

Patientenzentriertes Dashboard, Transformation longitudinaler Daten und Pseudonymisierung: Lösungen aus dem DIZ der Charité

MIRACUM-DIFUTURE School 2024

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Agenda

1. Patientenzentriertes FHIR-Dashboard
2. Transformation longitudinaler Daten mit HERALD
3. Pseudonymisierung mit ACE

1. Patientenzentriertes FHIR-Dashboard

Hintergrund

- Verfügbarkeit von FHIR in den DIZen
- Darstellung als patientenzentrierte „Read-Only-Akte“
- Macht das DIZ und den KDS „anfassbar“
- Hilft beim debuggen der FHIR-Daten bzw. Transformationsprozesse
- Perspektivisch Potenzial für klinischen Nutzen, bspw. Befundung
- Integration weitergehender Funktionen, wie Terminologien, und
- Integration unterschiedlicher Quellsysteme, bspw. für PROMs

Screenshots (1)

The screenshot shows a web-based FHIR Dashboard interface. At the top, there is a navigation bar with the 'iBIH MI' logo, a 'FHIR Dashboard' button, and a 'Home' button. On the right side of the top bar are 'Settings' and 'Logout' links. A pink arrow points from the text 'Suchfunktion' (Search function) in a purple box at the top right towards the search input field. Below the navigation bar is a search bar with a placeholder 'Search...' and a magnifying glass icon. The main content area consists of a grid of 12 cards, arranged in three rows of four. Each card contains patient information that has been redacted. The first card in each row is labeled 'REDACTED'. The other cards show patient details with some fields redacted:

| Patient ID | Date of birth | Gender | Address | Contact |
|------------|---------------|--------|----------|----------|
| [REDACTED] | [REDACTED] | FEMALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | FEMALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | FEMALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |
| [REDACTED] | [REDACTED] | MALE | REDACTED | REDACTED |

At the bottom left of the page, the URL 'https://dashboard.charite.de/patients' is visible.

Screenshots (2)

The screenshot shows a web-based FHIR dashboard interface. At the top, there's a navigation bar with the BIH MI logo, a 'FHIR Dashboard' button, and links for 'Home', 'Basic clinical parameters', 'Detailed labs and consent', 'Care intensity', 'Settings', and 'Logout'. Below this, patient details are displayed: 'Patient ID: [REDACTED]', 'Name: REDACTED', 'Date of birth: [REDACTED]', and 'Gender: FEMALE'. The main content area contains four data panels:

- Encounters**: A table showing patient encounters with columns for Admission, Discharge, Type, Reason, and Status. An arrow from a pink callout box points to the 'Discharge' column.
- Diagnoses and conditions**: A table listing diagnoses with columns for Date, Code, and Label. A detailed description of a diagnosis (R52.1) is shown in a tooltip.
- Procedures**: A table listing procedures with columns for Date, Code, and Label.
- Medication**: A table listing medications with columns for Date, Label, and Status.

Three pink callout boxes provide annotations:

- A box on the left points to the 'Discharge' column in the Encounters table with the text: "Möglichkeit der Einschränkung auf einen Fall".
- A box on the right points to the tooltip for the diagnosis R52.1 with the text: "Panels können frei angeordnet werden mit Persistenz im User-Profil".
- A box at the bottom right points to the search function within the panels with the text: "Suchfunktion innerhalb der Panels".

Screenshots (3)

BIH MI FHIR Dashboard Home Basic clinical parameters Detailed labs and consent Care intensity Settings Logout

Patient ID: [REDACTED] Name: REDACTED Date of birth: [REDACTED] Gender: FEMALE

| Labs and observations | | | | Trends of labs and observations | | | |
|-----------------------|-----------------------|-------|--------|---------------------------------|-----------------------|------------|--------|
| Date | Label | Value | Unit | Date | Label | Value | Unit |
| [REDACTED] 2024 | Albumin HP | 39.5 | g/l | [REDACTED] 2024 | CRP HP | [REDACTED] | mg/l |
| [REDACTED] 2024 | Bilirubin, gesamt HP | 0.39 | mg/dl | [REDACTED] 2024 | Calcium (HP) | [REDACTED] | mmol/l |
| [REDACTED] 2024 | CRP HP | 9.9 | mg/l | [REDACTED] 2024 | Creatinkinase (CK) HP | [REDACTED] | U/l |
| [REDACTED] 2024 | Calcium (HP) | 2.16 | mmol/l | [REDACTED] 2024 | GOT (AST) HP | [REDACTED] | U/l |
| [REDACTED] 2024 | Creatinkinase (CK) HP | 39 | U/l | [REDACTED] 2024 | GPT (ALT) HP | [REDACTED] | U/l |
| [REDACTED] 2024 | GOT (AST) HP | 76 | U/l | [REDACTED] 2024 | | [REDACTED] | |
| [REDACTED] 2024 | GPT (ALT) HP | 137 | U/l | [REDACTED] 2024 | | [REDACTED] | |
| [REDACTED] 2024 | Harnstoff HP | 31 | mg/dl | [REDACTED] 2024 | | [REDACTED] | |

