From Hospitals to Researchers: A Data-Trustee Infrastructure to Search and Use FHIR-Data for Retrospective Medical Research

Carolin Poschen, Joscha Grüger, Britta Berens,
Helene Christ, Lukas Meyer, Konstantin Knorr

Presenting: Carolin Poschen
Trier University of Applied Sciences, c.poschen@hochschule-trier.de

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Informatik
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S C H U L E
T R I E R

Introducing Carolin Poschen

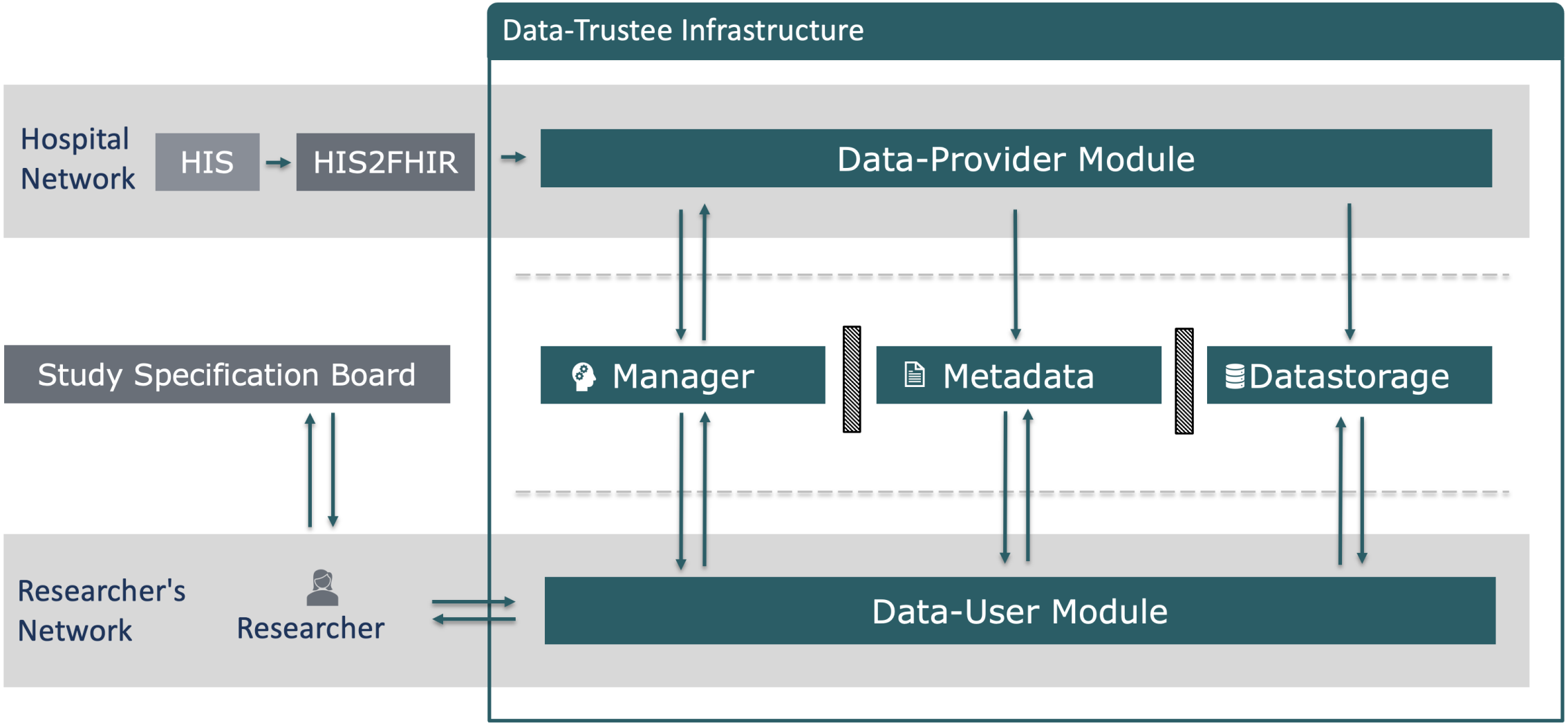
- B.Sc. Medical Informatics, Trier University of Applied Sciences
- M.Sc. Data Science, University of St. Thomas, MN, USA
- 01/2021 – 05/2023 various research projects in ML and AI
- Since 09/2023 Researcher and Project Lead at project DaTreFo at Trier University of Applied Sciences

