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DFG
NFDI initiative

53170 Bonn



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Münster, den 03.07.2019

NFDI Letter of intent: MDM-Portal
Non-binding letter of intent (anticipated submission in 2020)

1 Formal details

- Planned name of the consortium: Portal of Medical Data Models
- Acronym of the planned consortium: MDM-Portal

- Applicant institution:
Institute of Medical Informatics, University of Münster,
Albert-Schweitzer-Campus 1, Geb. A 11, 48149 Münster (IMI)
- Spokesperson: Univ.-Prof. Martin Dugas, dugas@uni-muenster.de, IMI

2 Objectives, work programme and research environment

- Research area of the proposed consortium (according to the DFG classification system): Medicine

- Concise summary of the planned consortium's main objectives and task areas:
The overall objective of the MDM portal (<http://medical-data-models.org>) is to develop a sustainable open-access platform for high-quality medical data models as an information infrastructure for medical research and routine healthcare. Semantic annotation, professional curation, user feedback, flexible search functions and format converters are important services of this system, which is developed in close cooperation between the Institute of Medical Informatics, University of Münster, and the University and State Library of Münster. Currently, the development of the portal is funded by the German Research Foundation (DFG). During the last years, the portal's content has grown significantly to more than 20,000 medical forms with approximately 500,000 data elements. In order to reach critical mass, it was initially focused on oncology. The aim of the consortium is to enhance and improve MDM contents, to increase the number of users (as of 2018, there are over 1,200 registered users and over 37,000 site visits), to upgrade MDM functionality and to guarantee sustainability of the system. The MDM portal is currently Europe's largest research infrastructure for medical forms (<http://portal.meril.eu/meril/view/facilitys/15547>).
- Brief description of the proposed use of existing infrastructures, tools and services that are essential in order to fulfil the planned consortium's objectives: All data models support versioning and are defined by rich metadata including unique and persistent model IDs, abstracts and MeSH keywords. In addition, a digital object identifier (DOI) request service is already implemented. MDM content will be indexed by ULB Münster and ZB MED Cologne, thereby it will be findable through search engines of ULB and ZB MED.
To make data **findable (FAIR-criterion 1)**, medical NFDI consortia need to establish and maintain medical data inventories as well as descriptions of data collection instruments. MDM provides Europe's largest collection of medical data models (i.e. largest medical metadata registry); the MDM team has eight years of experience with this task and is willing to share its knowledge and software tools. To make data **reusable (FAIR-criterion 4)**, annotation services to enrich medical metadata are required. The MDM team has manually curated semantic annotations for 500.000+ items. Both software tools to support annotation as well as large value sets for semantic annotations (e.g. regarding frequent laboratory codes, eligibility

criteria, adverse events) can be provided to our partners. In addition, MDM provides a DOI-service, which supports publication of metadata.

To foster interoperability, the MDM team has developed converters to transform data models in important, internationally established standards such as CDISC ODM, HL7 FHIR, openEHR ADL and many more (as of 07/2019: 18 different formats). Tools to compare different core datasets were developed. The MDM team is willing to share its expertise and software tools.

- Interfaces to other proposed NFDI consortia:

MDM is collaborating with a large number of international partners (see MDM homepage). MDM is interested to collaborate with all NFDI consortia in medicine which are committed to FAIR principles. Following the first NFDI conference in May 2019, contact persons from other consortia are approached.

Münster, July 4



(Prof. Dr. Martin Dugas)

Spokesperson of MDM-Portal

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