# A pivotal moment for a unified approach

International Registry for Alzheimer's disease and other Dementias (InRAD)

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# Disclosures

- JV is a consultant for InRAD
- InRAD is coordinated by the independent International Registry for Alzheimer's Disease and Other Dementias Foundation, a health-related not-for-profit entity incorporated in the Netherlands
- InRAD has received financial contributions from the pharmaceutical industry, including:
  - Eli Lilly
  - Schwabe Group
  - Novo Nordisk
  - BMS
- Others partners include: Alzheimer's Network, Icometrix NV, Neurophet
- InRAD does not endorse any companies or products
- InRAD is operated independently from these companies

https://www.inradnetwork.org/pharma-funding 18/09/2025

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# A Pivotal Moment for a Unified Approach

**The International Registry for Alzheimer's Disease and Other Dementias (InRAD)**

- What is InRAD?
- Minimum Data Set (MDS) and Extended Data Set (EDS)
- The InRAD cloud-based registry data entry platform
- The AURORA-AD (natural history) sub-study

InRAD: International Registry for Alzheimer's Disease and Other Dementias

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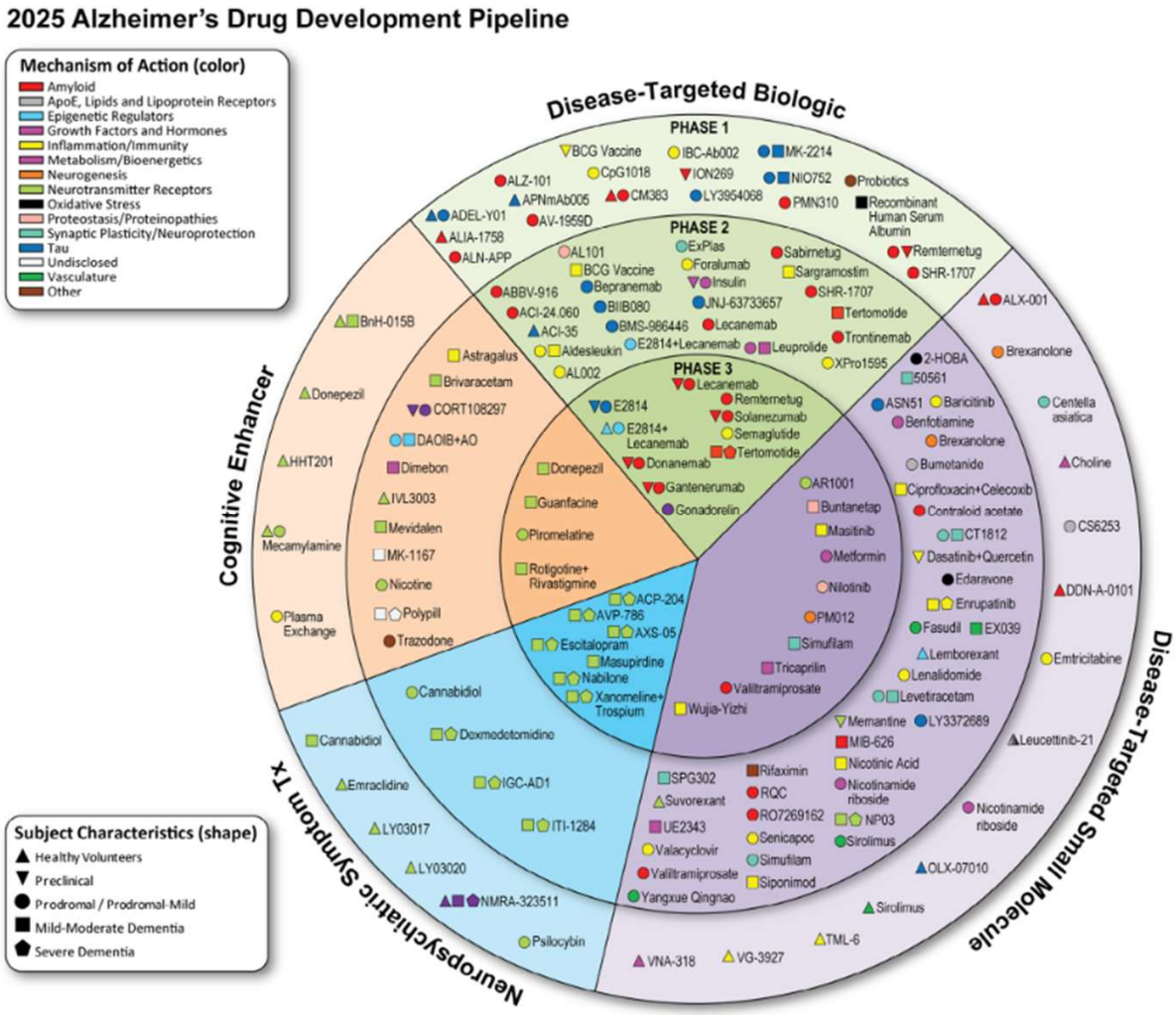
# Exciting times in AD

