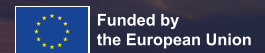# Navigating Research Ethics and Managing Sensitive Data in Complex European Projects

29th February 2024

POST WEBINAR REPORT

Keywords: #AI #bigdata #democracy #ethicaldata #pseudonymisation

🎤 SPEAKERS

Jennifer Edmond
Associate Professor of Digital Humanities at Trinity College Dublin, KT4D Coordinator

Alberto Bettiol
Partner at ICTLegal Consulting, compliance and legal expert

Kate Francis
Privacy and Ethics Researcher, Certified ECPC-B Professional DPO

As we saw in the first webinar, KT4D focuses on the optimisation of Knowledge Technologies - Artificial Intelligence (AI) and Big Data - to increase civic political engagement and defend democratic institutions. The development of these technologies has increased the ease of knowledge sharing, the interoperability of collaboration, and perhaps most importantly, introduced a new capacity to access, store, and manage scalable sets of data and resources. As a result, data privacy and security concerns have risen accordingly.

The second KT4D webinar, "Navigating Research Ethics and Managing Sensitive Data in Complex European Projects", highlighted guidelines to follow and strategies to implement to help researchers better understand the nuanced landscape of ethical data compliance.

Three Speakers:

Jennifer Edmond (Moderator) Associate Professor of Digital Humanities at Trinity College Dublin, KT4D Coordinator; *When doing the right thing seems impossible: Making ethical best practice work in complex research campaigns.*

Alberto Bettiol, Partner at ICTLegal Consulting, compliance and legal expert with specific focus on management of privacy related risks; *Preserving privacy while fostering innovation: How data protection can fuel ethical research.*

Kate Francis, Privacy and Ethics Researcher at ICTLegal Consulting, Certified ECPC-B Professional DPO, PhD Candidate at the Maastricht University Faculty of Law.

HIGHLIGHTS

The webinar "Navigating Research Ethics and Managing Sensitive Data in Complex European Projects" discussed the multilayered nature of European projects and acknowledged how these complexities can make it difficult for researchers to know how best to apply ethical research guidelines, in particular as it relates to the handling of human subject data.

Jennifer Edmond reinforced this notion that large-scale, collaborative research projects have many different tasks and workflows, a multiplicity of actors, varying national and local laws and regulations to follow, and tight deadlines, creating challenges for proper data collection and management. No two projects seem to face these challenges in the same way, meaning that best practice is also hard to define. Furthermore, Edmond highlighted the specialised nature of legal and ethical knowledge and oversight, which not every partner in a diverse consortium will have in-house access to. Ensuring this expertise is available at the project level can therefore be a key enabler for success. She concluded by saying how efforts to integrate ethical protocols into the fabric of research procedures can reduce the risk of project paralysis between an awareness of risks and a lack of knowledge to address them.

Kate Francis and **Alberto Bettiol** expanded on the discussion of data protection by dissecting the GDPR and applicable data protection regulations to be followed in the context of research. Although GDPR protocols can be difficult to navigate, Francis and Bettiol focused their attention on a few key points to help researchers maintain an ethical and compliant research strategy. They focused on pre-research activities, when it is imperative for researchers to provide informed consent to participants and clarify expected activities and potential harm that could occur. Additionally, Francis and Bettiol demonstrated how *researchers can and should seek out ethical oversight* from committees or agencies to ensure compliance codes are accounted for.

Additionally, the presentation by Francis and Bettiol explored the rights of data subjects, how to manage and store private data subject information, and dealt with the differences between pseudonymisation and anonymisation. While the process of *anonymisation* means a subject is unidentifiable through the available data and current technological means, *pseudonymisation* involves the removal of certain personal details, that can be provided later, to maintain confidentiality of a subject.

Although many challenges persist to interfere with the assurance of ethical data management and privacy compliance, the speakers highlighted how a correctly created Data Management Plan and procedures, when implemented prior to beginning research activities can ensure practices are carried out in a lawful and ethical manner.

QUESTIONS & ANSWERS

Question: Do you have any examples of communication platforms that are considered acceptable, easy to use and secure?

Answer: Jennifer Edmond explained how some of the data storage and communication options from the past may not align with current GDPR standards. KT4D does Google Suite approach. However, it is one that is paid for by a partner organisation that has GDPR protection capacity (unlike if you were to use it normally). She emphasised how whatever platform you decide to use, it is imperative to understand how they are managing your data and that they have data security measures in place.

Question: How can we merge older datasets if it's not possible to get permission from participants to share their data anymore?

Answer: Alberto Bettiol highlighted the challenges of secondary use of data when it is not possible to obtain specific and free consent. In these instances, Bettiold expanded on how researchers should disclose the potential negative impacts of possessing the data to the necessary authorities, where applicable. Prior to starting the project, Bettiol suggested that researchers should consult local data protection authorities to present the risks of possessing this type of data and either obtain authorisation or a recommendation on how to move forward.

