

Implementing a Data Sharing Agreement within a biomedical research consortium

Christoph Schickhardt¹, Christian Deisenroth^{2c}.

Main idea

Our project intends to establish a culture of data sharing in a German research consortium in the field of systems medicine by introducing a data sharing agreement as well as project-specific data usage agreements.

Practical relevance

Sharing research data is pivotal for successful research in systems medicine and in medical research in general. Our project is part of the e:Med-program, funded by the Federal Ministry of Education and Research. Building on a survey conducted among the consortium members and in further discussion within them we have developed and implemented a data sharing agreement as well as a template for project-specific data usage agreements. Our insights may serve as a best practice example for other projects in the field of biomedical research.

Innovative/scientific impact

Data sharing in medical sciences is reported to be less likely than in other disciplines. Tenopir et al. argue that this might be the case due to the higher sensibility of the data which often includes personal data from patients. However, if restrictions can be put on the possible use of the data, the willingness to share data increases. Some actions have already been taken to improve data sharing in the medical sciences like requirements that have to be met to publish a medical trial in ICMJE-Journal or the release of new data sharing guidelines of funding organisations (EU Horizon2020, NIH, MRC). What is still missing are use cases that may serve as best practice examples for the implementation of data sharing in the field of biomedicine. There are some ideas how sharing of medical research data could be encouraged but most of them are of a theoretical kind. Our project is an actual implementation of a data sharing concept in an active consortium, enabling us to collect hands on experiences that may be useful to other researchers in the biomedical field. The results of our survey showed that the major issues a data sharing agreement would have to address are: authorship, questions about the publication of results, the kind of metadata needed to understand a dataset, and rules and guidelines for the sharing of data in general. We also found out that the gathering, preparation and publishing as well as the analysis and evaluation of data are expected to be the main tasks regarding the publication of research results and that those tasks should be considered the most in decisions about the authorship. Those results were used to develop our data sharing agreement and the template for data usage agreements. We integrated Paragraphs concerning authorship, metadata and the division of labour in a project as mandatory parts to be addressed by every consortium-intern cooperation. As data counsellors we accompany and moderate the discussion about the individual data usage agreements between the consortium members.

The experiences we already have made and we will make in the future may help other researchers in their attempt to establish a culture of sharing in biomedicine and might therefore be a valuable contribution to the Open Science Movement.

¹ German Cancer Research Center, Heidelberg, Germany

^c Corresponding author

² National Center for Tumor Diseases, Heidelberg, Germany