# Gates Ventures' AD Program Focuses on Five Key Pillars
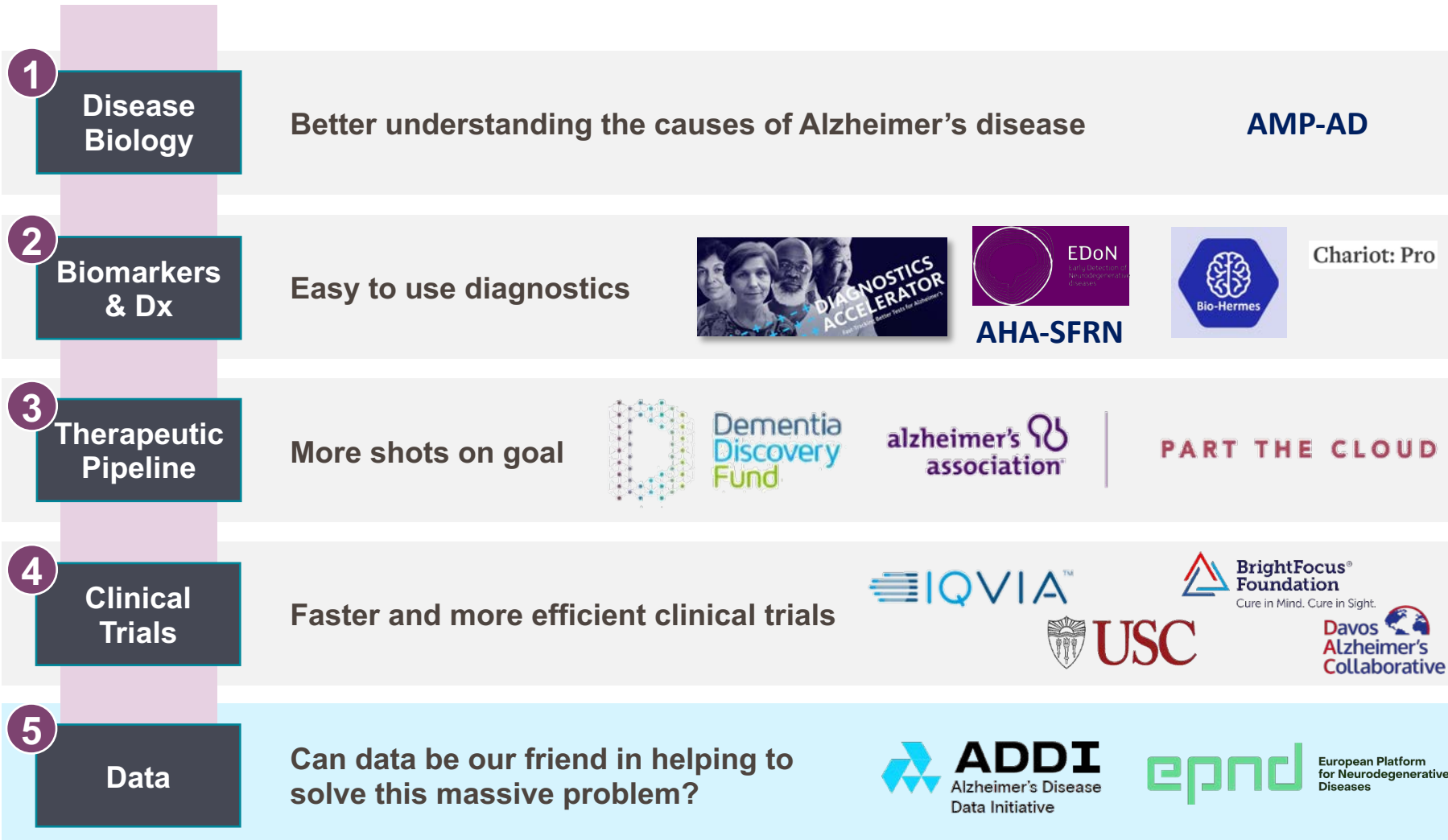
**ADDI** Alzheimer's Disease Data Initiative | **AD** Workbench

| 1 | **Disease Biology** | Better understanding the causes of Alzheimer's disease | **AMP-AD** |

| 2 | **Biomarkers & Dx** | Easy to use diagnostics | DIAGNOSTICS ACCELERATOR · EDoN Early Detection of Neurodegenerative diseases · **AHA-SFRN** · Bio-Hermes · Chariot: Pro |

| 3 | **Therapeutic Pipeline** | More shots on goal | Dementia Discovery Fund · alzheimer's association · PART THE CLOUD |

| 4 | **Clinical Trials** | Faster and more efficient clinical trials | IQVIA · USC · BrightFocus Foundation Cure in Mind. Cure in Sight. · Davos Alzheimer's Collaborative |

| 5 | **Data** | Can data be our friend in helping to solve this massive problem? | **ADDI** Alzheimer's Disease Data Initiative · epnd European Platform for Neurodegenerative Diseases |

