NUM-Infrastruktur: Perspektiven für einen nachhaltigen Betrieb

TMF Jahreskongress
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Strategic goals: (1) Connecting German AMCs to (2) improve crisis preparedness and (3) provide data for clinical research

1. Establish one-stop-shop for clinical research on national level
   - Researchers, including industry partners
   - Government decision-makers
   - Overarching governance framework

2. Improve pandemic and crisis preparedness
   - Public health authorities
   - Healthcare providers
   - Government decision-makers
   - Surveillance & rapid response platform

3. Provide comprehensive clinical research data space for Germany
   - Researchers, including industry partners
   - Patients
   - Modular clinical research (data) platform
NUM Clinical Research Data Space today: Modular infrastructure solutions, each tailored to different data types

NUM Clinical Research Data Space

- Manage interfaces and overlap, record linkage, FAIR-principles, scalability, ...

- Clinical data
- Biosample data
- Imaging data
- OMICS data

- Clinical Routine Data Platform
- Clinical Epidemiology and Study Platform
- Biosampling Platform
- Imaging Data Platform

NUM-external data (e.g. health insurances, disease registries)
NUM Clinical Research Data Space in the future: Full integration of modules, access to NUM-external data

Manage interfaces and overlap, record linkage, FAIR-principles, scalability, ...

- Clinical data
- Biosample data
- Imaging data
- OMICS data

Clinical Routine Platform
Biosampling Platform
Clinical Epidemiology Platform
Imaging Data Platform

NUM-external data (e.g., health insurances, disease registries)
Komponenten der NUM-Infrastruktur: Aktueller Stand und nächste Schritte

**DIZ der MI-I**

**NUM-Routinedatenplattform (NUM-RDP i.V.m. NUM-DIZ)**
- Zentrale Datenbank & Tools
- Föderierte Treuhandstelle
- Regulatorik und Datensicherheit
- Locale Schnittstellen & Datenhaltung
- Datentransfer-Knotenpunkt (DSF)

**NUM Klinische Epidemiologie- und Studienplattform (NUKLEUS)**
- Treuhandstelle
- DICOM-Mgmt.
- Bioprobenmanagement
- Ethik-Koordination
- Interaktions-kern
- Epidemiologiekern
- AKTIN Notaufnahme-register
- RACOON Radiologie-Plattform
- NATON Obduktions-register

**GKV-Daten**
- GenSurv
Current NUM governance: As decentralized as possible, but high-level decision-making when necessary

Steering Committee

Research Infrastructures

National Task Force
Federal Research Ministry (1), Federal Healthcare Ministry (1), CEOs of AMCs (4), Deans (2), State-level Research Ministry (1), DLR-PT (1), Coordination Office (1)

Coordination Office
coordinates & monitors

Expert Advisory Board
(Community Platform)
synchronizes
consults

Research projects
(each with its own steering committee)
directs
reports

Research infrastructures
(each with its own steering committee)
contracts, coordinates, monitors

36 Local Coordination Units
coordinates & administers

Centralized governance
Decentralized governance
Vielen Dank für Ihre Aufmerksamkeit!