

The Alleviate Advanced Pain Discovery Platform Data Hub

A national resource for accessing and sharing pain data

Gordon Milligan¹, Christopher Hall¹, Philip Appleby¹, Erum Masood¹, Gillian Martin², Jillian Beggs, Antony Chuter, Tom Giles³, Armando M Villalon³, Philip Quinlan³, Christian Cole^{1,4}

¹Health Informatics Centre, University of Dundee, Dundee, Scotland, UK ²Tayside Clinical Trials Unit, School of Medicine, University of Dundee, Dundee, Scotland UK ³Digital Research Service, University of Nottingham, Nottingham, UK ⁴Population Health & Genomics, School of Medicine, University of Dundee, Dundee, Scotland, UK



The Advanced Pain Discovery Platform (APDP) Data Hub

Abstract

There are many clinical and non-clinical datasets investigating pain that have been collected by researchers over many years, however, finding and getting access to them is challenging. The data are siloed in hard-to-reach places, in non-standard formats, and it is not possible to assess how relevant they are before getting access. This is a barrier to the pain research community and results in duplication of effort. It does not have to be this way and there are alternative solutions available. The Alleviate Advanced Pain Discovery Platform is an HDR UK Data Hub for the federated querying and secure sharing of UK pain data to researchers, analysts and clinicians at a national and international level. People with chronic pain have been involved in design and ongoing management of the platform.

Problem Statement

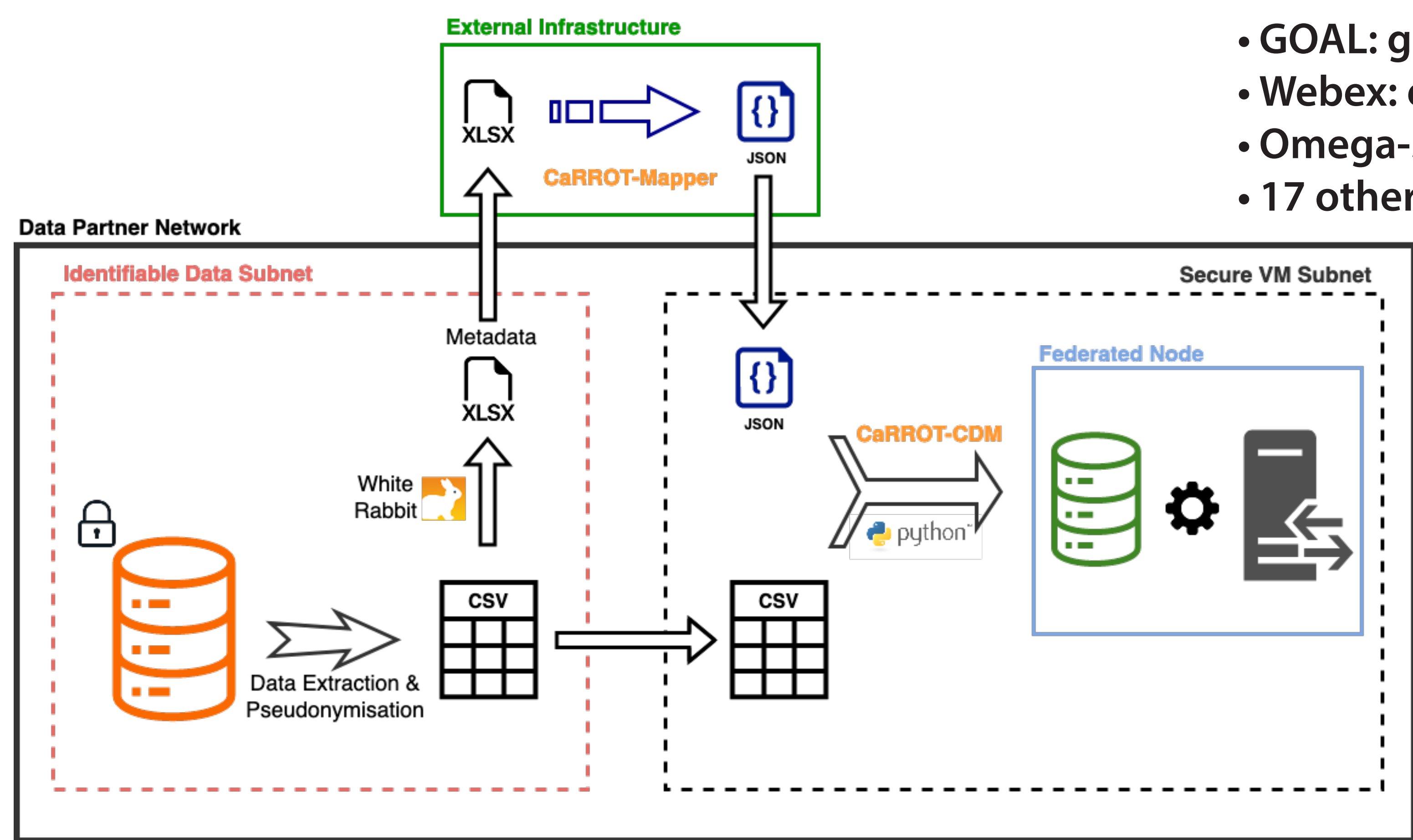
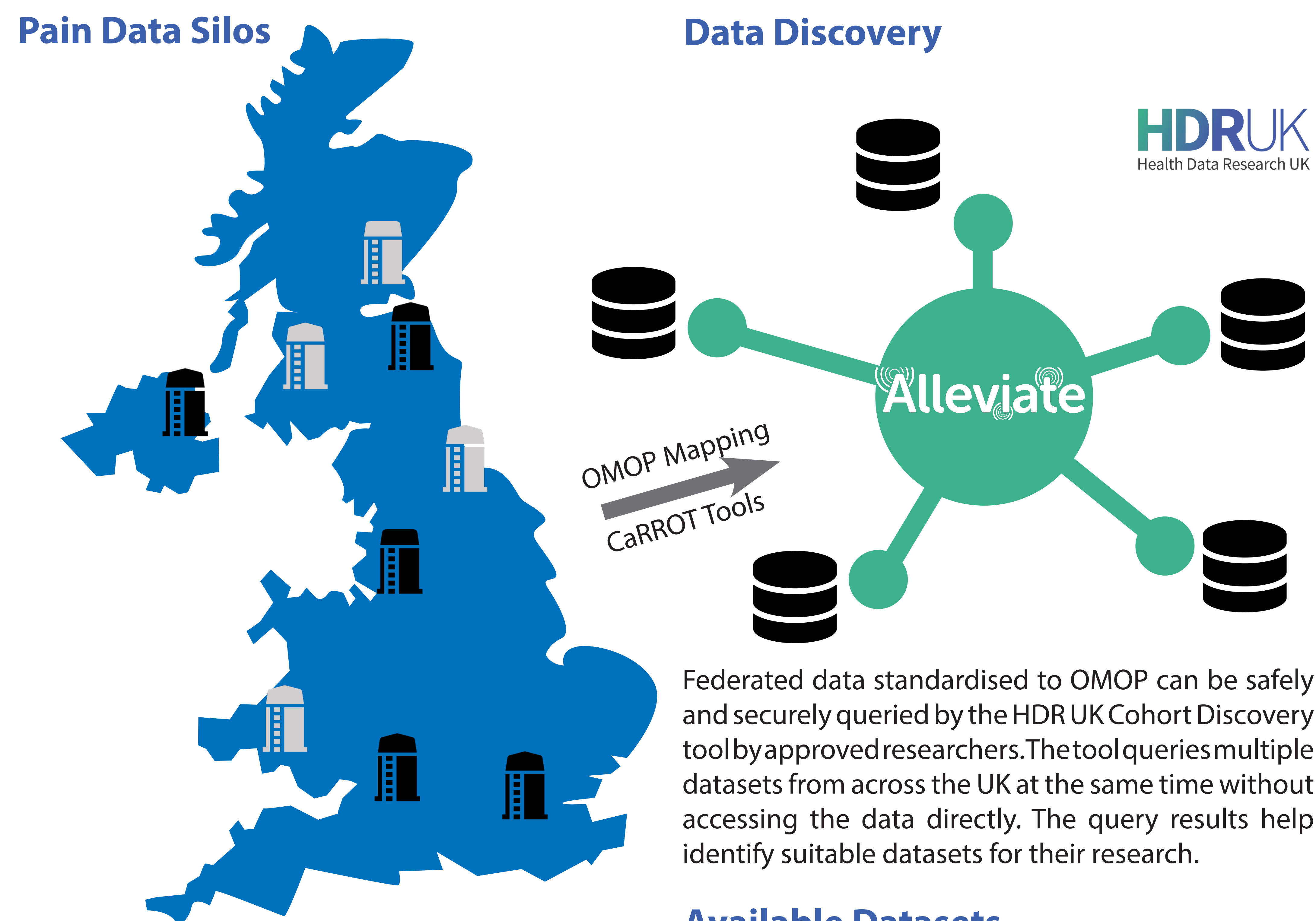
Research datasets in pain data are not readily available for reuse:

