The German Medical Informatics Initiative: Sharing Data for Research and Better Patient Care

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We need

- coordinated
- secure
- data protected
- governed

access to data

based on a trustworthy framework of technologies and policies
The German Medical Informatics Funding Scheme

- Improve research opportunities and patient care through innovative IT solutions (initially at university hospitals)

- Intensify the exchange and sharing of data between the research community and the health care delivery system

- Position medical informatics as a progressive field in research, teaching and continuing education

- As a key element of the funding scheme data integration centres are to be set up and interlinked by the university hospitals
The initiative so far...

Announcement 2015

Conceptual Phase 2016-2017

Development and Networking Phase 2018-2021

Supplementary Funding for
- young researcher groups and
- non-funded university hospitals
Governance of the national initiative

- TMF
  - Umbrella organization for networked medical research in Germany
- VuD
  - Association of the 33 German University Hospitals
- MFT
  - Association of the 37 German Medical Faculties
- NSG
  - PIs of the funded consortia
- Working Groups
  - Members of the funded consortia

- WG Interoperability
- WG Data Sharing
- WG Consent
The MIRACUM consortium

• Medical Informatics in Research and Care in University Medicine
  • eight University Hospitals and Medical Faculties, two Universities of Applied Science, and one industrial partner
  • across five German States
  • associated with four German Health Research Networks

• comprising ¼ of all German University Hospitals
• handling clinical and research data of more than 10 Mio patients
The MIRACUM Ecosystem is based on ...

- Medical Informatics ReusAble eCo-system of Open source Linkable and Interoperable software tools – X

MIRACOLIX

- MIRACOLIX is
  - pragmatic
  - modular
  - reusable
  - open source
  - interoperable
  - federated
MIRACUM DIC Architecture and Governance

DIC Governance Structures

DIC Governance Structures
Use cases of MIRACUM

**Alerting in Care**
- IT Support for Patient Recruitment
- Medical Informatics / Clinical Trials

**From Data to Knowledge**
- Clinico-molecular Predictive Knowledge Tool
- Biostatistics / Prediction Models / Med. Inf.

**From Knowledge to Action**
- Support for Molecular Tumor Boards
- Bioinformatics / Medical Informatics / Precision Medicine
Example: Feasibility and Federated Queries

- 11 University Hospitals
- 3.3 Mio Patients
- 30 Mio Diagnoses
- 23 Mio Procedures
Strengthening Medical Informatics

developers – operators – users

• New Master of Data Science
• Continuing education, PhD program, summer schools …
• work visits, internal knowledge management, virtual communities …

• More than 11 new professorships so far
  – Epidemiology and Health System Research, Otto-von-Guericke-University Magdeburg
  – Bioinformatics in Oncology, Goethe-University Frankfurt & DKFZ
  – Medical Informatics, Johannes-Gutenberg-University Mainz
  – Biostatistics, Otto-von-Guericke-University Magdeburg
  – e-Health and Medical Data Science, THM University of Applied Sciences, Gießen
  – Heidelberg University [Medical Faculty Mannheim]
  – Biomedical Informatics and Systematic Medicine for the Research Campus Central Hessen
  – Medical Data Science, Mannheim University of Applied Sciences
  – Research in Health Services and Clinical Epidemiology, Marburg University
  – eHealth / mHealth – Friedrich-Alexander-University Erlangen-Nürnberg
  – Bioinformatics, Marburg University
Kick–off Symposium

We present

- The MIRACUM DIC concept
- First achievements of our Use cases
- Potentials for first medical research projects based on the MIRACUM DIC
- International Keynote Speakers

22nd–23rd February 2018
Erlangen

Kai U. Haitmann: FHIR
HL7 Deutschland

Arie Hasman: Problems with medical data transfer
AMC Amsterdam

George Hripcsak: Results from OHDSI
Columbia University

Lisa McShane: Big data analytics
National Institute of Health (NIH)

Stefan Schulz: SNOMED in MI-I
Graz University

Frank Ückert: Access to Patients’ Data Treasures
DKFZ

Ahmet Zehir: cBioPortal
Memorial Sloan Kettering Cancer Center

And more

www.miracum.de