- Rich drug development pipeline
  - 138 drugs in development, Jan 2025[1]
  - Lecanemab, Donanemab
- Advances in biomarkers, diagnosis and prognosis evolving at fast pace[2]
- Lots of questions to be answered with the foundation of RWD[3-4]
  - New early AD natural history
  - Application of biomarkers & risk factors
    - Earlier diagnosis?
  - Long-term safety, effectiveness, value of treatments
  - … and many others




AD: Alzheimer's disease. RWD: Real-World Data

1. Cummings et al. Alzheimer's Dement 2025;11:e70098. 2. Hansson et al. Nat Aging. 2023;3(5):506-519. 3. Dang A. Pharmaceut Med. 2023;37(1):25-36). 4. Miller et al. Front Aging. 2023:4:1179275

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# InRAD, the first and only international clinical practice-based registry in AD

**Meaningful data** | **Sustainable platform** | **Collaborative science**

- Free-to-access cloud-based data platform and collaboration infrastructure
- Contributing doctors' centres own their data (Data Controller)
- Collaboration within and outside the network
- InRAD (Data Processor) coordinates international research and studies
- Participation in scientific agenda (e.g. own research; multicentre or national research studies)
- Data Quality workstream to support use cases

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# First step: reaching consensus on MDS/EDS

- Define **Minimum Data Set** (MDS) for Alzheimer's disease diagnosis and care
- Provide **Extended Data Set** (EDS) to enrich medical context
  - International Steering Committee
  - Multistakeholder consultation: clinicians & academics, patient representatives, pharmaceutical industry
  - Consensus agreement & Publication

## Minimum data set (MDS)

- Demographic, efficacy and safety data collected by every investigator

## Extended data set (EDS)

- Collected data collected where practice permits, certain instruments are used (e.g. those mandated by local authorities or that are part of local clinical practice) or when sites participate in registry studies

Perneczky et al. Real-world datasets for the International Registry for Alzheimer's Disease and Other Dementias (InRAD) and other registries: An international consensus, The Journal of Prevention of Alzheimer's Disease 2025 https://doi.org/10.1016/j.tjpad.2025.100096

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https://www.inradnetwork.org/resources

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## Consensus sponsors and partners

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# Minimum Data Set published in JPAD