- Lack of standardisation
- Data siloes
- Poor visibility of data
- Inability to query data for cohort suitability

OMOP Data Mapping

Working together with data partners the source data is mapped to the OMOP common data model (CDM) using the open source CaRROT Tools.

- **OHDSI White Rabbit**
Metadata extraction from dataset which is not disclosive.
 - **CaRROT-mapper**
Graphical tool to help map source metadata descriptors to OMOP standard.
 - **CaRROT-CDM**
Tool to systematically apply OMOP mapping rules to source data.
- The standardised data is readily incorporated within the Alleviate federated data model.



- Available Datasets**
- **GOAL:** genetics of osteoarthritis and lifestyle
 - **Webex:** exercise in patients with osteoarthritis
 - **Omega-3:** dietary impact of omega-3 on pain
 - 17 others in HDR UK Metadata Catalogue

- Trusted Research Environment**
- OMOP data can be ingested into Alleviate TRE
 - Cohort data linkage
 - Next-generation TRE in the cloud
 - Accredited and "5 Safes" compliant

Participate in PPIE Mini-Survey



- Patient Involvement in Research**
- **Chronic pain** affects 35-51% of the UK adult population (NHS Digital, 2019).
 - **Unmet need** of recognition and treatment.
 - People with lived experience (PWLE) often **missing** in research.
 - **Patient Panel** of 7 people and Patient Group of >100 people established.
 - Contribution of PWLE via blogs, newsletters and youtube.

FAIR Data

Data that is non-standard, incomplete and hidden is challenging to work with. By using FAIR principles data is readily available for reuse thereby enabling further research.

Conflict of Interest

The authors declare no conflict of interest.

