

Experiences from compiling a FAIR survey in the German Network University Medicine

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Abstract

The FAIR guiding principles for data stewardship are a set of recommendations for making research objects findable, accessible, interoperable and reusable. FAIR assessment tools implement measures for these principles and thus enable research networks to evaluate how good they comply with current standards in open and reproducible science. Based on questions from two different FAIR assessment tools, we built a tailor-made survey for the FAIR evaluation of projects within the German Network University Medicine (NUM). Established at the start of the Covid-19 pandemic outbreak, NUM addressed the need to collect and integrate Covid-19 data across German University Hospitals. Technical developments aimed to follow, among others, the FAIR principles. Interested in the actual status of FAIRness, we conducted an online survey in 2022 across German Network University Medicine projects. The goal was to identify positive examples of FAIR data in the German Network University Medicine thus to motivate other projects to take similar routes.

Keywords

FAIR, Survey, Medical Informatics

1. Introduction

The ongoing digitalization creates large amounts of data in health care and research. However, the majority of data remain difficult to find, access, and reuse, due to license restrictions and GDPR compliance regulations. Research networks hence spend time and effort on implementing strategies for data sharing such as supporting interoperability [1] or writing guidelines for FAIR data sharing [2]. A large portion of subsequent compliance requirements are based on the FAIR Guiding Principles for Data Stewardship [3] and then adapted to the specific domain or project of interest. In 2020 the German Network University Medicine (NUM) was founded to coordinate German COVID-19 strategies and research activities. Within NUM, the CODEX platform was

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developed to collect and share COVID-19 related data from all German hospitals to help the government make informed decisions (<https://www.netzwerk-universitaetsmedizin.de>). As the FAIR principles formed the basis for many projects associated with the CODEX platform, we were interested to comprehend the status of "FAIRness" at the end of the funding period.

2. Methods

We conducted a self-assessment survey with 33 questions [4] regarding level of FAIRness, experiences with FAIR evaluations, and specific questions along the FAIR categories. We reused previously established questions from online FAIR frameworks and FAIR self-assessment tools, in particular ARDC (<https://ardc.edu.au/resource/fair-data-self-assessment-tool>) and FAIR enough (<https://fair-enough.semanticscience.org/>). To obtain reliable data in the cross-site survey, we decided to use REDCap, a secure, GDPR compliant Research Electronic Data Capturing Tool. We disseminated the survey across all participants of a NUM-project and via social media.

3. Results and Conclusion

The survey was productive between September 1 and November 14, 2022. The overall participation in the survey was very low despite broad announcement. 107 people opened the survey, but only five entries were fully submitted from a total of three NUM projects. We hypothesise that the survey questions demanded too much technical detail about the IT infrastructure, potentially discouraging survey completion. Notably, none of the participants had used a FAIR evaluation tool before, but one participant had previously participated in a FAIR evaluation. However, the survey clearly showed that FAIRness is not yet a particularly high priority within NUM projects. A strategy for FAIRification is needed to ensure that data from within the German Network University Medicine can reliably be reused.

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