Research project to design and develop a data-trustee infrastructure to manage and provide medical data

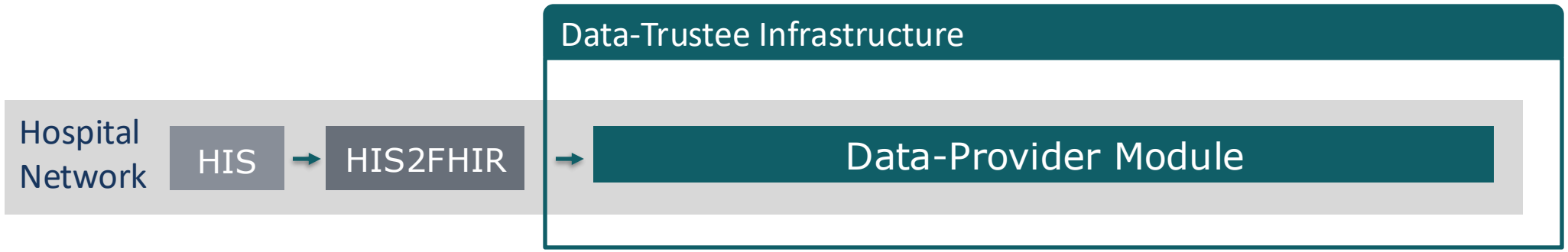
Secure data pipeline for privacy-compliant secondary use of medical data

Cooperation of Trier University of Applied Sciences with
Dedalus HealthCare GmbH and
German Research Center for Artificial Intelligence (DFKI)

DaTreFo Architecture

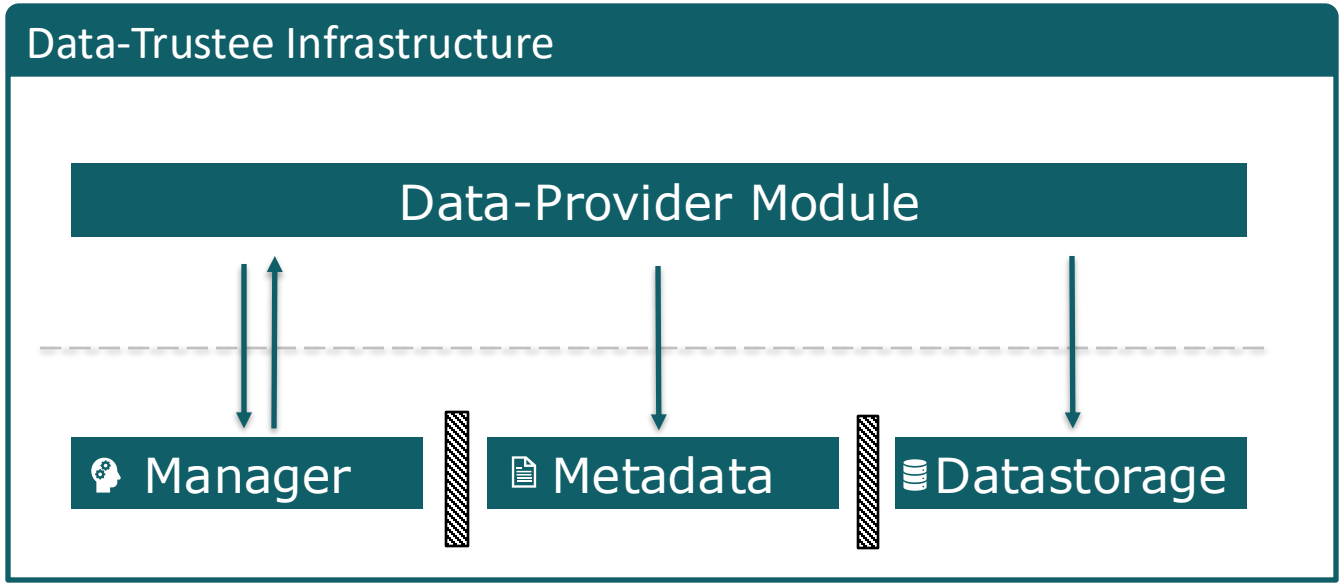


Data Split



- Data (medical, demographic, and consent) from the Hospital Information System (**HIS**) are extracted, transformed into the FHIR format (**HIS2FHIR**), and send to the Data-Provider Module (**DPM**)
- DPM splits data and preprocesses data to be stored in different modules