# ADDI Was Incubated by a Coalition of Partners

ADDI brought together a coalition of funding organizations interested in accelerating the use of data within ADRD research. We aim to support a series of initiatives related to:
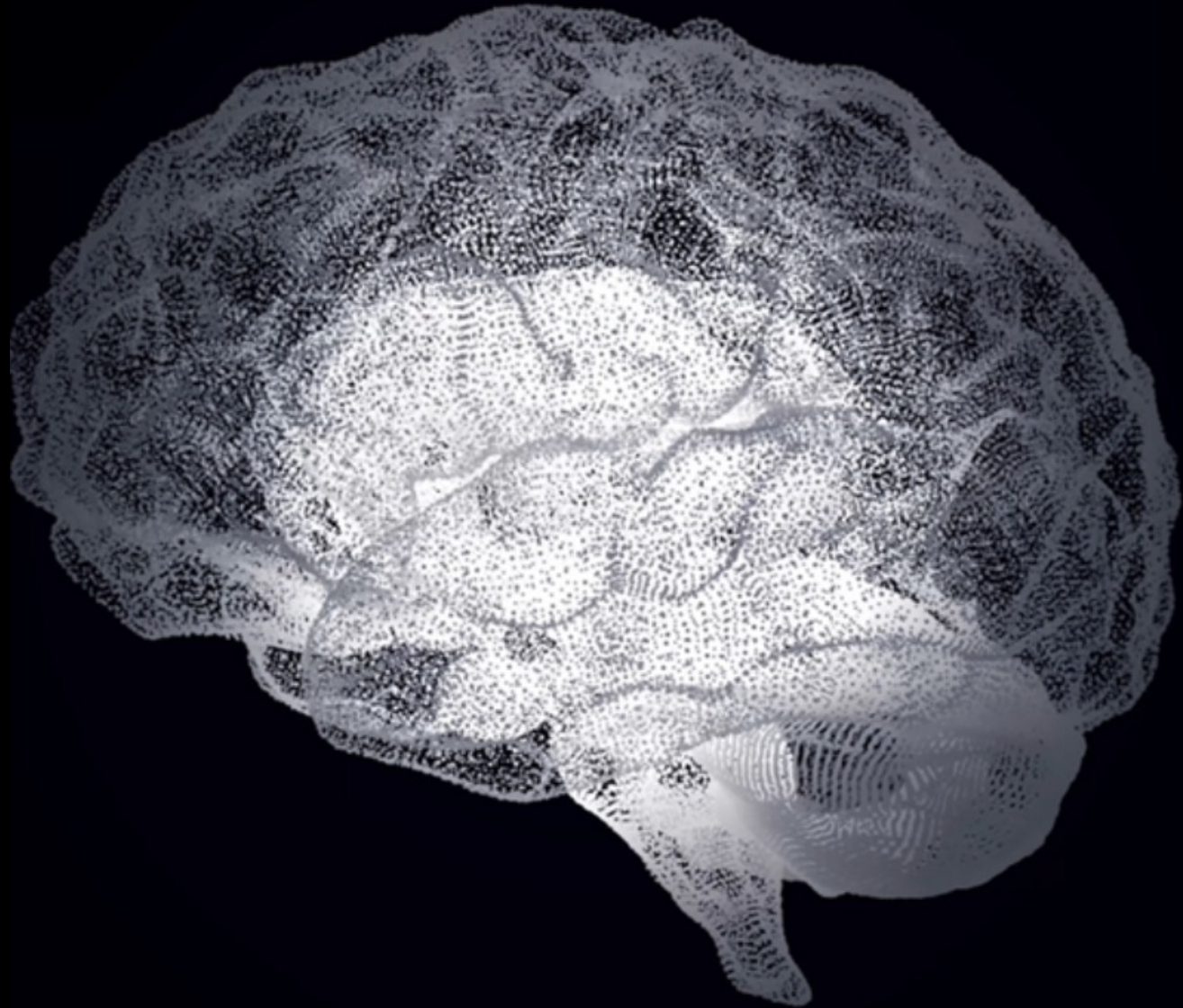
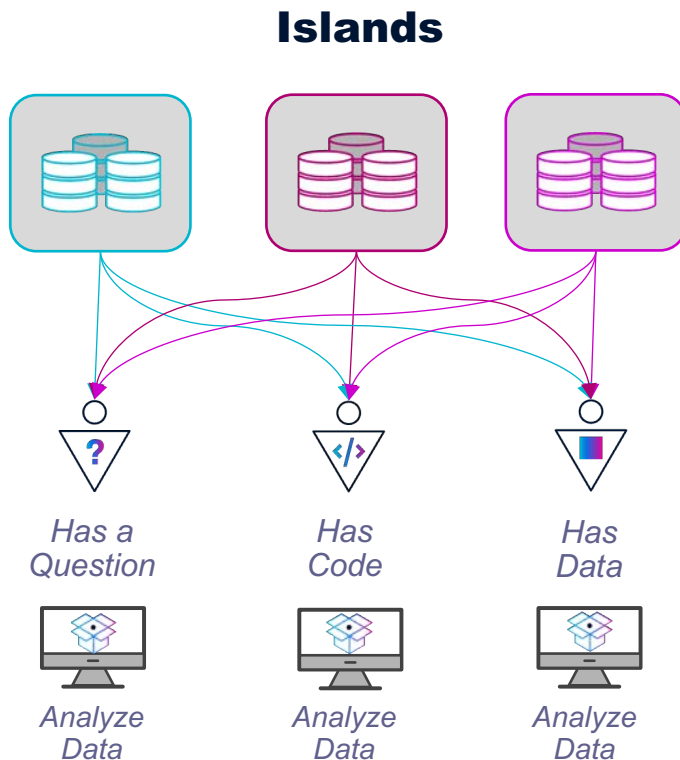| Enabling and accelerating data infrastructure through the **interoperability** of existing data platforms | Increasing the **sharing** of ADRD-related data from academic, industry, and government sources | Empowering scientists with data and platforms to make new discoveries by building and **enabling environment** |
| --- | --- | --- |

