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## Sensitive Data Workshop



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### **Sensitive data workshop**

**Let's meet at:** 14:00 - 18:00, Room: Sagres | 22 Jan 2018 and 09:00 - 12:30, Room: TBD | 23 Jan 2018

**Session Chair:** Francesca Maria Iozzi, UNINETT

**You can't miss it** if you are a researcher who deals with human health and genetics data, biosample data, and other forms of sensitive data as well as if you are a service provider handling personal sensitive data, sharing sensitive data for research purposes in European wide projects, aiming at exploring the enormous research potentiality provided by the combination of open and restricted data.

**Objectives:**

- Explore the complexity of the sensitive/personal data landscape for research, by collecting experiences and researcher needs from different environments
- Evaluate the state of art of the technical solutions currently in use for personal/sensitive data in research
- Evaluate the challenges related to the sharing of personal/sensitive data across disciplines and borders in the GDPR "era"
- Evaluate the challenges for the joint usage of sensitive data and open data in e-infrastructure based research
- Identify needs and possible technical solutions for the efficient use of sensitive data referenced to open access data in the context of the Open Science e-Infrastructure.

**Abstract:**

Nowadays data are collected and stored in unprecedented ways, thus enabling innovative investigations. In this digital data era, the Open Science paradigm together with FAIR principles provide scientists and technology providers with a new vision and methods for enhancing their research by fostering the cross-disciplinary access and (re)use of data and data technologies. Thanks to the data explosion, innovative research can now easier be explored also in the field of medical, social and environmental sciences, for the benefit of the world-wide population. But this research often includes personal or sensitive data that must be handled with consideration of the legitimate right to personal privacy. The GDPR is now setting the stage for accessing, sharing and processing of sensitive personal data in Europe. Many projects have developed legally compliant solutions to deal with using sensitive data for research. Several strategies have been adopted locally to comply with national privacy regulations. But there is still the need to implement policies and the technologies that effectively allow cross border, inter-disciplinary research on personal sensitive data.

By collecting the experience of several research communities, we will assess the requirements and the technological measures adopted in projects dealing with clinical studies, video and audio based social studies, medical imaging, sensor based and social engineering-based investigations. Questions related to policies for federated identities, anonymisation, ethical codes, security measures with regard to providing access and sharing of sensitive data across borders will be addressed. The ultimate goal is to define a technological and policy framework to enable the processing of personal data collected from different sources and disciplines, including clinics and social media, in combination with data from traditional openly accessible sources, such as climate and environmental data. The workshop is promoted by the EUDAT Sensitive Data Working group, a discussion arena established in 2016 to address the challenges related to the integration of the sensitive data solutions into e-infrastructure funded on the concept of Open Science. The workshop is for researchers, data scientists and technology service providers that are willing to explore the research possibilities opened by the jointly processing of health records, real world data, sensor data, social data, environmental data across borders.

**Agenda:****DAY 1 (22/01)**

13:00 - 14:00 Lunch

14:00 - 18:00

- The Sensitive Data Workshop ([Presentation](#))
- Introduction : The SW working group and the sensitive data landscape (Daan, Wolfgang) - 20 min
- Nelleke Oostdijk (Radboud University Nijmegen NL), 25 min
- Kersti Klette (University of Oslo) - 25 min
- Wolfgang Kuchinke (Heinrich-Heine University, Duesseldorf, ECRIN) - 25 min
- Arturo Arino (University of Navarra, LifeRespira) - 25 min

Break - 20 minutes

- Fabrizio Carinci (University of Surrey, Guildford, BridgeHealth and EUBIROD) - 25 min
- Janna Sinipuro, SITRA, Fi - 25 min
- Isabelle Perseil (INSERM, Fr) - 25 min
- Peter Løngreen/Ali Syed, Computerome, DK - 25 min
- General discussion - 25 min

19:00 Workshop Dinner

**DAY 2 - (23/01) 09:00-10:30**

- Trond Kvamme (NSD, No) - 20 min
- Willem Elbers, CLARIN ERIC - 20 min
- Antti Pursala (CSC), 20 min
- Maria Francesca Iozzi, Azab Abdulrahman (SIGMA2/UiO) - 20 min
- Discussion - 10 min

Break 30 mins 11:00-12:30

- Luiz Bonino, (DTL, FAIR NL) - 25 min

Break 5 mins

- Round table - 40 min

- The future of Sensitive Data Working group: search for useful arena (e.g. RDA) - 20 min



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