| Section | Field | Definition | Frequency | |
|---|---|---|---|---|
| | | | Entry Visit | Visit (minimum Annually |
| **Patient Profile/ Demographics** | Patient ID | Patient globally unique ID (system creates) | X | |
| | Consent | | X | |
| | Care partner | Availability as informant | X | X |
| | Sex at birth | M/F/other | X | |
| | Birth date | Year and month only | X | |
| | Race | | X | |
| | Place of residence | Country | X | |
| | Education | ISCED 2011 | X | |
| | Initial Living status | Alone, with family/partner, in care setting, other | X | X |
| | Height | cm | X | |
| | Weight | Kg | X | X |
| **Disease characteristics (diagnostic work-up)** | Family history of dementia | First degree relative | X | |
| | Date of first consultation for screening for dementia | | X | |
| | Syndrome | Normal/subjective cognitive decline/Mild cognitive impairment/Mild/moderate /severe dementia | X | |
| | Date of symptom onset | Date | X | |
| | Date of diagnosis | Date, where, and by whom | X | |
| | Diagnosis | AD plus others (from picklist) | X | |
| | Disease presentation | Predominent syndrome in the first 2 years | X | |
| | Amyloid positivity | Y/N/Not performed/Indeterminant | X | |
| | Tau positivity | Y/N/Not performed/Indeterminant | X | |
| | Imaging evidence of neurodegeneration | Y/N/Not performed/Indeterminant | X | |
| **Clinical outcomes** | Clinical staging | Global AD staging, NIA-AA 2018/24 | X | X |
| | Cognitive screening test | N/Y (MoCA or MMSE; score) | X | X |
| | Functional scale | N/Y, score | X | X |
| | Milestone events | Driving/working/living status | X | X |
| **Safety and relevant medical condition** | Serious Adverse Event (SAE) | Untoward medical occurrence (e.g., death, hospitalisation, illness resulting in major change) | | X |
| | ARIA | | | X |
| | Infusion/injection reaction | | | X |
| | Other AEs of interest | Serious malignancy, serious infection, other neurological conditions | | X |
| | Medical conditions | Relevant medical conditions (history and concomitant) | X | X |
| Imaging | Imaging | N/Y – type, date of scan and reason<br>• Screening/diagnosis<br>• Monitoring progression<br>• Monitoring Safety (e.g., ARIA) | X | X |
| **Treatments** | Disease modifying treatment | Treatment ID, name start/stop date | X | X |
| | Symptomatic treatments of interest | Treatment ID, name start/stop date | X | X |
| | Other treatments of interest | Treatment ID, name start/stop date | X | X |
| **Registry discontinuation** | Including death | Date and cause of death | | X |

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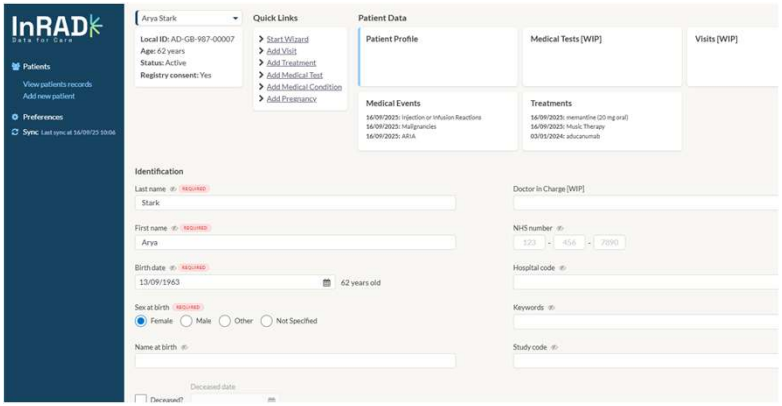
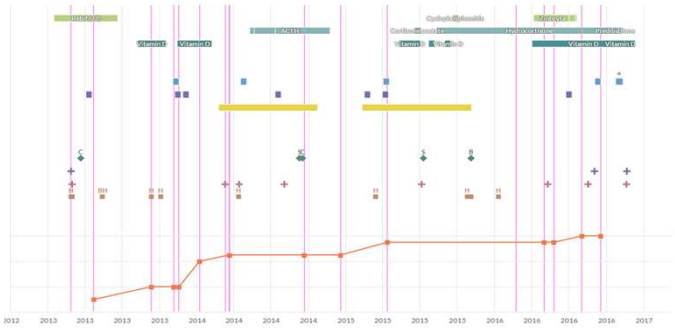
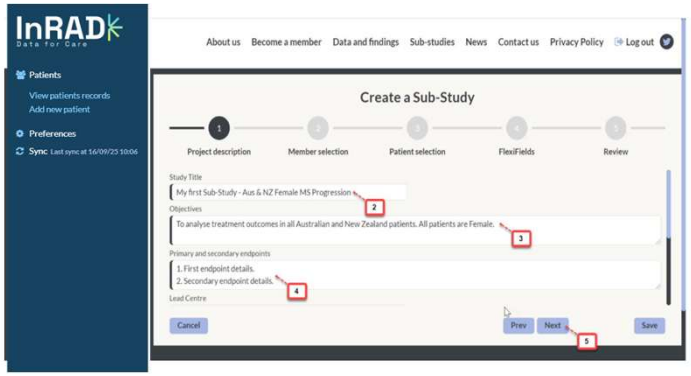
# InRAD platform is built on 20+ years of MSBase registry systems, operations and governance expertise






