Addressing legal and ethical dimensions of the processing of personal data in research contexts: The ELDAH Consent Wizard as a tool for fostering best practices for consent and transparency in DH.

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Abstract

One of the core concerns of research in the 21st century is to open up knowledge and science itself. This idea, at the heart of the Open Science movement, encompasses not only the idea of enabling democratic access to research results, but also a careful, responsible and transparent handling of the research process and the research objects themselves, especially when these objects are actually subjects (i.e. people).

The ELDAH Consent Wizard project, co-funded through the DARIAH-EU Working Group funding scheme and the Austrian national CLARIAH-AT funding scheme, set out to develop a "consent form wizard" which enables digital scholars and the wider research infrastructure community to quickly and easily obtain a standardized, GDPR-compliant consent form that is legally valid in all of the European Union, and also sets a best practice for transparency and ethical conduct towards research (and hence data) subjects. Depending on the context for which consent is obtained (e.g. use of images of people, processing of information shared in surveys, collection/processing of personal data), wizard users receive a consent form tailored to their specific needs after answering a series of questions.

In this workshop, participants will be instructed about the basics for approaching such problems. As a first step, an overview of the current legal situation in the area of data protection will be given by presenting the EU-wide General Data Protection Regulation (GDPR) and summarizing the necessities arising from it.

In a second step, the workshop organizers will present the usage of the ELDAH Consent Wizard tool by introducing its functionalities, presenting the predefined usage scenarios and the actual consent forms generated through the tool.

Consequently, participants will be able to use the tool themselves to generate consent forms based on their own needs and interests, and test the usability of the resulting consent forms by switching between the roles of data controller and data subject. The participants' feedback will be collected to further improve the development of the ELDAH consent wizard and identify additional community needs.

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General structure (incl. rough time estimates):

- (15 min) Welcome and introduction of the Consent Wizard Project
- (15 min) Introduction round (participants' name, affiliation, consent-related focus)
- (45 min) Introduction to European Data Protection laws and the GDPR
- (15 min) Q&A on general questions related to legal context

(Break)

- (30 min) Introduction of the tool and the usage scenarios
- (30-45 min) Interactive testing of the Consent Wizard tool
- (30-45 min) Feedback by participants on usability (and usefulness), collection of suggestions for improvement and further development

(15 min) Wrap-up

Target audience: international research community (as users of the tool who wish to tailor consent forms to their research purposes), general public (as potential consentees who will complete consent forms generated with the tool)

Scope: half-day workshop

Instructors: Vanessa Hannesschläger, Pawel Kamocki, Koraljka Kuzman Šlogar, Walter Scholger (ELDAH Working Group)

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