Trend of Creatinkinase (CK) HP

| Consents | | | |
|-----------------|-----------------|--|------------|
| Date collected: | Active: | Type: | Version: |
| [REDACTED] 2023 | Yes | MII Broad Consent | 1.6d |
| Start | End | Policy | Permission |
| [REDACTED] 2023 | [REDACTED] 2053 | N/A | ✗ (deny) |
| [REDACTED] 2023 | [REDACTED] 2053 | ► MDAT wissenschaftlich nutzen EU DSGVO NIVEAU | ✓ (permit) |
| [REDACTED] 2023 | [REDACTED] 2053 | ► MDAT zusammenfuehren Dritte | ✓ (permit) |
| [REDACTED] 2023 | [REDACTED] 2028 | ► IDAT bereitstellen EU DSGVO NIVEAU | ✓ (permit) |
| [REDACTED] 2023 | [REDACTED] 2028 | ► IDAT erheben | ✓ (permit) |

Screenshots (4)

Nur eine
Spielerei

The screenshot displays a web-based FHIR dashboard for a patient. At the top, the URL is https://dashboard.charite.de/patients/[REDACTED]. The header includes the iBIH MI logo, a fire icon, and navigation links for 'FHIR Dashboard' and 'Home'. Below the header, patient details are shown: Patient ID [REDACTED], Name: REDACTED, Date of birth: [REDACTED], Gender: FEMALE. A 'Basic clinical parameters' section is partially visible. The main content area is divided into several sections:

- Encounters:** A table showing patient interactions. The columns are Admission, Discharge, Type, Reason, and Status. The data shows multiple entries for INPATIENT and AMBULATORY encounters, mostly marked as INPROGRESS.
- Charlson comorbidities:** A section showing comorbidity status. Buttons include 'Any Malignancy Except Skin' and 'Metastatic Solid Tumor'.
- Charlson comorbidity index:** A table listing properties and their values. Properties include Last contact (2024), Age (58), Charlson comorbidity index (9/37), In-hospital mortality rate (31.00), One year mortality rate (0.85), and Ten year survival rate (0.00).
- Care intensity:** Two horizontal bar charts comparing AMBULATORY and INPATIENT ENOUNTERS across different timeframes. The top chart shows data for 'Encounters within one year', and the bottom chart shows data for 'Encounters within five years'. The x-axis for the charts ranges from 0 to 8.

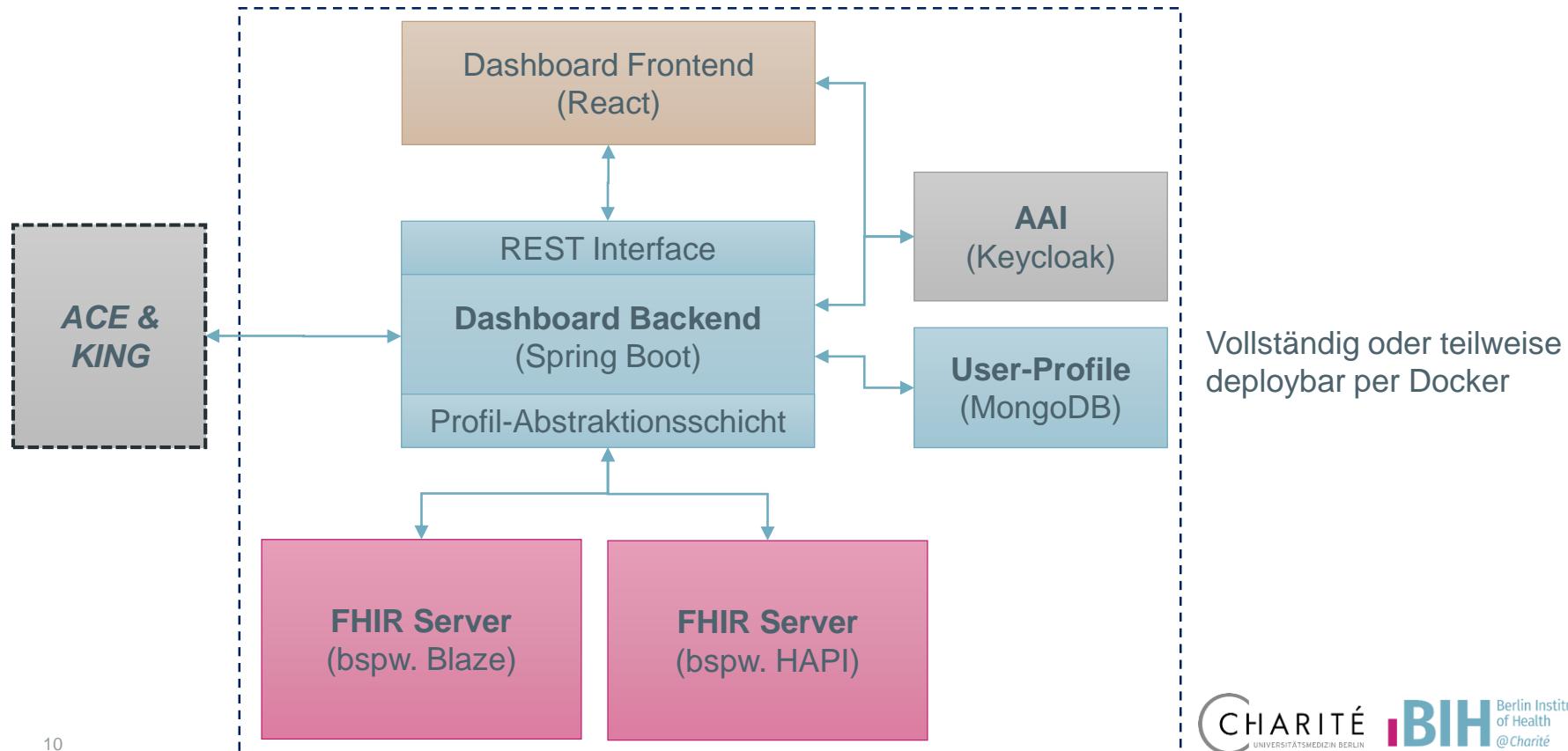
Screenshots (5)

