

Data sharing in neurodegenerative disease research: challenges and learnings from the innovative medicines initiative public-private partnership model

Bradshaw A, Hughes N, Vallez-Garcia D, Chokoshvili D, Owens A, Hansen C, Emmert K, Maetzler W, Killin L, Barnes R, Brookes AJ, Visser PJ, Hofmann-Apitius M, Diaz C and Steukers L

Efficient data sharing is hampered by an array of organizational, ethical, behavioral, and technical challenges, slowing research progress and reducing the utility of data generated by clinical research studies on neurodegenerative diseases. There is a particular need to address differences between public and private sector environments for research and data sharing, which have varying standards, expectations, motivations, and interests. The Neuronet data sharing Working Group was set up to understand the existing barriers to data sharing in public-private partnership projects, and to provide guidance to overcome these barriers, by convening data sharing experts from diverse projects in the IMI neurodegeneration portfolio. In this policy and practice review, we outline the challenges and learnings of the WG, providing the neurodegeneration community with examples of good practices and recommendations on how to overcome obstacles to data sharing. These obstacles span organizational issues linked to the unique structure of cross-sectoral, collaborative research initiatives, to technical issues that affect the storage, structure and annotations of individual datasets. We also identify sociotechnical hurdles, such as academic recognition and reward systems that disincentivise data sharing, and legal challenges linked to heightened perceptions of data privacy risk, compounded by a lack of clear guidance on GDPR compliance mechanisms for public-private research. Focusing on real-world, neuroimaging and digital biomarker data, we highlight particular challenges and learnings for data sharing, such as data management planning, development of ethical codes of conduct, and harmonization of protocols and curation processes. Cross-cutting solutions and enablers include the principles of transparency, standardization and co-design – from open, accessible metadata catalogs that enhance findability of data, to measures that increase visibility and trust in data reuse.

Published: 20 July 2023

Frontiers in Neurology

<https://doi.org/10.3389/fneur.2023.1187095>

Download the PDF [here](#).