## Data entry system

- User-friendly data entry system
- Intuitive, roll-out menus
- Access through patient profile, disease ‘sections’
- PDF-extractable summary reports for patient HER (electronic health record)

## Patient Overview Graph

- Increased functionality at point-of-care
- Valued by clinicians to enable day-to-day patient management as well as accessible clinic data management
- Future external data source integration e.g. blood markers, ePROs, imaging solutions

## Registry and collaboration

- Tool for Investigator-initiated prospective ‘sub-studies’
- Filtering for defined sub-set of patient records
- Allows for the creation of national, supranational and regional studies

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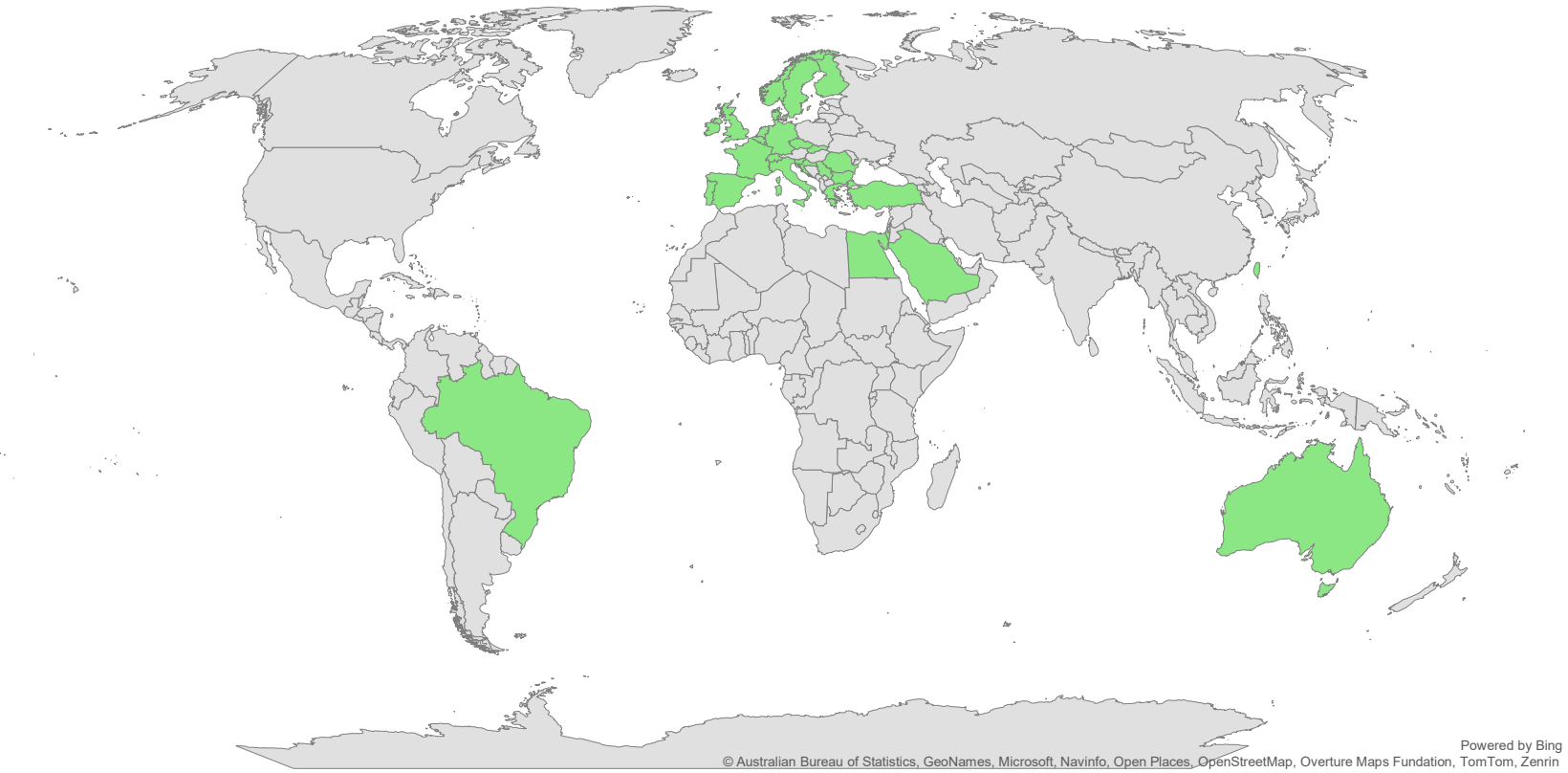
# Launching InRAD Around the World




