

Guide to Available Data sets

UsAgainstAlzheimer's AD PACE Data Commons

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The AD PACE Data Commons includes datasets from several different sources. Our intent is to have this Data Commons become a dynamic and expanding resource of contributed data sets from a range of studies and surveys gathering information from persons living with Alzheimer's and/ or those who care for them on preferences, insights, opinions, and outcomes that matter most to them across the Alzheimer's lived experience. As of the date noted below, the AD PACE Data Commons includes underlying data sets from the following sources:

- AD PACE® What Matters Most Study
- A-LIST® What Matters Most Insights Study
- Company-contributed preference and insights study data
- C-PATH- datasets developed by the CPI Pro Consortium

Information about available datasets (generally including screeners, interview guides, findings, and publications)-is provided in the table below.

Updated as of: **(3/17/23)**

Source	Name of Study or Survey	Brief Description of Study Objectives & Dataset	Sample Size	Date Conducted
AD PACE	What Matters Most Qualitative Research	Individual in-depth (concept elicitation interviews)	60 clinically referred individuals with MCI/AD/evidence of pathology and care partners (5 stages)	2019/2020
AD PACE	What Matters Most Quantitative Research	Web-based survey to rate importance of 42 concepts of interest	274 clinically referred individuals with MCI/AD/evidence of pathology and	2022/2023

			care partners (5 stages)	
AD PACE	Poster: Concept of Interest Elicitation – “Quantifying What Matters Most to Patients and Care Partners in Alzheimer’s Disease”	Evaluation of 42 COIs		
AD PACE	Technical Assessment “Evaluation of What Matters Most in Existing Clinical Outcomes Assessments in Alzheimer’s Disease”	Evaluation of 42 COIs compared to most commonly used existing scales		
AD PACE	“The Importance of Care Partner Input in Alzheimer’s Disease (AD) Drug Development”	Feedback from Care Partner Surveys on the importance of 42 COIs		
AD PACE	Lilly (Name)	NEED TO GET THIS FROM RTI/confirm use by individual organizations		
AD PACE	Biogen	TBD		
AD PACE	Lundbeck/Otsuka – Patient Survey and Interview Study in Mild Alzheimer’s Disease	Patient attitudes toward AD, attitudes and expectations for treatments and COA measure concepts that are most important to people		
C-PATH	Summary report	Summary report from CPI PRO consortium covers the entire research process -SLRs – report of 3 expert panels (9/11/09, 5/10/10, & 1/23/12) – concept elicitation	Composite report. Focus groups n=144,	2/4/13

		focus group findings (patients, informants, cognitively intact) – conceptual framework & cognitive item eval – insight interviews (pt/cg dyads) – mini delphi panel clinical experts – informal translatability assessment – qualitative item reduction integrating findings from mini-Delphi & qual results – cognitive debriefing via interviews – input during F2F mtg (4/2010) – FDA response to SSSD submission (3/2011) – PRO consortium cognition WG expert panel summary 1/23/12, item tracking matrix (1/2013)	Dyads n=11 pairs, mini Delphi n=3, cogn debrief n=40	
C-PATH	Appendix D1: SLR overview of measurement in AD/MCI	Foundation for new instrument development; primary aim – to ID existing measures used for collecting information on patient- & CG-based outcomes & to provide a summary of measure development and psychometric performance of them	N/A	9/10/09
C-PATH	Appendix D2: SLR on insight in MCI	To assist with development of new measures in MCI, by developing a foundational understanding of early declines. Patient self-reports in pts with cognitive declines psychometricians and researchers. SLR objective to summarize existing evidence based on patient insights in MCI. Also includes some AD learnings.	N/A	8/24/10
C-PATH	Appendix A1: PRO consortium, Scoping stage summary doc	Focus on measure development plan related to patient self-report among patients with MCI	N/A	12/6/10
C-PATH	Appendix D4: Analysis plan for qual	Table series 1.1 – 8.2	N/A	2/4/13 (revised)

	assessment of Pt/Informant perspective on MCI & probable AD			
C-PATH	Appendix D5: Analysis plan for qual assessment of Pt/Inform perspective on MCI & probable AD	Table series 1.1 – 5.2 (additional vs above)	N/A	1/22/13 (revised)
C-PATH	Appendix D6: Mini-delphi - Cognitive initiative item pool eval exercise	Goal to initiate item selection of most promising items for item pool originally generated 6/2010 with focus on CADLs. Method: re-review of qual data.	Delphi n=3 clinicians	2/15/11 (revised)
C-PATH	Appendix D7: Qual analysis for item reduction	Tables with CADLs, assessing insight, relevance, and sensitivity	N/A	8/1/11
C-PATH	Appendix D11: Summary of findings from cognitive debriefing interviews	Includes all the tables and figures by wave of debriefing exercise, interviews conducted.	N=28	1/18/12
C-PATH	Appendix D12: Item tracking matrix from cognitive debriefing interviews	Assesses each item for qualitative item reduction (Aug 2011) and cognitive debriefing and expert panel (Jan-May 2012)	N/A	1/2013 (revised)
C-PATH	Appendix D13: Expert panel meeting summary	Meeting summary: topics included - tool development and qualification, interim C-PATH project updates, review of items based on cognitive debriefing, conclusions/next steps	N/A	1/23/12
A-LIST	Caregiver Physician Relationships	Evaluation of patient, caregiver and physician relationships and areas for improvement	691	12/2018

