UsAgainstAlzheimer's

Alzheimer's Disease Patient and Caregiver Engagement Initiative (AD PACE)

Request for Proposal for Round 3

Due September 4, 2026

Background

The AD PACE What Matters Most Research Program launched in 2018 as a patient- and care partner-engaged precompetitive, multi-stakeholder collaboration. The goals of this Research Program are to identify and incorporate the views of patients and care partners about what outcomes matter most to them in Alzheimer's disease (AD). Results are intended to enhance the measurement of treatment outcomes and to improve communication about the value of treatments from the perspective of those diagnosed with AD and those who care for them. Insights from this work are intended to be useful to regulators, payers, and the life sciences industry, as well as clinicians, patients, and families.

More information on AD PACE is available on the UsAgainstAlzheimer's website: AD PACE | UsAgainstAlzheimer's.

Research from the AD PACE Initiative has proceeded in two prior Rounds. Round 1 was focused on qualitative work to identify and measure treatment-related needs, preferences, and priorities of individuals with or at risk for AD and their care partners across the continuum of the disease. In Round 2, the resulting 50-item What Matters Most (WMM) survey was administered in English or Spanish to over 600 people at one time point. Participants were recruited into 5 discrete groups: those with biomarkers indicating risk for AD, those with diagnosed Mild Cognitive Impairment, those with diagnosed probable mild Alzheimer's Disease, and caregivers for those with moderate to severe disease. Recruitment addressed the representativeness of the US population by race and ethnicity. Additional measures administered were the Cognitive Function Index, the EQ-5D-5L, and the QOL-AD.

AD PACE is now seeking applications for Round 3 work as detailed below.

Project Goals

AD PACE is looking for a research partner or research partners to build on the data and findings from Rounds 1 and 2 of the What Matters Most (WMM) Research Program, to accomplish the following goals collaboratively with the AD PACE team.

Please note that applicants may respond to one, two, or all three goals in response to this RFP. Applicants may present a single solution for each goal or may present multiple potential options. If presenting multiple potential options, please include the advantages and disadvantages of the options, including from a cost and timeline perspective.

AD PACE Goals, Round 3:

1. Refine the existing WMM Survey.
    - Recommend item and scale analyses to be completed using the Round 1 and/or Round 2 data to enable AD PACE to refine the WMM Survey for subsequent use in clinical trials, in clinical communication, and/or in evaluation of meaningful treatment outcomes. This may include recommending item revision, different response options, item deletion, and/or scale reassignment of some items.
    - Some primary data collection including testing with additional participants, may be included as part of this work.
    - While Clinical Outcome Assessment (COA) qualification is beyond the scope of this RFP, applicants are encouraged to ensure that documentation of methods and results conforms to current FDA requirements for COA qualification.
    - Note: If recommending a focus on specific severity levels rather than across the full spectrum of disease severity, please provide rationale for selection of those levels.

    We anticipate that the budget for this goal will not exceed $180,000.

2. Develop and pilot-test a communications tool useful for clinicians, in practice, as a means of communicating with patients and families about AD and treatment impacts. This tool should support communication for translation between information about disease progression and severity, and What Matters Most to patients and caregivers. The tool should aid patient and caregiver understanding of how results from clinical trial findings and potentially also from clinical assessments link to outcomes most meaningful to them. Specifically,
    - The What Matters Most conceptual disease model and concept items should be referenced in development of this tool. The tool should provide a link between What Matters Most to patients and caregivers, per the prior AD PACE work, and measures used in clinical trials of AD, specifically those included in product labels for marketed drugs for AD. At a minimum, the tool should reference the Clinical Dementia Rating Scale (CDR) Sum of Boxes.
    - The tool may also provide a link to other measures used as AD trial endpoints beyond the CDR Sum of Boxes. Please provide rationale for selecting other measures.
    - The tool may also provide a crosswalk between What Matters Most to patients and caregivers, with reference to the WMM Survey, and tools used by clinicians in practice to quantify AD disease severity level and progression of disease, such as the MMSE.

    We anticipate that the budget for this goal will not exceed $200,000.

3. Evaluate clinical meaningfulness of a measure or multiple measures used in clinical trials for AD as an endpoint, using patient and caregiver input on outcomes that matter most to them. This work may include the following activities:
    - Use the WMM Survey to aid with establishing patient and caregiver-based estimates of clinical meaningfulness for the CDR Sum of Boxes. Round 2 data are cross-sectional. Applicants may propose use of Round 2 data in conjunction with other methods or datasets, such as simulation modeling, and/or additional participant interviews about meaningfulness. Applicants may also propose collection of additional quantitative data.
    - Use the WMM Survey to aid with establishing estimates of clinical meaningfulness of at least one additional AD trial endpoint; provide rationale for inclusion of the selected additional measure(s) in the analysis.
    - For a range of AD severity groups, quantify between-group differences that are

considered meaningful from both the patient and caregiver perspective; compare against published clinical meaningfulness thresholds for the Cognitive Function Index.
- Provide the rationale for patient-caregiver dyad data collection or rationale for pursuing input from patients or caregivers separately.
- Coadminister the WMM Survey in ongoing data collection, for example with existing studies and cohorts, to further assess the link between What Matters Most to patients and caregivers and other data collected in studies of AD.
- Note: If recommending a focus on specific severity levels rather than across the full spectrum of disease severity, please provide rationale for selection of those levels.

