

3. “How Might we Design Consent Experiences for Data Sharing?”, Dr Arianna Rossi & Xengie Doan, 5th May 2022

Speaker Bio

Arianna Rossi is an associate researcher at the Interdisciplinary Center for Security, Reliability and Trust (SnT) of the University of Luxembourg. She carries out research at the intersection between design, computer science, law, and linguistics concerning online manipulation, usable privacy and legal design. Arianna has a mixed background, with a joint international Doctoral Degree in Law, Science and Technology (University of Bologna) and a Ph.D. degree in Computer Science (University of Luxembourg). She holds a M.Sc. in Linguistics with a focus on Natural Language Processing. She has been an invited speaker at international conferences in EU and US and she routinely gives seminars about law, design and technology to academic students and practitioners.

She also organizes events to promote an open culture for law and technology with the Luxembourg chapter of the global grassroots movement Legal Hackers.

Xengie Doan received a Master's in Bioinformatics from the University of Oregon and a Bachelor's in Biology from Willamette University where their interest in collaborative research began. Prior to joining the Interdisciplinary Centre for Security, Reliability and Trust (SnT) at the University of Luxembourg, they worked as a bioinformatician at the Stowers Institute for Medical Research and at Sage Bionetworks in the US. Their PhD topic is part of Legality-Attentive Data Scientists (LeADS), an EU funded project, with the IRISC lab researching transparent, secure, and private user-centered eHealth data sharing for the EU.

Video

Intro & Summary

The complex ecosystem where manifold transactions can be automatically enabled by smart contracts contributes, at least in principle, to establish greater transparency about data use towards the many parties involved. However, the mere fact of building such a verifiable and traceable architecture does not automatically translate into understandable communications, easily applicable instructions and smooth transactions for human beings. For instance, informed consent is hindered by the complex mix of legal, medical and technical information through which participants need to orient themselves when they make decisions about data sharing permissions. In data-driven environments, the way options are designed and presented can stimulate privacy-preserving practices or, on the contrary, unwanted data disclosure. This talk will address some challenges and discuss possible solutions currently experimented in consent design.

Arianna's talk "*Transparency & Data Protection*" [SLIDES](#)

Xengie's talk "*Conciseness, interest, and unexpectedness: user attitudes towards infographic and comic consent mediums*" [SLIDES](#)

Links and Resources

Paper, [Conciseness, interest, and unexpectedness: user attitudes towards infographic and comic consent mediums](#) (2022)

Paper, [When Design Met Law: Design Patterns for Information Transparency](#) (2019)

Paper, [Proactive Legal Design for Health Data Sharing Based on Smart Contracts](#)

Paper, [Transparency by design in data-informed research: A collection of information design patterns](#) (2020)