The screenshot shows the 'Settings' page of the FHIR Dashboard. A pink callout box on the left points to the 'Information to display' section, which lists various clinical data items. The 'Language' dropdown is set to 'en-GB'. The 'Workspace labels' section defines three workspaces: 'Workspace 1' (Basic clinical parameters), 'Workspace 2' (Detailed labs and consent), and 'Workspace 3' (Care intensity). The 'Information to display' section includes the following items:

- Diagnoses and conditions
- Encounters
- Procedures
- Lab results and further observations
- Medication history
- Timeline of lab results and observations
- Clinical notes
- Diagnostic reports
- Trend of lab results and observations
- Charlson comorbidity index
- Charlson comorbidities
- Care intensity
- Consents

Layout options (rows x columns): 2 x 2

Architektur und Technologie



2. Transformation longitudinaler Daten mit HERALD

Herausforderungen

Klinische Routinedaten sind ...



...hierarchisch

...longitudinal

Viele Analysen benötigen...

| Patient ID | Age | Sex | FirstCancerDiagnosis | FirstChemoRadio | ProcedureCount | Medication | Hemoglobin | Glucose |
|------------|----------|----------|---|---|----------------|-----------------------------|----------------|-----------------|
| #Values: | #Values: | #Values: | #Values: | #Values: | #Values: | #Values: | #Values: | #Values: |
| 338) | 338) | 338) | (#Values: 338) | (#Values: 338) | (#Values: 338) | (#Values: 328) | (#Values: 151) | (#Values: 144) |
| 120820 | 51 | M | Non-small cell carcinoma of lung TNM stage 4 (disorder) | Combined chemotherapy and radiation therapy (procedure) | 9 | PACLitaxel 100 MG Injection | 5.9000 % | 69.00000 mg/dL |
| 121087 | 60 | M | Non-small cell carcinoma of lung TNM stage 4 (disorder) | Combined chemotherapy and radiation therapy (procedure) | 8 | Cisplatin 50 MG Injection | | |
| 121125 | 46 | F | Non-small cell carcinoma of lung TNM stage 4 (disorder) | Combined chemotherapy and radiation therapy (procedure) | 4 | PACLitaxel 100 MG Injection | | |
| 121287 | 46 | F | Non-small cell carcinoma of lung TNM stage 4 (disorder) | Combined chemotherapy and radiation therapy (procedure) | 7 | PACLitaxel 100 MG Injection | 6.00000 % | 82.00000 mg/dL |
| 121505 | 44 | F | Non-small cell carcinoma of lung TNM stage 4 (disorder) | Combined chemotherapy and radiation therapy (procedure) | 8 | Cisplatin 50 MG Injection | 6.90000 % | 117.00000 mg/dL |
| 121934 | 52 | F | Non-small cell carcinoma of lung TNM stage 4 (disorder) | Combined chemotherapy and radiation therapy (procedure) | 2 | Cisplatin 50 MG Injection | 6.30000 % | 83.00000 mg/dL |

