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INTERNATIONAL REGISTRY FOR ALZHEIMER'S DISEASE AND OTHER DEMENTIAS (InRAD): DESIGN, DATA MODEL, AND INTEROPERABILITY

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Background & Rationale

Alzheimer's disease is entering a new era with disease modifying therapies (DMTs), where clinical trials leave critical gaps – for example, how well new therapies work over the long term or in broad patient populations. Real-world disease registries can help fill these gaps by systematically collecting patient data from routine care. The International Registry for Alzheimer's Disease and Other Dementias (InRAD) is an international, practice-based AD registry, designed to harmonize global real-world data for research and patient care[1]. InRAD has been collaborating with ALZ-NET (Alzheimer's Network for Treatment and Diagnostics) from the US Alzheimer Association, a major registry that focuses on the real-world safety and effectiveness of new amyloid-targeting therapies. However, even these two "standardized" datasets have notable differences. Aligning InRAD and ALZ-NET data models is important because they do not yet speak the same data language. Bridging these differences is vital to enable data sharing and answer research questions that no single registry can tackle alone (e.g. long-term outcomes across diverse populations). Here, we compare the InRAD and ALZ-NET data models to identify overlaps, highlight mismatches, and outline a path towards true interoperability.

Objective

To compare the structure and content of the InRAD AD-UDM (Alzheimer's Disease Unified Data Model) v2.2 with the ALZ-NET CRF (case report form). in order to quantify their overlap and differences and to propose strategies that improve data interoperability between these registries. Ultimately, the goal is to inform how we can move toward a unified global Alzheimer's dataset that leverages real-world data from multiple registries for research and clinical insights

Methods

We reviewed the latest **InRAD AD-UDM** (version 2.2, 28 January 2026),[3] and the public **ALZ-NET CRF** documentation (version 14, February 2026[3]). The two data models were compared on: (1) **Overall structure:** number and type of major data categories ("base objects" in InRAD, analogous to main CRF sections in ALZ-NET) and their sub-components; (2) **Content coverage:** specific variables and domains captured, including any "gating" logic (yes/no prerequisite questions); and (3) **Use of standard terminologies**. Key quantitative metrics (counts of data fields, modules, etc.) were tabulated for each system. We also examined one representative domain, the **Diagnosis** data fields, in depth to map corresponding variables between InRAD and ALZ-NET, illustrating the effort required for one-to-one data mapping.

Results

The InRAD and ALZ-NET data models show both significant overlap and important differences:

- **Data Model Composition:** The InRAD AD-UDM comprises **10 primary "base" objects** (e.g. Patient Profile, Visits, Diagnosis, Treatments, Medical Events, etc.) along with **>50 linked local objects** (subsections for detailed information). Collectively, the InRAD schema can capture around **446 distinct variables per patient per time point.** In comparison, the ALZ-NET CRF is organized into **13 main sections** (forms capturing domains like Enrollment, Diagnosis, Medications, etc.) with **16 sub-forms**; the total number of variables is of a similar order of magnitude (several hundred), ensuring both systems have extensive clinical coverage.

- **Common Domains (Overlap) :** We identified clear alignment in at least **three key domains** that both registries collect in very similar ways – **Demographics (Patient identification), Diagnosis**, and **Treatment** data.

