



cord_mi

The Collaboration on Rare Diseases (CORD-MI): A National Initiative to Improve the Documentation and Joint Use of Rare Disease Data in German University Hospitals

Participating institutions are listed below*

Summary

The **Collaboration on Rare Diseases of the Medical Informatics Initiative (CORD-MI)** is a new German initiative that aims to:

- improve the visibility of rare diseases
- provide new insights into the reality of care
- improve the quality of patient care
- stimulate research

CORD-MI is funded since February 2020 for two years with almost 6 million Euro by the Federal Ministry of Education and Research (BMBF) and currently includes 20 German university hospitals and partner institutions.*

Methods

- Building on the core data set of the Medical Informatics Initiative (Fig. 1), CORD-MI will rely on **international standards and terminologies** (e.g., **Orphanet nomenclature** or **Human Phenotype Ontology**) to improve documentation of rare diseases in German university hospitals.
- CORD-MI will use new methods for the **privacy-preserving analysis of distributed health data** (e.g., Secure Multi-Party Computation) to enable cross-institutional data use.

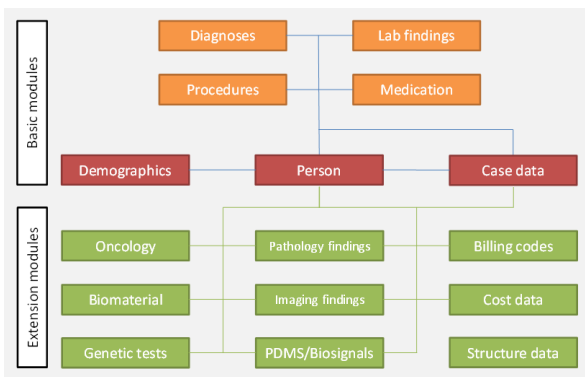


Figure 1: Core data set of the Medical Informatics Initiative

*Hospitals and partner institutions

Klinikum rechts der Isar der Technischen Universität München, Ludwig-Maximilians-Universität München, Universitätsklinikum Regensburg, Universitätsklinikum Tübingen, Universitätsklinikum Ulm, Berlin Institute of Health, Charité – Universitätsmedizin Berlin, Technische Universität Darmstadt, Universitätsklinikum Heidelberg, Deutsches Krebsforschungszentrum Heidelberg, Universitätsklinikum Köln, Universitätsklinikum Münster, Universitätsklinikum Würzburg, Technische Universität Dresden, Universitätsklinikum Frankfurt am Main, Universitätsklinikum Freiburg, Universitätsklinikum Gießen, Universitätsklinikum Magdeburg, Universitätsklinikum Mannheim, Universitätsklinikum Marburg, Universitätsklinikum Aachen, Rheinisch-Westfälische Technische Hochschule Aachen, Universitätsklinikum Bonn, Allianz Chronischer Seltener Erkrankungen e.V., Deutsches Institut für Medizinische Dokumentation und Information, Geschäftsstelle des Nationalen Aktionsbündnisses für Seltene Erkrankungen, Humboldt Institut für Internet und Gesellschaft, MONARCH Initiative, MII-Koordinationsstelle der Technologie- und Methodenplattform für die vernetzte medizinische Forschung e.V.

<https://www.medizininformatik-initiative.de/en/CORD>

Organization

CORD-MI is organized into the following **six work packages** (Fig. 2):

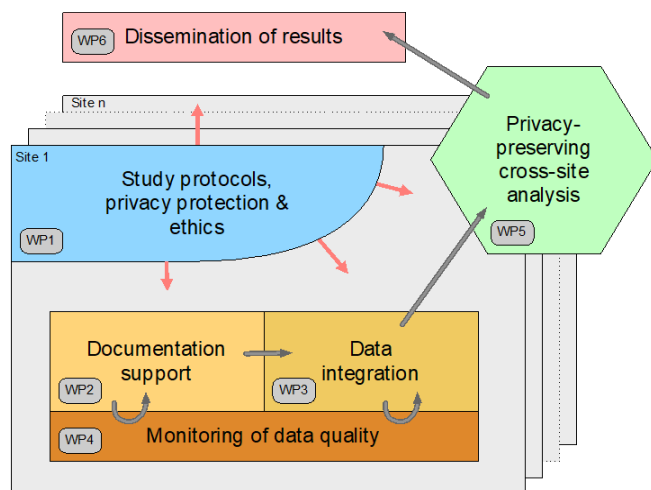


Figure 2: CORD-MI work packages

Use Cases

The benefits of CORD-MI will be demonstrated in **five use cases** that focus on the following diseases:

- 1) Cystic fibrosis:** Analysis of the quality of care during pregnancy
- 2) Phenylketonuria:** Analysis of quality of care and long-term morbidity
- 3) Fabry disease:** Quantification of psychic/psychiatric morbidity
- 4) Isolated sagittal suture synostosis:** Identification of patients with underlying hypophosphatasia and investigation of quality of care
- 5) Proopiomelanocortin (POMC) deficiency:** Identification of undiagnosed patients and investigation of epidemiology

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Contact: josef.schepers@bihealth.de