

Key Takeaway

Findings from Japanese memory-clinic patients with early Alzheimer’s show ePSOM is feasible, acceptable, and culturally appropriate, enabling multinational trials to consistently capture participants’ personally meaningful priorities and complement objective endpoints with the patient voice.

Background

With the emergence of new disease modifying therapies for Alzheimer’s disease (AD), **there is an ever greater need to demonstrate how clinical trial findings translate into meaningful outcomes for individual patients.** Linus Health’s electronic Person Specific Outcome Measure (ePSOM) tool captures each participant’s unique priority areas of life in their own words and prompts individuals to rate how confident they feel in each area.

The ePSOM tool was designed to assess meaningful treatment effects in areas of life that matter most to individuals, with outputs that can complement objective trial endpoints with the patient voice.

Here, we report findings from a study to assess the feasibility, applicability, and user acceptability of ePSOM among Japanese memory-clinic patients with early symptomatic AD.

Methods

- We conducted **a cross-sectional study** across two sites (Kobe University and the Tokyo Metropolitan Institute for Geriatrics and Gerontology) between August – October 2025.
- Participants were ≥60 years old with **MCI or early dementia due to AD** as confirmed by local clinical guidelines.
- The study obtained **ethics approvals from Kobe University Research Ethics Board** and local site level approvals.
- All study related procedures were conducted **on site in Japanese**, either as self-reports or with assistance from care partner or clinical team where required.
- Each participant completed
 - the ePSOM tool** (confidence rating 1–5 in each personal priority, higher score = greater confidence, total score range 5–25)
 - an 11-item **user-acceptability questionnaire** with qualitative multiple-choice responses (six items with three response levels; five yes/no), and optional free text comments.

We quality controlled (QC) the free text ePSOM Japanese responses against predefined criteria:

- An activity the participant currently does rather than a future goal;
- One activity per response;
- Standalone i.e., independently understandable;
- Unique answer i.e., no two same entries) to identify responses that were missing, non-interpretable, or otherwise not analysable.

Analysis of the free-text ePSOM data

Japanese ePSOM free text was professionally translated to English. Using SBERT embeddingsWe , we linked the translated Japanese responses to 74 UK/US-derived priority themes^{3,6} via cosine similarity to quantify alignment between Japanese responses and US/UK derived themes and detect likely Japan-specific priorities amongst data which did not link well with the UK/US-derived themes. Links were flagged “uncertain” if similarity <0.30 or near-tied (Δ≤0.01) and reviewed qualitatively by the author group for cultural nuance. UAQ free-text was analysed descriptively.