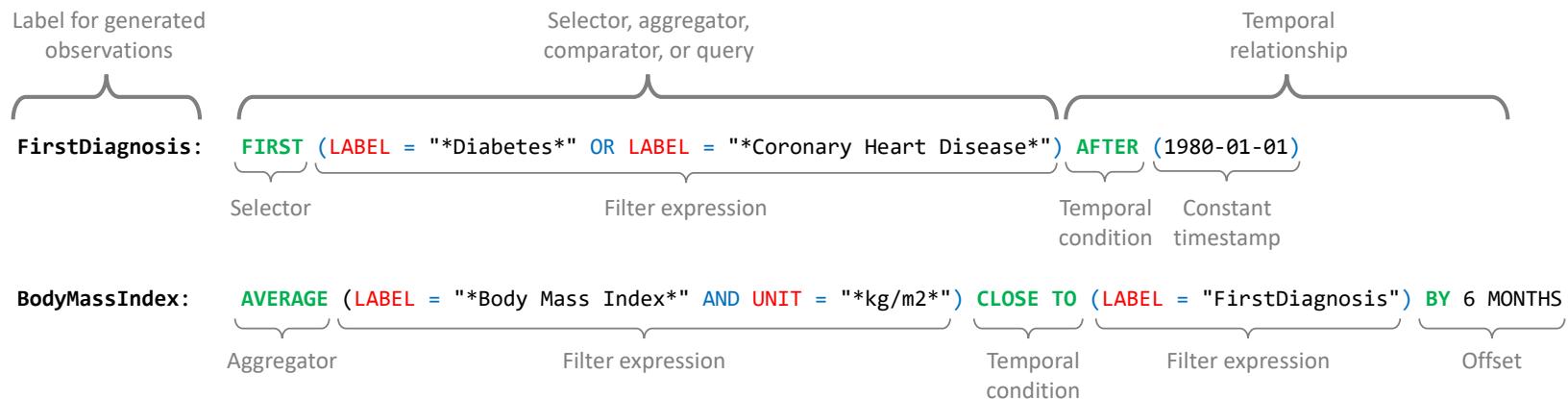
...tabulare Querschnittsdaten

Ansatz: Domänenspezifische Sprache HERALD

A.

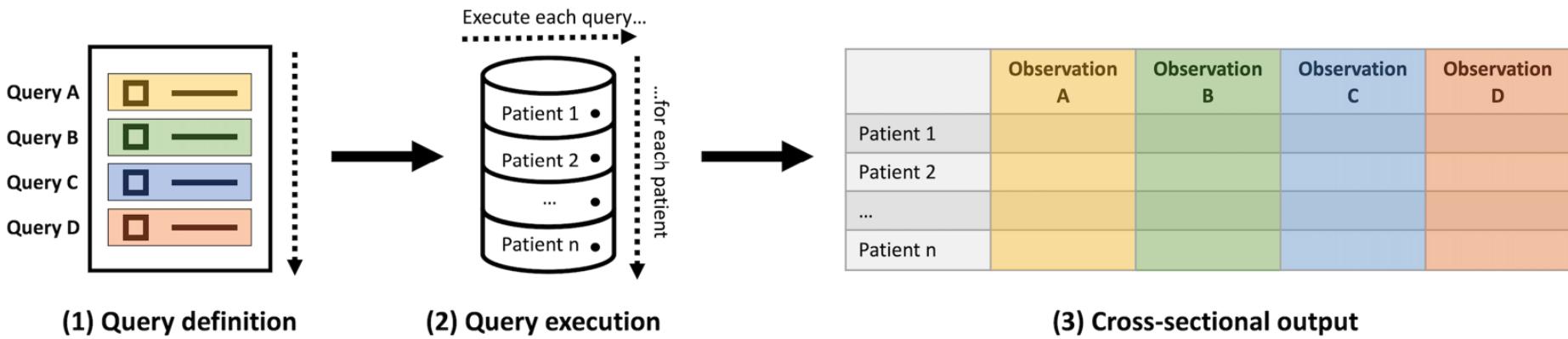
```
FirstDiagnosis: FIRST (LABEL = "*Diabetes*" OR LABEL = "*Coronary Heart Disease*") AFTER (1980-01-01)
Comorbidities: EXISTS (LABEL = "*Diabetes*") AND EXISTS (LABEL = "*Coronary Heart Disease*")
BodyMassIndex: AVERAGE (LABEL = "*Body Mass Index*" AND UNIT = "*kg/m2*") CLOSE TO (LABEL = "FirstDiagnosis") BY 6 MONTHS
LDLCholesterol: FIRST (LABEL = "*LDL Cholesterol*" AND UNIT = "*mg/dL*") AFTER (LABEL = "FirstDiagnosis") BY 4 WEEKS
HDLCholesterol: ANY (LABEL = "*HDL Cholesterol*" AND UNIT = "*mg/dL*") CLOSE TO (LABEL = "LDLCholesterol") BY 1 DAY
CholesterolRatio: RATIO BETWEEN (LABEL = "LDLCholesterol") AND (LABEL = "HDLCholesterol")
```

B.



Ausführung von HERALD Queries

- Eine Datendefinition ist eine Liste von Queries, die jeweils eine Beobachtung produzieren
- Jede Query verarbeitet alle Beobachtungen als Eingabe und erzeugt eine Beobachtung
- Queries werden nacheinander für jeden Patienten in der aufgeführten Reihenfolge ausgeführt
- Queries können sich auf Beobachtungen beziehen, die von früheren Queries erzeugt wurden



Beispielimplementierung: Datendefinition

Select cohort(s)

Coronary Heart Disease
 Diabetes

Specify observation(s) to analyze

| | | |
|------------------|--|--------|
| FirstDiag | FIRST (LABEL = "*Diabetes*" OR LABEL = "*Coronary Heart Disease*") AFTER (1980-01-01) | Edit ▾ |
| Comorbidities | EXISTS (LABEL = "*Diabetes*") AND EXISTS (LABEL = "*Coronary Heart Disease*") | Edit ▾ |
| BodyMassIndex | AVERAGE (LABEL = "*Body Mass Index*" AND UNIT = "*kg/m2*") CLOSE TO ("FirstDiag") BY 6 MONTHS | Edit ▾ |
| LDLCholesterol | FIRST (LABEL = "*Low Density Lipoprotein Cholesterol*" AND UNIT = "*mg/dL*") AFTER ("FirstDiag") BY 4 WEEKS | Edit ▾ |
| HDLCholesterol | ANY (LABEL = "*High Density Lipoprotein Cholesterol*" AND UNIT = "*mg/dL*") CLOSE TO ("LDLCholesterol") BY 1 DAY | Edit ▾ |
| CholesterolRatio | RATIO BETWEEN ("LDLCholesterol") AND ("HDLCholesterol") | Edit ▾ |

