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Barriers and concerns for the sharing of cohort data and the implications for data sharing platforms

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Abstract

Infrastructures are being developed to enhance and facilitate the sharing of medical data internationally. However, empirical studies show that many barriers impede data sharing. Therefore, our aim is to describe the barriers and concerns for the sharing of this data, and the implications for data sharing platforms. Seventeen participants involved in developing these platforms, or tied to datasets that are to be submitted to platforms, were recruited for semi-structured interviews to share views and experiences regarding data sharing. Credit and recognition, the potential misuse of data, loss of control, lack of resources, socio-cultural factors, and ethical and legal barriers are elements that influence decisions on data sharing. Core values underlying these reasons are equality, reciprocity, trust, transparency, gratification, and beneficence. Therefore, data producers might use data sharing platforms primarily for collaborative modes of working and network building. Data producers might be unwilling to contribute and share for non-collaborative work, or if no financial resources are provided for sharing data.

Slides

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Author biography

[Thijs Devriendt](#) (KU Leuven) completed a Master in Biomedical Sciences (2018). Between 2017-2018, Thijs worked on ethical issues within the field of anti-doping research, such as usage of samples coming from sports drug testing, enrolling human subjects in research, and access of athletes to Athlete Biological Passport (ABP) data. Thijs initially did an internship as part of his studies, and later carried out his master's thesis, under the supervision of Pascal Borry. Thijs started his PhD *Data Sharing in Biomedical Sciences: The Impact of Incentive Policies and Data Governance Models* in April 2019.