Data Split

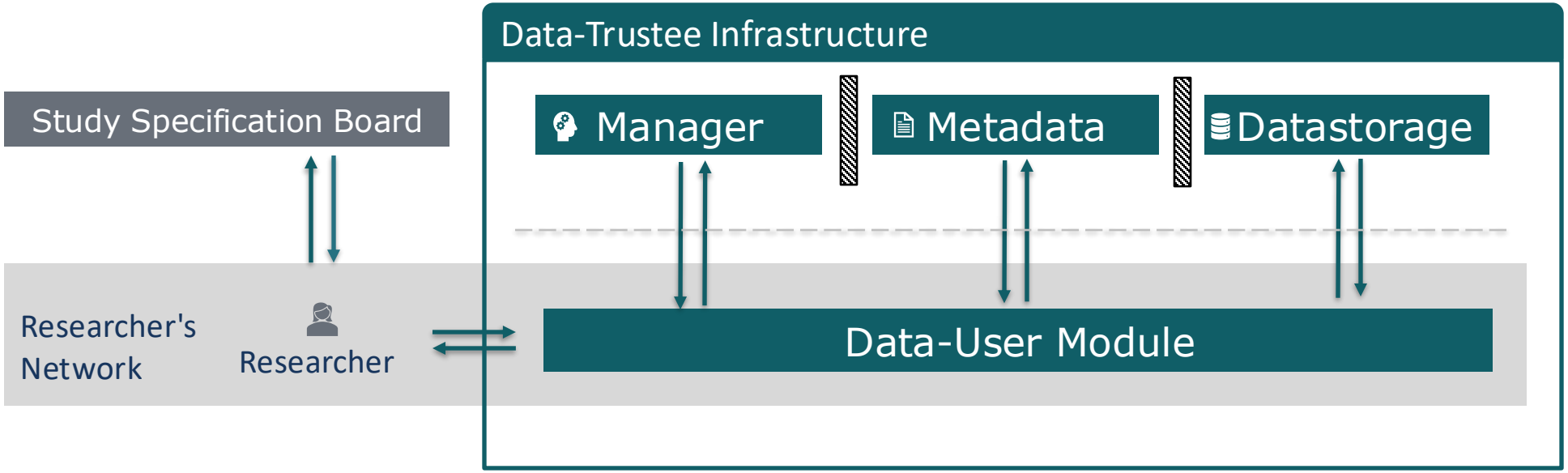


Demographic data, consent, and medical data IDs are stored in the **Manager** module

Metadata for each data entry are stored in the **Metadata** module

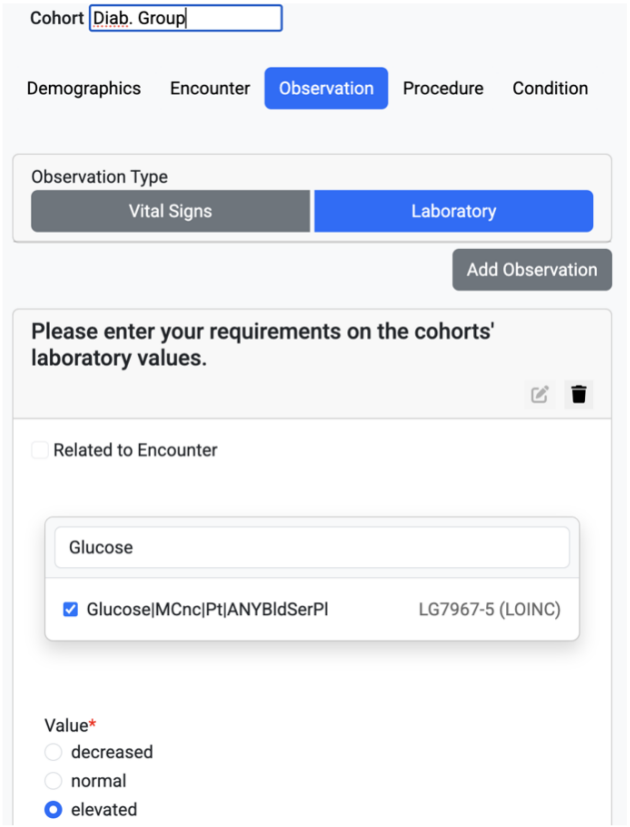
Raw medical data are encrypted and stored in the **Datastorage** module

