

Investigating Collateral Informant-based Tools for the Screening & Assessment of Neurodegenerative Diseases: A Systematic Review

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Introduction

Family members and caregivers often notice early diagnostic changes and provide valuable longitudinal and diagnostic information that may not be captured in patient self-report or brief clinical testing (Kaur et al., 2026; Neubauer et al., 2023). Informant-based assessment tools aim to capture these insights and an important part of diagnostic assessment. However, existing evidence remains fragmented across tools, disease groups and healthcare contexts and previous reviews have mainly focused on dementia-specific tools (Harrison et al., 2016; Taylor-Rowan et al., 2022), with limited synthesis across broader neurodegenerative conditions or emerging digital and AI-based approaches.

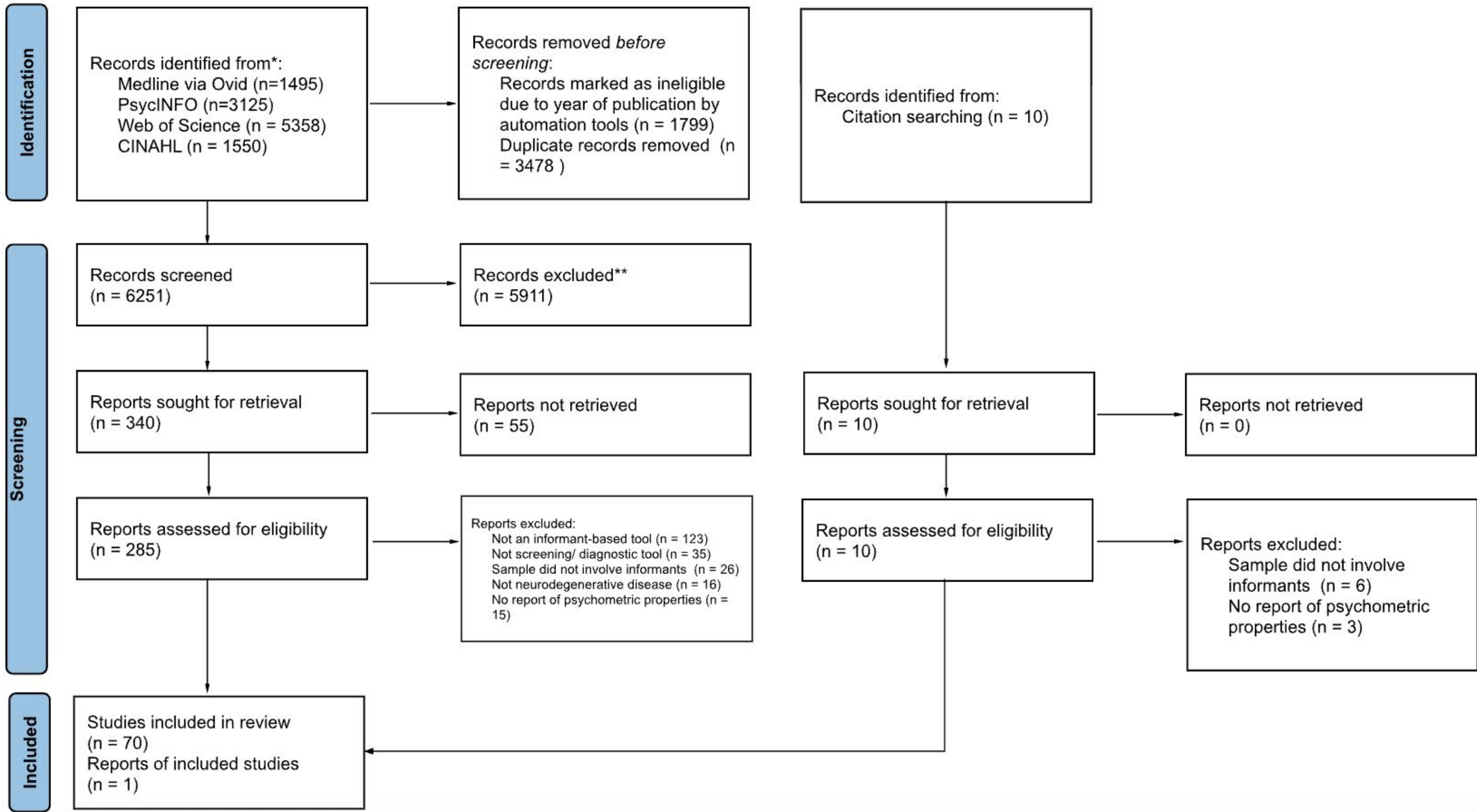
- Aims:**
- To identify current informant-based tools used for the screening and assessment of neurodegenerative diseases, including traditional paper-based and emerging AI-based approaches
 - To synthesise their psychometric properties, diagnostic performance and clinical utility.

Methods

Registered with PROSPERO (#CRD42025637939) and conducted in accordance with PRISMA guidelines (Page et al., 2021).

MEDLINE, PsycINFO, Web of Science and CINAHL were searched from January 2005 to April 2025, with an updated search conducted on 17 April 2026.

