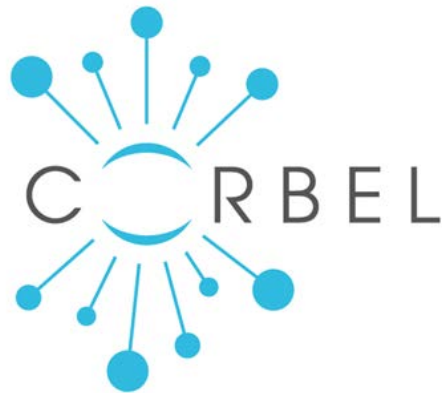


EUDAT Pilot of the ECRIN Community: long-term storage of clinical trials data

Wolfgang Kuchinke (HHU Düsseldorf)
CORBEL ECRIN Partner's Meeting
13. Dec. 2016, Paris

Individual participant level data (IPD)



Transparency and Access to research data are key factors of research

influences data quality and efficient use of data
„Community Driven Cross-Infrastructure Joint Research“

- Development of a **Pilot / Demonstrator** for re-analysis / meta-analysis of anonymised patient data
 - Part of a research environment
 - Storage and access of individual participant level data
 - Semantic annotation, metadata management, access management (rights and responsibilities)
 - Collaboration with other research infrastructures
 - Involvement of e-Infrastructures as service providers

