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Governing Sensitive Personal Data Access and Data Publication in Intra-, Inter- and Transdisciplinary Research

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Open Research Data (ORD) is fundamental to the transparency and reproducibility of scientific results. It fosters scientific exchange and networking. In line with ORD strategies and funding agencies' requirements, research data should be published as openly as possible. Despite the advantages ORD brings to research, however, the publication of research data can be subject to restrictions. This applies to sensitive personal data, health-related data, synthetic data, and copyright protected data (e.g., software, protected works of literature, art and related works). Additionally, the rapidly increasing research on and with Artificial Intelligence (AI) in intra-, inter- and transdisciplinary studies, particularly in biomedicine and engineering, health and environmental sciences, poses certain risks when working with sensitive data. Therefore, researchers need best practices for their work with sensitive data considering ethical questions before data collection and/or developing of AI as well as throughout the research data life cycle; they also need to be aware of the lack of control and the potential risks when processing unpublished and sensitive research data with AI.

The Data Stewards of the Open Science Team at the University Library of Bern support researchers across the University of Bern and Insel Hospital by developing guidelines on sharing and publishing sensitive and personal data. These guidelines are intended to ensure that the management and publication of sensitive, personal and protected data comply with ethical as well as legal requirements and FAIR principles.

In our presentation, we will address key aspects of these guidelines on managing and publishing sensitive, personal and protected data across different disciplines. Firstly, we will show how to manage access to sensitive personal data, health-related data, synthetic data, and non-personal protected research data, which are subject of the Swiss cantonal and federal regulations and recommendations aligning with General Data Protection Regulations, which are relevant for research projects supported by the European Commission. Secondly, we will draw on how to publish unprocessed (raw) data, pseudonymized and synthetic data, anonymized and copyright-protected data to facilitate transparency and excellence of research data in intra-, inter- and transdisciplinary research projects. The third aspect concerns data protection, security and privacy when personal data is being processed with AI. Finally, we will discuss how regional and national heterogeneity in guiding researchers working with sensitive data can be governed and aligned in research data management globally.

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