"Ethical issues in Citizen Science": Output Paper of the StepChange Mutual Learning Exercise

The Step Change consortium presented and discussed (together with external experts Sonja Bjelobaba representing BRIDGE project and Dorothea Sturn and Stefanie Schürz representing ProEthics) the key takeaways from the work on its "Citizen Science Initiatives" (CSIs) in regard to the "Ethical issues" during the project activities. Several major lessons learnt in relation to the widely challenges are listed below, along with some experiences, tested solutions and results:

In addition to the CSIs' exchange of experiences and mutual learning from this exercise, we also want others to be able to benefit from our findings.

The output paper was prepared by the ZSI team (Carmen Siller, ilse Marschalek, Elke Dall, Elisabeth Unterfrauner) with inputs from all consortium partners.

1. Identification of relevant ethical issues

CSI experiences: CSI experiences were expressed as challenges, such as how to screen all potential issues at the start of a project and identify which aspects of the research may be sensitive. Related to this was also the topic of who can decide about it, as different people do have different opinions. The challenge is thus also to identify the "non-issues". For instance, is hunting animals in itself an unethical activity (as a comment from an ethics committee to one of the STEP Change CSIs suggested)? Furthermore, very specific topics require very specific solutions, so there is no "one size fits all" solution available. In particular, issues also depend on the type of citizen science approach that is being implemented (e.g. "extreme CS" vs. a more conventional researcher-led CS project) or at different points in the project timeline (e.g. "ethical publishing" and questions about co-authorship come up at the end of the project, but there are also issues that go beyond the run-time of the project).

Tested solutions: CSIs wanted to bear in mind that ethical issues and data protection are very important and should not be considered as "annoying add on". To conduct responsible research, it is necessary not only to obey the law, as something legal can still be unethical, e.g. in terms of social or moral values. Therefore, the teams should always consider "do no harm" as their basic guiding principle.

Findings: Identifying the ethical issues might be easier in areas such as medicine and health, where people are already well aware. In some areas of social and natural sciences, it is more difficult.

Key lessons learned:
- It is important to understand the context, as there are no universal ethical issues. Therefore, CSIs must start thinking about specific ethical issues from the beginning of the project design phase. It is also recommended to read guidelines or take courses in research ethics. A good starting point could be a book published by the SEI on the "Ten principles of citizen science", complemented with an article by ECSA about the characteristics of CS.
- It is advisable to engage with specialists and experts to get profound advice relevant to the topic of your CSI, which would be highly dependent on the context, i.e. the institutional specifications, thematic foci, geographical contexts, etc. Because CSI-teams are not experts on everything, the input of external expertise could be invaluable; for example, various ethical issues should be considered in terms of planning and budget.

2. Assigning appropriate importance

CSI experiences: CSIs mentioned that not everyone understands the importance of addressing ethical issues. Different expectations must be managed, even if responsibilities are sometimes unclear. In many cases, institutional standards and policies or templates to be applied are lacking, and the requirements might be different on a national or institutional level.

Tested solutions: In order to address this issue, CSIs decided to dedicate more time to ethical issues and data protection. Regular reminders that it is essential for responsible research were brought up. The choice of actions resulted in integrating ethical issues within the CSI and should not be considered only as a "ticking a box" exercise. Instead, recognizing and reminding ourselves that spending time on this topic is worth every minute.

Findings: Compliance at the national and local (and sometimes even the international) levels must take place. Trust and confidence on all sides are required and the different expectations need to be managed, in cooperation with the citizen scientists directly. It is important to know the community the CSI works with and its specificities.

Key lessons learned:
- It is important to involve stakeholders and citizen scientists in the process to manage their expectations. Internally, the importance must be emphasized, and templates and processes have to be created to be used in future projects. The lessons learned should be spread among other researchers at conferences and networking events. Also, it is advised to get engaged at the governmental level and work on raising awareness of the importance of ethics in research.

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3. Ethics take time and decisions might interfere with plans

CSI experiences: To consider and address ethical issues is a time-consuming task. Time is needed for communication and documentation. In addition, it is critical to explain and describe the project to obtain the informed consent. Often, it needs several exchanges with the ethical officers or boards. Obtaining ethical approval could be a time-consuming and bureaucratic process. Therefore, delays in the process might occur. Delays also occur when ethics committees meet infrequently or are slow to make decisions, which can disrupt the project schedule. Their decisions can also interfere with the project plan. For example, CS are not allowed to have access to patients at all or interact with them, they might not be allowed to access personal data, etc. Ethics committees can have doubts about some important aspects of the project.

