Alzheimer's Europe 2025, Bologna, Italy, Poster number: POS17-33

THE INTERNATIONAL REGISTRY FOR ALZHEIMER'S DISEASE AND OTHER DEMENTIAS (InRAD): CAPTURING REAL-WORLD DATA TO IMPROVE THE LIVES OF PEOPLE WITH AD AND THEIR CAREGIVERS

InRAD Data for Care

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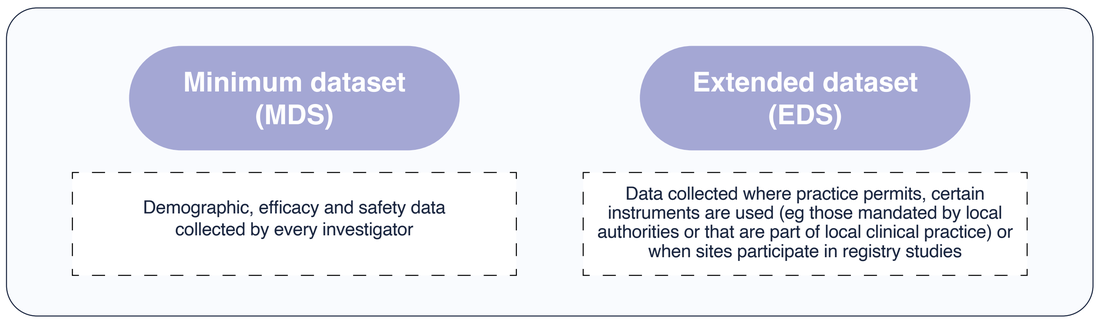
Introduction

- Alzheimer's disease is entering a new era with disease modifying therapies (DMTs) – there were ≈138 agents in development as of January 2025)[1] – as well as blood test driven diagnosis, but trials alone cannot address long term safety, effectiveness, and applicability in diverse populations. High-quality real-world data is essential to evaluate treatment outcomes, validate biomarkers, and also understand early disease trajectories in both treated and untreated patients.
- Many local or national registries and simple databases for dementia and AD operate without standardisation or longitudinal/long-term comprehensive RWD collection, which restricts research and the potential for positive impacts on patient care.[2]
- An international RWD registry could provide epidemiological and natural history data, evidence of treatment effectiveness and safety outside of research settings and help identify patients most likely to respond to personalised care.[2]
- To meet this need, international experts created the International Registry for Alzheimer's Disease and Other Dementias (InRAD): a global initiative to standardise AD RWD collection and better understand AD progression and treatment efficacy in everyday clinical practice.
- The InRAD registry will be free to use for clinical investigators and provide them with point-of-care information to facilitate patient counselling and education, and track changes in outcomes.
- The InRAD registry will use minimum (MDS) and extended datasets (EDS)[2] to capture and report pseudonymised longitudinal individual and aggregated RWD using a cloud-based, secure platform for data storage, sharing and analysis, where investigators are the Data Controllers.
- Adopting the InRAD data entry platform would simplify collaboration. Existing registries can align with the InRAD MDS, EDS and data dictionary, which will enable seamless multi-registry studies.
- InRAD allows benchmarking against other countries and populations, offers opportunities for publication acknowledgment as a data contributor and the potential to run own sub-studies.

