

The Alleviate Project: Federated Discovery of Chronic Pain Data

Philip Appleby¹, Erum Masood¹, Gordon Milligan¹, Esmond Urwin², Philip Quinlan², Christian Cole^{1,3}

¹ Health Informatics Centre, University of Dundee, Scotland UK

² Digital Research Service, University of Nottingham, UK

³ Population Health and Genomics, School of Medicine, University of Dundee, Scotland UK

Background

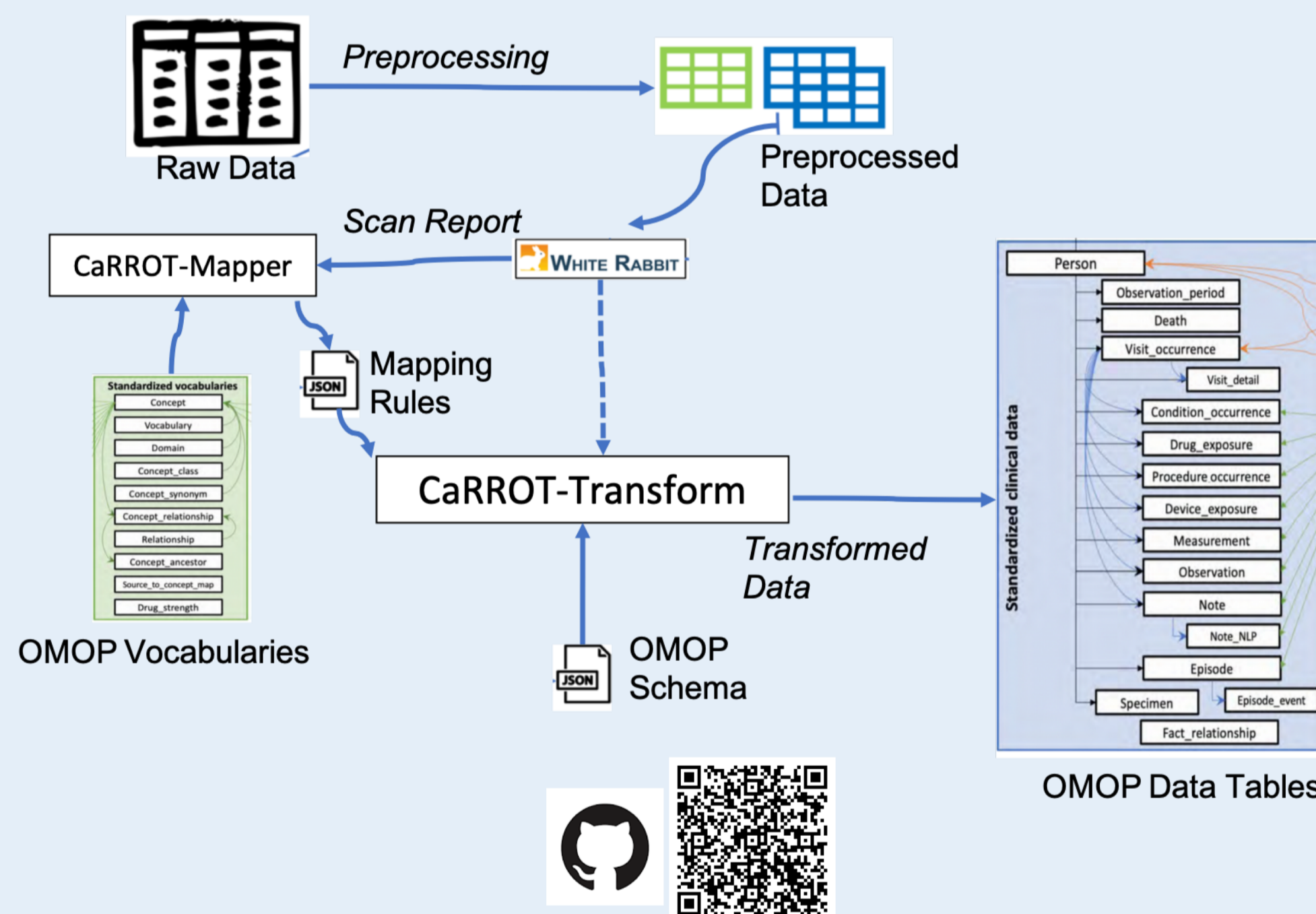
Pain data sets are currently held by a number of organisations in the UK, collected for specific pain projects or as part of wider studies. The principle problem is that such data tend to be stored in discrete silos and are difficult to discover and access from external bodies.

The Solution

The Alleviate project makes data sets with pain-related content, controlled by various organisations, available for query. There are *Federated Data Hubs* to enable common queries. Standardisation is to the **Observational Medical Outcomes Partnership Common Data Model version 5.3.1 (OMOP CDM 5.3.1)**.

Semi-automated standardisation methodology.

- **Pre-Processing:** dates, units and numeric values, remove duplicates, interpolate missing data (where possible) and pseudonymize personal information.
- **CaRROT Mapper:** centralized web app. Uses metadata (produced by the OHDSI WhiteRabbit scanning tool) to build term and structural mappings from standard vocabularies defined in the OMOP Common Data Model.
- **CaRROT Transform:** command line tool installed at Data Partner sites. Transforms data using mappings generated by CaRROT Mapper.



