
Values in data collection

TRANSCRIPT

Research Ethics Online Course

1. How research values relate to Data collection
2. Every society places values on how people, animals, environment and objects should be treated. No matter where you come from in the world, you will have been introduced to a set of values which guide your behaviour in relation to others, animals, the environment and objects around you.
3. When you enter the research society, you will need to know the values which guide the treatment of people, animals, environment and objects in this context. It may or may not be different from what you are used to. These values are important for the integrity of the research community.
4. In this presentation we are going to explore how these values apply to data collection with the help of Alex and Anna. Alex's research relates to human subjects while Anna works with animal data.
5. The importance of ethical values in the data collection phase of your research is explicitly mentioned in many ethical guidelines for research. Importantly The Finnish guidelines for responsible conduct of research state that: "The methods applied for data acquisition as well as for research and evaluation, conform to scientific criteria and are ethically sustainable. " This leads us to ask So what makes data acquisition ethically sustainable?
6. Every community has values around similar questions and the research community is no exception. Three values are typically raised. The first value relates to autonomy. Values around autonomy help a community identify boundaries for individual decision-making – what everyone should be allowed to decide for themselves and when can individual freedom be restricted by others. Secondly, there are values around doing good and not harm that help a community to define what is considered to be beneficial or harmful to individuals, animals, environment, and artefacts. The emphasis in doing good and not harm also invites the community to explore when, if ever, it is ok to do harm in order to achieve something good. Lastly, communities have considerations around justice. Every community needs to consider what is a fair and just process to deal with different situations. Our focus here is on the research community and how these values are defined and used to inform our data collection methodologies.

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7. Let's start with autonomy. In data collection, autonomy is related to key concepts of privacy and confidentiality. Privacy means that everyone has full ownership of their private information including their thoughts, values, experiences and preferences. Privacy means everyone has a right to make decisions on how they share any personal information with others. Everyone has a right to privacy. Privacy is a right that is in many countries, including Finland guaranteed in the constitution. Confidentiality is the corresponding duty. Everyone collecting or dealing with private information has a duty to maintain confidentiality, in other words, make sure private information is kept private.
 8. Informed consent is the process that we use in research to respect autonomy and fulfil our duty of confidentiality. There are two aspects to informed consent. Firstly, The researcher needs to ask if people are willing to share their information. the participants need to know all relevant aspects of the research project and how information is collected, before they can make the informed decision to participate or not. The informed consent procedure can be very complicated. At least the following considerations are necessary to make sure the process is as ethically robust as possible: Are there either rewards or coercion that might make it difficult not to consent to the research. When consent is asked and who asks for it may influence how people feel about the research and how free they feel to say no to it. How much information should be given and what type of language should be used to make sure people are truly informed about the proposed research? And cultural elements regarding decision-making and the potential of peer pressure should be considered in how researchers seek consent. Informed consent can be collected in many different ways: sometimes even a gesture may be enough, sometimes asking the question and getting an answer is sufficient or the participants can be given written information and then proceed to give their informed consent in writing. No matter which way informed consent is gained, it is important to record how and when consent was given. Lastly, participants can withdraw their consent to participate at any time. They also need to know they can do this.
 9. The second value is to 'Do good and not harm'. To do good is a core principle. In research doing good is typically about generating new knowledge and understanding. The good can be in the pure increase of knowledge or in our ability to apply what has been discovered in order to make the world a better place in some way. The other half of this value suggests we should do no harm in the process. However, sometimes it is impossible to learn more without some harm to either individuals, groups, animals, environment, or artefacts. We are then required to find a balance between good and harm.
 10. In these situations it is essential for the process to remain ethically sustainable, which means the good must outweigh the harm. In other words a positive balance between the benefits of the research and the harm it causes.
 11. People understand harm and benefit differently. it is almost guaranteed different people will make different judgments on what constitutes harm and what constitutes benefit. To decide if benefits do outweigh will be difficult even if people could agree on the definitions of harm and benefit in any given scenario.

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12. Let's consider two examples. Anna could say: "I study reproductive patterns of mammals and my study involves exposing experimental animals to known toxins." As Alex knows very little about Anna's study, so he might respond - "The animals are clearly exposed to harm. I am not sure if your research benefits outweigh the harm it causes?"
 13. To convince someone that the balance of benefit and harm is a positive one, it is usually essential to give a little more information, so Anna could offer to expand on her study "Would it make a difference to your thinking if the study was for a cancer cure or the animals were just observed in captivity rather than exposed to harm?" -
 14. "I think it would. The balance of harm and benefit is contextual and difficult to draw without knowing a lot more about your work. That is why we have committees helping us to find the balance."
 15. "I study how people view workplace policies and I do interviews. My population is well defined and I am afraid it would be quite easy to figure out who said what and I cannot really guarantee privacy." -
 16. "So you are worried about not being able to present some really valuable data unless you take a risk of harming your informants?"
 17. "Yes, I am balancing achieving my research aims, as the material is very interesting and worth publishing and then taking the risk of harm. Would the harm be worth it, assuming I did everything I could to maintain confidentiality?" -
 18. "I guess there is a balance of how sensitive and personal that information is and what kind of harm the exposure could create. And how big is the risk. I wonder if you could ask your informants their opinion on this?"
 19. The last value considered here is justice. Justice can mean a lot of things in different contexts, but for the purposes of considering values in data collection and within the research community, "Justice is often about treating everyone fairly. In data collection we need to consider equal access to research, data, and opportunities to take part."
 20. Things are rarely all that simple, sometimes it is beneficial to be part in a study - you may get opportunities no one else gets. Or being part can present a significant risk of harm. Considering how to divide these benefits and harms is part of justice.
 21. As a summary, when collecting data, we should make reference in our planning at least to values of autonomy, doing good, not harm, and justice. These considerations invite us to consider both consequentialist ethical approaches where we need to seriously focus on considering and defining harm and benefit to multiple different stakeholders. Simultaneously we are also invited to consider core rights of different stakeholders and key concepts like what is fair?
 22. How do these values apply to your research?