GOALS

- The aim of the Medical Informatics Initiative (MII) is to digitally network data from routine care across Germany and make it available for medical research.
- Medical research helps to better recognise and treat diseases and to prevent them as effectively as possible.
- The initiative additionally strengthens medical informatics in research, education and skills development.

FUNDING PHASES

The German Federal Ministry of Education and Research (BMBF) is investing a total of more than 400 million euros in the Medical Informatics Initiative through 2026. In addition, the BMBF is funding “Digital Hubs: Advances in Research and Health Care” (2021-2025). These integrate data from regional and outpatient care into the structures of the MII.

CONSORTIA

Within the four funded consortia – DIFUTURE, HiGHmed, MIRACUM and SMITH – all German university hospitals and medical centres at over 30 locations cooperate with non-university clinics, research institutions, businesses, health insurers and patient representatives. Their mission is to create an environment that allows research findings to be used to the direct benefit of patients – while ensuring robust data protection and security.
INITIAL RESULTS

→ Template text for patient consent forms (Broad Consent), developed in cooperation with German Federal and State data protection agencies and the Association of Medical Ethics Committees in Germany
→ Contractual framework for the use of patient data, biosamples, analytical methods and routines (user agreement and framework participation agreement)
→ Data protection concept
→ Use and access policy
→ German Portal for Medical Research Data (FDPG)
→ Shared core data set in line with international standards
→ Specifications for harmonised metadata
→ Paper summarising key points on interoperability
→ MII roadmap for enhanced research, education and skills development

PROJECT STRUCTURE

→ The consortia meet regularly within the initiative’s National Steering Committee (NSC) to coordinate activities and agree key parameters.
→ The NSC is supported by consent, data sharing, interoperability, external data and communication working groups, which develop specialist resources.
→ The main committee coordinates the “Module 3 projects” and the “Digital Hubs”.
→ Dialogue forums involve relevant stakeholders in the strategic development of the MII.
→ An international Scientific Advisory Board and a Patient Advisory Board provide specialist expertise to help advance the initiative.
→ Collaboration between and beyond consortia is the remit of a coordination office operated by TMF (Technology, Methods and Infrastructure for Networked Medical Research) with MFT (German Association of Medical Faculties) and VUD (German Association of Academic Medical Centers).