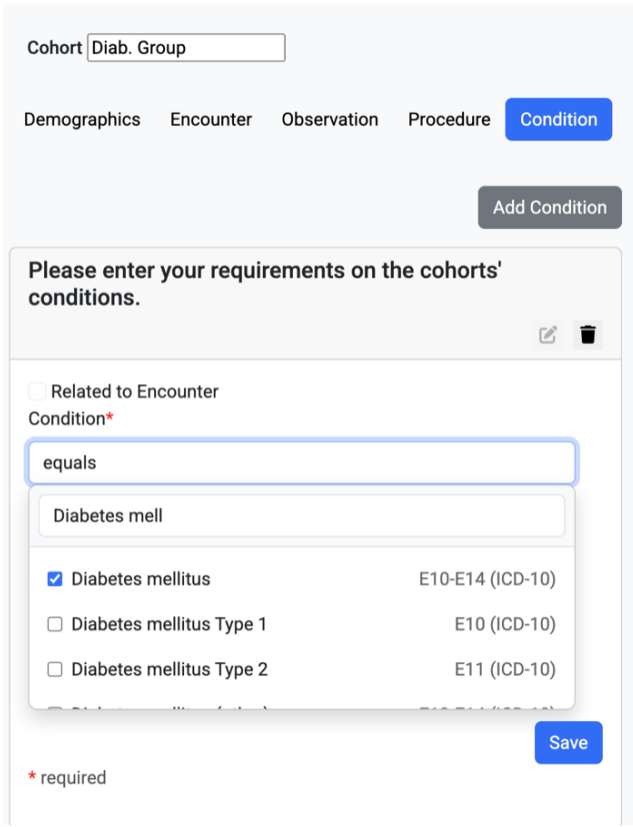
Data Access

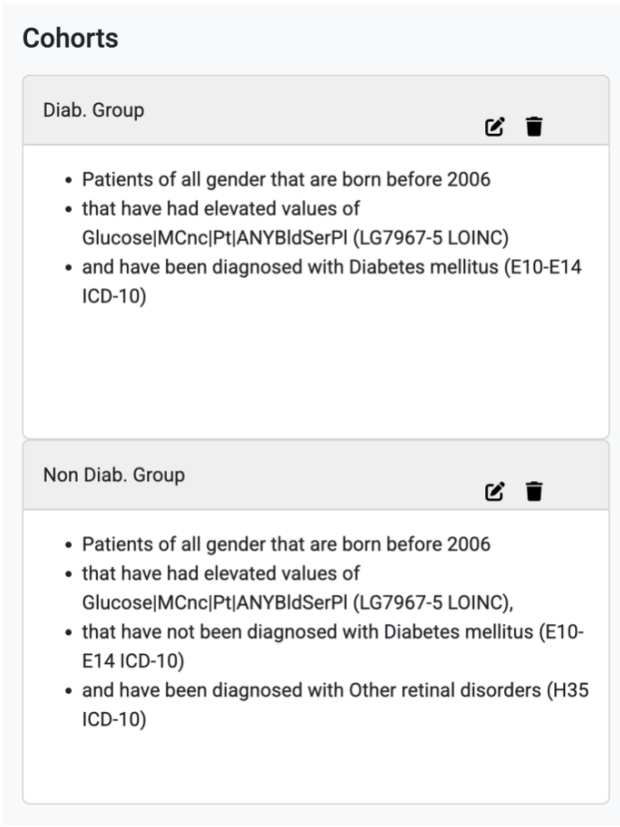


- Researchers receive a customized Data-User Module (**DUM**) with their Study Specification Document
- DUM starts automated search on demographic data and metadata
- After a successful search, data are downloaded from the Datastorage module

