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Research with Sensitive Personal Data in the EOSC

Wednesday, 10 October 2018 15:00 (1 hour)

In the present era of digital data explosion, the Open Science paradigm, together with FAIR principles, offer scientists and technology providers a new vision and methods for enhancing research through the fostering of cross-disciplinary access and (re)use of data and data technologies. Data sharing and data cross-linking is the basis for innovative research in many fields of knowledge including health and medical science, but this research often involves personal or sensitive data that must be handled with due consideration of the legitimate right to personal privacy. Whilst several solutions have been developed to facilitate research involving sensitive data in compliance with privacy regulations, there is still the need to implement platforms and protocols that effectively allow cross border, inter-disciplinary research on personal sensitive data. Mechanisms for authentication and vetting, authorization, register data sharing, and analysis of aggregated datasets (possibly from different sources) are all still open questions, both at technological and policy level. Solutions require coordinated efforts, transversally involving service providers, scientist and communities.

The session will bring together service providers and communities dealing with sensitive data. We will explore state of the art solutions currently in use in regional or community specific settings and now also offered in the EOSC. We will investigate solutions developed and/or adopted by large advance community to work and share on personal sensitive data transversally across research infrastructures. We will identify gaps between science communities needs and the current offering of e-infrastructures (regional-based or community-based). We will discuss the requirements for an effective research infrastructure for sensitive data that allows data use and re-use within the EOSC. We will explore possible strategies to enhance interoperability between the existent e-infrastructure, with the goal eventually of enabling cross-border, Europe-wide user scenarios in the EOSC framework. The roles of funders and policy makers in this enabling process will be also discussed.

Type of abstract

World Cafe Session

Summary

Human health is a global issue.

Today we have more health data than ever before, but sharing them across borders for the greater good of global research remains challenging. Public good must still be balanced against the privacy of individuals. This workshop will review the state-of-the-art in digital services for research with sensitive data, particularly in the field of health. It will identify gaps between science communities'needs and the current offerings of e-infrastructures, and will discuss requirements for an effective research infrastructure that can support the cross-border sharing of sensitive data within the EOSC.

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Session Classification: Research with Sensitive Personal Data