Tested solutions: CSIs worked closely with the relevant stakeholders through consultative meetings to ensure that all the documentation, information and protocols are clear and submitted as requested. After submission, they made all the clarifications required and clearance was finally provided. In cases where ethics approval was requested from multiple organizations, the CSI complied with the requirements of ethics approval from all relevant parties. In the case where access by CS to patients was not allowed, the plan was adapted and only clinical researchers were allowed to have direct access to research subjects.

Findings: Based on feedback from ethical committees, some aspects of the project might not be possible to implement as originally planned (e.g. working with specific groups such as youths, etc.), and so it is always good to allow for flexibility in terms of timelines and to have a Plan B.

Key lessons learned:

- CSIs have to always realise and remind themselves that spending time on ethical issues is worth every minute (not to get annoyed by the requirements). However, one should not underestimate the efforts required. Therefore, CSIs have to start right away with applying for permits after the project is approved. Allow sufficient time and plan for contingencies.
- Also, consult and exchange pro-actively, regularly and from early stage with ethics bodies and officers. It is recommended that previous project know-how be used and that experienced individuals be included in the process.
- Project teams have to be flexible and adapt the project plan if necessary. They shall use common judgement to find and co-create realistic and pragmatic solutions.

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4. The target group in itself is "sensitive"

CSI experiences: In their preparatory work, the CSI learned that the target group itself could be considered sensitive or even unethical. As mentioned in an earlier section, the activities of hunters had been considered unethical by an ethical commission consulted. Other CSIs reflected on questions of how to work with patients who are directly affected, or how to work with marginalised or underprivileged groups, or how to address the differences of citizen scientists in terms of their different abilities, capacities and knowledge.

Tested solutions: One of the CSIs experienced that their CS felt inadequate or unskilled for a particular activity. As a result, their reaction has been to encourage participation, explain the importance of diversity of persons, and emphasise the added value of contributions from CSs with diverse abilities and experiences. Furthermore, they addressed the issue by working on different discussion and engagement techniques, e.g. to avoid asking a specific person directly their ideas, or asking them to propose something during the meeting; to leave participants free to speak when they feel ready; and to provide methods for participants to provide anonymous answers (e.g. the use of post-it); asking researchers to develop a positive listening attitude and to avoid being overly critical of what it is said; to start the meeting with an informal ten minutes of coffee time to chat friendly among participants in order to create a more relaxed and confident environment; to work on reinforcement of knowledge by workshop or face-to-face conversation with member(s) of the core team. For example, two training activities to provide CSs with scientific information and technical information to handle literature and data have already been planned at the beginning of the implementation phase. By splitting participants into smaller groups, these methods resulted in more productive discussions. Furthermore, CSIs collaborated with trusted focal points to provide clear explanations.

Findings: An inclusive dialogue with CS is necessary to avoid the exploitation of CS. The power imbalance must be addressed, and CS should be included in more than just data collection without further communication. One should look for tailored methods for specific target groups, even for informed consent, both in terms of content and format. One such example the chapter on "Ethical Challenges and Dynamic Informed Consent" in "The Science of Citizen Science[1]".

Key lessons learned:
- When working with vulnerable groups, one must be very aware of power gaps. Respect for different abilities, availabilities, etc. is necessary. It is also imperative to devote sufficient resources to the informed consent processes and to clearly explain everything. Furthermore, a dynamic informed consent allows the CS to renegotiate their consent.