Patient age Patient sex [Quick add ▾](#) [Check specification](#)

Query-Editor

Specify an observation to be used in the analysis X

Label: FirstDiag

Selection

FIRST ▼ (LABEL = "*Diabetes*" OR LABEL

AFTER ▼ Date ▼ (1980-01-01) Without offset

Add rule Add group AND OR

Delete LABEL equal *Diabetes*

Delete LABEL equal *Coronary Heart Disease*

Cancel OK

Ontologie-Ansicht

Select field or value X

Search... Include homonyms Include specializations

- Conditions

- Diagnosis
 - Coronary Heart Disease
 - Value: Coronary Heart Disease
 - Diabetes
 - Value: Diabetes

+ Demographic Information

- Observations

- Body Mass Index
 - Unit: kg/m²
- Low Density Lipoprotein Cholesterol
 - Unit: mg/dL
- High Density Lipoprotein Cholesterol
 - Unit: mg/dL

Beispielimplementierung: Analysen und Visualisierungen

A. Data quality report

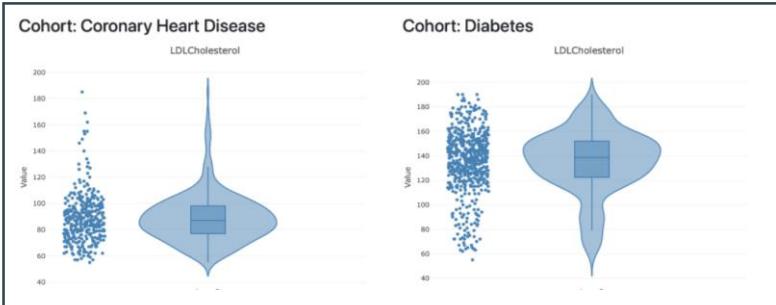
Data quality report for Cohort Coronary Heart Disease

| Label | Completeness (%) | Missing rate (%) | Uniqueness (%) | Data Type | Unit |
|------------------|------------------|------------------|----------------|-------------|-------------------|
| FirstDsg | 100.00 | 0.00 | 99.56 | Categorical | Unknown |
| Comorbidities | 100.00 | 0.00 | 100.00 | Categorical | Boolean |
| BodyMassIndex | 66.18 | 33.82 | 100.00 | Decimal | kg/m ² |
| LDLCholesterol | 48.25 | 51.75 | 99.70 | Integer | mg/dL |
| HDLCholesterol | 45.92 | 54.08 | 99.68 | Integer | mg/dL |
| CholesterolRatio | 45.92 | 54.08 | 100.00 | Decimal | (mg/dL) / (mg/dL) |

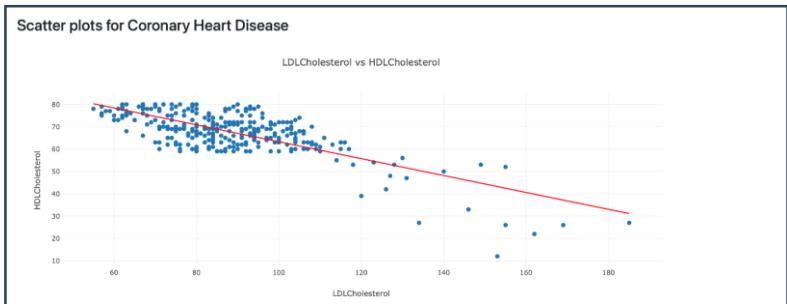
Data quality report for Cohort Diabetes

| Label | Completeness (%) | Missing rate (%) | Uniqueness (%) | Data Type | Unit |
|------------------|------------------|------------------|----------------|-------------|-------------------|
| FirstDsg | 100.00 | 0.00 | 99.85 | Categorical | Unknown |
| Comorbidities | 100.00 | 0.00 | 100.00 | Categorical | Boolean |
| BodyMassIndex | 76.30 | 23.70 | 99.80 | Decimal | kg/m ² |
| LDLCholesterol | 80.48 | 19.52 | 99.81 | Integer | mg/dL |
| HDLCholesterol | 78.69 | 21.31 | 99.43 | Integer | mg/dL |
| CholesterolRatio | 78.69 | 21.31 | 100.00 | Decimal | (mg/dL) / (mg/dL) |