ADDI is a 501(c)(3) non-profit medical research organization whose mission is to fundamentally transform Alzheimer's disease research, accelerating progress towards new treatments and cures for AD and related dementias.

https://www.alzheimersdata.org

# Problems with the Status Quo

**Islands**



Has a Question — Analyze Data

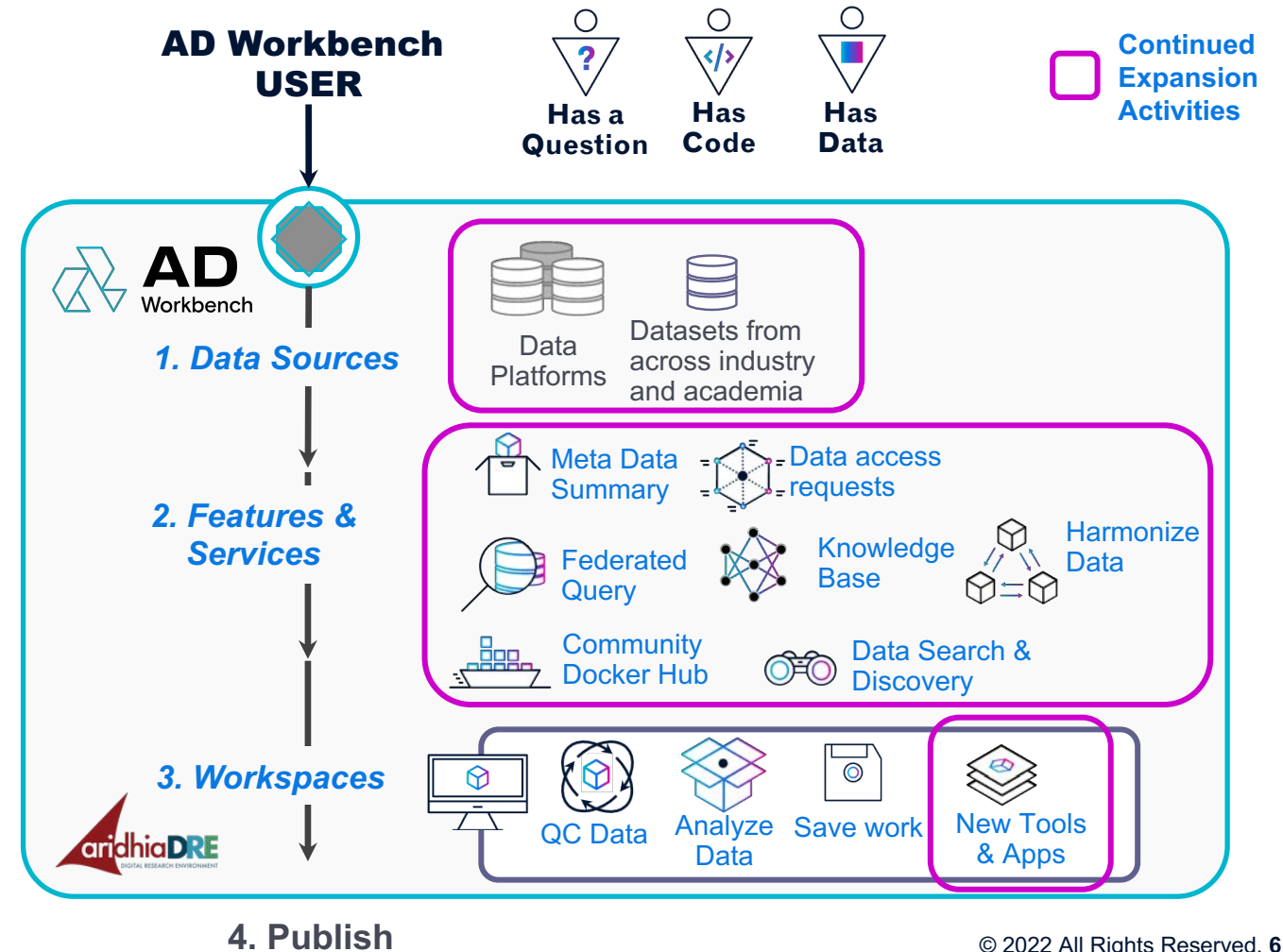Has Code — Analyze Data

Has Data — Analyze Data

- Users must contact multiple sites and/or log in to multiple platforms to access data

- Data sharing equates to data copying