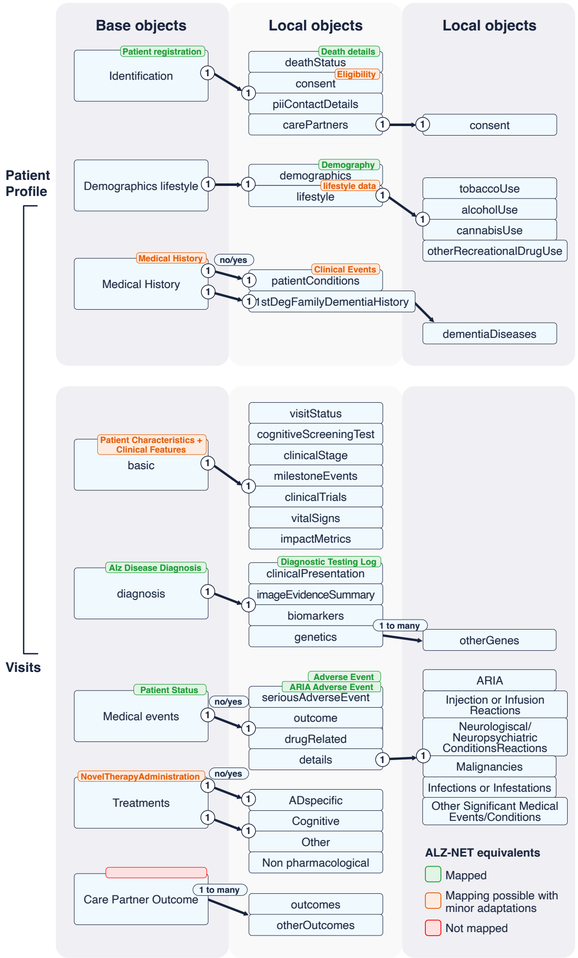

Figure 1: Examples of Base Object Comparisons InRAD & ALZ-NET InRAD & ALZ-NET

Medical Tests and Clinical Outcomes comparison showed that mapping was possible with minor adaptations (not shown due to space limitations)

InRAD AD-UDM	Transformation / Harmonisation	ALZ-NET Baseline CRF
Diagnosis assessment status, diagnosisDate, serviceOfDiagnosis clinicalPresentation, biomarkers, genetics	**Dates→Age / Year** Onset/diagnosis dates→age and year for CRF	
Clinical stage visits.basic.clinicalStage.stage Stage3=MCI, 4=Mild, 5=Moderate, 6=Severe Stages 0-2: pre-MCI	**Stage mapping** UDM Stage3→MCI; 4→Mild; 5→Moderate; 6→Severe Stages 0-2→pre-MCI (not represented in CRF)	**clinical disease stage** MCI; Mild, Moderate; Severe
Clinical presentation predominantSymptomSyndrome: • Amnestic (typical) • Posterior cortical / PPA / Frontal Other	**Phenotype mapping** Amnestic→Typical AD Posterior cortical / PPA / Frontal / Other→Atypical ... tick relevant atyical sub-checks in CRF	**AD presentation** Typical vs Atypical Atypical sub-checks (non-memory primary, mixed course ...)
Biomarkers amyloidStatus / tauStatus: Positive / Negative / Indeterminate / NotDone confirmedBy = PET / CSF / Blood	**Phenotype mapping** UDM Positive/Negative/Indeterminate →CRF Consistent/Not consistent/ Indeterminant confirmedBy selects CRF Testing Type: CSF / Blood Imaging	**Diagnostic Testing Log** APOE; CSF; Blood-based; Imaging Imaging subtype: Amyloid PET / Tau PET / FDG-PET / MRI
Other etiologies Lewy body, Vascular, FTD, PDP, CBD, ...	**Etiologies mapping** Direct list mapping; retain MedDRA codes internally	**Etiologies suspected** AD, VaD, LBD, FTD, Other
Genetics APOE genotype; APP / PSEN1 / PSEN2	**Genetics** APOE: direct category mapping APP/PSEN1/PSEN2: not captured in baseline CRF	

Figure 2: Example – Diagnosis field-by-field Mapping

- **Use of ontology standards:** InRAD's data model incorporates internationally recognized ontology standards for several elements (e.g. MedDRA for adverse event classification and diagnoses, WHO ATC codes for treatments). ALZ-NET's CRF does not appear to use these standard ontologies in its current form. The lack of common coding means that even when both registries collect a similar data item (for example, comorbid conditions or medication names), their entries might not automatically match.
- **Interoperability Approaches:** Despite differences, the high-level design of InRAD and ALZ-NET is comparable. Both systems use a modular approach (dividing data into thematic sections) and cover a broad spectrum of patient data. Two principal strategies for data integration emerge from this comparison **(Figure 3): (A) Direct bilateral mapping** – i.e. creating a comprehensive crosswalk so that each field in ALZ-NET is translated into the equivalent InRAD field (and vice versa) – or **(B) Common data model integration** – mapping both InRAD and ALZ-NET data into a **third, central** standard schema (a "hub" model, such as the OMOP common data model).

