Al-Powered Identification, Access and Utility Mapping of Real-World Data Sources for Alzheimer's Disease in Europe



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INTRODUCTION

Alzheimer's disease (AD) is a growing health crisis in Europe (EU) driven by an aging population. An estimated 7 million people currently live with the disease in the region¹.

Conventional clinical trials often lack the diversity necessary to fully assess disease impact across populations, making RWE essential for understanding the spectrum of patient experiences and outcomes. RWE is increasingly accepted currency for healthcare decision making, but robustness and speed of insight are essential, not mutually exclusive.

While vast amounts of RWD can be found in existing databases, the ability to identify, access and assess robust RWD sources can be complex, time consuming and prone to bias. Some RWD sources can be easily detected but other more appropriate data might get overlooked.

OBJECTIVE

Our research aims to identify and evaluate RWD sources for AD in the EU, with a focus on understanding their accessibility, coverage, and utility for evidence generation studies.

Our findings will inform the development of evidence generation plans and guide the selection of data sources for RWE study designs.

By identifying and leveraging RWD from diverse sources we aim to enable a more comprehensive understanding of AD's clinical, economic, and societal impact in the region.

METHOD

An artificial intelligence (AI)-powered systematic literature review of academic publications (2014-2024, PubMed) was conducted to identify RWD sources for AD in the EU. Leveraging Large Language Models (LLMs), our proprietary AI system employed a semantic search protocol to identify relevant data sources and extract key information including database type, coverage, demographics, treatments, clinical, humanistic, and economic data. Results were manually validated by two independent reviewers.

Identified data sources were categorised into four key types: cross-sectional studies² (including population surveys), patient registries,³ national databases (including insurance databases) and EMR/EHRs.

Data sources cited more than once were prioritised for an in-depth assessment of data utility, focusing on variable coverage and availability across key RWD categories.

RESULTS

A total of 167 citations were retrieved, with 141 unique data sources identified after manual validation. Data sources spanned 17 EU countries. Coverage was highest in Sweden (15%), followed by Spain (13%), Germany (13%) and France (12%). Regional databases contributed 9% of all data sources.

Patient registries account for the largest proportion (50%) of data sources, followed by cross-sectional studies (including population surveys; 28%), EMR/EHRs (19%) and national databases (3%) (Table 1). National databases identified included a mix of insurance databases and government networks that coordinate various national data sources to support diverse research and administrative needs.

29 data sources were prioritised for an in-depth utility assessment. Data utility, measured by the breadth of variables available, was most substantial in Sweden, followed by France and Spain (Figure 1).

The reported variables were classified into ten key RWD categories:

1. Demographics 6.

6. Direct cost data

To contextualise the utility of available data, RWD sources were evaluated against key requirements for RWE and health economic and outcomes research (HEOR) studies. The corresponding studies that can be conducted with the available data demonstrate the potential for evidence generation to support access and value demonstration for AD interventions in each market (Table 2).

In the region, the limited availability of QoL and lifestyle data pose challenges for conducting utility and HR QoL studies. Additionally, gaps in cost indictors restrict HEOR studies, including cost of illness, budget impact and cost-effectiveness analysis.

Table 1. Summary table of all real-world data source types by country

| Country | Cross-sectional study ² | EMR/EHR | National database | Patient registry ³ | Total |
|-------------------------|------------------------------------|---------|-------------------|-------------------------------|-------|
| Austria | 0 | 0 | 0 | 2 | 2 |
| Belgium | 0 | 1 | 0 | 0 | 1 |
| Croatia | 1 | 0 | 0 | 0 | 1 |
| Czech Republic | 0 | 0 | 0 | 2 | 2 |
| Denmark | 1 | 1 | 0 | 4 | 6 |
| Europe-wide initiatives | 0 | 0 | 0 | 13 | 13 |
| Finland | 1 | 0 | 0 | 5 | 6 |
| France | 5 | 3 | 3 | 6 | 17 |
| Germany | 7 | 0 | 0 | 11 | 18 |
| Greece | 1 | 0 | 0 | 0 | 1 |
| Hungary | 0 | 2 | 0 | 0 | 2 |
| Italy | 4 | 1 | 1 | 5 | 11 |
| Netherlands | 5 | 1 | 0 | 4 | 10 |
| Norway | 4 | 0 | 0 | 3 | 7 |
| Portugal | 1 | 0 | 0 | 0 | 1 |
| Spain | 6 | 5 | 0 | 8 | 19 |
| Sweden | 2 | 12 | 0 | 7 | 21 |
| Switzerland | 1 | 1 | 0 | 0 | 2 |
| Total | 39 | 27 | 4 | 70 | 140 |

- 2. Medical / clinical data
- 3. Treatment-related data
- 4. Lifestyle data
- 5. Quality of life (QoL) data
- Indirect cost data
 AD-specific outcome
- 8. AD-specific outcomes
- 9. Insurance claims data
 10. Economic evaluation data

The most widely reported variables were AD-specific outcomes and patient demographics, while indirect and direct cost indicators, lifestyle information, as well as QoL data were less frequently captured.

Figure 1. RWD accessibility vs. utility by market



*Data source RightTimePlace Care European project, includes data sources from 7 countries (Estonia, France, Finland, Germany, Netherland, Spain, Sweden)

Table 2. RWE and HEOR study feasibility based on available data in each market

| Type of Study | Data requirements | Austria | Denmark | Estonia* | Finland | France | Germany | Italy | Netherlands | Norway | Spain | Sweden |
|--|----------------------|---------|---------|----------|---------|--------|---------|-------|-------------|--------|-------|--------|
| Cost of illness / Burden of illness | 1, 2, 6, 7, 8 | | | | | | | | | | | |
| Utility / HR QoL | 4, 5, 8 | | | | | | | | | | | |
| HCRU | 3 | | | | | | | | | | | |
| Patient segmentation | 1, 3 | | | | | | | | | | | |
| Clinical effectiveness / safety | 2, 3 | | | | | | | | | | | |
| Treatment pathway / compliance | 3 | | | | | | | | | | | |
| Budget impact analysis | 9, 10 | | | | | | | | | | | |
| Cost-effectiveness analysis | 5, 6, 7, 10 | | | | | | | | | | | |

Feasible with comprehensive RWD (defined as at ≥ 2 data sources reporting the required variables i.e., robust coverage)

Moderate feasibility with some RWD (defined as at least 1 data source reporting the required variables i.e., less robust coverage)

Not feasible with no RWD detected in current search

*Feasibility in Estonia is based on local RWD contributions to regional data sources

CONCLUSIONS

There is significant value in mapping AD RWD for assessing the feasibility of RWE and HEOR studies and informing downstream evidence generation activities. Pharmaceutical companies must strategically navigate this complex RWD landscape to develop effective evidence generation plans and select robust data sources for retrospective, prospective, and hybrid RWE study designs.

Sweden, Spain, Germany, France, Finland & Denmark are key contributors of AD RWD, offering diverse datasets for better understanding and management of AD in the EU. Further, the expanding network of regional data sources reflects ongoing initiatives aimed at enhancing health data access and utility across Europe. This highlights significant opportunity for regional collaboration to harmonise data collection practices, expand access to underrepresented data categories, and improve RWD utility.

However, variability in RWD availability and utility across EU markets remains. Gaps in data sources and availability of certain variables hinder comprehensive evaluations of the clinical, economic and humanistic burden of AD.

Our findings underscore both the potential and challenges of leveraging RWD for AD research in the region. Addressing these challenges will enhance the quality of RWE studies, supporting informed decision-making and ultimately improve AD patient outcomes across Europe.

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