



Establishing a Sensitive Data Interest Group

**RDA 17th Plenary Meeting
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Sensitive Data IG co-chairs

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- **Romain David, European Research Infrastructure on Highly Pathogenic Agents**
- **Steven McEachern, Australian Data Archive**
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Thank you also to

- **Stefanie Kethers, Australian Research Data Commons and RDA**
- **Keith Russell, Australian Research Data Commons**
- **Frankie Stevens, Australia's Academic and Research Network and RDA**



Sensitive Data definition

A working definition of sensitive data is: Information that is regulated by law due to possible risk for plants, animals, individuals and/or communities and for public and private organisations. Sensitive personal data include information related to racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership and data concerning the health or sex life of an individual. These data that could be identifiable and potentially cause harm through their disclosure. For local and government authorities, sensitive data is related to security (political, diplomatic, military data, biohazard concerns, etc.), environmental risks (nuclear or other sensitive installations, for example) or environmental preservation (habitats, protected fauna or flora, in particular). The sensitive data of a private body concerns in particular strategic elements or elements likely to jeopardise its competitiveness.

Adapted from: David et al., 2020, "Templates for FAIRness evaluation criteria - RDA-SHARC IG" <https://zenodo.org/record/3922069#.YCJU7ehKq2w>

Background

- How do we assess the level of data sensitivity across different contexts and disciplines?
- What are the risks associated with re-identification of different types of sensitive data, and how does re-identification occur?
- What guidance can we offer to researchers to help them share sensitive data safely and ethically?
- How do we balance sharing and reuse (e.g., FAIR) with cultural and ethical considerations (e.g., CARE)?
- How do different consent models affect the primary and secondary use of sensitive data?

Objectives

- **Develop a shared understanding and refined definition of sensitive data.**
- **Define various levels of sensitivity for data and develop tools to assess this sensitivity.**
- **Develop an understanding of how sensitivity relates to openness.**
- **Identify different consent models.**
- **Identify types of sensitive data holdings and resources across various domains.**
- **Identify existing data definitions and standards for different types of sensitive data.**
- **Identify challenges in collecting, using and sharing sensitive data.**
- **Engage with key stakeholders working in the area of sensitive data management/analytics.**
- **Identify existing solutions for sensitive data collection, analysis, storage and dissemination.**
- **Identify differences in how sensitive data is managed between groups and regions.**

Intended outcomes

- **Identify the key expectations of the community and use these to refine the IG's objectives.**
- **List different types of data across disciplines (e.g., health, social sciences) and how different levels of sensitivities apply to different types of data.**
- **Identify best practices in sensitive data management across multiple regions, domains and disciplines and how to adapt the best practices.**
- **Engage with relevant RDA IGs, WGs and CoPs to identify priorities in the area of sensitive data management.**
- **Gather common guidelines and recommendations for working with sensitive data in different disciplines and in different regions.**
- **Catalogue ethical, philosophical and cultural principles that underpin the use of sensitive data assets.**

Where do we go from here?