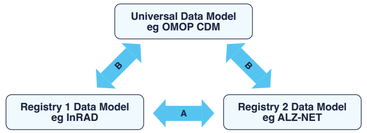

Figure 3: Interoperability Pathways

While using a widely adopted common model (OMOP or similar) is a potential long-term solution for **scalable interoperability** across many systems, it may require adaptation for the dementia domain. In the near term, a direct mapping between InRAD and ALZ-NET on a per-variable basis may be more immediately attainable, and can serve as a **proof-of-concept** for broader efforts.

Conclusions

Merging the InRAD and ALZ-NET datasets is within reach, but it will require focused effort on standardizing and mapping data elements. We found substantial overlap in the fundamental "building blocks" of the two registries, supporting optimism for pooled analyses resulting in global data, based on both registries. At the same time, resolving differences at the variable level (in definitions, formats, and coding) is crucial to truly harmonize the data. The next step will be to perform a full InRAD and ALZ-NET field-by-field mapping and assess data transformation needs. Future mapping to common vocabularies will also enhance data mergeability and clarity across international projects.

Clinical Impact & Call to Action

- For clinicians and researchers, this interoperability effort is more than a technical exercise: it directly enables **larger, more powerful analyses** of real-world outcomes in Alzheimer's disease.
- **InRAD www.inradnetwork.org** provides an open, international platform to collect data that can reveal insights on long-term therapy effectiveness, safety, and patient trajectories in routine care. By collaborating to bridge InRAD with ALZ-NET and other registries, we move closer to an integrated evidence base that benefits the entire global AD community.
- We encourage memory clinics, research networks, and other national registries to **join the InRAD network or align their data models** with InRAD's standards. For groups without an established registry, adopting the InRAD data model from the start is a viable strategy to ensure future compatibility.
- Initiatives like **ACCESS-AD[4]** in Europe are using the InRAD data structure as a common foundation, demonstrating its suitability for broader adoption.
- This **poster is call for collaboration** – by sharing data, expertise, and feedback – to accelerate research and ultimately improve patient care worldwide. To join InRAD, download the InRAD governance pack at www.inradnetwork.org or email info@inradnetwork.org

Disclosures: WF: As of 1-11-2025, WF is executive director at Alzheimer Nederland, Amersfoort the Netherlands. | Before 1-11-2025, 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 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). | Before 1-11-2025, WF has been an invited speaker at Biogen MA Inc, Danone, Eisai, WebMD Neurology (Medscape), NovoNordisk, Springer Healthcare, European Brain Council. WF has been consultant to Oxford Health Policy Forum CIC, Roche, Biogen MA Inc, Eisai, Eli-Lilly, Owkin France, Nationale Nederlanden Ventures. WF has participated in advisory boards of Biogen MA Inc, Roche, and Eli Lilly. All funding has been paid to Amsterdam UMC. | In 2024-2025, WF has been member of the steering committee of phase 3 EVOKE/EVOKE+ studies (NovoNordisk). In 2025, WF has been member of the steering committee op phase 3 Trontinemab study (Roche). All funding has been paid to Amsterdam UMC. | WF was associate editor of Alzheimer, Research & Therapy in 2020/2021. WF was associate editor at Brain 2021-2025. WF is chair of the Scientific Leadership Group of InRAD. 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.

References: 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. JPAD 2025 https://doi.org/10.1016/j.tjpad.2025.100096. **2.** InRAD AD UDM available at https://www.inradnetwork.org/data-set. **3.** ALZ-NET CRFs available at https://www.alznetproviders.org/Network-Operations/ALZ-NET-Data. **4.** ACCESS-AD consortium, www.access-ad.org