puts more emphasis on this point, as more formal guidance currently seems to be missing.

Ethical issues in CS

Overall, it should be noted that a detailed ethical analysis proves challenging because not all of the documents analyzed identify the ethical issues they address explicitly as issues of ethics. Whereas some guidelines point to the need to clarify certain ethical issues, others already make normative statements in their regard without labeling them as such. For example, the German Green Paper for Citizen Science dedicates entire subchapters to normative statements on data quality and data management, on the need to integrate citizen science in existing scientific processes and on strengthening volunteer training. However, the Green Paper lists "ethical framework conditions" in a separate subchapter that does not relate to the previous topics, although there are inherently ethical dimensions to the issues of data quality and data management.

Taken together, the documents not only address issues within the narrow scope of individual citizen science projects, but also focus on the role and place of citizen science within the larger landscape, such as with regard to policy-making or science funding. Amidst the wide range of issues that could be classified as ethical issues, a few recurrent ones will be presented in greater detail below, starting with beneficence.

Several documents contain general statements about shared benefits. For instance, the CCPH Principles state that partners should "share the benefits of the [...] accomplishments." Similarly, the Austrian Quality Criteria ask that "[t]here must be an added value for all participants, both citizen scientists and professional scientists". The ECSA principles, too, request that "[b]oth the professional scientists and the citizen scientists benefit from taking part." Nonetheless, in contrast to the two previous examples, the ECSA principles specify some of the possible benefits. These include "publication of research outputs, learning opportunities, personal enjoyment, social benefits, satisfaction through contributing to scientific evidence [...]." Other specific benefits of Citizen Science are for example stated in the ECSA Policy Paper 2 and include "building an inclusive and sustainable global knowledge societies" and the enhancement of "research integrity trough increasing transparency and participation." The GEWISS Handreichung presents an array of presumed[6] benefits for science, society and stakeholders in an overview table (p. 8).

Risks or potential harms are mentioned less frequently than benefits but and occur in relatively few guidelines overall. A notable stand out is the Belleville document, which presents a long list

[6] The GEWISS Handreichung warns that not every project creates every benefit. Furthermore, the document acknowledges that there is no scientific proof for actual occurrence of each benefit listed.

of potential harms as a justification for the need to adopt ethical principles. Otherwise, potential risks are mostly mentioned in an implicit or in a generic way. An implicit mention can be found in both Draft DYIbio Codes of Ethics. Specifically, the statements that biotechnology should "only be used for peaceful purposes" implies that it could, potentially, be used for harmful purposes. Similarly, CCPH principle number five, stating that power among partners should be balanced -- which could be read as a response to the potential risk of power imbalance. An example of the generic mention, is principle number six of the ECSA Principles, which states that "limitations and biases [...] should be considered and controlled for." Strikingly, it is not stated how or by whom, which is characteristic for a general lack of references to oversight within the documents analyzed.

Further, the ethical issues identified by Cooper et al. (2019) around attribution and intellectual property versus confidentiality and privacy matters (cf. section 3 above) do not seem to be adequately addressed within the current documents. Several guidelines make normative statements regarding some of their aspects -- for instance the 10 ECSA Principles request that Citizen scientists should be "acknowledged in project results and publications". Nevertheless, it remains unclear how potential conflicts would be resolved. A case in point is the Austrian Quality Criteria document. This document states that all data, metadata and results must be made publicly available or published open-access "provided there are no legal or ethical arguments against doing so." Keeping the different types of Citizen Science projects in mind, it is clear that there *may* indeed be legal or ethical arguments against doing so in many cases. The challenge is to determine, for each project, whether the ethical case for publishing openly is stronger than the ethical case for not doing so[7]. In other words, the document in question is only begging the question and does not actually provide any guidance in this regard.

[7] In addition, it is of course crucial to consider *who* will get to make this call. This issue is thoroughly addressed in the next section.

Overall, the nature of the documents is so heterogeneous that a more detailed ethical analysis proofs to be very challenging. Differences between codes inspired by medical research ethics (e.g. the Belleville Principles, or the Beyond Sabor Code of Ethics), performative high-level declarations (e.g. ECSA's Ten Principles) and report-length examinations of specific topics (e.g. the GEWISS documents) are hardly comparable. Furthermore, the ethical analysis is made more challenging by the wide range of organizational forms and formats each document considers to be "citizen science", and the breath of issues addressed within.

