# Collaborative Approaches towards Interoperable, Secure Medical Data Sharing

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# **Prof. Dr. Thomas Ganslandt**Heinrich-Lanz-Center for Digital Health (HLZ)



# Challenges towards the Application of AI in Healthcare

How can we How can we define How can we objectively How can we achieve harmonized consistent (broad) consent measure and optimize securely implement ML data structures? and governance policies? data quality? training and application? Governance of Structured Datasets Routine Data dataaccess Patient Consent Application of Applicate





# The German Medical Informatics Initiative (MII)

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# Nationwide Coverage of all University Hospitals

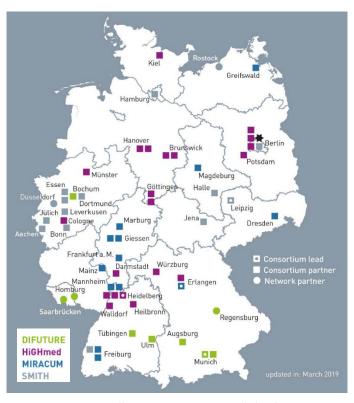


Image source: http://www.medizininformatik-initiative.de/en/node/5

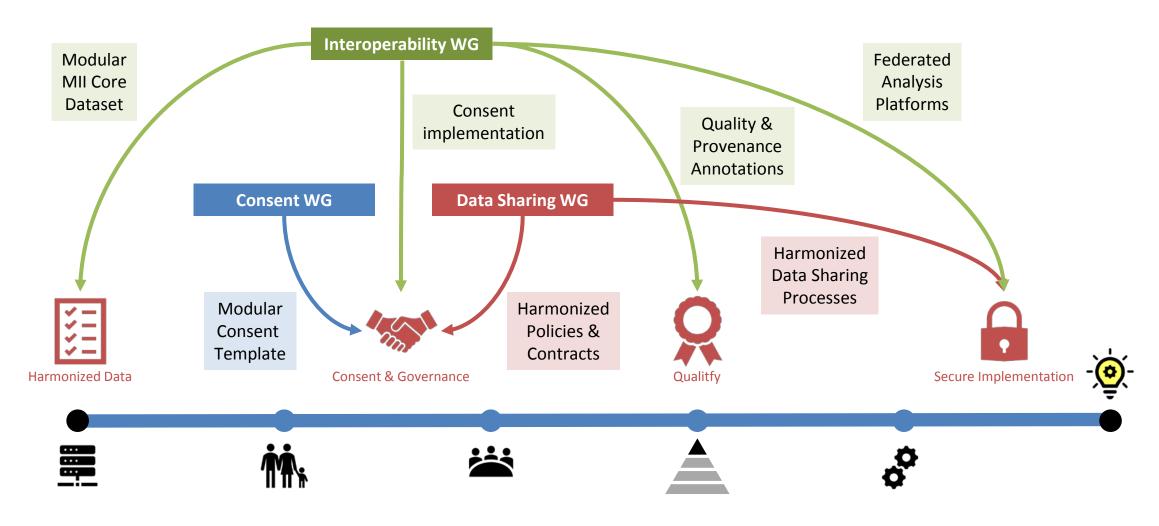




Informatics as a discipline



# **Collaborative solutions through MII Working Groups**





# Interoperability WG

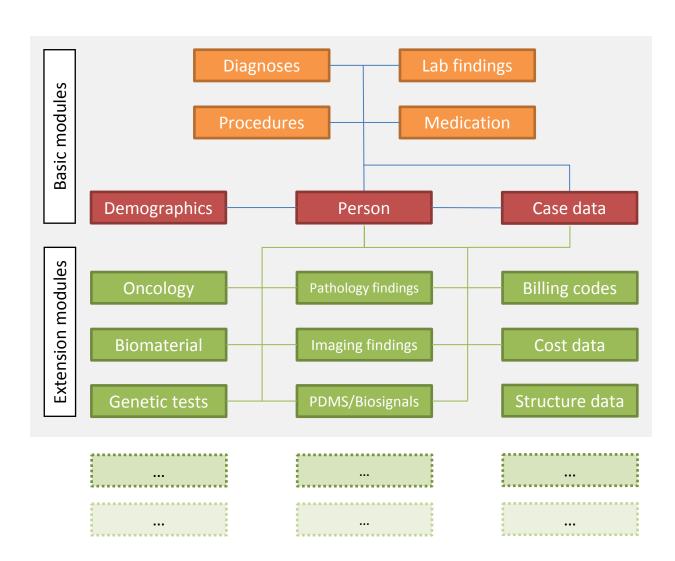
### **MII Modular Core Dataset**

Data structures based on HL7 FHIR Standard



Semantic annotation based on international terminologies









Collaborative tools for requirements specification and data modelling





Open governance processes and balloting





### **Consent WG**

# **Data Sharing WG**

#### **Harmonized Consent & Governance**

In negotiation with ethics committes and data protection officers

Modular **Broad Consent Template** 



Legal Guidance for Use





Structured Consent Representation



**Patient** Information Materials

Patient **Empowerment** 

Harmonized **Data Use Policy** 





Harmonized Data Use Contract



**Data Sharing Process Models** 



In collaboration with Interoperability WG

In negotiation with all participaing university hospitals







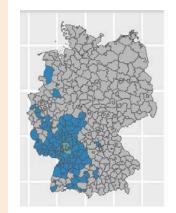
# Demonstrator Study: Iterative approach, harvesting low-hanging fruit

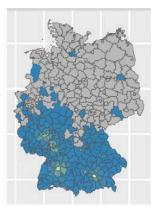


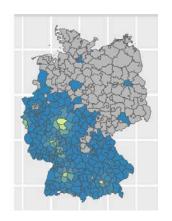


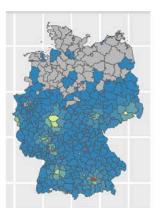


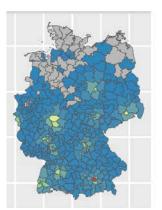


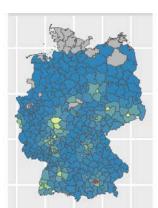


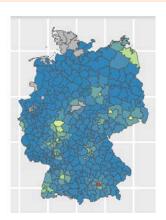












(09/2018 - 03/2019)





# Patient Participation: they want to donate, and they place trust in academia

Representative phone survey carried out by FORSA in 08/2019 (1,006 German participants) for TMF e.V.

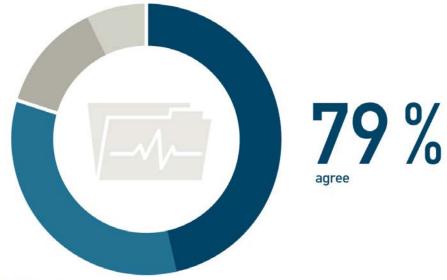
Consent to data donation for medical research

46% fully agree

33 % agree

13% disagree

7% strongly disagree



Source: TMF e. V. 2019 | Data base: 1006 respondents aged 18 and older in Germany

With whom would Germans share their health data?

97% Scientists at universities and public research institutions

17% Scientists from industry and private companies



97% support public research





# Conclusions & Outlook: How we should approach Medical Data Sharing for Al