We anticipate that the budget for this goal will not exceed $600,000 if the proposal includes primary data collection.
We anticipate that the budget for proposals for secondary analyses only will not exceed $325,000.

Potential Deliverables and Activities
Please include information on development and management of an overall project plan and research strategy. This would include:

- Study design specifying secondary analyses and/or primary data collection and/or specific ongoing research projects to leverage to meet project goals
- Individual study/project design protocols
- IRB approvals
- Secondary analyses of WMM data and other data sets as needed
- Recruitment of participants if needed, along with data collection and delivery of deidentified raw data sets
- Statistical analysis plan
- Data Management Plan
- Data analyses to include data tables and graphs and narrative explanation
- Written report on project work
- Slides and brief summary for each deliverable
- Presentation of updates to the AD PACE Executive Steering Committee

Please include description of dissemination plans, to include peer-reviewed publications, submission of abstracts for presentation at professional conferences, and other types of communications such as blogs and webinars. Dissemination should also include direct to consumer communications about the project and results, such as visual abstracts, brief summaries, and/or infographics.

Please include plan and timelines for project team meetings, data management, and reporting.

Minimum proposal elements
Proposals should include the following sections. Note: specify the Goal or Goals your proposal addresses. Details on the page limit for each element are outlined in the RFP Elements and Page Limits table below.

I. Project approach, including plans by project phase
II. Analysis plan and expected outputs
III. If collecting primary qualitative and/or quantitative data, include recruitment strategy, planned number of participants required with rationale for the sample size, and plans for human subjects submissions
IV. Proposed structure for deliverables for each stage, e.g., slides, tables, written reports
V. Project methods
VI. Proposed Budget Proposed Timeline. Note that AD PACE is a consortium. Please ensure timeline allows for associated reviews and feedback
VII. Why AD PACE should choose your organization

Final reports for each major deliverable will be required throughout the project. We also request that the proposal, budget and timeline include development of up to 2 manuscripts for submission to peer-reviewed journals, and any budget required to support up to 2 anticipated conference presentations. UsAgainstAlzheimer's as the nonprofit convener will retain ownership of data and information generated through this work.

Applications will be evaluated based on the following criteria. See Proposal Evaluation Criteria table below for more detail:

- Quality of the proposed project plan including methods to be used and identification of options to pursue (60%)
- Qualifications of the project team (20%)
- Evidence of relevant prior work (10%)
- Cost, timeliness, and overall value (10%).

Nondisclosure agreement for access to Round 2 AD PACE Results
Applicants will be asked to sign a confidentiality agreement to receive detailed information about the data and analyses completed in Round 2 of AD PACE to assist with proposal preparation. To receive this information please email Grayson Donley at GDonley@UsAgainstAlzheimers.org. Note that information submitted through this RFP will be shared with the Executive Steering Committee for AD PACE.

Note — DO NOT UPLOAD AD PACE INFORMATION TO AI TOOLS: Any information provided by UsAgainstAlzheimer's in connection with this RFP, including Round 2 research data, findings, and related work product, must not be uploaded, submitted, or otherwise input into any artificial intelligence application, tool, platform, or service (including, for example, ChatGPT, Copilot, Gemini, Claude, or similar generative AI tools), or shared with any company or other third party that provides such tools, without UsAgainstAlzheimer's prior written consent. This restriction is a binding obligation under the confidentiality agreement executed in connection with this RFP, and a violation may result in disqualification from the RFP process, in addition to any other legal remedies available to UsAgainstAlzheimer's.

Time and place of submission of proposals
The deadline for proposals is 11 PM ET on September 4, 2026. Please send completed proposals to Grayson Donley at GDonley@UsAgainstAlzheimers.org and include the words "WMM Round 3 RFP: RFP Application" in the subject line.

Anticipated selection schedule
AD PACE anticipates that selection will be made by September 25, 2026. AD PACE reserves the right to finalize project scope and budget after vendor selection.

Project Timeline
Anticipated start date for the work will be Q4 2026. Please include the duration of project in your proposal along with a GANTT chart indicating timeline for completion of project tasks. Applicants should complete the work as expeditiously as possible. Note that all work should be completed by June 2028.

Inquiries
The AD PACE team is available for questions until August 28, 2026. Please contact GDonley@UsAgainstAlzheimers.org.