This challenge is perhaps best demonstrated by way of a specific example; that is, the instances in the documents that were, during the analytical phase, coded with the innocuous label of "communication."[8] Indeed, several documents contain references to the importance of transparent communication, in particular by project leaders. The quality criteria document by the Austrian Citizen Science platform serves as an illustration of this trend. This document states that "the project definition and objectives are open, clear, easily found and communicated in a generally comprehensible manner." Another slightly different example can be found in the GEWISS Green paper, according to which "fostering of regular communications between actors" should even be a guiding principle of Citizen Science. The CCPH principles also highlight the importance of "clear and open communication" between project partners by declaring it "an ongoing priority." These three quotes already illustrate the challenge of defining communication. In particular, whether communication mainly serves to establish transparency, or whether the goal is the process of communicating in and by itself, speaks to potentially different ethical principles. Transparency notably speaks to the respect of persons and is an enabling factor for informed consent and, thus, autonomy (Beauchamp & Childress 2001). The importance of communication as a process between partners, on the other hand, appears closer to the process of negotiating a reflective equilibrium and, thus, related to the principle of justice (Daniels, 1996).

[8] A related problematization of communication in citizen science can be found in Vries et al., (2019).

This illustrates the subtleties of *how* one ethical issue is addressed within a given guideline may have potentially significant implications on other ethical issues. Because the documents are not necessarily ethically coherent internally, a more detailed analysis has been deemed too costly and abandoned in favor of a second focus on governance. Instead of revealing ever more potential conflicts or dilemmas of ethical issues it is important to know *how* they will or should be resolved.

Governance of ethical issues

How ethical issues are dealt with, particularly regarding how potential conflicts or dilemmas of ethical issues are governed, is in and by itself an important ethical issue. It is therefore striking that advice and guidance regarding the governance of the ethical issues that may occur within citizen science projects are quasi absent from many citizen science association documents.

According our analysis only three documents, the GEWISS Green Paper, ECSA's Ten Principles, and the Belleville document, explicitly address governance, though in very different ways. The Green Paper explicitly addresses the challenge of *how* governance should be set up. In particular, it identifies the need to "[clarify] the legal and ethical framework conditions for citizen science"[9] and specifies that ethical issues relating to all aspects of citizen science should be reviewed (p. 28). It therefore recommends the establishment of an ethics working group or an ethics board "which examines ethical questions that arise in relation to the possibilities and limitations of Citizen Science."

In contrast, the last one of ECSA's Ten Principles states *who* they recommend be in charge of governing ethical issues: the "leaders of citizen science projects." They should "take into considerations the legal and ethical issues surrounding copyright, intellectual property, data

[9] This point is also referenced in the ECSA Policy Paper #1 but clearly only as a quote from Green Paper without discussing this point any further.

sharing agreements, confidentiality, attribution, and the environmental impact of any activities." Although the ethical issues listed are salient, it is important to note that such a recommendation implies no external oversight of citizen science project. Moreover, it centralizes a lot of responsibility, but also of decision power, at the position of the project leaders.

The Belleville document also speaks to *who* should matter when it comes to ethics but proposes a different answer than ECSA and puts a potential power differential center stage. It states that in the case of disagreements, "refusal to test the different positions can be cruel to those holding the minority position" and therefore recommends to "consider all of the ethical principles of our community." (Arguably, a similar point could be said to be made in an implicit manner in the CCPH Principles, as they repeatedly refer to the importance of everyone involved collaborating as equal partners.) This position thus describes an inclusive approach to the governance of ethical issues.

Another interesting governance-related aspect is the fact that the Green Paper and the second GEWISS publication, the Handreichung, are the only two documents where we identified explicit references to compliance with specific existing laws, notably data protection laws and legislation related to insurance issues. Otherwise, oversight is not mentioned in the documents we analyzed. This is a surprising shortcoming considering the many ethical challenges novel research configurations such as citizen science bring with them.