Data dictionary and harmonised data collection

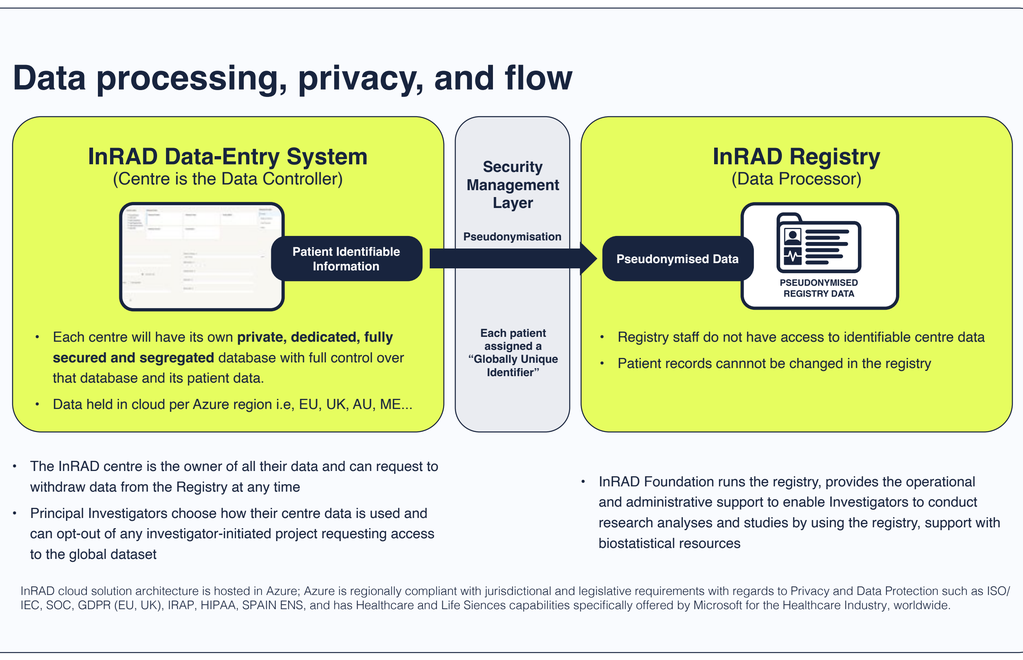
The MDS and EDS (figure 1), obtained by international consensus, is now published[2] and freely available at https://doi.org/10.1016/j.tjpad.2025.100096 . It forms the basis of the InRAD data dictionary. The MDS is designed to fit into routine practice (figure 2), ensuring quick and easy RWD entry. The EDS allows deeper phenotyping where feasible.

Figure 1: Defining the minimum dataset and extended dataset



Download our MDS & EDS manuscript[2] and our data dictionary at www.inradnetwork.org/data-set

Figure 2: InRAD cloud-based data entry system & pseudonymisation before sharing with InRAD Registry

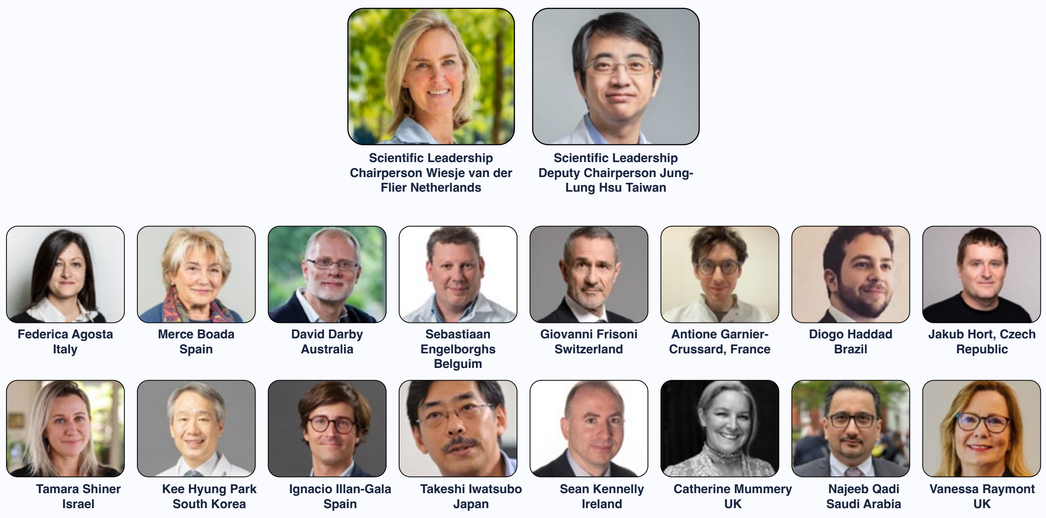


Governance and data protection

InRAD offers a comprehensive governance and data protection package to help centres comply with local regulations. People with AD and their care partners provide consent to provide their data to participating centres, who own the data for scientific purposes.

