
Ethical and legal considerations in obtaining, sharing and reusing data from human participants - workshop proposal

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Abstract

It is now beyond question that opening up access to scholarly knowledge is a key value of the academy in the 21st century. The Open Science paradigm however is not only restricted to facilitating democratic access to knowledge but also accommodates a set of key values of present-day knowledge creation such as fairness, transparency, equality and increased rigour and accountability in scholarly activities. Open Science therefore involves a cultural shift in the science ecosystem where research workflows are made transparent and subject to greater scrutiny from the early stages of protocols and planning through publication and data sharing.

This is especially the case in research projects involving humans participants as subjects. Privacy and confidentiality become key ethical questions when research data is based on humans. For that reason, modern researchers are facing a complex set of legal issues and ethical dilemmas whenever they want to store, use, publish and share data collected from human participants. On the top of such dilemmas, researchers are also challenged by the perceived confrontations between the open research culture and the proliferation of ethical review procedures and legal requirements for data protection.

In our workshop, we are aiming to address such challenges and deliver targeted advocacy for arts and humanities scholars working with data obtained from human participants. Making good use of the knowledge base and previous work that have been carried out in DARIAH's Ethics and Legality in Digital Arts and Humanities (ELDAH) Working group, we will recommend concrete steps that should be taken in order to secure ethically responsible research and present several guidelines and regulations that exist on issues related to informed consent and confidentiality.

Outline

The workshop will be organized along the following proposed outline:

Introduction into ethical and legal issues in conducting research with human participants.
How to align openness with proper data protection? (15 minutes)

^{*}Speaker

What data protection is all about and what has changed with GDPR? Rules, principles, and good enough practices from case studies (30 minutes)

Presentation and analysis of GDPR-compliant consent form samples (15 mins)

Breakout session: create your own consent form. During this session workshop attendees will have the opportunity to work together on consent forms designed to different research scenarios such as organizing a conference, conducting a research project based on interview data, or designing a citizen science project and discuss the methodological pitfalls, unexpected challenges and solutions that might occur in engaging such activities. (45 minutes)

Wrap-up, takeaways, questions (15 minutes)

Planned outcomes

Our previous experience gained from workshops and collaborations of different kinds with arts and humanities research communities clearly shows that there is an increasingly strong need for advocacy in legal and ethical issues. As the main outcome of the workshop, we aim to equip arts and humanities scholars with tools, practical advice but also with twists in mindsets that will help them in establishing ethically committed, optimal research workflows. We wish to showcase and co-create research scenarios in which the open research culture is well aligned with responsible conduct and where the reuse potentials of hard-obtained data are maximized. On the other hand, the conversation with the workshop attendees and their input from their own research settings will expand the knowledge base of the Working Group as it provides us with valuable insights fuelling better-informed and better-targeted advocacy.

Speakers

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