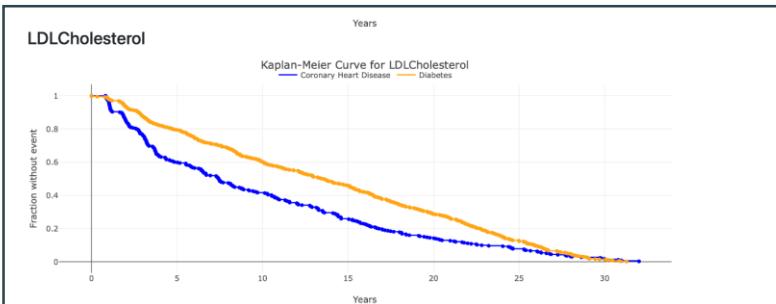
B. Cohort comparison



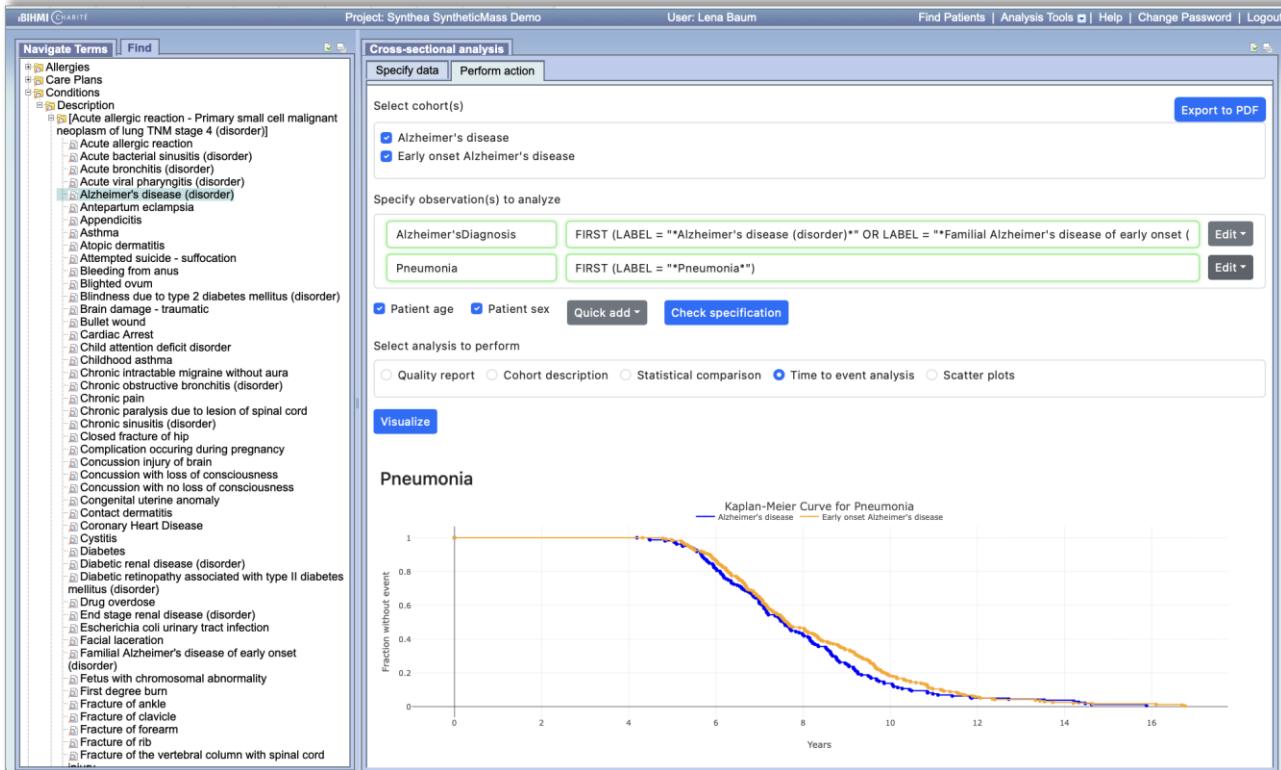
C. Scatter plot



D. Time-to-event analysis



Beispielimplementierung: i2b2-Integration



Weiterführende Informationen und Online-Demo

HERALD Project - Web Demo



HERALD

HERALD (Human-centric Extraction for Research and Analysis of Longitudinal Data) is a query language designed to facilitate the extraction and aggregation of longitudinal health data into cross-sectional tables suitable for statistical analysis and machine learning. Its syntax closely mirrors natural language. The implementation consists of a parser and an execution engine, combined with a graphical query editor, and analytics functionalities. Below you'll find three different examples provided as a web demo, that are based on subsets of the synthetically generated patient records from the [Synthea SyntheticMass dataset](#).

Example 1: Coronary Heart Disease vs. Diabetes
A comparative analysis between two cohorts of patients with a primary diagnosis of either coronary heart disease or type 2 diabetes. The example supports a comparison of demographic variables (age, sex) and common risk factors (BMI, LDL and HDL cholesterol levels) as well as comorbidities.

[Open](#)

Example 2: Alzheimer's Disease
Comparison of patients with early-onset Alzheimer's with those diagnosed at a later stage. The example supports a comparison of basic demographic information (age, sex), Mini-Mental State Examination (MMSE) scores to assess cognitive function, pneumonia incidence, care plans and medications.

[Open](#)

Example 3: Lung Cancer
Comparison of patients diagnosed with non-small cell carcinoma of the lung of TNM stages 1 to 4, who have received combined chemotherapy and radiation therapy. Additional information on basic demographics (age, sex), BMI, related medication and selected lab values (Hemoglobin, Glucose and eGFR) is provided.