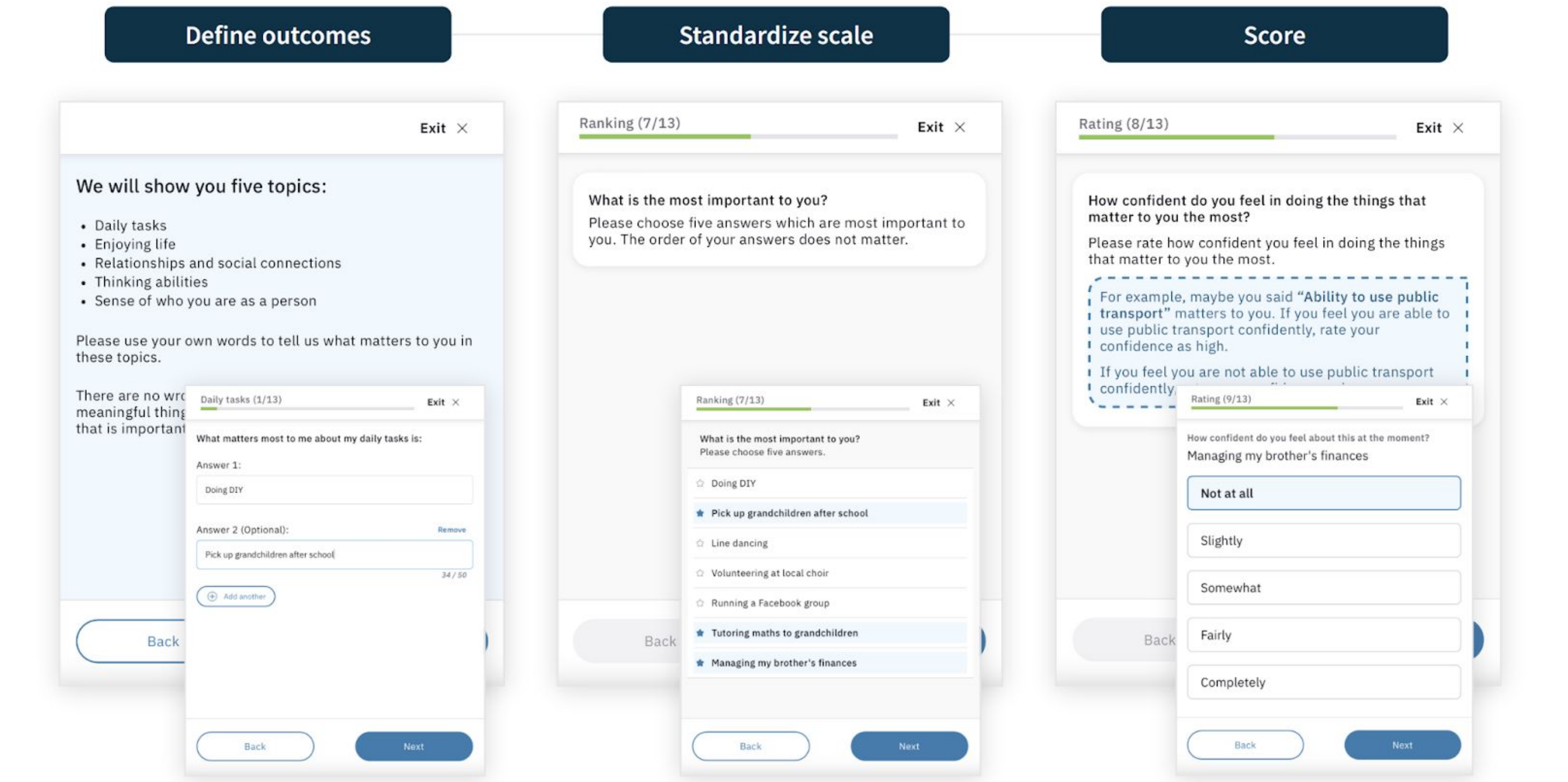


Figure 1. The ePSOM tool elicits free-form responses for what matters to participants in five domains. The tool instructs participants to narrow “Top five” priorities across the domains and prompts the participant to rate how confident they feel in their ability to manage each personally defined priority.



Figure 2. The ePSOM tool was translated into Japanese to assess ePSOM’s feasibility, applicability and user acceptability in Japanese memory clinics

Results

A total of 50 participants took part in the ePSOM Japan feasibility study.

Sample characteristics		
Number of participants		N=50
	Men	n=20 (40%)
	women	n=30 (60%)
Diagnosis		MCI or early dementia due to AD diagnosis MMSE mean=23.8 (SD=3.5)
Age		Mean: 76 (SD=6.0)
Education	Degree or higher	n=18 (36%)
	No degree	n=32 (64%)

Feasibility

- 100% completion with no missing data; assisted completion N=48 (96%); median completion time 17 min.

Results (contd.)

Acceptability of ePSOM tool

- Age, education and MMSE score were not associated with reporting a positive completion experience (logistic regression; both p>0.5).
- User Acceptability Questionnaire results indicated largely positive (48%) or neutral (44%) acceptability and most participants reported no effort (44%) or moderate effort (48%) completing ePSOM.
- There were almost no ethical concerns (92%) and comprehension was largely favourable (42% completely and 48% somewhat understood questions) with most questions clear and easy (66%).
- Most participants endorsed the ePSOM domains as covering important areas (80% yes) and willingness to complete again (64% yes).
- Notably, 46% felt ePSOM would help a doctor understand what matters most when making treatment decisions but 40% were not sure; however 54% felt ePSOM would improve communication with a doctor about what is personally meaningful for them.
- Finally, most participants felt neutral on how easy or difficult it was to complete the assessment independently (52%) and on a device (42%).

A total of 62 free form comments were left as qualitative feedback.

- Overall, the comments suggest that the concept is seen as favourable, illustrated by quotes: *“It was a great opportunity to reflect on myself and what I can and can’t do.”* (Participant KB002), *“I think it’s very good to be able to express what’s inside my heart.”* (Participant KB017), *“I felt that my thoughts were accepted as they were.”* (Participant TK003).

- Usability concerns related to typing the answers, as illustrated by quotes: *“Since I can’t use a computer, I need someone to help me”* (Participant KB018); *“It was difficult to operate because it was a different computer than the one I usually use.”* (Participant TK025).

- Feedback also indicated some of the questions required assistance from clinical teams *“I was able to understand it after a medical professional explained it to me.”* (Participant KBO05).

Conclusion

- Findings support feasibility, high acceptability, and cultural appropriateness of ePSOM in a Japanese clinic context.
- The ePSOM tool performed well in Japan without changing its structure as the free- text response format removed the need for cultural adaptation, demonstrating that ePSOM can be deployed in multinational AD trials under a consistent protocol, preserving consistency and comparability while reflecting what matters most to participants.
- These findings suggest ePSOM may be a practical way to incorporate individual participants’ voices into study endpoints in different cultural settings.

References

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