- Researchers provide study requirements and cohort descriptions
- Data requirements based on generalized data







Original Data

```
{
  "resource": {
    "resourceType": "Patient",
    "id": "Patient-1234",
    "birthDate": "2005",
    "gender": "male"
  }
}
```

Study Specification Document

```
{
  "resource": {
    "resourceType": "Patient",
    "id": "Patient-1",
    "birthDate": {
      "operator": "$lte",
      "value": "2006"
    },
    "gender": {
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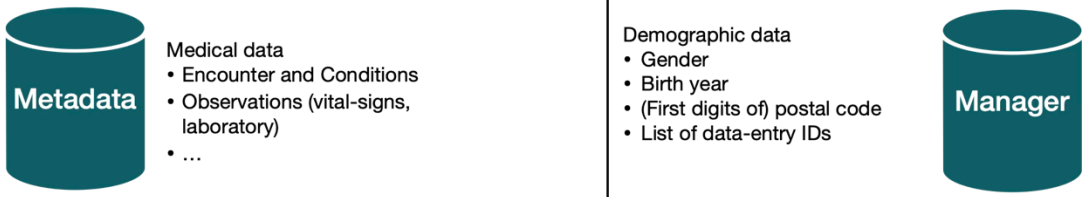
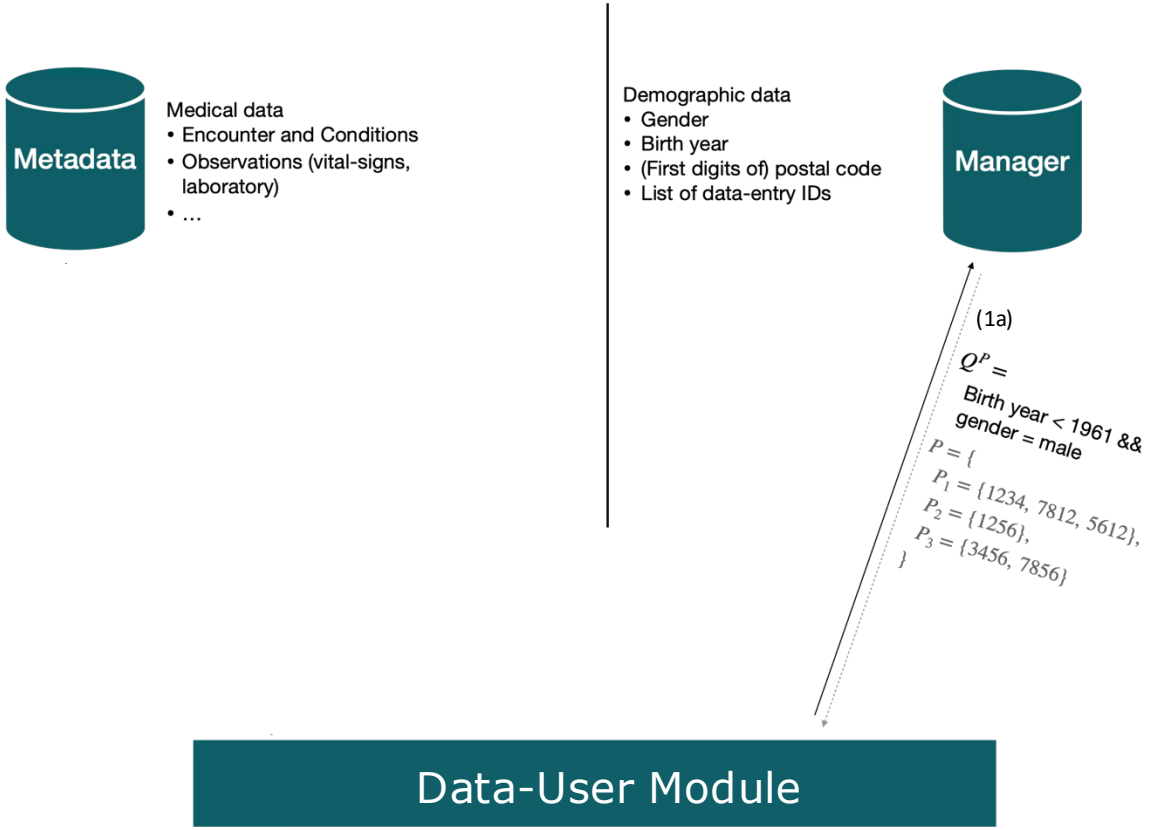
"Male patients born before 1961 that have had an inpatient encounter after 2017 due to atrial fibrosis and take or have taken beta blockers."



Data-User Module

"**Male patients born before 1961** that have had an inpatient encounter after 2017 due to atrial fibrosis and take or have taken beta blockers."



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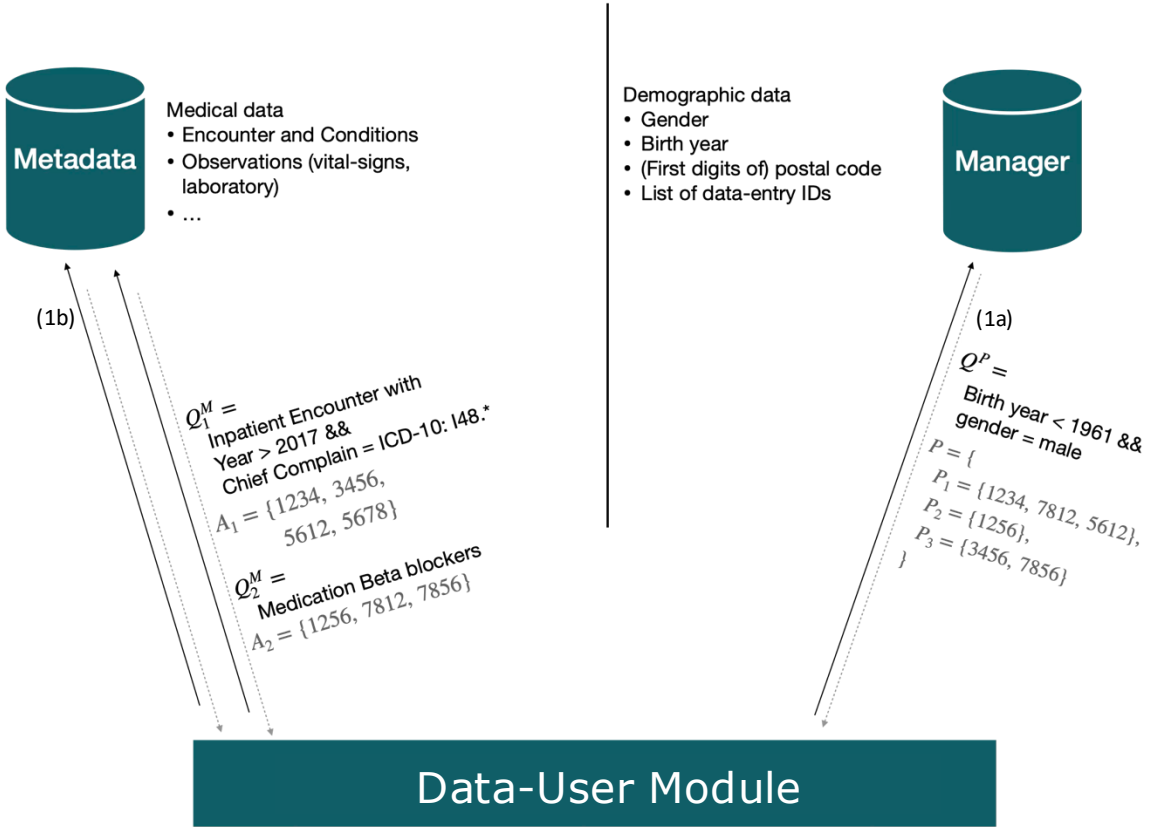

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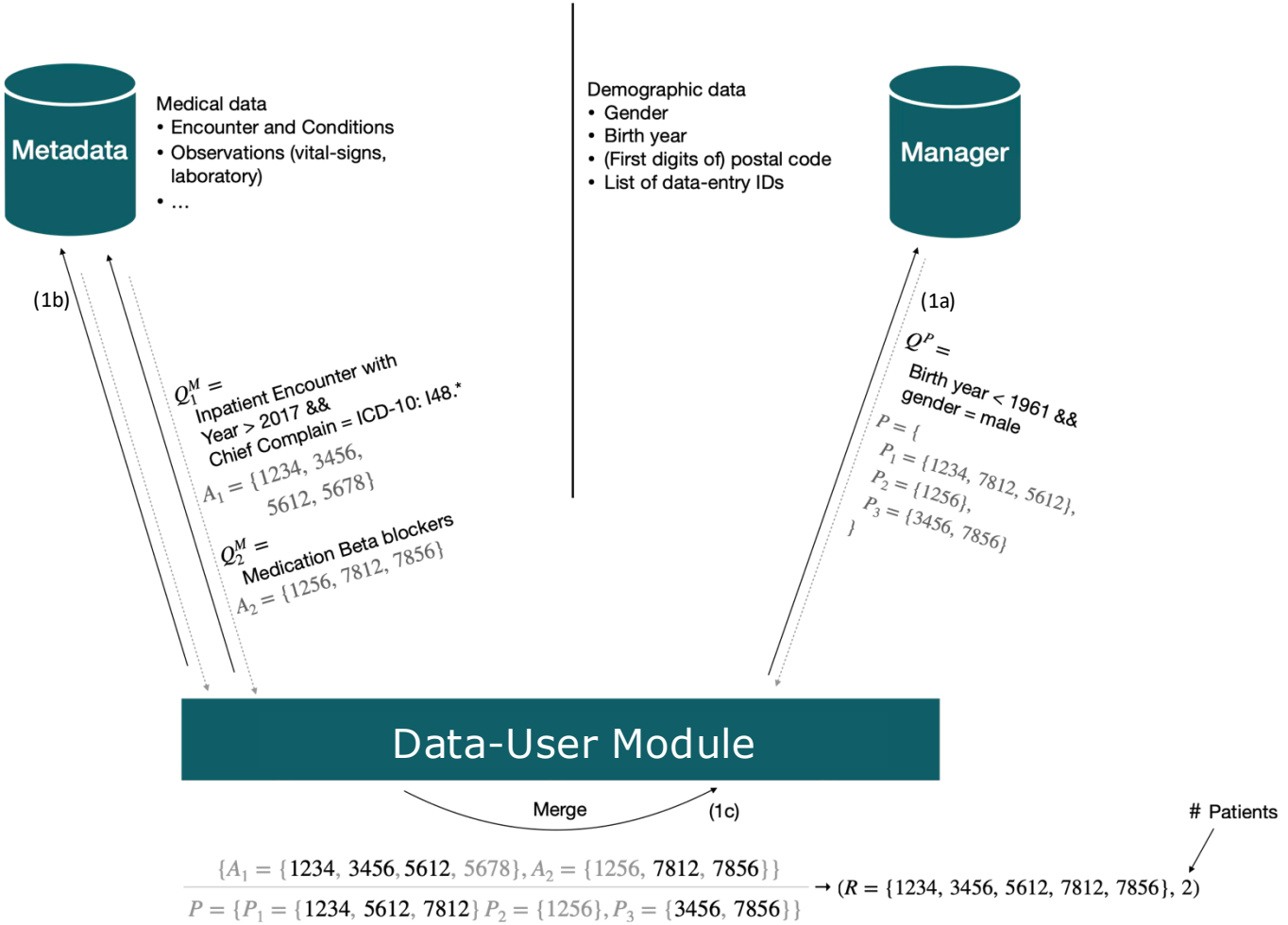