EUDAT Services



B2DROP
Sync and Exchange Research Data

B2SHARE
Store and Share Research Data

B2SAFE
Replicate Research Data Safely

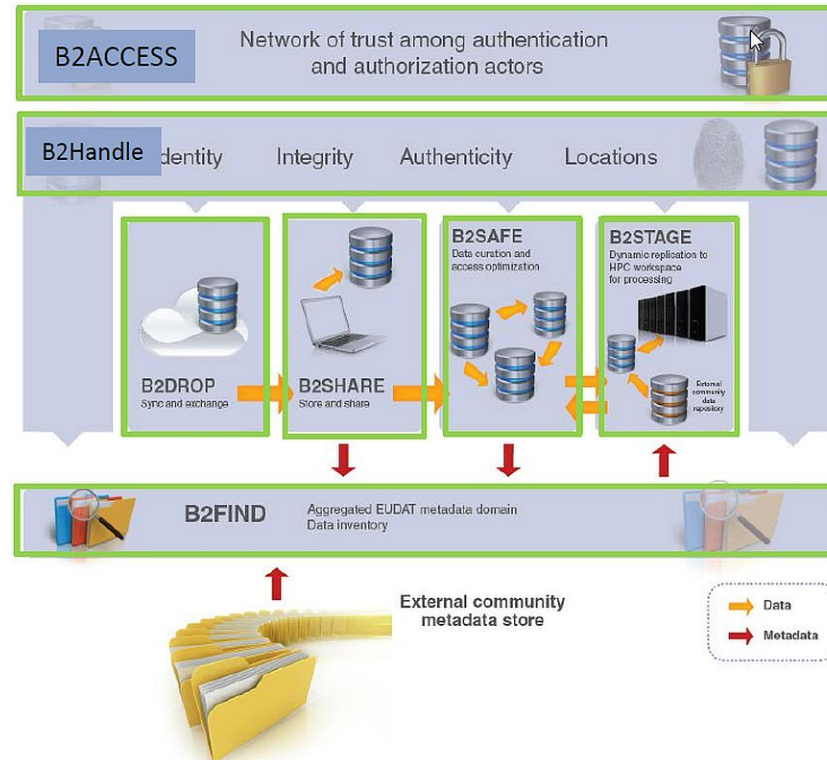
B2STAGE
Get Data to Computation

B2FIND
Find Research Data

B2HANDLE
Register your Research Data

B2ACCESS
Identity & Authorisation

B2 Service Suite

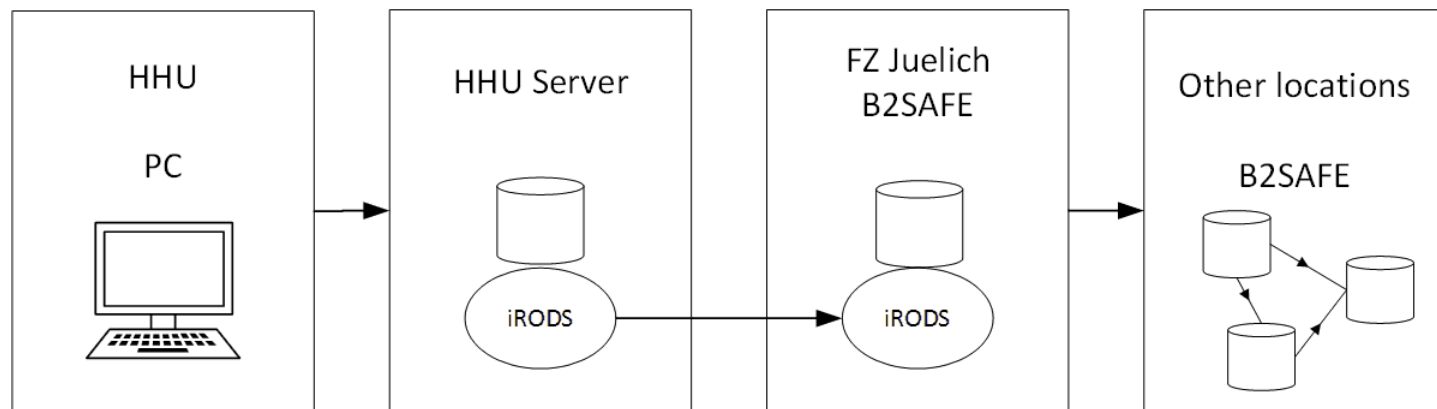


ECRIN Pilot / Demonstrator

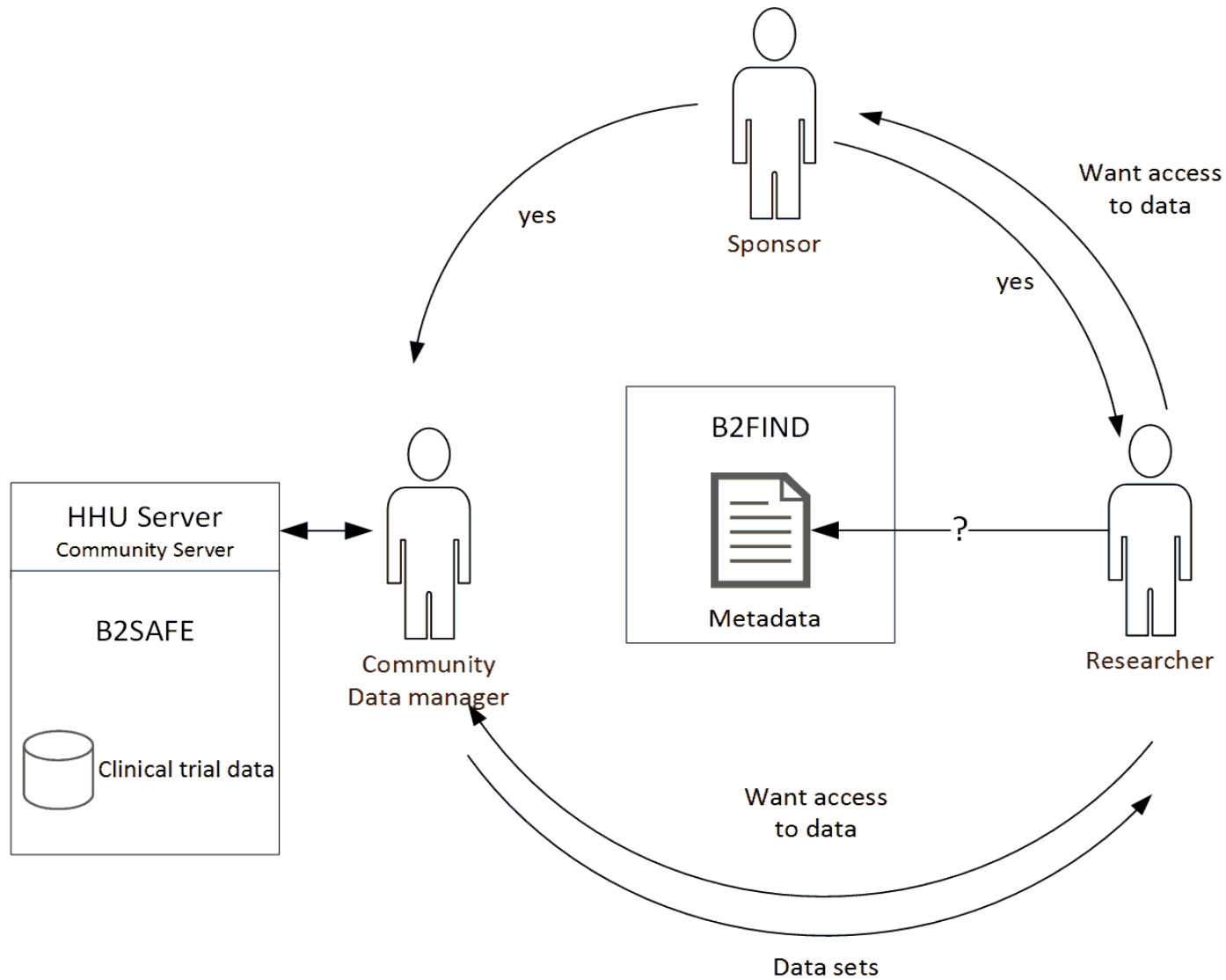
- Implementation of an IT platform and corresponding procedural solutions
- **B2SAFE** for long-term storage of clinical trials data
 - Possibility to add other EUDAT services according to requirements of the ECRIN community
 - Full control by data manager of the community
- But:
 - Encryption of data necessary
- Advanced Use Case
 - **B2FIND** for publication of metadata
 - **B2SHARE** for distribution of open information