[Open](#)

Explore our Code on GitHub

[HERALD Lang](#) Repository with the core components of HERALD, including a parser, an execution engine, and a graphical editor.

[HERALD Demo](#) Repository containing the code of this online demo.

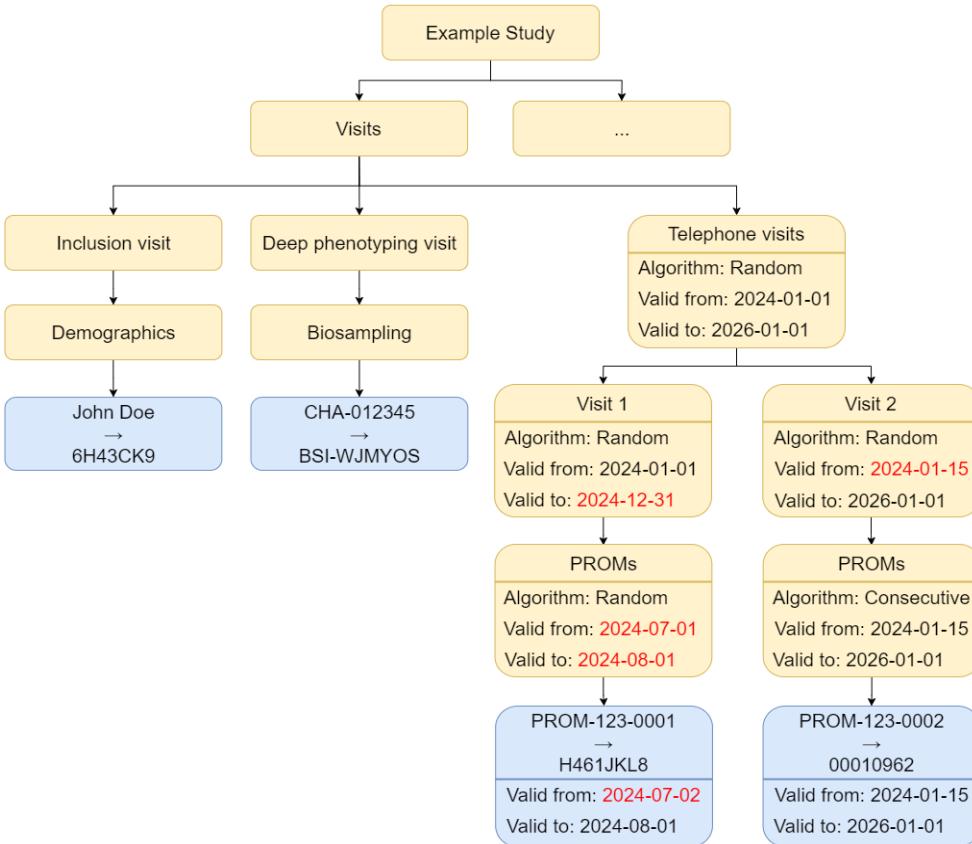
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<https://www.herald-lang.org>