- Low security (data downloaded to user locations)

- Users require their own compute infrastructure

- Encourages siloed research

# ADDI is Building a Global Community Around the AD Workbench
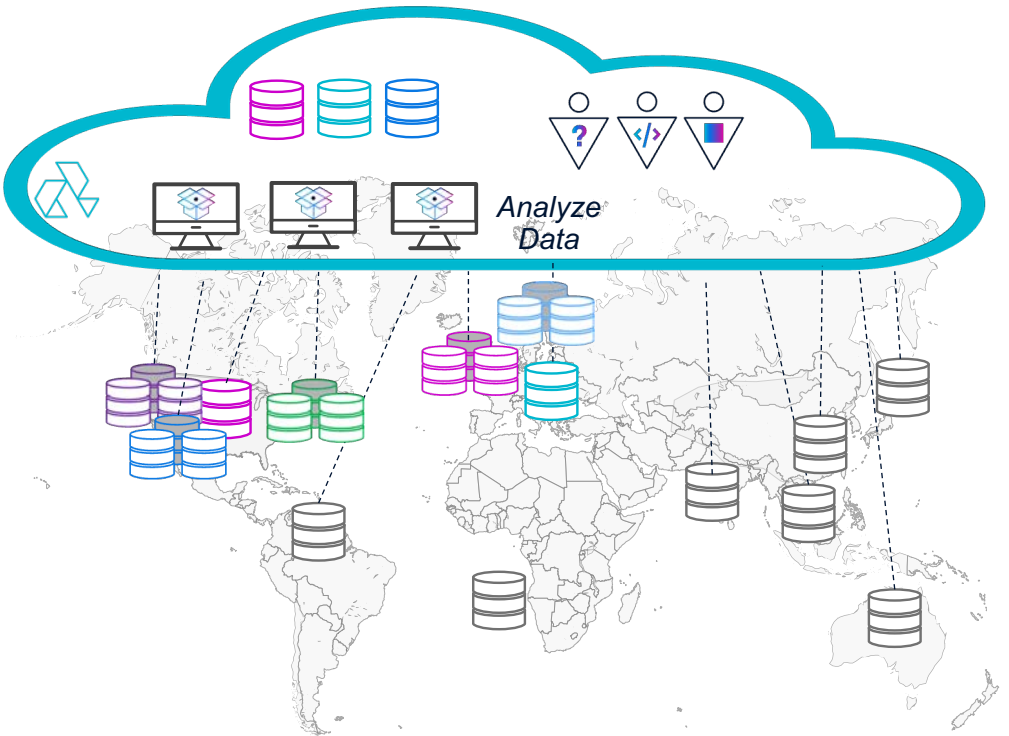


**What's Different about the AD Workbench**

- ✓ Global platform
- ✓ Diverse datasets and users
- ✓ Breaks down siloes to increase data accessibility
- ✓ Free collaborative workspaces
- ✓ Free cloud-based compute
- ✓ Sharing of tools and knowledgebase
- ✓ Optimized security and provenance
- ✓ Long term sustainability