Indeed, the question of who gets to decide which issues matter is all the more important in new research configurations. The epistemological shift from citizens being research subjects to being research participants is the locus of new ethical challenges. At the example of community-engaged research, Bromley et al. (2015) draw on semi-directed qualitative interviews with principal investigators from both academia and community-based initiatives. These results show that, although they identify similar ethical principles, applying these principles create misalignments or dilemmas. They further show that, because the context and involvement of research by participants is fundamentally different from the “subjects” as described by the Belmont report. Accordingly, traditional ethical frameworks (such as the Belmont report) alone are ill-equipped to resolve the new ethical dilemmas (Bromley et al. 2015, cf. also Cooper et al. 2019).

For ethical citizen science, the emphasis must therefore lie on ethical governance that is inclusive of citizens' participants. The views of citizens, a fortiori in the context of citizen science, should count when evaluating the necessity and the modalities of ethics evaluation. Involving citizens in decisions that ultimately aim at protecting them and ensuring their autonomy is imperative and, coherently, grants citizens greater self-determination. It should therefore not be an afterthought to any discussion about ethics and ethical oversight but an integral part throughout the research lifecycle.

6 - RECOMMENDATIONS

In the context of Citizen Science as envisaged by the CCCS Zurich, where citizens are enrolled in collaborating or partnering with academic scientists but presently have no formal role, the issue of ethical governance is particularly salient.

On the following page, we therefore include a flowchart (Figure 2) with our recommendation for the CCCS regarding the governance of ethical issues arising within their projects. We will explain its conclusion in the following:

1. Citizen science research which falls into the category of human subject research in need of authorisation according to Swiss legislation (cf. Chapter 2) needs to be submitted for evaluation to the Cantonal Ethics Committee.

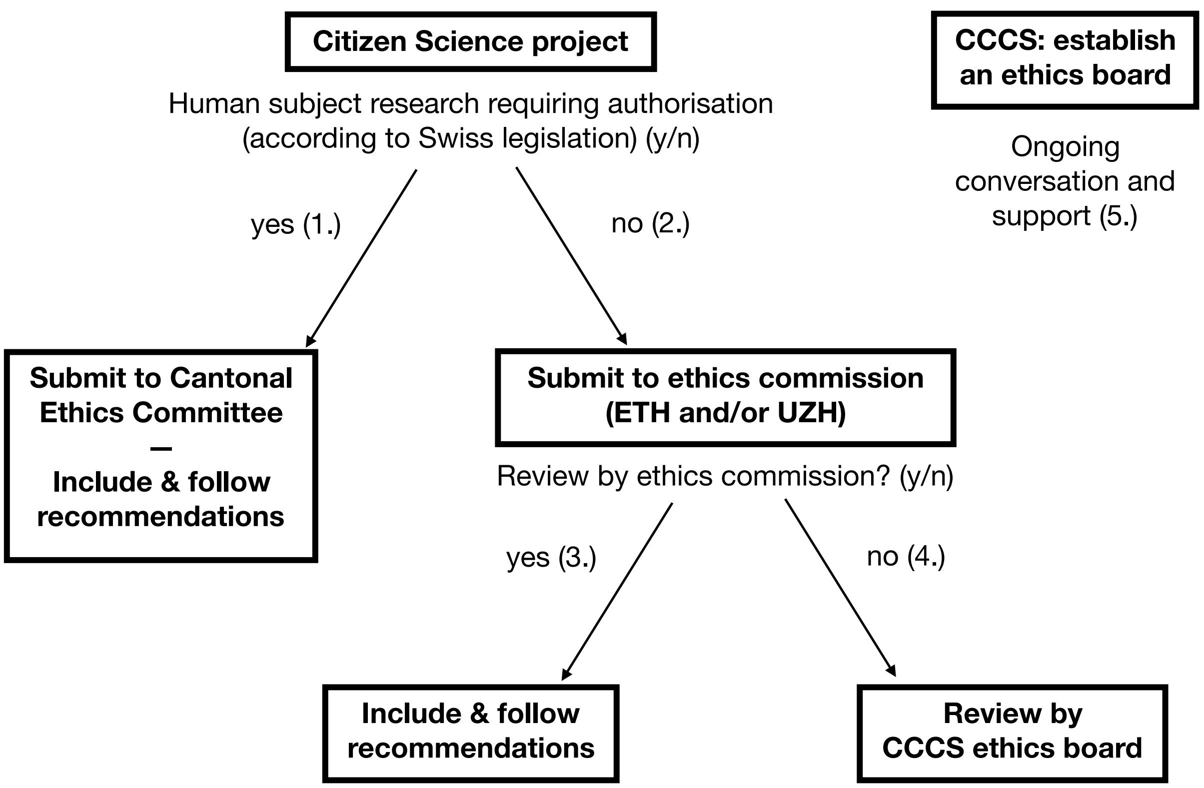
2. Citizen science research that is not subject to authorisation by the Cantonal Ethics Committee may nonetheless be considered to be human subject research and, accordingly, subject to approval by the relevant institutional ethics committees at ETH or the University of Zurich (or both[10]). Moreover, there might be potential ambiguities around the collection of health-related data or other personal information, in particular if the research project involves ICT (cf. Chapter 3). Therefore, we recommend that projects not requiring authorisation from the Cantonal Ethics Committee be submitted for formal institutional ethics review to the ETH Ethics Commission Office and/or the University of Zurich Ethics Commission. This is in line with the CCCS's own 2016 development plan, which stipulates: "**All** citizen science projects hosted and supported by the center must pass the relevant ethical review at ETH and UZH" (p. 5, emphasis ours).