- If *enough* IDs match, in the Data-User Module:
  - Request medical data from Datastorage module
  - Request demographic data and keys from Manager module

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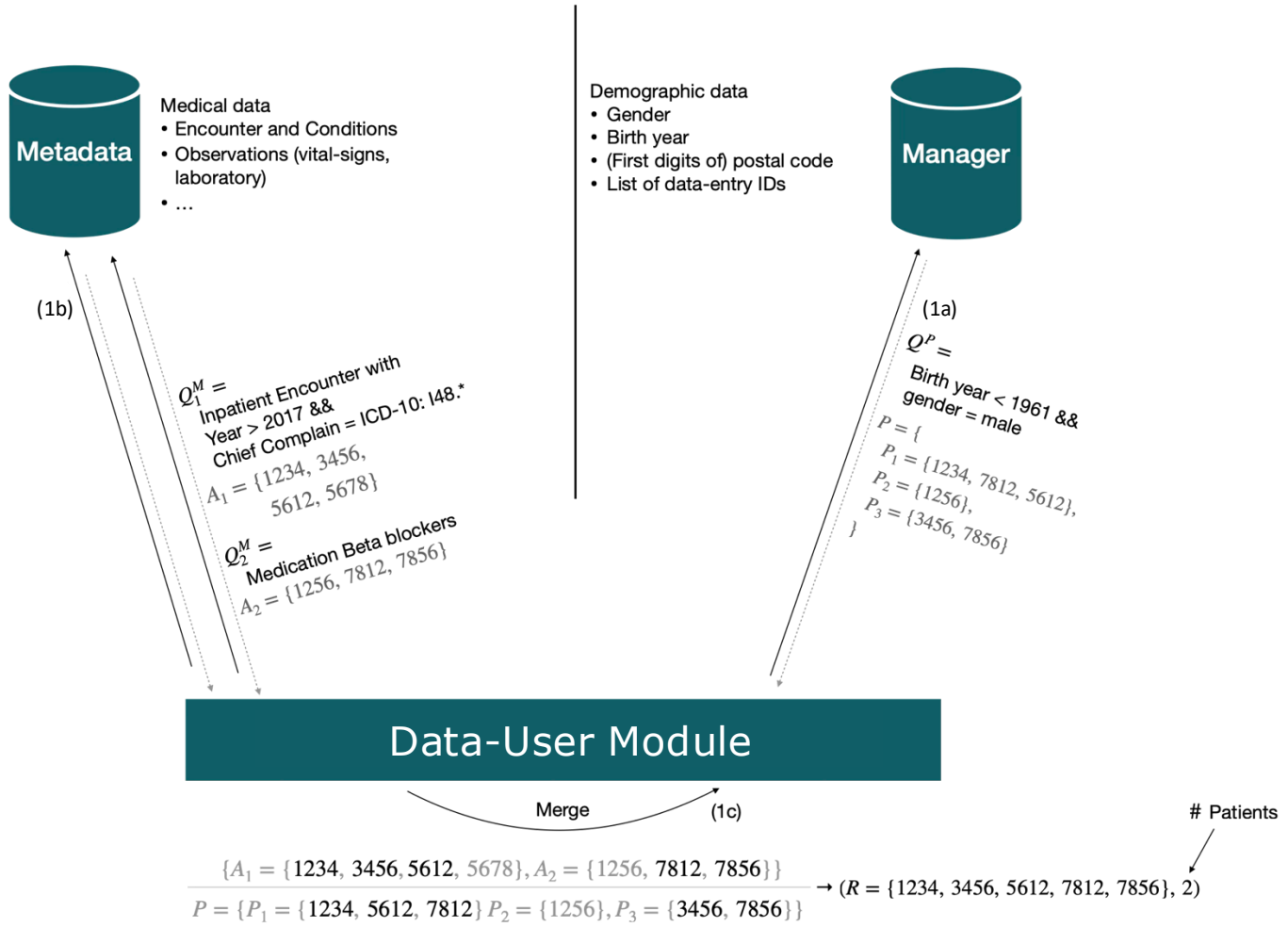

Strengths and Limitations

- ✓ Nearly fully-automated pipeline from hospital to researcher
- ✓ Separation of concern in core-DTI: no module has access to both patient identity and medical data
- ✓ FHIR resources enhance interoperability
- ✓ Privacy-preserving search allows access only to data meeting the study requirements
- ✗ Architecture requires own module for each participating hospital and researcher
- ✗ Generalized metadata simplifies data requirement specification but limits granularity for data queries

Further Discussion

Carolin Poschen
Trier University of Applied Sciences
Germany

c.poschen@hochschule-trier.de

LinkedIn Profile

Project Website

DaTreFo
Datentreuhänder mit geschützten Datenschätzen für die Forschung

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