

# Alzheimer's Disease Data Initiative – Data Pilots

## Overview

The Alzheimer's Disease (AD) Data Initiative Data Pilots are enabling international access to valuable UK research datasets. The AD Data Initiative Data Pilots will enable researchers to harness the power of health data to transform our understanding of Alzheimer's disease and other types of dementia. The initiative will unlock potential data-driven solutions for faster diagnosis and better treatment options to improve both patient and public health outcomes in the long-term.

### Dataset Characteristics

- AlzEye (Moorfields Dementia Dataset) contains over six million routinely collected retinal images linked to thousands of NHS hospital records including over 13,000 dementia cases. Moorfields Eye Hospital is expanding this resource using infrastructure and data curation capabilities from the INSIGHT Health Data Research Hub.
- The University of Edinburgh and Public Health Scotland (PHS) are enhancing the comprehensive Scottish Medical Imaging (SMI) dataset which contains brain imaging from over 1.7 million computed tomography (CT) and magnetic resonance imaging (MRI) studies. Data linkage has been performed with routinely collected health record data across the Scottish population, resulting in a data resource called the Brain Health Data Pilot (BHDP).

### Data Pilots Background

Health Data Research (HDR) UK and the AD Data Initiative are working with The University of Edinburgh, PHS and Moorfields Eye Hospital NHS Foundation Trust in a two-year programme of data pilots, aiming to make some of the UK's most comprehensive routine health imaging data more findable and accessible for dementia research projects both within the UK and internationally.

Research projects are being supported to make better use of these data in a safe and secure manner through two exemplar datasets or 'data pilots', which have been chosen for their potential to answer key research questions about dementia.

This work is funded by the Alzheimer's Disease Data Initiative (AD Data Initiative) and convened by Health Data Research UK. It uses data provided by patients and collected as part of their care and support by Public Health Scotland and Moorfields Eye Hospital NHS Foundation Trust.

### Discover the Data Pilots:

- The Data Pilots objective is to make metadata FAIR for the AlzEye (routine ophthalmic imaging) and SMI (Whole Scottish Routine Medical Imaging) datasets.
- UK researcher access for these datasets is currently available for request through the [Health Data Research Gateway collection for the Alzheimer's Disease Data Initiative – Data Pilots](#), with federated data access using the AD Data Initiative's [AD Workbench](#) being piloted.
- As our Data Pilot projects advance and international research partners validate secure access mechanisms, these valuable resources will be accessible for federated analysis globally.
- For more information on the Data Pilots please contact: [eoghan.forde@hdruk.ac.uk](mailto:eoghan.forde@hdruk.ac.uk)

Scan QR code to  
find out more about  
the Data Pilot  
Projects:



# Alzheimer's Disease Data Initiative – Data Pilots

## International Access through Federation

The Data Pilots supports researchers in analysing valuable datasets securely to investigate critical research questions, such as predicting dementia onset before symptoms appear thereby enabling earlier recruitment for clinical trials and treatments.

### Research and Data Custodians

As part of the partnership, we will also pilot the AD Workbench a secure, global Trusted Research Environment (TRE), to facilitate trustworthy international data sharing and access for dementia researchers, supporting collaborative research to accelerate diagnosis and treatments for dementia patients on a global scale.

During the Data Pilots:

- Approved UK and International researchers receive dedicated workspaces within the AD Workbench TRE hosted in their own geographies
- Data Partners authorise federated researcher access
- Researchers perform federated queries remotely via the AD Workbench
- Analysis utilises the Federated Data Sharing Appliance (FDSA) and dedicated Federated Query Builder Tool (QBT)
- Results are released only after comprehensive output verification

This controlled access framework ensures data security while enabling vital cross-border research collaboration. The Data Pilots will produce a comprehensive report on International Data Transfers, specifically designed to accelerate research insights for brain health worldwide.