In addition, InRAD's board (Professor Frank Jessen, Professor Robert Perneczky, Professor Philip Scheltens and Jean Georges from Alzheimer Europe) ensure robust governance. The Scientific Leadership Group (figure 3) includes 18 leading international experts and is responsible for scientific analyses. While pharmaceutical industry partners may contribute funding, the InRAD registry maintains independence and transparency.

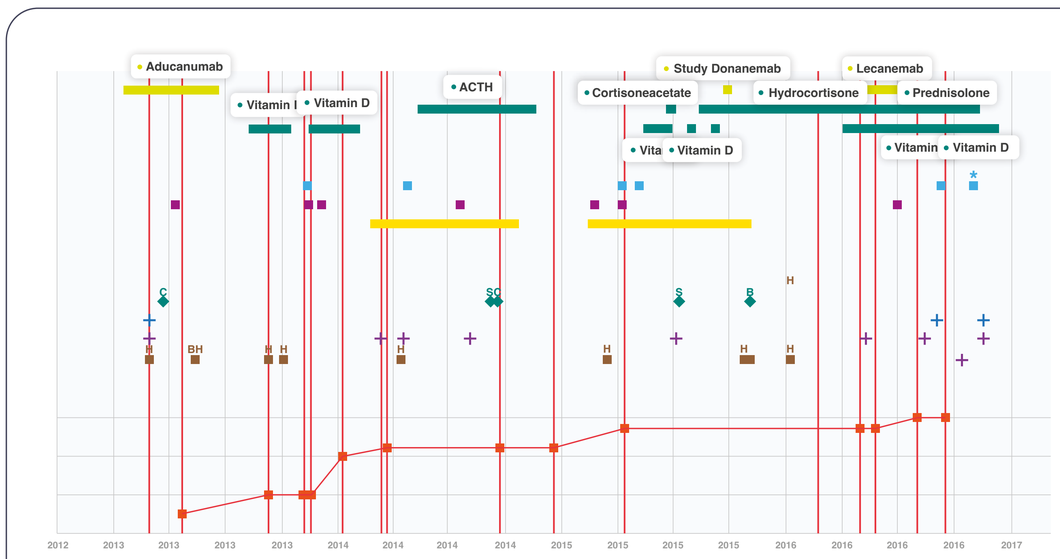
Figure 3: InRAD's Scientific Leadership Group



InRAD adheres to the General Data Protection Regulation and globally accepted data governance standards, ensuring that all patient data is pseudonymised, securely stored within Microsoft Azure's ISO/IEC 27001 and SOC-compliant infrastructure and is only accessible for approved research under strict data use agreements. There is interest from around the world and the pilots are planned in Ireland and Australia in November 2025 before a wider international roll-out in January 2026.

One of the key features of InRAD is its Patient Overview Graph (Figure 4) which brings together participants' key health information—like test results, treatments, and important milestones—into one easy-to-understand dashboard. This will help clinicians to see progress over time, make informed decisions together, and keep track of everything that matters to patient care like MRI. The graph can also include information from other sources, such as blood tests or home questionnaires, making clinic visits more focused on patients.

Figure 4: Patient Overview Graph (mock-up)



Advantages for people with AD and their families:

- Contribute to their care
- Aid visibility of history and changes in their condition
- Enable personal contribution to advance understanding of AD and patient, access and management InRAD can fill critical evidence gaps left by traditional trials empowering clinicians, researchers, and care teams to improve outcomes for people living with AD.

Conclusions

- InRAD, the first and only international registry in AD and other dementias, provides a structured framework for capturing longitudinal RWD in diverse clinical settings.
- InRAD's consensus-defined data dictionary standardises RWD collection and enables systematic tracking of disease progression, treatment responses and outcomes in routine practice.
- Governance safeguards uphold data integrity and ethical standards, while facilitating international collaboration.
- InRAD can fill critical evidence gaps left by traditional trials empowering clinicians, researchers, and care teams to improve outcomes for people living with AD.
- All centres caring for people living with Alzheimer's disease are welcome to join InRAD. Early collaboration is essential to accelerate progress and improve outcomes for tomorrow. Visit www.inradnetwork.org for more information.

