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Implementing a Data Sharing Agreement within a biomedical research consortium

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Introduction

It is pivotal for the accomplishment of data driven research like Systems Medicine to share research and health data. Although many researchers accept this notion, the rate of shared data is still low. This somewhat paradox situation is caused to a great deal by the researchers' fear of giving away opportunities by sharing data with other researches in their field. To find a solution for this dilemma was a main objective for the development of a Data Sharing Agreement within the e:Med networking consortium.

Development Process and Methods

We also conducted a survey among the members of the consortium using questionnaires with multiple choice and open questions.

For the development we started with a systematic online research on guidelines for data sharing published by international

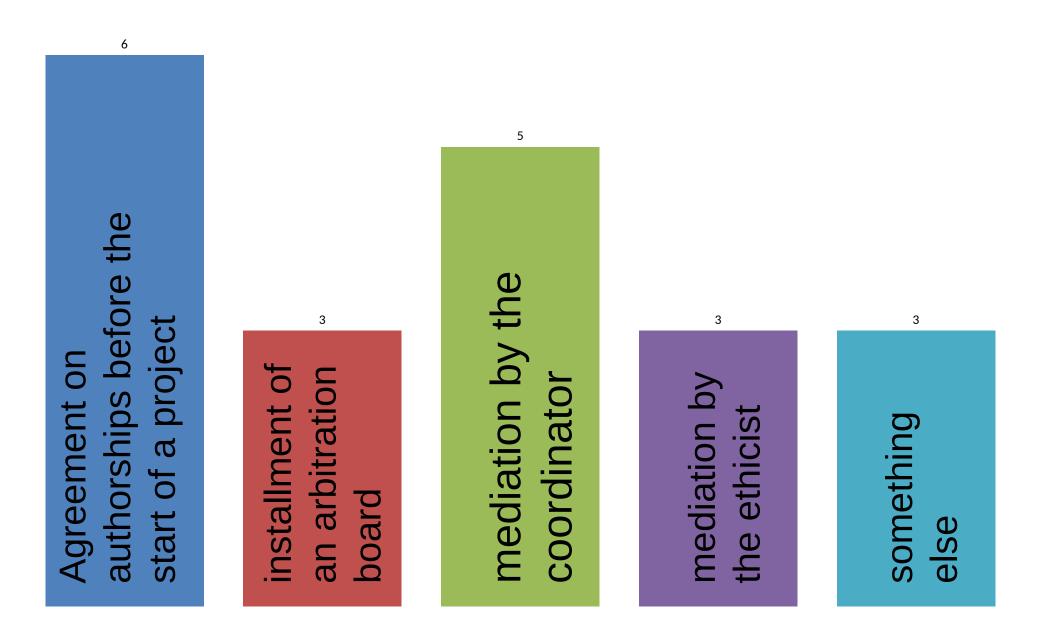
research and funding organizations.

Our first draft of the Data Sharing Agreement was discussed during a workshop on data sharing by the consortium members and accepted in consensus.

After another review of the Data Sharing Agreement it signed by all members of the consortium.

Survey Results (Examples; N = 9 [of all consortium PIs])

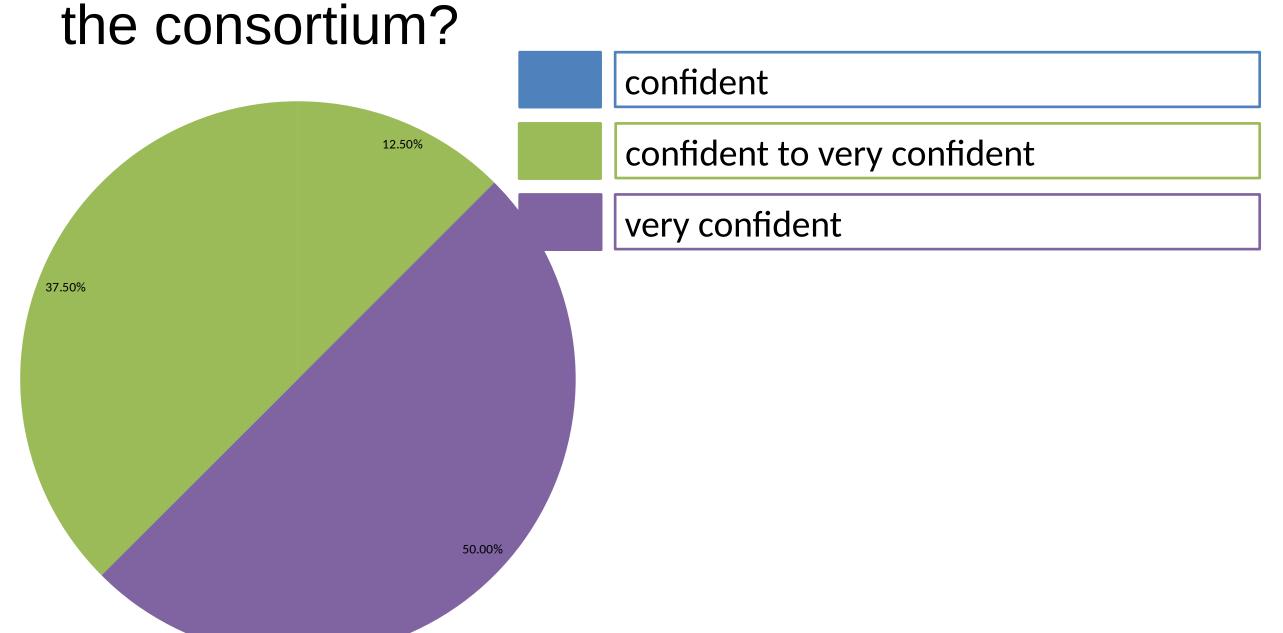
What do you think is most important for successful data sharing in a consortium?



In your opinion: What are the main tasks that should be considered when deciding on authorship?



How confident are you about being treated fairly in



Conclusions and Results

The development of a data sharing agreement bears the possibility to induce trust and confidence within a group of researches. By addressing the main questions that could hinder the exchange of data (authorship, distribution of tasks, ...) it may help to encourage data sharing.

Results:

- 1. Data Sharing Agreement with an example scenario (implemented)
- 2. Template for a Data Usage Agreement (implementedt)
- 3. First Use-Cases for data exchange between consortium-members





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