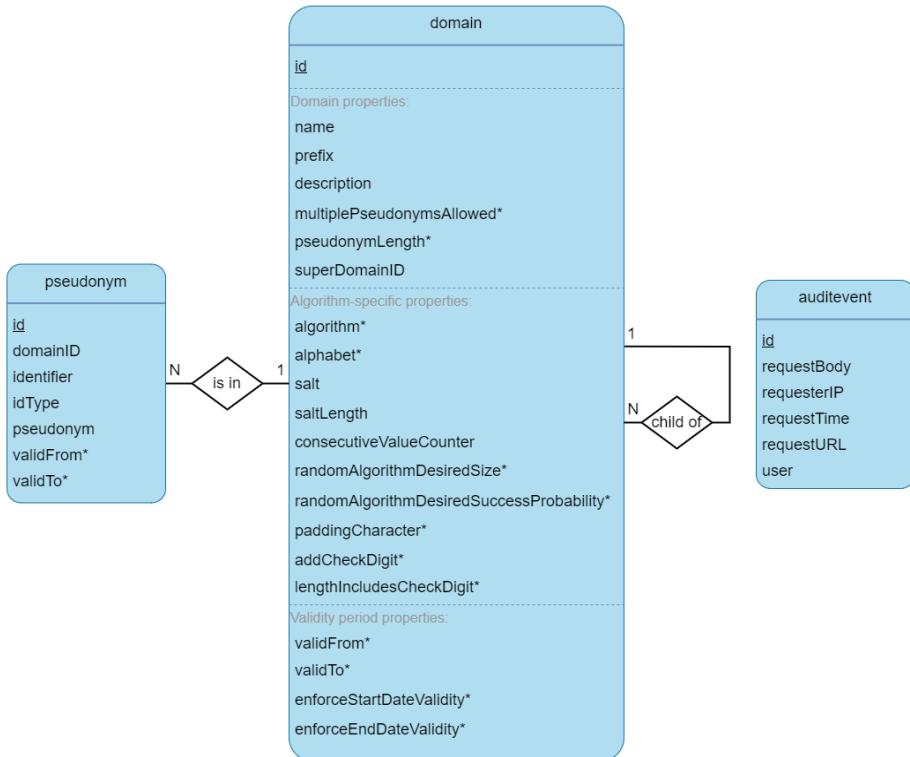
3. Pseudonymisierung mit ACE

Herausforderung und Lösung



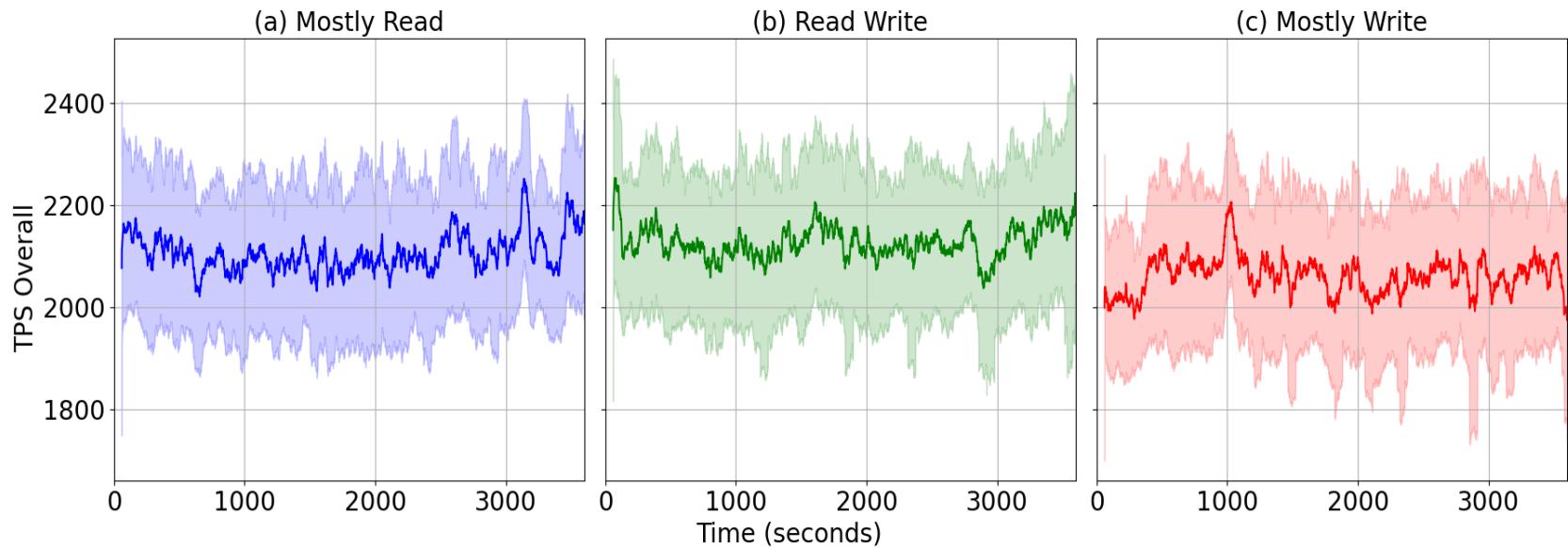
- Komplexe Anforderungen an die Pseudonymisierung (u.a. primär, sekundär, Datenarten, Audit Trail, Gültigkeiten)
- Hohe Skalierbarkeit benötigt (bspw. im DIZ der Charité 4 Mio. Patienten, 16 Mio. Fälle)

Design und Features



- Hierarchisches Domänenmodell mit Gültigkeitszeiträumen und Vererbung
- Docker, PostgreSQL, Spring Boot, Keycloak
- Berechtigungsmodell: Nutzer x Domäne x Operation
- Konfigurierbar:
Pseudonymisierungsalgoritmus,
Alphabet, Checksums
- Vollständiger Audit-Trail

Performance



Weiterführende Informationen

THS-MED  TrustDeck A 

Open-Source-Werkzeuge für Treuhandstellen in der Translationalen Medizin



ACE
Advanced Confidentiality
Engine

ACE bietet eine robuste Lösung für Pseudonymisierungsdienste und zeichnet sich durch seine hohe Skalierbarkeit und einen integrierten Audit-Trail aus. Seine Architektur ermöglicht die Bildung von Domänenhierarchien mit vererbaren Eigenschaften.



KING
Key Index of Names and
General Identification
Numbers

KING bietet fortgeschrittene Funktionen im Bereich Identitätsmanagement. Es ist hochskalierbar und in hohem Maße konfigurierbar. Verschiedene Record-Linkage-Verfahren sind integriert, um die Bedürfnisse unterschiedlicher Anwendungsfälle



HEART
Holistic Electronic
Agreement Recording
Tool

HEART ist ein spezialisiertes Tool zur elektronischen Erfassung und Verwaltung von Einwilligungsdokumenten. Es ist flexibel konfigurierbar, unterstützt die semantische Annotation von Einwilligungsdokumenten und ist für den Einsatz auf Tablets und

<https://www.ths-med.de>

Danke für Ihre Aufmerksamkeit!

mi.bihealth.org
medic.charite.de