Proposal Evaluation Criteria

Criterion	Weight
Quality of the proposed project plan: • Approach and methods to be used, with rationale, including ways in which representativeness of US population is addressed. • Soundness and feasibility of options presented	**60%**
Qualifications of the project team, highlighting relevant projects and publications, and roles of project staff	**20%**
Evidence of relevant prior work, including quality and impact of that work and evidence of work representing a range of affected populations, including by race/ethnicity. Indicate experience working with regulatory authorities (e.g., Food and Drug Administration) and/or payers.	**10%**
Cost, timeliness, and overall value Total project cost, details of cost by project elements; Detailed timeline and work plan	**10%**

RFP Elements and Page Limits

RFP Element	Details to Include	Page Limit per Goal**
Overview of project approach	Specify which Goal(s)* your proposal addresses. Provide a high-level description of how you propose to meet the Goal.	2
Methods	If proposing secondary analyses, provide details of analyses with rationale. If collecting primary data (qualitative and/or quantitative), include recruitment strategy, planned number of participants required with rationale for the sample size, plans for humans subjects submissions, and proposed analyses.	4
Deliverables	Specific planned deliverables (e.g., slides, tables, written reports)	1
Proposed Budget (separate by Goal*)	Total requested amount and cost categories (e.g., staff, dissemination, data collection)	1
Proposed Timeline	Note that AD PACE is a consortium. Please ensure timeline allows time for associated reviews and feedback.	1
Why AD PACE should choose your organization?	Include qualifications of the project team, highlighting relevant projects and publications, roles of project staff.	2
Supplementary Material (Not Required)	Biosketches for key personnel	3 pages each

* Goal 1: Refine WMM Survey, Goal 2: Develop and Pilot Test Communications Tool for Clinicians, and Goal 3: Evaluate Clinical Meaningfulness

**Proposals addressing all 3 goals have a total page limit of 29 pages, excluding Supplementary Material. Proposals addressing 2 of the 3 goals have a total page limit of 25 pages, excluding Supplementary Material.

Select AD PACE Publications

1. DiBenedetti DB, Slota C, Wronski SL, et al. Assessing what matters most to patients with or at risk for Alzheimer's and care partners: a qualitative study evaluating symptoms, impacts, and outcomes. *Alzheimer S Research & Therapy*. 2020;12(1):90. https://doi.org/10.1186/s13195-020-00659-6.
2. Hauber B, Paulsen R, Krasa HB, et al. Assessing what matters to people affected by Alzheimer's disease: a quantitative analysis. *Neurology and Therapy*. 2023;12(2):505-527. https://doi.org/10.1007/s40120-023-00445-0.
3. DiBenedetti DB, Menne H, Paulsen R, et al. Technical review of clinical outcomes assessments across the continuum of Alzheimer's Disease. *Neurology and Therapy*. 2023;12(2):571-595. https://doi.org/10.1007/s40120-023-00443-2.
4. Callahan LF, Samsell B, DiBenedetti D, et al. Evaluating Elements of the Care Partner Experience in Individuals Who Care for People with Alzheimer's Disease Across the Severity Spectrum. *Neurology and Therapy*. 2023;13(1):53-67. https://doi.org/10.1007/s40120-023-00558-6.
5. Paulsen R, Romano C, Frangiosa T, et al. How do we put meaning into meaningful benefit? Perspectives from the lived experience. *Alzheimers Dement. (TRCI)*. 2025;11(2). https://doi.org/10.1002/trc2.70095.

Select AD PACE Presentations

1. Hartry A, Menne H, Wronski S, et al. Evaluation of What Matters Most in Existing Clinical Outcomes Assessments in Alzheimer's Disease. Poster presented at Alzheimer's Association International Conference; July 2020; virtual.
2. Hauber B, Paulsen R, Callahan L, et al. Quantifying What Matters Most Patients and Care Partners in Alzheimer's Disease. Poster presented at Alzheimer's Association International Conference; July 2020; virtual.
3. Majid T, Paulsen R, Callahan L, et al. The Importance of Care Partner Input in Alzheimer's Disease Drug Development. Poster presented at Alzheimer's Association International Conference; July 2020; virtual.
4. Romano C, Slota C, Bratlee-Whitaker E, et al. Measuring "What Matters Most" to People Living with Alzheimer's Disease and Care Partners: A Next Generation Conceptual Model of Alzheimer's Disease. Poster presented at Alzheimer's Association International Conference; July 2023; Amsterdam, Netherlands.
5. Romano C, Bratlee-Whitaker E, Herring W, et al. Measuring What Matters Most to People Living with Alzheimer's Disease and Care Partners: What Matters Most Qualitative Research. Poster presented at Clinical Trials on Alzheimer's Disease; October 2023; Boston, MA.
6. Romano C, Bratlee-Whitaker E, Hartry A, et al. Measuring What Matters Most to People Living with Alzheimer's Disease and Care Partners: What Matters Most Quantitative Research Development. Poster presented at Alzheimer's Association International Conference; July 2024; Philadelphia, PA.
7. Romano C, Bratlee-Whitaker E, Hartry A, et al. Priority Ranking: What Matters Most to People Living with Alzheimer's Disease and Care Partners. Poster presented at: Alzheimer's Association International Conference; July 2025; Toronto, Canada.
8. Romano C, Mogle J, Gold A, et al. Best-Fit Clinical Outcomes Assessment Measures to Evaluate What Matters Most in Alzheimer's Disease: Identifying a Core Outcomes Set from Existing Measures. Poster presented at: Clinical Trials on Alzheimer's Disease; December 2025; San Diego, CA.