# **Supplement 4. References to the included articles.**

**Qualitative studies:**

Bardach SH, Parsons K, Gibson A, Jicha GA. “From Victimhood to Warriors”: Super researchers’ Insights Into Alzheimer’s Disease Clinical Trial Participation Motivations. *The Gerontologist*. Published online July 19, 2019:gnz096. doi:10.1093/geront/gnz096

Brehaut JC, Carroll K, Presseau J, et al. A patient-focused, theory-guided approach to survey design identified barriers to and drivers of clinical trial participation. Journal of Clinical Epidemiology. 2021;132:106-115. doi:10.1016/j.jclinepi.2020.12.013

Cox CG, Ryan BA Mary M, Gillen DL, Grill JD. A Preliminary Study of Clinical Trial Enrollment Decisions Among People With Mild Cognitive Impairment and Their Study Partners. *The American Journal of Geriatric Psychiatry*. 2019;27(3):322-332. doi:10.1016/j.jagp.2018.10.016

Damron L, Litvan I, Bayram E, Berk S, Siddiqi B, Shill H. Hispanic Perspectives on Parkinson’s Disease Care and Research Participation. Journal of Alzheimer’s Disease. 2021;81(2):809-819. doi:10.3233/JAD-210231

Hedman R, Hellström I, Ternestedt BM, Hansebo G, Norberg A. Sense of Self in Alzheimer’s Research Participants. Clin Nurs Res. 2018;27(2):191-212. doi:10.1177/1054773816672671

Karlawish JHT, Casarett DJ, James BD. Alzheimer’s Disease Patients’ and Caregivers’ Capacity, Competency, and Reasons to Enroll in an Early-Phase Alzheimer’s Disease Clinical Trial. Journal of the American Geriatrics Society. 2002;50(12):2019-2024. doi:10.1046/j.1532-5415.2002.50615.x

Karlawish JHT, Casarett D, Klocinski J, Sankar P. How do AD patients and their caregivers decide whether to enroll in a clinical trial? Neurology. 2001;56(6):789-792. doi:10.1212/WNL.56.6.789

Kehagia AA, North TK, Grose J, et al. Enhancing Trial Delivery in Parkinson’s Disease: Qualitative Insights from PD STAT. J Parkinson’s Dis. 2022;12(5):1591-1604. doi:10.3233/JPD-212987

Kim SYH, Holloway RG, Frank S, et al. Volunteering for early phase gene transfer research in Parkinson disease. Neurology. 2006;66(7):1010-1015. doi:10.1212/01.wnl.0000208925.45772.ea

Kim SYH, Wilson RM, Kim HM, et al. Comparison of enrollees and decliners of Parkinson disease sham surgery trials. Movement Disorders. 2012;27(4):506-511. doi:10.1002/mds.24940

Lawrence V, Pickett J, Ballard C, Murray J. Patient and carer views on participating in clinical trials for prodromal Alzheimer’s disease and mild cognitive impairment. International Journal of Geriatric Psychiatry. 2014;29(1):22-31. doi:10.1002/gps.3958

Marquez DX, Perez A, Johnson JK, et al. Increasing engagement of Hispanics/Latinos in clinical trials on Alzheimer’s disease and related dementias. Alzheimers Dement Transl Res Clin Interv. 2022;8(1). doi:10.1002/trc2.12331

Olsen L, DePalma L, Evans JH. Self-Interested and Altruistic Motivations in Volunteering for Clinical Trials: A More Complex Relationship. *Journal of Empirical Research on Human Research Ethics*. 2020;15(5):443-451. doi:10.1177/1556264620914463

Ottenhoff L, Vijverberg EGB, Visser LNC, et al. Experiences of and recommendations on clinical trial design in Alzheimer’s disease from the participant’s point of view: a mixed-methods study in two clinical trial centers in the Netherlands. Alzheimers Res Ther. 2023;15(1):72. doi:10.1186/s13195-023-01190-0

Solomon A, Akenine U, Andreasen N, et al. Practical Lessons from Amyloid Immunotherapy Trials in Alzheimer Disease. Current Alzheimer Research. 2012;9(10):1126-1134. doi:10.2174/156720512804142958