[10] It is in the interest of the CCCS to clarify respective institutional responsibilities and their mutual compatibility and, if unclear, initiate a conversation aiming at harmonizing processes for CS projects.

3. If the ETH Ethics Commission Office and/or the University of Zurich Ethics Commission evaluate a project, their recommendations should be incorporated into the project and followed.
4. It is to be expected that the institutional ethics commissions will not review all citizen science projects that are submitted, especially if they are comparable to type 3 and type 4 research according to Cooper et al. (2019). However, all projects that are not reviewed externally should be reviewed internally. To this purpose, we recommend that the CCCS establishes an internal ethics board that includes citizens or citizen representatives.

5. The CCCS ethics board should not only review projects before they begin but establish a conversation with all ongoing projects and be available to consider arising ethical issues together with project representatives from academia and citizen stakeholders.

Figure 2: Recommendation for the CCCS Zurich



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APPENDIX 1

Determinants for human research projects

(from: https://www.kofam.ch/en/research-on-humans/determinants-for-human-research-projects/)

- *Is the project scientifically relevant? (Social or scientific value)*
  "The first question establishes whether the research project actually aims at a scientifically relevant advancement of knowledge."

- *On whom or on what is the research conducted?*
  "This question concerns the research subject: Is the research being conducted on living or deceased persons or on embryos or foetuses from abortions? Are health-related data or biological material being analysed?"

- *How is the research being conducted?*
  This question concerns the type of research: Are participants being actively influenced or is the research purely observational? Are health-related personal data anonymised or encrypted?

- *In what area is the research being conducted?*
  This question concerns the type of research: Are participants being actively influenced or is the research purely observational? Are health-related personal data anonymised or encrypted?

- *What substances and techniques are being used in the research?*
  This question addresses the status the utilised substances or techniques have in Switzerland – are they approved and established, being used for purposes other than those intended or unauthorised?

- *Does it involve radiation?*
  This question establishes whether the radiation dose is within or above the statutory threshold value.

- *Is the risk/benefit ratio adequate?*
  Finally, the focus is on establishing the relation between the project’s expected benefit and the risk for the research participants.

APPENDIX 2

Documents analyzed

Name of document	**Issuer**	**Date**
Citizen Science für alle. Eine Handreichung für Citizen Science-Beteiligte	GEWISS	2016
Green Paper. Citizen Science Strategy 2020 für Germany	GEWISS	2016
Qualitätskriterien für Citizen Science Projekte auf Österreich forscht (v. 1.1)	Österreich forscht	2018
Ten Principles of Citizen Science	ECSA	2015
North American DIYbio Code of Ethics	DIYbio	2011
European DIYbio Code of Ethics	DIYbio	2011
Beyond Sabor Code of Ethics	Beyond Sabor project leaders	2010
Belleville Committee Ethical Principles	Belleville Research Ethics Committee	2017
CCPH Guiding Principles of Partnership	Community-Campus Partnerships for Health (CCPH)	2013

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