**PILOT - November 2025**

**Wave 1 deployment**
**January 2026**
18 countries
27 PIs

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# AURORA-AD

## A prospective, observational, InRAD registry-led sub-study, to shed light on the progression and transitions of Alzheimer's disease, and burden on patients, care partners, and healthcare systems

Evaluating the natural history of Alzheimer's disease in the emerging setting of disease-modifying treatments and timely and accurate diagnosis supported by biomarkers

| **Study Type** | Prospective, Observational, InRAD registry-led registry substudy |
|---|---|
| **Primary objective** | Define global disease trajectories (time to transition between AD stages) |
| **Secondary objectives** | • Characterize cognitive trajectories and their interactions with clinical and biomarker risk factors<br>• Assess disease burden on patients, caregivers, and healthcare systems (resource utilization)<br>• Explore the impact of comorbidities and concurrent treatments on disease progression |
| **Exploratory Objectives** | • Identify high- and low-risk progression profiles<br>• Examine blood biomarkers for early diagnosis and progression prediction<br>• Evaluate patient (and care partner)-electronic PROs<br>• Evaluate digital solutions for cognitive assessment for early diagnosis<br>• Investigate imaging biomarkers (e.g. MRI mediotemporal lobe atrophy) as predictors of deterioration |
| **Patient population** | Patients from first presentation to health services and diagnosis |
| **Enrollment** | TBC |
| **Study duration** | 5 years TBC |
| **Locations** | AURORA-AD serves as an umbrella protocol. Will run across Europe with ca. 30 EADC sites + Others TBC |

Example of sub-study proposal being scoped

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# A Pivotal Moment for a Unified Approach

- **InRAD** is a **foundation** to overcome fragmentation, building a **sustainable data collection and collaboration platform**
- We defined a **Minimum Data Set (MDS) and Extended Data Set (EDS)**, ensuring **standardised, high-quality data collection** across AD registries[1]
- We developed a data dictionary and common data model, providing a **blueprint for structured and harmonised data capture**, enabling seamless integration across diverse healthcare systems
- **The registry build is underway** – the foundation is set, and we are preparing to launch the registry:
  - Pilot starting in **November 2025**
  - Wider international roll out from **January 2026**
  - Natural History study protocol in development
- **Joining InRAD means making a bigger impact** than any single centre could alone.
  - The unified, longitudinal data that is shared will drive faster insights and better treatments – directly benefiting patients and the field of Alzheimer's disease at large.

📍 **Learn More & Shape the Future of AD Care**

📌 Visit our **poster POS17-33** tomorrow 8th October 10:00-15:45

📌 InRAD **resources available** https://www.inradnetwork.org/resources

1. Perneczky et al. Real-world datasets for the International Registry for Alzheimer's Disease and Other Dementias (InRAD) and other registries: An international consensus, The Journal of Prevention of Alzheimer's Disease 2025 https://doi.org/10.1016/j.tjpad.2025.100096

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# Thank you! Questions?