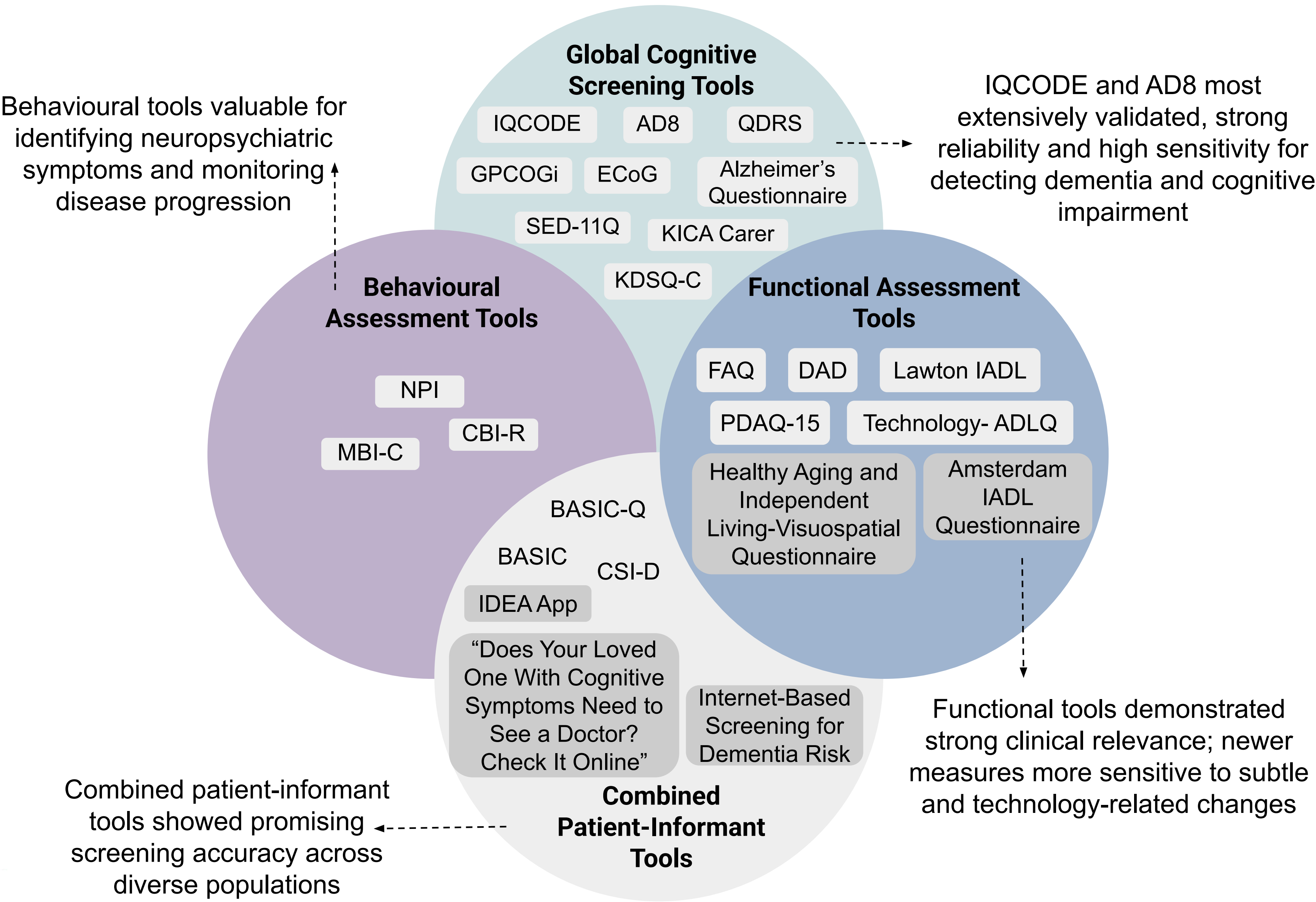
	Main Concepts	Alternative Terms
	Assessment Tools	(assess* OR diagnos* OR screening* OR instrument* OR tool* OR questionnaire* OR interview* OR digital tools OR telemedicine OR "mobile application" OR e-health OR mHealth OR AI OR "artificial intelligence" OR "remote assessment" OR web-based)
AND	Neurodegenerative Diseases	("Neurodegenerative disease*" OR Dement* OR Alzheimer* OR Parkinson* OR "Lewy body" OR Frontotemporal OR Huntington* OR ALS OR MND OR "cognitive impairment" OR MCI)
AND	Informant	(Caregiver OR Informant OR Family OR Spouse OR Partner OR Proxy)
AND	Specific Instruments	("Cambridge Behavioural Inventory" OR CBI OR IQCODE OR AD8 OR NPI-Q OR DAD OR FAQ OR BRIEF OR "Neuropsychiatric Inventory" OR "Zarit Burden Interview" OR "Functional Activities Questionnaire" OR "Clinical Dementia Rating" OR CDR)



Results

Study Characteristics (n = 71)

- 25+ counties:** United States (n=16), Brazil (n=8), Netherlands (n=5), Taiwan (n=5) United Kingdom (n=4) and more
- Settings:** Specialist Memory Clinics (n=26), Research Environments (n=17), Community-based Setting (n=13) and more
- Administration:** Pen-and-Paper (n = 63); Digital/ Web-based (n = 8).



Conclusion

- Informant-based assessments offer advantages over brief cognitive tests (MMSE, MoCA) by capturing longitudinal changes and being less influenced by education, literacy and cultural factors.
- However, specificity varied across primary and community settings, suggesting better suited to early screening and triage.
- Digital and AI-based tools remain underdeveloped, with most tools simply digitising existing questionnaires.
- Limitations of Evidence:** Small clinic-based convenience samples. Limited longitudinal evidence. Informant characteristics inconsistently reported.
- Limitations of Review:** Only English-language studies. Considerable methodological heterogeneity across study populations, assessment tools and reported outcomes limited direct comparison between studies and meta-analysis.
- Future:** Development and validation of digital/ AI-based informant assessment tools

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