The Cohorts

The Alleviate project has:

- Registered 21 datasets with pain content on HDR UK's Metadata Catalogue
- Converted 6 pain-specific datasets for query via the HDR-UK Innovation Gateway, Cohort Discovery Tool
- Plus pain content in 3 large cohorts: SHARE, Generation Scotland, Twins UK

Dataset	Person Count
TWINS UK	~15k
DOLORisk UK	~10k
GOAL	~3100
Webex	~140
Omega-3	~75
MICA	~70
CTS-PINS	~150



>300,000



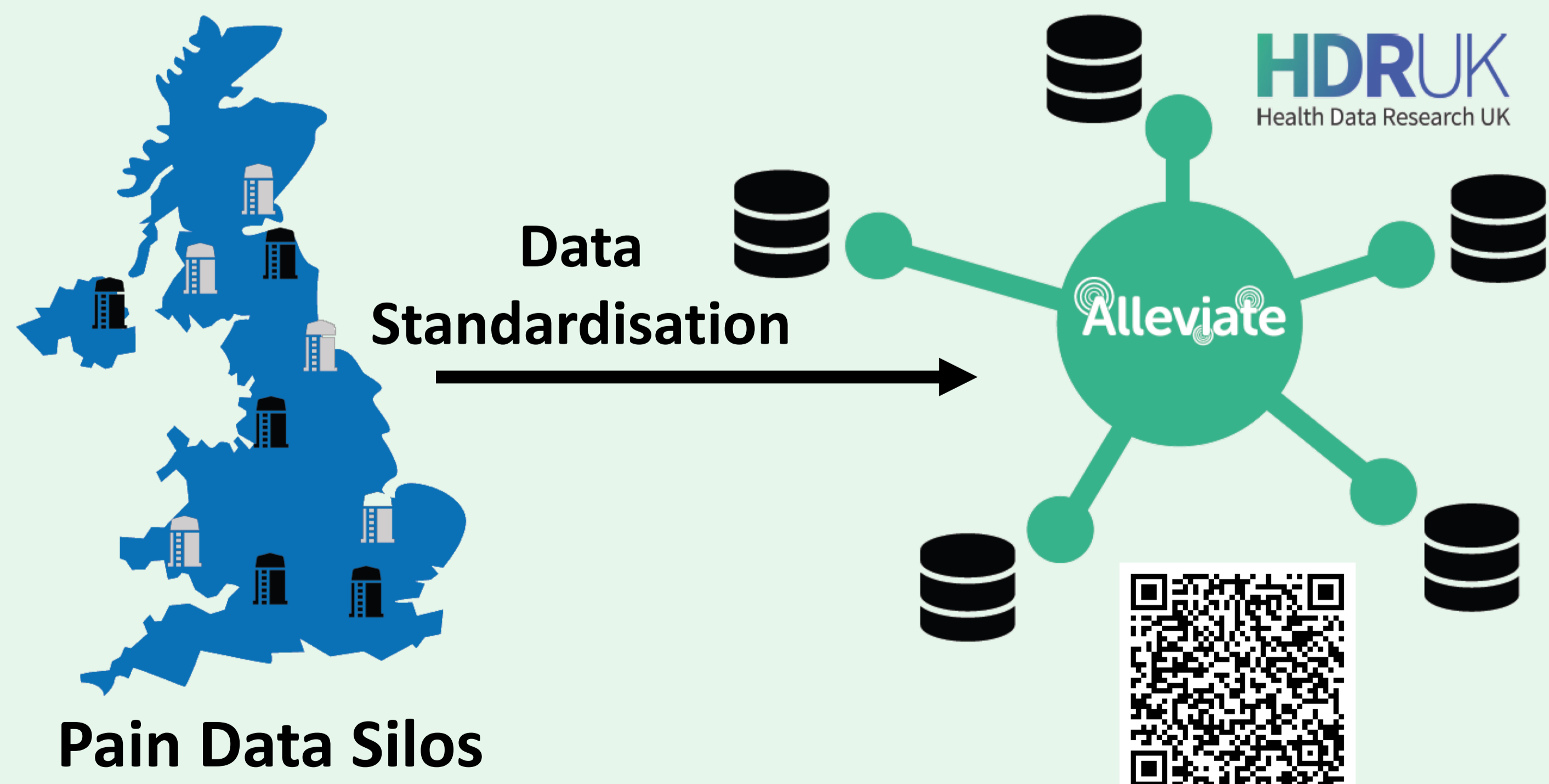
>36,000

Selected most-reported Pain Data Items

Dataset	Pain Description	Concept Id	Count
TWINS UK	Heat Pain Threshold Value	3959539	2614
GoDARTS DOLORisk	Pain Catastrophizing Worry	3956960	1806
GOAL	Pain finding at anatomical site	4132926	3165
MICA	EuroQol five dimension three level pain/discomfort score	701336	71
SHARE	acetaminophen 500 MG Oral Tablet *	19020053	1.6m

* Pain relief reported as a proxy

Alleviate - Overview



Data Discovery

- Federated data are standardized to OMOP CDM.
- Approved researchers can safely and securely perform federated data queries using the HDR UK Cohort Discovery tool.
- The discovery tool can query multiple datasets from across the UK at the same time to identify suitable data for use in research.
- Following data discovery, researchers apply to data controllers for access to the relevant study data.

Trusted Research Environments

- Alleviate OMOP Data can be imported into Trusted Research Environments.

Findable

Accessible

Interoperable

Reusable