### Federated Data Sharing

The FDSA is an integral part of the AD Workbench product suite, enabling Data Custodians to securely make data available for researchers while retaining control over the data. As a plug-in for trusted research environments, the FDSA empowers Data Custodians to publish remotely accessible pseudonymised datasets, making previously inaccessible research data available for discovery and analysis.

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### Advantages of Federation

Directly supports the 5 safes:

#### Safe People

- Researchers reviewed by the Data Custodian

#### Safe Data

- Researchers never see or directly access data
- Data stored remotely in a secure environment and never moves
- Only pseudonymised data used

#### Safe Projects

- All projects reviewed and approved by the Data Custodian panel
- Model code reviewed before execution for added security

#### Safe Settings

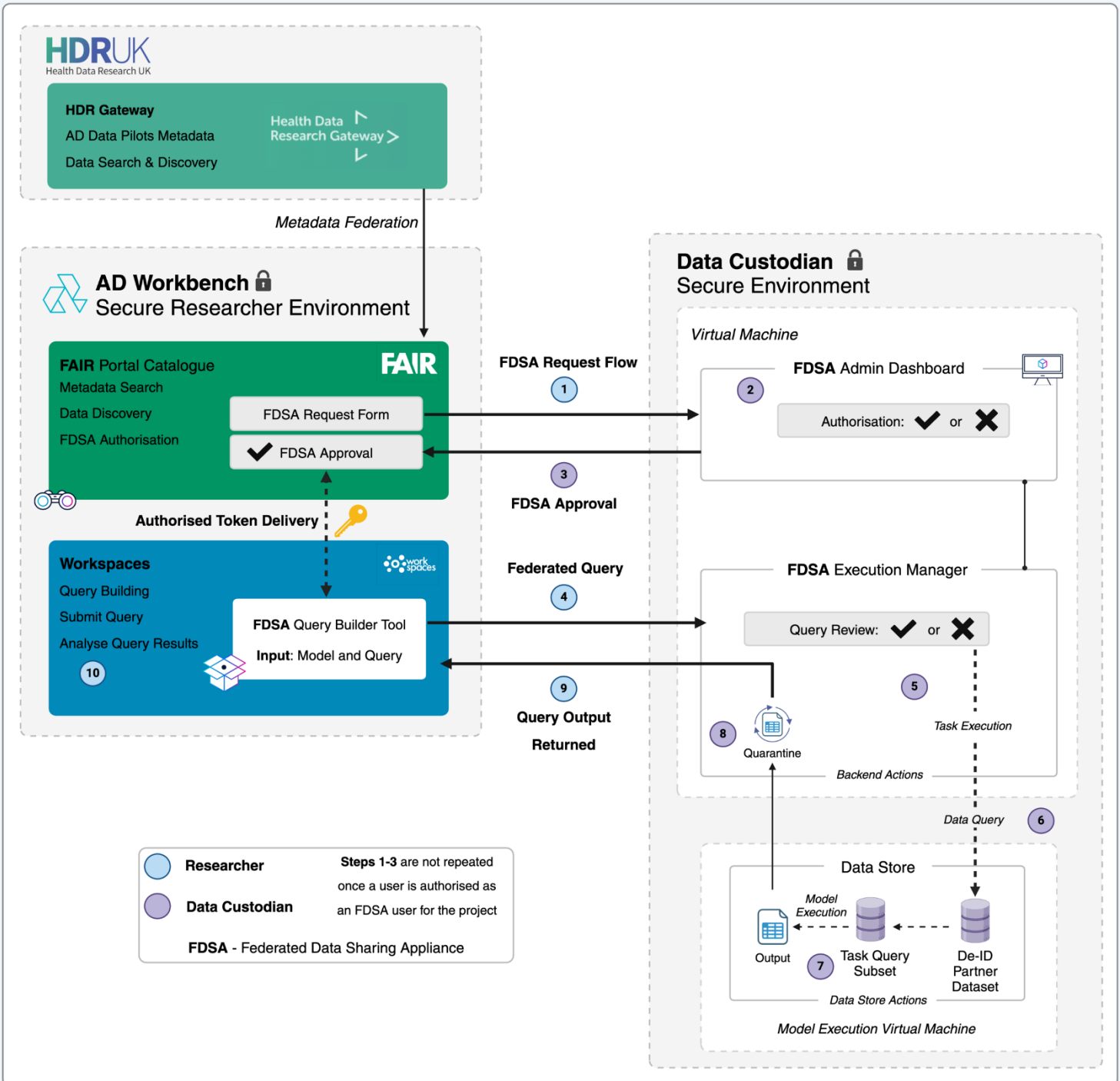
- AD Workbench: Highly secure, certified research environment