A-LIST	State of the Union	Attitudes toward federal policy related to Alzheimer's; provided to the White House for SOTU	544	12/2018
A-LIST	It's Personal – Marriage	Impact of dementia on personal relationships	1074	2/2019
A-LIST	myMemCheck test	Voice of patients/caregivers in development of myMemCheck tool	177	4/2019
A-LIST	Mother's Day Feelings	Impact of holiday on those affected by dementia	2982	5/2019
A-LIST	Father's Day Feelings	Impact of holiday on those affected by dementia	150	6/2019
A-LIST	Loss of Self	Impact of diagnosis on self image	974	7/2019
A-LIST	Travel and Vacations	Impact of diagnosis on travel and vacations	440	8/2019
A-LIST	Brain Health 1	Preliminary survey on attitudes toward brain health	1449	9/2019
A-LIST	Paid Family Leave V1	Opinions on value of paid family and medical leave	43	12/2019
A-LIST	Paid Family Leave V2	Opinions on value of paid family and medical leave	322	12/2019
A-LIST	Lucidity in Dementia – 1	Initial survey on prevalence and characteristics of lucidity In dementia to support NIA R21 grant request by Mayo	413	12/2019
A-LIST	Caregiver Challenges in ADRD & MS	Key challenges for caregivers identified	661	3/2020
A-LIST	Impact of Covid restrictions – 1	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	621	3/2020
A-LIST	Impact of Covid restrictions – 2	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	803	4/2020

A-LIST	Impact of Covid restrictions – 3	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	683	5/2020
A-LIST	ADRD & MS	(AD & MS) Caregiver expectations of health care providers	924	5/2020
A-LIST	Impact of Covid restrictions – 4	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	715	6/2020
A-LIST	Impact of Covid restrictions – 5	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	809	7/2020
A-LIST	Impact of Covid restrictions – 6	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	1001	9/2020
A-LIST	Impact of Covid restrictions – 7	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	592	10/2020
A-LIST	Alzheimer's Treatments	Voice of those affected by Alzheimer's describing trade off in decision making on whether to take novel drug; letter to FDA	845	1/2021
A-LIST	Lucidity in dementia – 2	Deep dive on caregiver perspectives on lucidity in dementia to create typologies in support of Mayo NIA R21 grant	538	2/2021
A-LIST	Impact of Covid restrictions – 8	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	719	2/2021
A-LIST	Caregiver Strain Index	Partnership with RTI in support of ICER evaluation of AD drugs	370	3/2021
A-LIST	Lucidity in dementia - 3	Clarification around demographics related to prior Lucidity in dementia survey - 2	171	5/2021
A-LIST	Early diagnosis	Importance of early diagnosis and treatment	923	7/2021

A-LIST	Brain Health – 2	Day to day actions to maintain brain health and limit risk importance of early diagnosis and treatment	1628	9/2021
A-LIST	Impact of Covid restrictions – 9	Longitudinal study on impact of COVID restrictions on patients, caregivers, brain healthy	827	11/2021
A-LIST	CMS Decision	Voices of Alzheimer’s describing trade offs in decision making on whether to take a novel drug	752	1/2022
A-LIST	Dementia 101 for Healthcare Providers	Voice of patient and caregiver for CME on brain health	643	3/2022
A-LIST	Stigma & Dementia	Varied perspectives (patient, caregiver, brain health) on stigma associated with dementia	682	4/1/22
A-LIST	Nutrition	Voice of patient and caregiver for CME on brain health and impact of nutrition	719	6/1/22
A-LIST	Sleep & Social Isolation	Voice of patient and caregiver for CME on brain health and impact of sleep & social isolation	695	7/1/22
A-LIST	Physical Activity and Blood Pressure	Voice of patient and caregiver for CME on brain health and impact of physical activity and blood pressure	632	9/1/22
A-LIST	WMM classification	Data collected on our cohort. Additionally asked questions on diagnosis and diagnosing physicians for a company. Lastly, asked A-LIST members why they are so invested	1058	October 2022/November 2022
A-LIST Ad Hoc	Lakelyn Hogan PhD thesis	Recruited for PhD thesis on characteristics of dementia family caregivers who use paid professional in-home respite care	98	July 2022
A-LIST Ad Hoc	Acadia DRP study	Dementia Related Psychosis qualitative interviews and quantitative survey	Poster: Qual n=1 pt., n=11	Poster: AAIC July 2020,

			caregivers Quant n=11 pt., n=95 caregivers Pub: Qual n=1 pt., n=15 caregivers Quant n=26 pt., n=186 caregivers	Pub: Clinical Gerontologist, 2022
A-LIST Ad Hoc	Otsuka Agitation in Dementia	Caregiver perspectives on the burden and impact of agitation in caring for loved ones with dementia/Alzheimer's disease: A collaboration with UsAgainstAlzheimer's A- LIST® (Agitation in Dementia qualitative interviews supporting COA dossier for sNDA for brexpiprazole)	Poster: Qual n=4 caregivers, Quant n=395 caregivers (of which n=297 had loved ones with agitation)	Poster: CTAD Nov. 2020
A-LIST Ad Hoc	UT Dallas	Research in support of Brain Health improvement techniques	1355	Jan/Feb 2023