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[1] https://link.springer.com/book/10.1007/978-3-030-58278-4

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5. Ethics is a point of view

CSI experiences: Apart from general ethical guidelines that exist on different levels, ethical guidelines are often decided on a very individual basis. CSIs reported that the targets were set based on personal preferences. One CSI was warned by the ethical commission that they should be aware that by partnering with a hunting organisation they get involved in ethically suspicious actions (hunting) and that they need to be aware of this aspect when collaborating with them. This warning came despite the hunting organisation is having an ethical code in place. The CSI felt that this was a biased evaluation from the commission and that the members of the ethical commission likely mixed their personal opinions with their professional duties. On some occasions, the personal opinions of members of the commission and the social climate of society can also have an influence on the work done in CS initiatives.
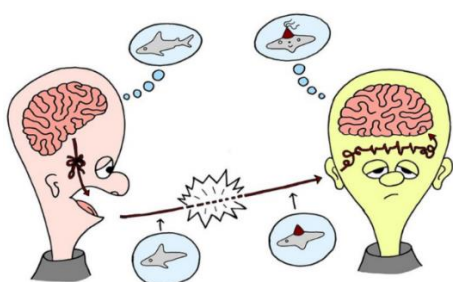
Picture by Jurgen Appelo on Flickr (illustrating the challenge of the CSI)

Tested solutions: In order to address this problem, they decided to write a rebuttal letter, but the answer to the letter was an even more polarised view of the hunter's work. They thus decided not to respond further and proceed with their work. Other solutions were to refocus the discourse, e.g. by expressing the issue as a project with "conservationists" – a part of the work hunters do, and using a word with a more positive connotation.

Findings: There are various boundaries in the ethical discourse, be it that ethical issues are controversially discussed or that they are still so explorative that there are still few regulatory proposals. In some cases, socio-political issues (rather than ethical ones) might be involved, and so certain target groups might cause problems obtaining ethical approval. Ethic commissions might judge something that is outside the realm of what they are asked for. If several bodies are involved, different administrative processes are required, and different ethical issues might be addressed.

Key lessons learned:

- CSIs have to try to comply with "all" the different requirements. It is recommended to anticipate questions, explain the ethical codex, proactively provide additional information (e.g. the ethical code of a hunting organization), and finally to co-create joint perspectives.

6. Research integrity and data management

CSI experiences: In terms of ethical requirements, the regulations for data protection have to be considered as well. For example, as mentioned above, some CS might not be allowed to get involved in direct data collection from patients, or they might need to consent to personal data processing. There are different requirements for data protection law and project or programme requirements. Standardised forms are sometimes not adjustable to CSIs.

An important issue in the discussion about the involvement of citizens in research activities is the quality of the data collected. The question is whether CSs are appropriately trained and literate for the data collection, and is their work reliable? As in all research projects, it needs to be assured that the tools applied really measure what they are supposed to measure. One CSI found that even after the researchers explained the different categories, their participating CS struggled to grasp the exact meaning of certain classifications or terminologies. As a result, researchers discovered that the work was occasionally unreliable.

Tested solutions: In order to address it, they decided to edit the explanation provided about the CSI to make it clearer and to offer more support to CS during the process of classification. In any case, researchers kept track of which phases of work felt more reliable than others in such a way as to best value the citizens' points of view. This choice of actions resulted in a more reliable process of classification that still cherished the unique insight of citizens. One way to overcome data collection constraints is to delegate data collection tasks to others who have the permission to carry them out.

Findings: Data management is regarded as one of the most common critics of citizen science; therefore, it is even more important to show that protocols are in place and CS are trained on how to execute different aspects of the projects properly.

The visualization of data also helps make sure CS can understand what this means.

It seems unrealistic to check the data if it is only slightly deviating; therefore, the CSIs need to have some trust. Socially desired answers are an issue to take into account in the social sciences and when working with CS, as this can result in some bias. It should be noted that there may be hidden agendas from organizations involved in supporting the recruitment of CS, which may impact data quality and consequently results; this must be thoroughly checked. The issue of data quality and the importance this topic has for the recognition of CS has been addressed, for example by the European Commission on its Mutual Learning Exercise on Citizen Science Initiatives – Policy and Practice website. Topic 2 - thematic report deals with ensuring good practices and impacts.

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Key lessons learned:

- It is important to invest in quality assurance, validation, verification and other checks of data. It is recommended to support CSs during the process of classification, and to ensure training and adequate protocols and monitoring sessions are in place.

- Another connected issue is related to open science: It is recommended to share data, not only the results but also raw data, for replicability and to increase trust in the processes.

- It is important to have a clear strategy and a good process for data anonymization to allow maximum access for all parties to analytical steps. A detailed documentation of data collection and analysis must be planned from the beginning.

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