Acknowledgements The InRAD not-for-profit Foundation has received funding from the pharmaceutical industry, including Eli Lilly and Company, Schwabe Group, Eisai, Novo Nordisk, Bristol Myers Squib. The InRAD Foundation does not endorse any companies or products. The InRAD Foundation is operated independently from these companies. **Mark Greener**, on behalf of TW1 Healthcare Consulting Limited, provided medical writing support. TW1 Healthcare Consulting Limited provided project management support. TW1 Healthcare Consulting Ltd provides consultancy services to InRAD. **CB, JLV, JVB** and **RH** have no competing interests. **WMF**: Research programs of Wiesje van der Flier have been funded by ZonMW, NWO, EU-JPND, EU-IHI, Alzheimer Nederland, Hersenstichting CardioVascular Onderzoek Nederland, Health~Holland, Topsector Life Sciences & Health, stichting Dioraphte, Noaber foundation, Pieter Houbolt Fonds, Gieskes-Strijbis fonds, stichting Equilibrio, Edwin Bouw fonds, Pasman stichting, Philips, Biogen MA Inc, Novartis-NL, Life-MI, AVID, Roche BV, Eli-Lilly-NL, Fujifilm, Eisai, Combinostics. WF holds the Pasman chair. WF is recipient of ABOARD, which is a public-private partnership receiving funding from ZonMW (#73305095007) and Health~Holland, Topsector Life Sciences & Health (PPP-allowance; #LSHM20106). WF is recipient of TAP-dementia (HYPERLINK "http://www.tap-dementia.nl/"www.tap-dementia.nl), receiving funding from ZonMw (#10510032120003). TAP-dementia receives co-financing from Avid Radiopharmaceuticals, Roche, and Amprion. WF is recipient of IHI- PROMINENT (#101112145) and IHI-AD-RIDDLE (#101132933). PROMINENT and AD-RIDDLE are supported by the Innovative Health Initiative Joint Undertaking (IHI JU). The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, EFPIA, EuropaBio, MedTech Europe and Vaccines Europe, with Davos Alzheimer's Collaborative, Combinostics OY., Cambridge Cognition Ltd., C2N Diagnostics LLC, and neotiv GmbH. All funding is paid to her institution. WF has been an invited speaker at Biogen MA Inc, Danone, Eisai, WebMD Neurology (Medscape), NovoNordisk, Springer Healthcare, European Brain Council. All funding is paid to her institution. WF is consultant to Oxford Health Policy Forum CIC, Roche, Biogen MA Inc, Eisai, Eli-Lilly, Owkin France, Nationale Nederlanden Ventures. All funding is paid to her institution. WF participated in advisory boards of Biogen MA Inc, Roche, and Eli Lilly. WF is member of the steering committee of phase 3 EVOKE/EVOKE+ studies (NovoNordisk). WF is member of the steering committee op phase 3 Trontinemab study (Roche). All funding is paid to her institution. WF is member of the steering committee of PAVE, and Think Brain Health. WF is Chair of the Scientific Leadership Group of InRAD. WF was associate editor of Alzheimer, Research & Therapy in 2020/2021. WF is associate editor at Brain. WF is member of Supervisory Board (Raad van Toezicht) Trimbos Instituut. **JLH** has no competing interests. He is Deputy Chair of the Scientific Leadership Group of InRAD. **FJ** received a research grant from Roche, honoraria from Eisai, Lilly, Novo Nordisk and has provided consultancy services for Eisai, Lilly, Novo Nordisk, Abbvie & AC Immune. FJ is a founder Board Member of InRAD. RP has received research grants from Roche, Astra Zeneca, Bayer, Takeda and GE. He has received honoraria from Roche, Eisai, Biogen and Janssen-Cilag. **RP** provided consultancy services for Roche, Eisai, Biogen, Janssen-Cilag, Lilly, Astrazeneca, Grifols, Novo Nordisk, Abbvie and GSK. RP is a founder Board Member of InRAD.
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