#### Safe Outputs

- All outputs undergo checks to ensure they are non-disclosive
- Only high-level results with low number suppression

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## Federated Data Analysis Workflow



# Alzheimer's Disease Data Initiative – Data Pilots

## Research Projects

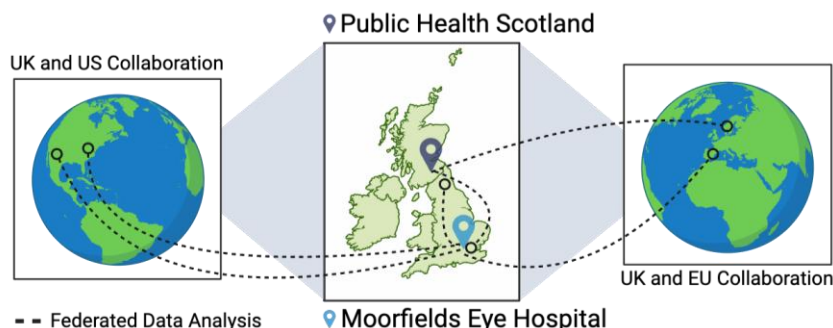
This Data Pilots are a two-year pilot programme, supported by the Alzheimer's Disease (AD) Data Initiative, aiming to demonstrate legally compliant methods of increasing international collaboration in brain health data science.

### Research and Data Custodians

The pilots will improve the “research readiness” of data access mechanisms to flagship NHS datasets for research related to Alzheimer's disease internationally. It is focused on improving use of and access to key brain and retinal imaging data from Public Health Scotland and Moorfields Eye Hospital NHS Foundation Trust. The aim of the pilot is to make data FAIR and demonstrate use by approved researchers through the AD Workbench both within the UK and internationally, in a safe, trustworthy and legally compliant manner.

### Pilots Overview

**The University of Edinburgh and Public Health Scotland Data Pilot** involves a series of studies, the first of which involves comparing brain age calculated with CT scans with brain age calculated with MRI. The study will investigate whether having an “older brain age” increases the chance of dementia. The second study will involve the development of a foundation model using the linked BHDP datasets to help understand the underlying patterns in these data.



**The Moorfields Eye Hospital Data Pilot** will investigate if AI-derived retinal features can discriminate between individuals with and without all-cause dementia across datasets located in the UK, enabling pilot access to this data through the FDSA for collaborators in the US. This will be followed by an analysis of interocular asymmetry (the difference in retinal nerves between the two eyes of the same individual) in distinguishing vascular dementia from AD.

### Geographical coverage

The Data pilot research projects involve researchers collaborating from:

#### USA:

- University of Washington
- Stanford University

#### Europe:

- Finland
- Technical University Berlin

#### UK:

- University of Edinburgh
- University College London
- Moorfields Eye Hospital

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## Metadata Federation

The Health Data Research Gateway is a national platform designed to streamline access to health data for research and innovation. It serves as a trusted, secure, and transparent environment where researchers, clinicians, and innovators can discover and request access to a wide range of health datasets.