**AD Workbench USER**

**Has a Question**  
**Has Code**  
**Has Data**

**Continued Expansion Activities**

**AD Workbench**

**1. Data Sources**
- Data Platforms
- Datasets from across industry and academia

**2. Features & Services**
- Meta Data Summary
- Data access requests
- Federated Query
- Knowledge Base
- Harmonize Data
- Community Docker Hub
- Data Search & Discovery

**3. Workspaces**
- QC Data
- Analyze Data
- Save work
- New Tools & Apps

aridhiaDRE — DIGITAL RESEARCH ENVIRONMENT

**4. Publish**

# ADWB Security Architecture

**ADDI** Alzheimer's Disease Data Initiative | **AD** Workbench

**Microsoft Azure Compliance:** [Azure compliance documentation | Microsoft Docs](#)

**Aridhia Digital Research Environment Certifications:** ISO27001, Cyber Essentials, NHS Data Security, ICO, HITRUST, HIPAA, Employee criminal background checks, Employee Security Training

**Aridhia Digital Research Environment Development Standards:** OWASP Top 10, OS Patching, Nightly backups, Quarterly BCP/ER exercises.

**ADWB Data & Access Management:**
- HTTPS-TLS 1.2+
- Encryption in transit
- Encryption at Rest (FIPS 140-2)
- 2-Factor Login Req'd
- Intrusion Protection-Security Alerts
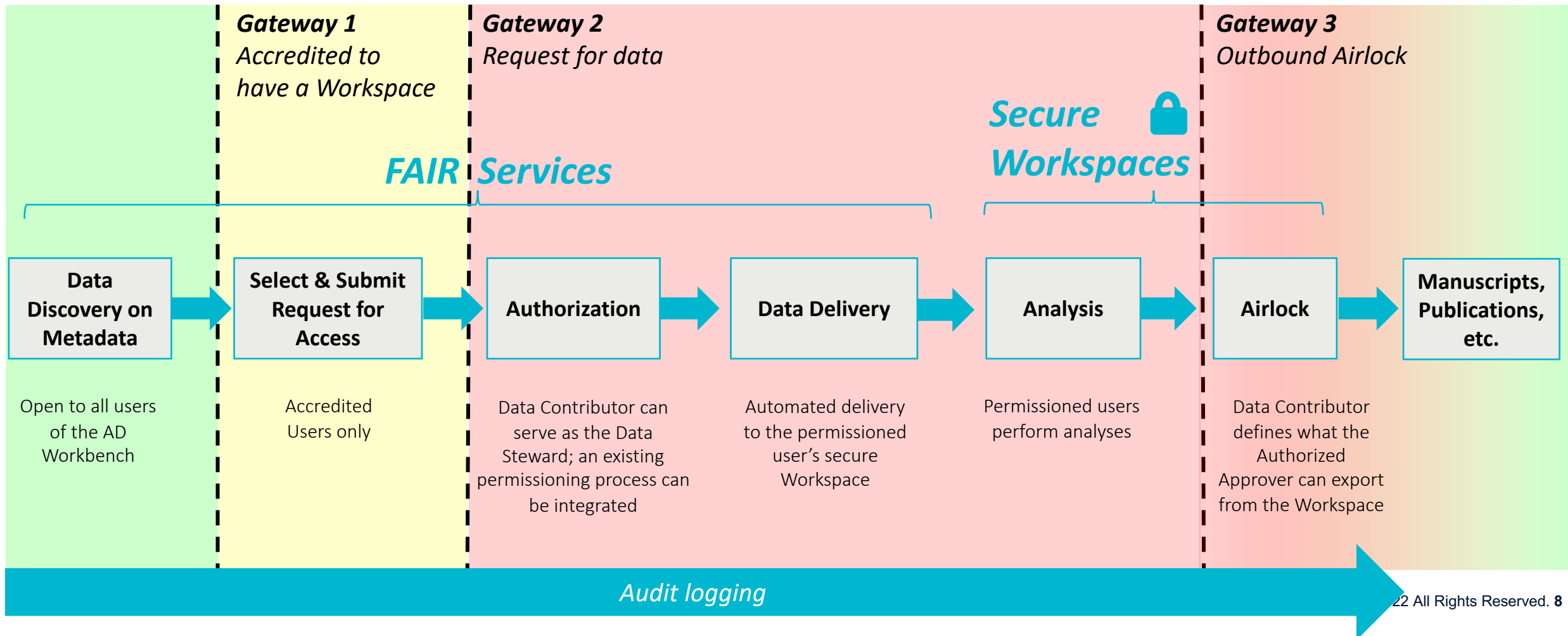- Regular audits of privileged accounts

**ADWB Data Access Requests:** Customized Data Access Request workflows ensure strict compliance with Partner Data Use Agreements.