EUDAT pilot architecture

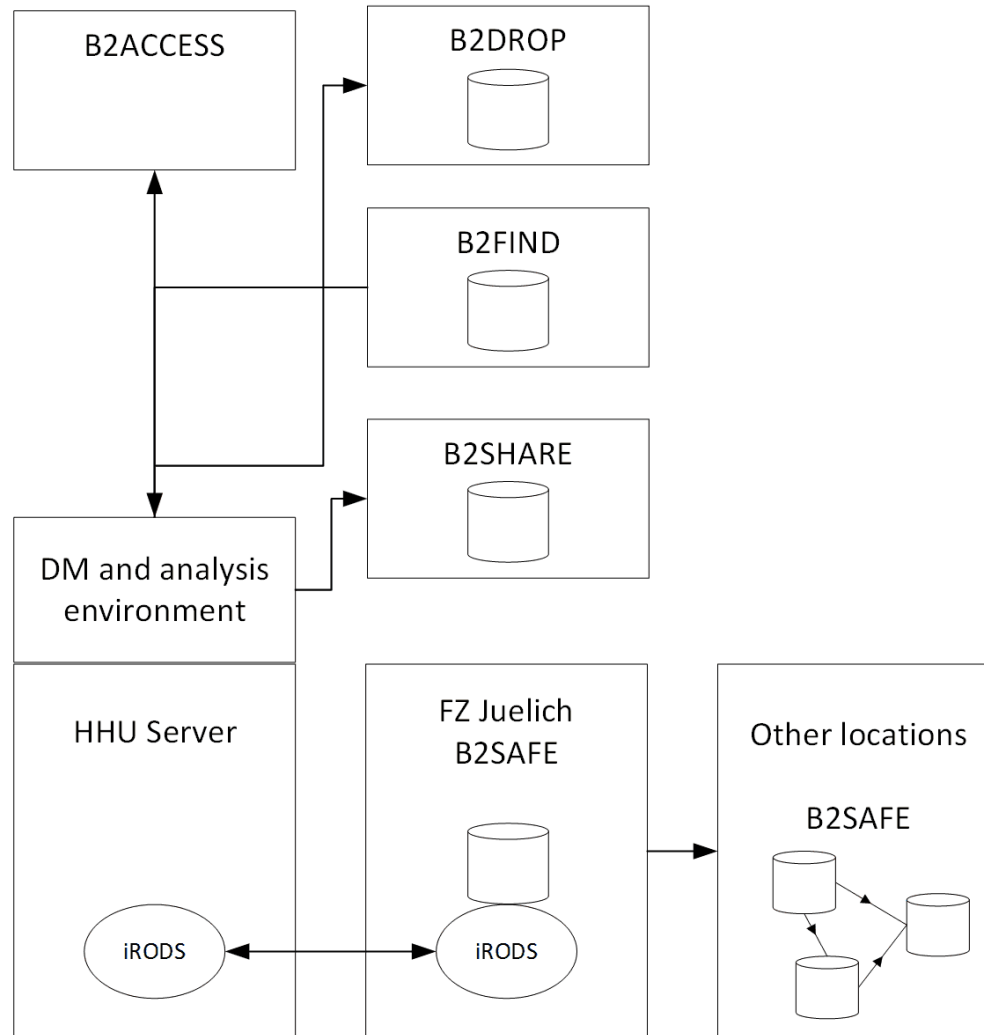
Basic configuration



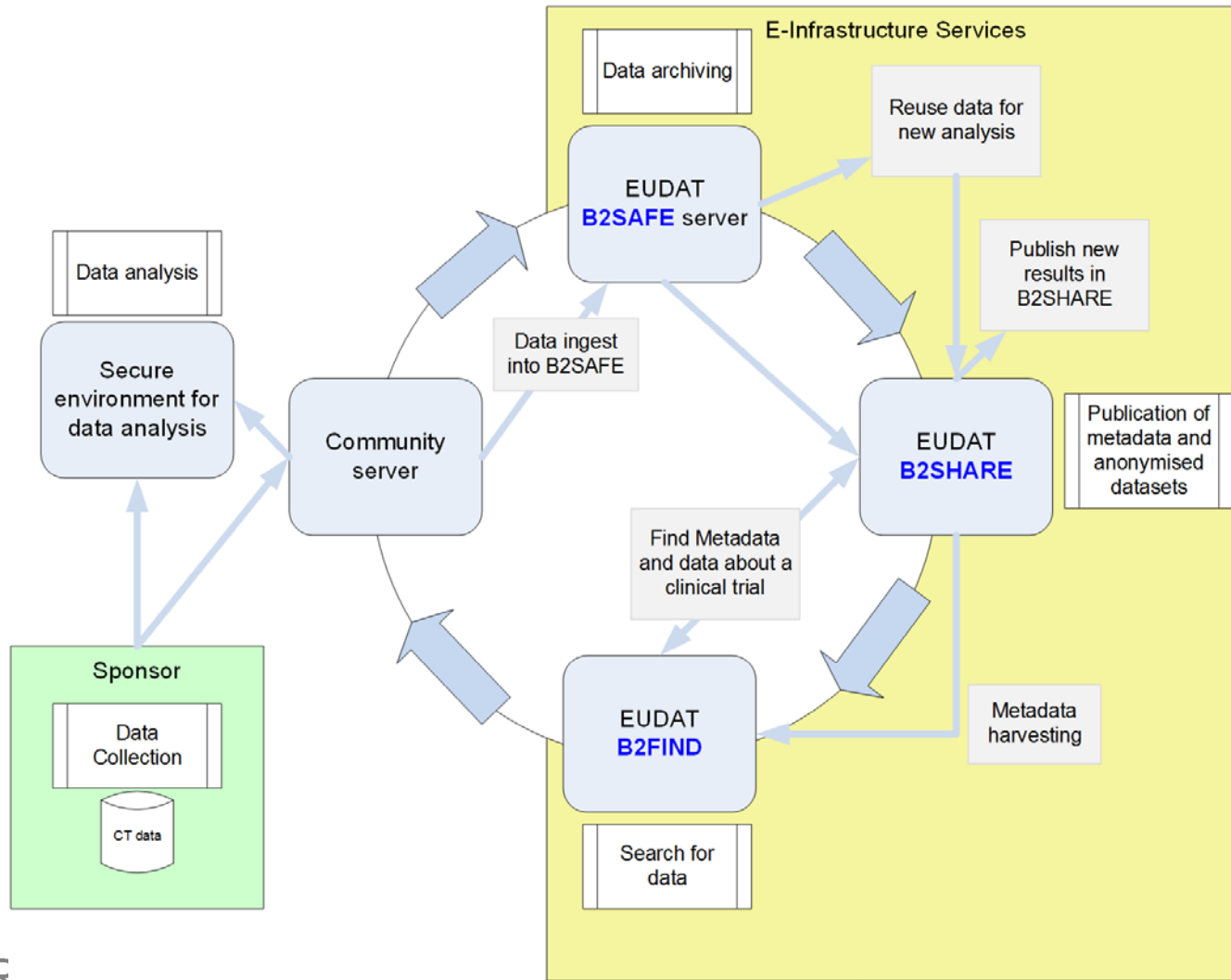
Use Case



Advanced configuration



Advanced scenario for pilot



EUDAT Working Group on Sensitive Data: problem statement

- **Sensitive data**
 - Needs special protection
 - Can only be made available under certain conditions: informed consent or anonymisation
 - Obligation to provide sufficiently strong access protection against any unauthorized user
- Unfortunately, most research infrastructures have only limited facilities to support sensitive data sharing

Sensitive data compliant EUDAT Services

- **B2SHARE** for secure storage
 - Currently open access only with possibility of embargoes
 - Metadata is always open access
 - Support for access control (not in current version)
- **B2SAFE** for secure long-term storage
 - Authentication and authorization available
 - Dedicated iRODS zones with sensitive data policies
 - Encryption / anonymisation of data
- Authentication / authorisation services,
deidentification, anonymisation services,
virtualisation

Thank you!

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