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Milligan, Gordon; Hall, Chris; Appleby, Phil; Masood, Erum; Martin, Gillian; Beggs, Jillian

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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}

¹ Health Informatics Centre, University of Dundee, Dundee, Scotland, UK

² Tayside Clinical Trials Unit, School of Medicine, University of Dundee, Dundee, Scotland UK

³ Digital Research Service, University of Nottingham, Nottingham, UK

⁴ Population Health & Genomics, School of Medicine, University of Dundee, Dundee, Scotland, UK



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. Alleviate 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. Alleviate is the Data Hub for the Advanced Pain Discovery Platform (APDP), a £24 million research initiative to break through the complexity of pain and reveal potential new treatment approaches to address a wide spectrum of chronic and debilitating clinical conditions.

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

Patient Involvement and Pain Research

- **Chronic pain** is one of the largest medical health problems
- **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.

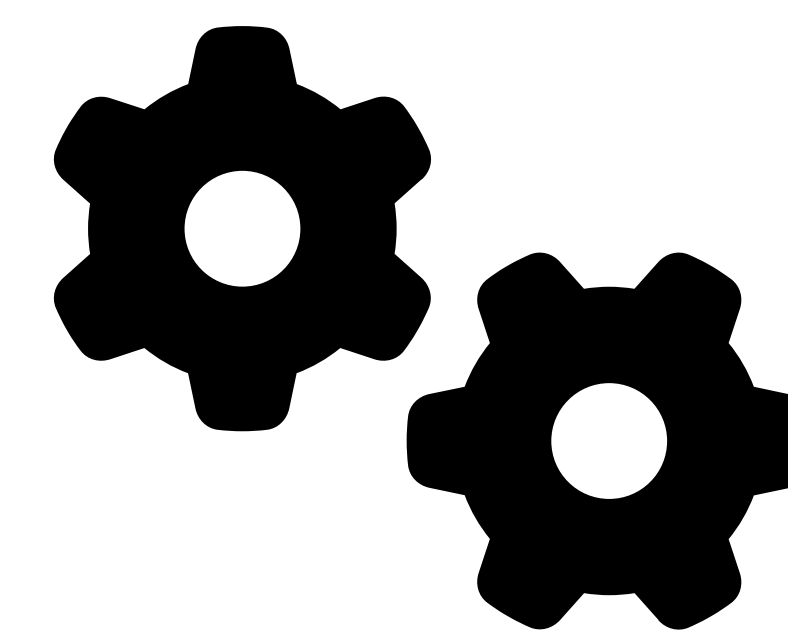
Scan to find out more



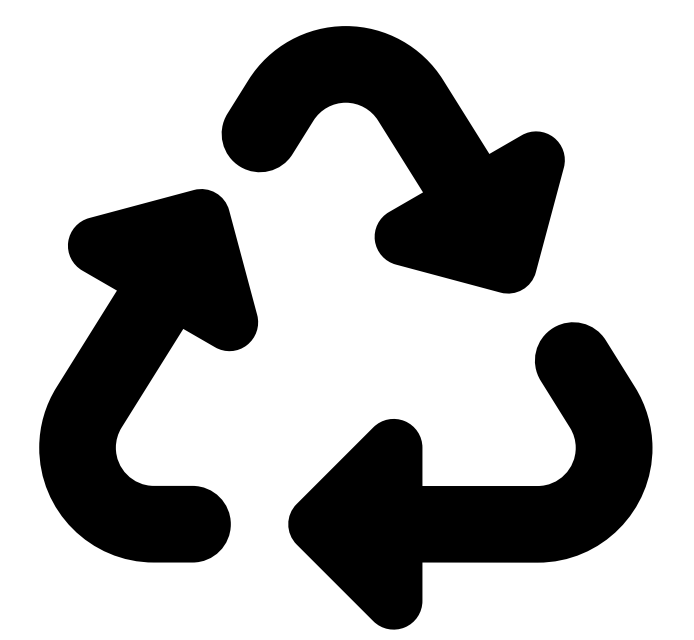
Findable



Accessible

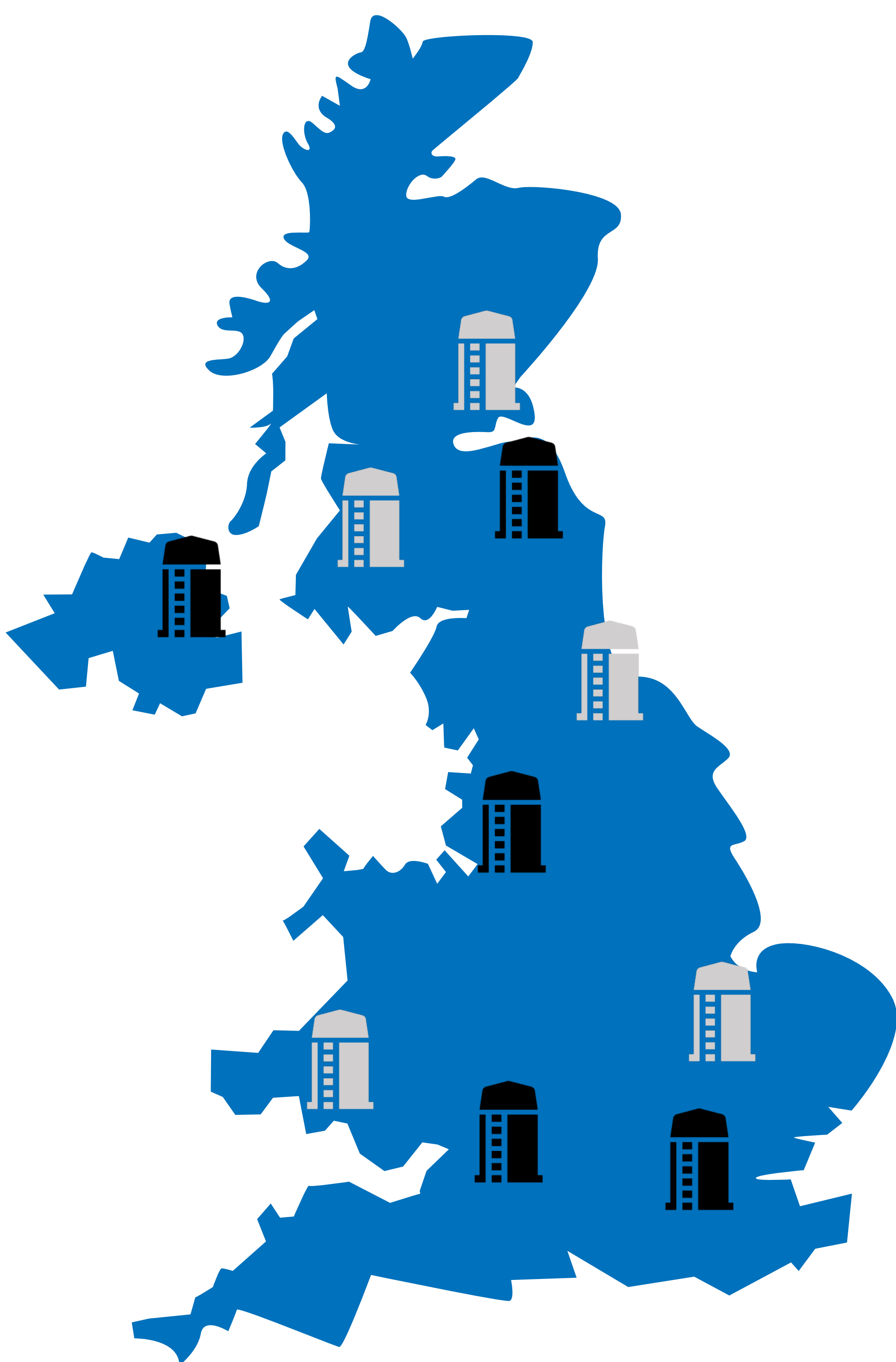


Interoperable



Reusable

Pain Data Silos