**ADWB Isolated Secure Workspace Environment:**
- Virtual Network Configurations enforced through permissions.
- Full Audit reporting of all events
- Workspace Teams (Administrators & Standard User permissions)
- All uploads pass through malware scanning
- All extractions are Air-Locked and require Workspace Admin approval for export.

https://knowledgebase.aridhia.io/aridhia-security-and-compliance/#

# Data Contributors Control Who Uses their Data and on What Terms

**ADDI** Alzheimer's Disease Data Initiative | **AD** Workbench

**Gateway 1**
*Accredited to have a Workspace*

**Gateway 2**
*Request for data*

**Gateway 3**
*Outbound Airlock*

*Secure Workspaces* 🔒

*FAIR Services*

| Data Discovery on Metadata | Select & Submit Request for Access | Authorization | Data Delivery | Analysis | Airlock | Manuscripts, Publications, etc. |
|---|---|---|---|---|---|---|

Open to all users of the AD Workbench

Accredited Users only

Data Contributor can serve as the Data Steward; an existing permissioning process can be integrated

Automated delivery to the permissioned user's secure Workspace

Permissioned users perform analyses

Data Contributor defines what the Authorized Approver can export from the Workspace

*Audit logging*

# Connectivity Options for Data Contributors

**ADDI developed APIs to enable three levels of connectivity to maximize data access for researchers by accommodating a range of data providers**

## 0

- Data and metadata are hosted in territory on the AD Workbench cloud platform
- Ideal User Experience

**CENTRALIZED**

## 1

- Metadata are discoverable on the AD Workbench
- Data are hosted remotely at source location and can be queried remotely by users
- Selections of the record-level data are transferred to trusted ADDI Workspaces
- Ideal User Experience

**DISTRIBUTED**

## 2*

- Metadata are discoverable on the AD Workbench
- Data are hosted at source by the data provider; record-level data never leave the source location
- Queries and compute tasks can be sent to and executed at source
- Only approved results are released by data providers to trusted ADDI Workspaces

**FEDERATED**

*Level 2 is a fully-federated model that supports connections to highly protected datasets where record level data must remain at source. There is a minor impact to the User Experience; since users do not get direct access to record level data, their analysis must be performed at the source via containerized executable scripts.
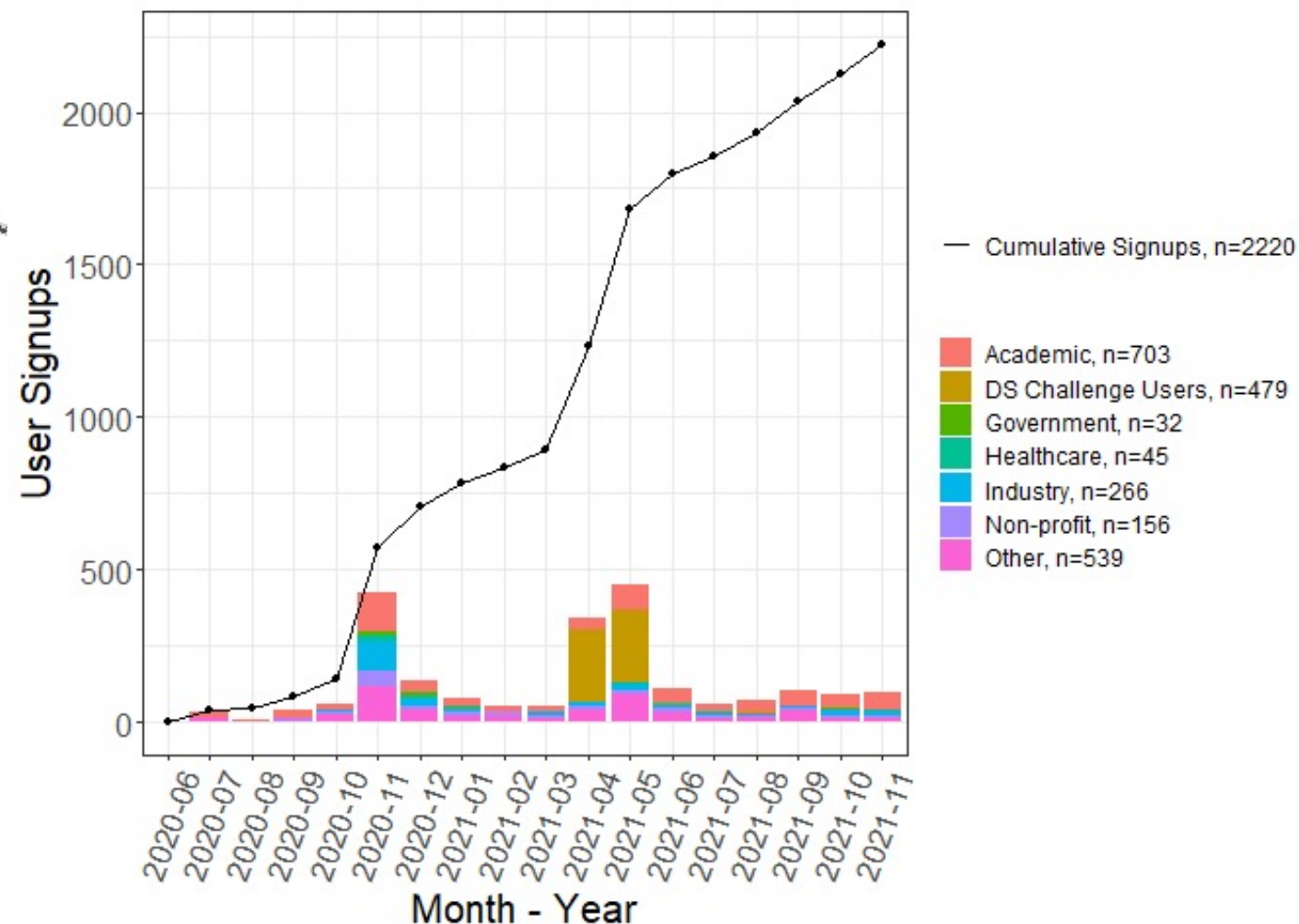
# Strong Growth in Users and Datasets