Question: What actions should a project be sure to take at proposal stage to address ethical issues that may come up later?

Answer: The proposal stage is the ideal time to safeguard against procedural violations and ensure that research is conducted in an ethical manner by default. Connecting with internal legal partners or external institutions for oversight while designing research frameworks can give researchers clarity on what is acceptable, as well as the peace of mind moving forward that they are observing ethical and legal guidelines.

Question: How can data protection issues be effectively dealt with in EU projects?

Answer: While the GDPR aims to protect fundamental rights of data subjects and requires that organisations implement best practices for ethical data collection, management, storage, and processing which are proportional to the risks posed by processing, it is a complex space to navigate and comprehend. What can assist researchers in overcoming this dense landscape, is focusing on the purpose of the research overall and the activities required for successful implementation and compliance. Researchers should prioritise collecting only the data they strictly need. They should also implement technical and organisational measures to ensure the security of data, facilitate transparency towards research participants, and ensure that the rights of participants are protected.

Click to learn more about Data Protection and Pseudonymisation Guidelines

WEBINAR IN NUMBERS

The webinar was free to attend and attracted a diverse audience from various disciplines, including representatives from research & academia, tech professionals, industry & consulting, civil society organisations from across Europe. Below, you'll discover a detailed breakdown of registrants and attendees categorised by stakeholder type.
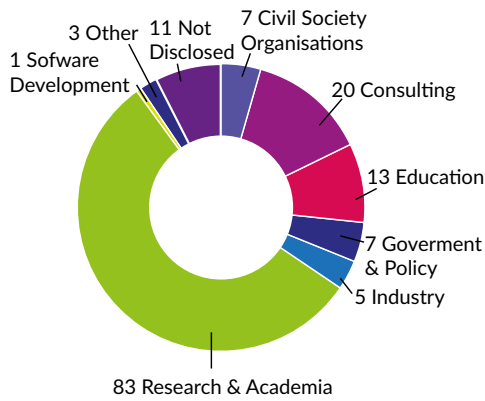
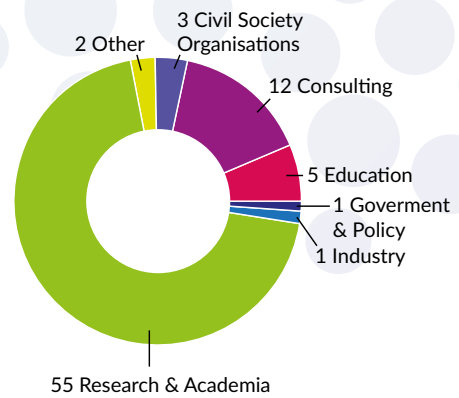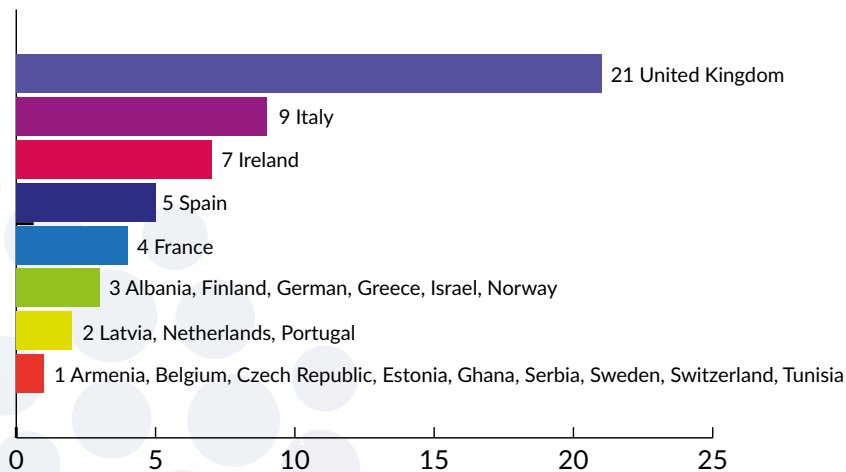Registrants: **150**   Total Attendees: **79**   Duration: **60 min.**

Registrants by Stakeholder Group

- 7 Civil Society Organisations
- 11 Not Disclosed
- 3 Other
- 1 Sofware Development
- 20 Consulting
- 13 Education
- 7 Goverment & Policy
- 5 Industry
- 83 Research & Academia

Attendees by Stakeholder Group

- 3 Civil Society Organisations
- 2 Other
- 12 Consulting
- 5 Education
- 1 Goverment & Policy
- 1 Industry
- 55 Research & Academia

Country Representation

- 21 United Kingdom
- 9 Italy
- 7 Ireland
- 5 Spain
- 4 France
- 3 Albania, Finland, German, Greece, Israel, Norway
- 2 Latvia, Netherlands, Portugal
- 1 Armenia, Belgium, Czech Republic, Estonia, Ghana, Serbia, Sweden, Switzerland, Tunisia

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