

Archiving sensitive data

Transcript of video

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Intro by interviewer Aysa Ekanger (AE): Making qualitative research data openly available is not always straightforward, especially when working with vulnerable groups of study participants. There appears to be a conflict between the intent of sharing data openly and protecting the interests of the participants of a study. We will now talk to two researchers who will tell us how they approach this dilemma. Professor Ann Therese Lotherington and post doc Lilly Mittner; You work on a project called the Artful Dementia Research Lab. Tell us about your research!

Ann Therese Lotherington (ATL): The Artful Dementia Research Lab has over the last four years grown into a research community in which we do experimental art intervention together with people living with dementia. So, the key words are 'art–dementia–research'. The intention is to generate new knowledge about life with dementia, and use this knowledge to fight stigma and shame, as that's often related to people with a dementia diagnosis. I would add that the research approach is fundamentally ethical, which means that before we take any action, all our plans go through a reflection process in the Lab. And when out in the field, we observe the art practices, not only with our analytical gaze but also with sensitivity to how the participants are faring. This is our strategy to make sure that no one suffers, but rather gains, from taking part in the art sessions, and that the results may constitute moral standards for how we should relate to people living with dementia.

AE: What is your motivation to openly share research data from this project?

ATL: The main motivation behind making the data openly available is to make external scrutiny of our research possible. This is important because it is almost impossible to apply standard validity and reliability tests to our research. Another motivation is opening the data and the research process, to not only make the participants visible and vulnerable, but also the researchers. This is scary, but it contributes to more equal and ethical relationships between researchers and other participants, and it adds value to our fundamentally ethical research approach. However, as already mentioned, this is not straightforward when working with vulnerable people.

Lilli Mittner (LM): The arts are not simply a means to disseminate research findings, but also to collect and analyse the data. Our motivation to share data is twofold:

We want to give insights into our work process, both our methods and our results.

Giving insight into our research process is also part of our community science approach. Our results will mainly benefit society at large, and thus it is of utmost importance to be able to share our results with the public.

We want to give other researchers the possibility to build on our experience, to further use the data we collected and to drive the research field of art and dementia forward.

AE: Can you tell us more about the data you collect?

LM: During a co-creative art session we produce a variety of qualitative and arts-based data. We are catching what we call resonating moments. Those 'moments' are our data units which we collect and further explore. We could describe resonating moments in which people connect with words only, but then we lose a lot of sensory information. These data we recall in our collective analysis sessions and use to build our arguments. The combination of qualitative and arts-based data is essential to conducting aesthetic analysis of resonating moments.

AE: This sounds fascinating. And what is the format of the data you intend to share?

LM: We gather traditional qualitative data, such as photos, sound and video recordings, field notes, and logbooks. But also, what we call 'arts-based data', such as scribes, croquis or small pieces made of music or dance.

AE: What is it that needs protection in your data? Why do you need to be cautious when sharing them?

ATL: Even though we neither collect health data nor other sensitive information, we do work with a vulnerable group of people who should be protected. This is an established ethical standard. But, very important in this context is that our audio and video recordings, per definition, are considered personal information, simply because individuals may be identified. We, therefore, must comply with the data protection legislation (GDPR).

AE: In quantitative research, and also in some qualitative studies, the data can be anonymised so that the GDPR no longer applies to the data. Why is that not an option for you?

ATL: First, I must say that we do anonymise our data if appropriate. We do, for example, use fictitious names all along, from writing logs to writing up our research. However, for audiovisual material this is not feasible, because: When we analyse the data and transform cases into stories, we direct our

attention to what happens in the group, and how relationships emerge between people, irrespective of the individual status or health situation. And to grasp what happens and how relationships emerge and develop, we need to see facial expressions, touch, and bodily motion. To document hands and backs only, or to blur faces, would not make sense, because when we work with people who might have lost their language and ability to express themselves orally, they must be allowed to express themselves otherwise. They “talk” with other means, and that is what we seek to document. Our wish to open the research process for others means that we must let them see what we have seen. By showing facial expressions and bodily motion we document moments that made sense to us and, therefore, that mattered for our analysis and results. We therefore publish non-edited pictures and film clips, either together with text, or on their own.

AE: I see, it is impossible for you to anonymise these data without losing the information which is important. This is probably something researchers working with transcriptions, and even quantitative data, also can relate to. Anonymisation tends to reduce the information in the data, and therefore can affect the usability of the dataset, and even the accuracy of the results. But, tell us how you are able to share these data legally.