**2,220 users from 80 countries:**
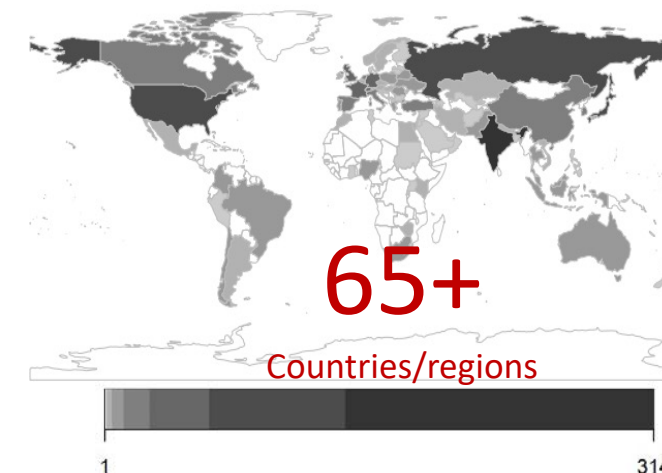**477 users from 40 low- and middle-income countries**
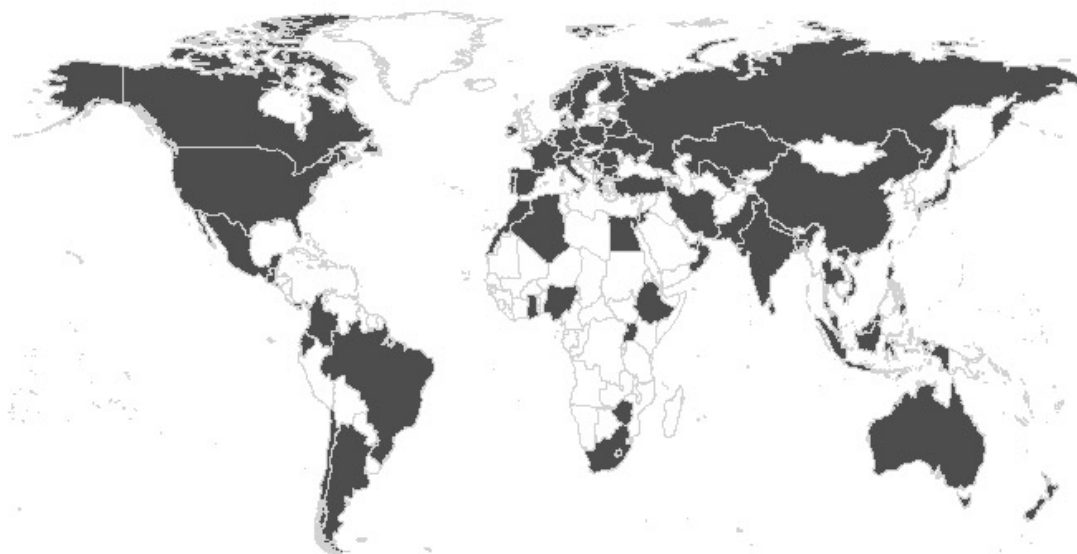