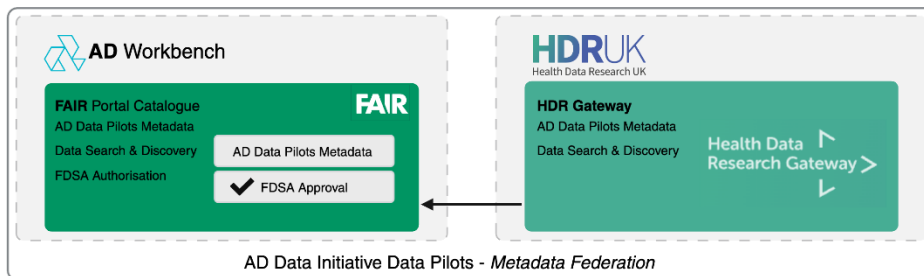
### Data Pilot Data Discovery

The Gateway plays a pivotal role in supporting the Alzheimer's Disease (AD) Data Initiative Data Pilots by enhancing data discoverability and accessibility for dementia research.

- **Enhanced Data Discoverability:** The Gateway enables access to metadata from datasets like AlzEye (Moorfields Dementia Dataset) and SCANDAN
- **Secure Access:** The Gateway provides a centralised, streamlined and easy-to-use solution to facilitate data access requests between researchers and data custodians
- **Future Collaboration:** Integration with platforms like the AD Workbench promotes global collaboration in dementia research

### Data Pilot Metadata Federation

The Gateway and AD Workbench use a Metadata Federation approach to enhance dataset discoverability and accessibility. This method ensures consistent and interoperable metadata across platforms, supporting secure, transparent data access and governance. The Gateway manages metadata consistency and archival processes, while the AD Workbench enables federated analysis. Together, they advance the AD Data Initiative Pilots, accelerating research to improve the diagnosis, treatment, and understanding of Alzheimer's and other dementias.



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### FAIR metadata:

- Metadata is data that describes and provides information about other data, such as its structure, origin, and usage.
- FAIR metadata refers to data that is Findable, Accessible, Interoperable, and Reusable, ensuring that research data can be easily shared, understood, and reused by others.
- FAIR metadata ensures datasets are easily discoverable and accessible for researchers.
- Promotes collaboration across institutions and countries, accelerating research.
- Well-structured metadata ensures research can be reliably replicated, improving the quality of findings.
- Enables seamless integration of diverse datasets, fostering comprehensive analysis of Alzheimer's Disease.

Find out more  
about the Data Pilot  
Collection on the  
Gateway:





## Alzheimer's Disease Data Initiative – Data Pilots

1

### Dementia Challenge

UK Dementia cases to reach  
1.6 million by 2050



With associated healthcare costs  
estimated at £47 billion



£47 Billion

2

### AD Data Initiative Data Pilots

#### Unlocking Data for Research

**Health Data Research (HDR) UK** and the **AD Data Initiative** are working with The University of Edinburgh, Public Health Scotland (PHS) and Moorfields Eye Hospital NHS Foundation Trust in a two-year programme of data pilots.



The Data Pilots aim to make some of the UK's most comprehensive routine health imaging data more findable and accessible for dementia research projects both within the UK and internationally.

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### Data Pilot Datasets

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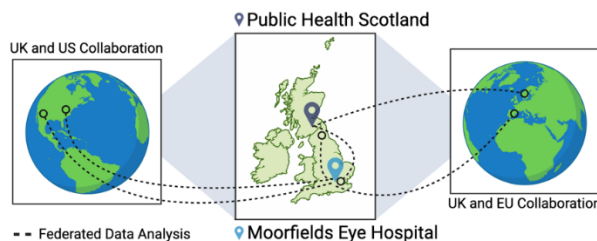


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### Data Governance and Sharing

**Secure, Federated Access** via HDR Gateway and the AD Data Initiative **AD Workbench**. Ensuring compliance with governance frameworks while facilitating **global research collaboration**.



#### Key Outcomes

1. Enabling Early Diagnosis & Better Treatments through open yet secure data access.
2. Informing **International Data Sharing Best Practices** to guide future research initiatives.
3. Development of a **Comprehensive Data Sharing Report & Governance Guidance** to support global-scale dementia research.