LM: We are able to share the data by using a combination of informed consent, and depositing some of the material in a repository with restricted access. When we collaborate with people with dementia, whether as co-researchers or co-creators of art, we face some ethical dilemmas. For example, current ethical guidelines for collaborating with people with dementia are based on biomedical/clinical frameworks. According to these frameworks, informed consent requires understanding of complex written documents. As a result, many people with cognitive difficulties, such as those living with dementia, are excluded from participation in creative, arts-based projects. Therefore, we explore to what extent ethics and ethical guidelines might be usefully extended with reference to aesthetic and artistic values.

AE: Can you take us through the process?

LM: Generally, we gather consent through three different methods throughout the project: First, before the project starts, we obtain legal consent through a written consent form. This is provided either by the person living with dementia, or their legal representative, as consent by proxy.

We make sure that this consent is specific and granular.

We use several checkboxes so that it is clear that they consent, not only to the participation, but also to open publishing of video material that they have approved, and also to the long-term archiving for the purpose of future research. The second form of consent is obtained continuously during the data collection phase. This happens within the creative art sessions.

We use art and creative methods to obtain a form of consent that we conceptualise as Aesthetic Consent.

It is a form for relational consent for which it is necessary that the researcher is involved in the relationships that are studied. How could I know that a person agrees to become involved in a specific interaction without being part of it myself?

And this processual consent comes in addition to the documented, legal consent. And third, at the end of the project, we ask for “consent by editing”. This is to approve parts of the material to be shared, either with restricted access for other researchers, or with the broader community, as openly published videos.

AE: I see. With all these steps it must be important to plan everything from an early time?

LM: It is crucial. Already before the project starts, we must have a clear idea of what data we intend to share, what we intend to deposit in an archive, and what should be deleted at the end of the project. We started by making a tabular overview of all the different data materials that we will process. The table gives an overview of where it will be stored, and who will have access throughout the process.

AE: You intend to deposit the bulk of the raw data in an archive with controlled access – how is that access managed?

ATL: The metadata will be openly available and findable through search engines, but we will also refer to the datasets in our publications. This will make them findable. And if there are researchers who want access to the data, they must register and apply. Then curators of the repository will check that the new research follows the terms of the dataset, including the consent given by the participants.

AE: According to the GDPR, the participants have the right to have their information deleted. How does that affect your work?

LM: Of course, we need to comply with that right, if that should happen. We are filming a group collectively, so one person withdrawing their consent would compromise the material greatly. Therefore, it affects how we have formulated the informed consent. We communicate clearly from the beginning of the project about the broad outline of the project: this means its open research and its community science driven by transformational research. We communicate further how we collect data, and what will happen to the data. We make sure that those who would like to become involved, understand from the very beginning that they become involved in their role as equal co-creators of art and knowledge, or even engage as a dementia activist (ADLab, 2021). The consent

form is specific and granular, so that is clear to the participants what happens to the different data. Data which is deposited in the access-controlled archive can be deleted by the curators upon request. However, for the openly published material, we explain that it may be technically difficult, if not impossible to retract it. And we inform the participants of the date of publication and press the importance of withdrawing before that date – if they decide to do so. So, the group consent explicitly to open publishing twice, both in the written consent and later as Consent by Editing.

AE: Thank you both for taking the time to talk to us. Do you have any final advice for researchers who want to share their data?

ATL: As a qualitative researcher I was very sceptical about Open Data when I first learned about it. I thought it was impossible, not least because the consent forms and agreements we normally use promise full anonymity. A traditional consent letter also states that the data will be used for this project only and deleted after a certain period. But the thing is, we need to think differently about these issues now. That is what we have done, and still do in this project. Hopefully, others can learn from our experiences. And as we have said already, planning is the key. One must prepare for Open Access from the very beginning, and part of that planning is to decide what can be open for everyone, what needs curating and limited access, and what cannot be open at all. Finally, I would say that the trust and confidence we as researchers manage to create with the partners in our projects is crucial for what we can do with the data. Of course, building trust takes time, but research needs time to become good.

Conclusion by AE: I could not agree more. Not all data can be shared openly. But the work at the Artful Dementia Research Lab demonstrates how it is possible to archive and share material which contains personal information, by using a combination of 'Informed Consent', and 'regulated access control' at the repository.