## User Segments

- Patients / Family members
- Data science community
- Bioinformaticians

- Pharmaceutical
- Academia
- Clinicians

# The Potential of Global Data Challenges

- Identify specific, high priority questions that the field needs to answer

- Make relevant datasets available via the ADWB

- Openly promote the problems to a global community of solvers

- Assess the findings, award prizes, and consider multi-year continuations



ADDI ALZHEIMER'S DETECTION CHALLENGE

$50,000 CASH PRIZES | 3 PS 5 | 1 XBOX SERIES X | 5 DJI MAVIC MINI 2 | 5 OCULUS QUEST 2

By ADDI | 32.7k | 1216 | 103 | 7177 | 76 | Follow

Challenge: Completed

No Dementia (Healthy)     Mild to Moderate     Severe

65+
Countries/regions

1     314

# Thank You!

Tetsu Maruyama

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alzheimersdata.org

Patrick Brannelly

Patrick.Brannelly@
alzheimersdata.org

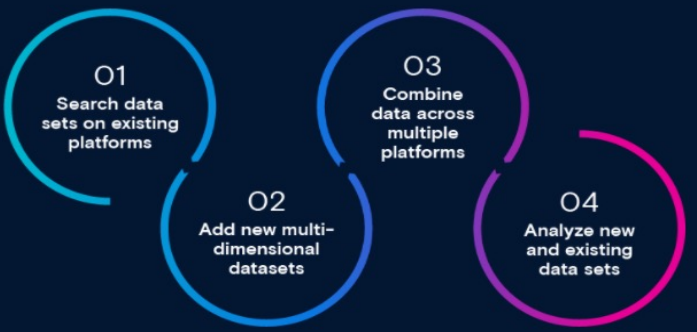**ADDI** Alzheimer's Disease Data Initiative

**AD** Workbench

# Visit us:

**ADDI**
Alzheimer's Disease
Data Initiative

https://www.alzheimersdata.org

**AD**
Workbench

https://portal.addi.ad-datainitiative.org/

**ADDI**
Alzheimer's Disease
Data Initiative

**AD** Workbench

**FAIR** Data Services

**Workspaces**

Matt Clement  MC

# Overview

The Alzheimer's Disease Data Initiative (ADDI) aims to enable easier data access and sharing with a view towards accelerating Alzheimer's disease (AD) innovation. Our approach is to connect researchers with the data they need to generate insights that will inform the development of a deeper understanding of AD and related dementias. This deeper understanding will, in turn, inform the identification of new drug targets, the discovery of better biomarkers, the development of earlier diagnostic tests, and the improvement of clinical trial efficiency. All these things will be essential to delivering the treatments we desperately need for people with AD and other dementias.

A coalition of organizations have collaborated to build the ADDI Alzheimer's Disease Workbench, a user-friendly way to enable data analyses across disparate datasets and data environments allowing researchers to:

O1 Search data sets on existing platforms

O2 Add new multi-dimensional datasets

O3 Combine data across multiple platforms

O4 Analyze new and existing data sets

The AD Work Bench (ADWB) addresses a key limitation of existing data and data platforms, which is that they cannot easily be combined to create the most effective scale. ADWB enables data and platform interoperability across existing AD datasets, facilitates data sharing protocols and encourages consortia of researchers within healthcare, academia, and industry to collaborate.
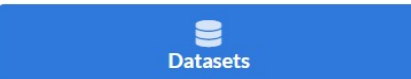
## Getting Started

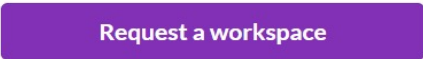### Access the Alzheimer's Disease Workbench ⓘ

Follow the links below to get started and access the AD Workbench services. The ADDI FAIR data services help you **find data**. The ADDI Workspaces help you **work with data** using data analytic tools.

## Quick Start

### 1. Find Data  **FAIR**

1. Go to FAIR Data Services

   **FAIR** Data Services

2. Review the existing datasets: Click 'Datasets' and select 'All datasets' in the dropdown

   🗄 **Datasets**

3. Click on an individual dataset to review its metadata.

### 2. Request a Workspace ❗

1. **When you have found a dataset of interest**, request a project workspace

   **Request a workspace**

2. Once you have a workspace, make a data access request in FAIR.

### 3. Request Data ❗

Now you are ready to request data.

1. Go back to FAIR
2. Navigate to the relevant dataset
3. Request a dataset by clicking on the Request Icon 🔑 in the menubar.
4. Fill in the form – you will receive feedback from the data owner.

### Apply to Submit Data 📅

Accelerate AD innovation by sharing your dementia-related data on the ADWB. If you would like to contribute data, please visit the ADDI website and **complete the form**.

### Knowledge Base ❓

Useful information and 'how to' guides on the AD Workbench Workspaces and FAIR services can be found in the **Knowledge Base**.