

## DEMENTIA CARE PRACTICE

Korean JOint RegistrY for ALZheimer's Treatment and  
Diagnostics (JOY-ALZ): Establishing a Nationwide RWD  
Registry for Alzheimer's Disease in Korea

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## Abstract

Alzheimer's disease (AD) is undergoing a transformation with disease-modifying therapies (DMTs) and advanced biomarkers, shifting from symptomatic management to targeted interventions. However, high costs, potential side effects, and limited awareness hinder real-world integration, particularly in underrepresented East Asian populations like Koreans. Preliminary data suggest East Asians may experience lower rates of Amyloid-Related Imaging Abnormalities (ARIA), emphasizing the need for region-specific treatment guidelines.

To address this, the Korean Dementia Association (KDA) launched JOY-ALZ (Korean JOint RegistrY for ALZheimer's Treatment and Diagnostics) in 2024 to establish a real-world data (RWD) platform for AD therapies in Korea.

Overall objectives of JOY-ALZ are:

- Develop a collaborative network across multiple sites for systemic patient data collection.
- Record comprehensive patient data on cognitive, functional, and safety outcomes.
- Enhance data acquisition by integrating neuroimaging, genetic, and biomarker data
- Assess health outcomes using existing databases for long-term evaluation.
- Maximize data sharing with researchers and stakeholders.

To achieve this, JOY-ALZ employs the CURE Framework, which encompasses four specific aims:

- Creating the RWD platform infrastructure

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- Uncovering outcomes: collecting data to evaluate long term safety and clinical outcomes
- Reinforcing collaborations: co-enrollment with affiliated studies
- Enabling global sharing: data sharing and linking

Following Korean regulatory approval of lecanemab in May 2024, JOY-ALZ published Appropriate Use Recommendations (AUR) in October 2024 and hosted educational symposia. IRB submissions were initiated in December 2024 across 41 hospitals, with approval expected by June 2025 to enable comprehensive real-world data (RWD) collection, including clinical data, neuroimaging, and biosamples.

In the long term, JOY-ALZ will complement global platforms like ALZ-NET, informing Korean-specific treatment guidelines, promoting equitable access to AD therapies, and fostering international collaboration by contributing high-quality RWD to the global research community. **JOYALZ will play a key role in advancing AD research by leveraging RWD collected through Korea's dementia clinic network.**