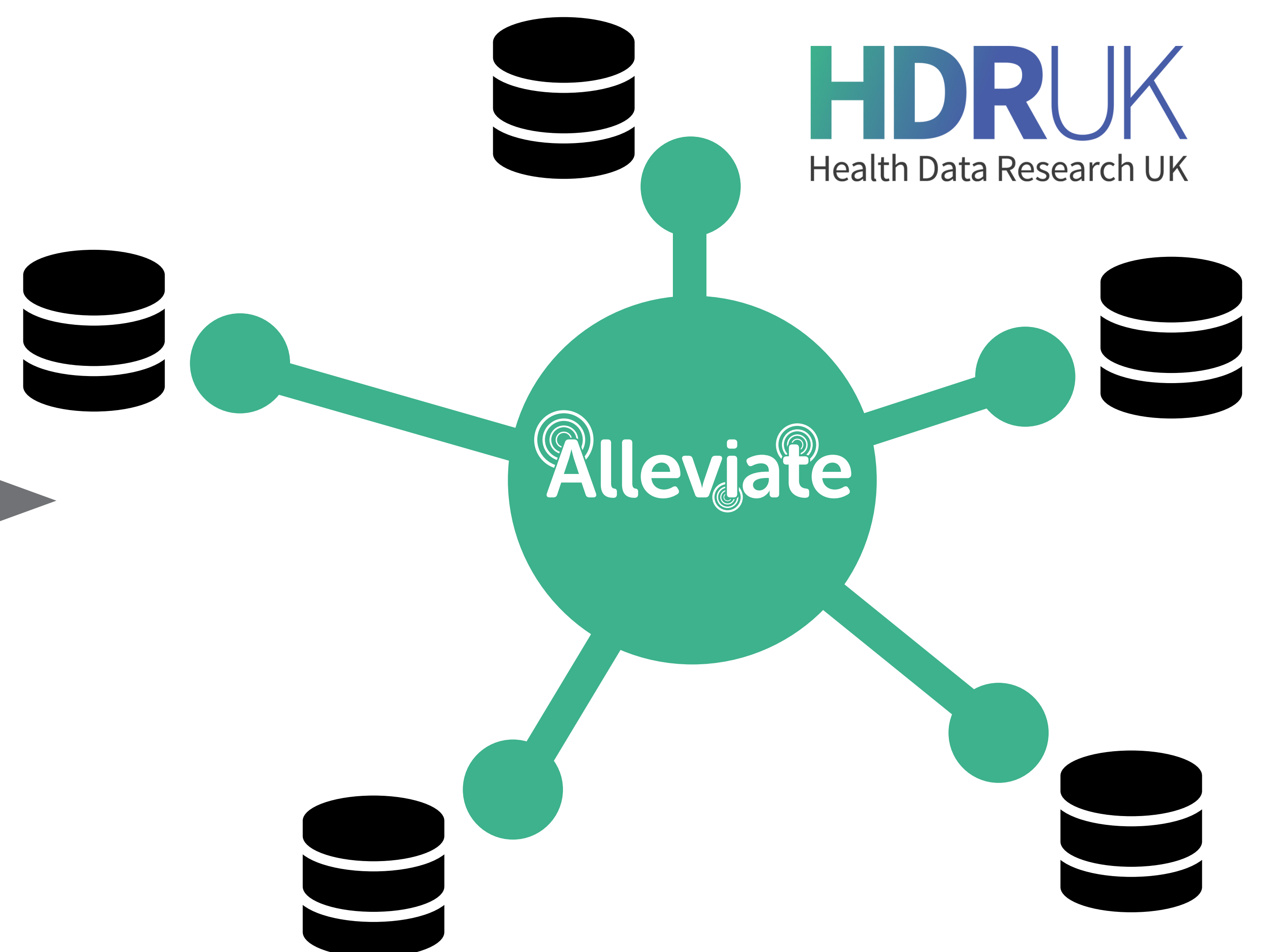
Data Mapping

Together with data partners the source data is mapped to the OMOP common data model (CDM) using the open source CaRROT Tools. The standardised data is readily incorporated within the Alleviate federated data model.

Data Discovery

Federated data standardised to OMOP can be safely and securely queried by the HDR UK Cohort Discovery tool by approved researchers. The tool queries multiple datasets from across the UK at the same time to identify suitable data for their research.

OMOP Mapping
CaRROT Tools



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

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



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