Sugarman J, Cain C, Wallace R, Welsh-Bohmer KA. How Proxies Make Decisions about Research for Patients with Alzheimer’s Disease. Journal of the American Geriatrics Society. 2001;49(8):1110-1119. doi:10.1046/j.1532-5415.2001.49218.x

**Quantitative studies:**

Bardach SH, Holmes SD, Jicha GA. Motivators for Alzheimer’s disease clinical trial participation. Aging Clin Exp Res. 2018;30(2):209-212. doi:10.1007/s40520-017-0771-2

Bedlack RS, Pastula D, Welsh E, Pulley D, Cudkowicz ME. Scrutinizing enrollment in ALS clinical trials: Room for improvement? Amyotrophic Lateral Sclerosis. 2008;9(5):257-265. doi:10.1080/17482960802195913

Bedlack RS, Wicks P, Heywood J, Kasarskis E. Modifiable barriers to enrollment in American ALS research studies. Amyotrophic Lateral Sclerosis. 2010;11(6):502-507. doi:10.3109/17482968.2010.484494

Damron L, Litvan I, Bayram E, Berk S, Siddiqi B, Shill H. Hispanic Perspectives on Parkinson’s Disease Care and Research Participation. Journal of Alzheimer’s Disease. 2021;81(2):809-819. doi:10.3233/JAD-210231

DasMahapatra P, Raja P, Gilbert J, Wicks P. Clinical trials from the patient perspective: survey in an online patient community. BMC Health Serv Res. 2017;17(1):166. doi:10.1186/s12913-017-2090-x

Disbrow EA, Arnold CL, Glassy N, et al. Alzheimer Disease and Related Dementia Resources: Perspectives of African American and Caucasian Family Caregivers in Northwest Louisiana. J Appl Gerontol. 2021;40(2):209-219. doi:10.1177/0733464820904568

Elad P, Treves TA, Drory M, et al. Demented patients’ participation in a clinical trial: factors affecting the caregivers’ decision. *International Journal of Geriatric Psychiatry*. 2000;15(4):325-330. doi:10.1002/(SICI)1099-1166(200004)15:4<325::AID-GPS117>3.0.CO;2-9

Gabel M, Bollinger RM, Coble DW, et al. Retaining Participants in Longitudinal Studies of Alzheimer’s Disease. *J Alzheimer’s Dis*. 2022;87(2):945-955. doi:10.3233/JAD-215710

Galvin JE, Meuser TM, Boise L, Connell CM. Predictors of physician referral for patient recruitment to Alzheimer disease clinical trials. Alzheimer Dis Assoc Disord. 2009;23(4):352-356. doi:10.1097/WAD.0b013e31819e0cac

Goetz CG, Janko K, Blasucci L, Jaglin JA. Impact of placebo assignment in clinical trials of Parkinson’s disease. Movement Disorders. 2003;18(10):1146-1149. doi:10.1002/mds.10504

Jefferson A, Lambe S, Chaisson C, Palmisano J, Horvath K, Karlawish J. Clinical Research Participation among Aging Adults Enrolled in an Alzheimer’s Disease Center Research Registry - IOS Press. Accessed March 3, 2023. <https://content.iospress.com/articles/journal-of-alzheimers-disease/jad101536>

Júlio F, Blanco R, Casanova JP, et al. Perceptions about Research Participation among Individuals at Risk and Individuals with Premanifest Huntington’s Disease: A Survey Conducted by the European Huntington Association. Journal of Personalized Medicine. 2021;11(8):815. doi:10.3390/jpm11080815

Khan S, Foo JYJ, Chia NSY, et al. Attitude of Asian Parkinson Patients towards Clinical Research and Tissue Donation. Parkinson’s Disease. 2020;2020:e2542756. doi:10.1155/2020/2542756

Mastwyk M, Macfarlane S, LoGiudice D, Sullivan KA. Why participate in an Alzheimer’s disease clinical trial? Is it of benefit to carers and patients? Int Psychogeriatr. 2003;15(2):149-156. doi:10.1017/s1041610203008834

Mastwyk M, Ritchie CW, LoGiudice D, Sullivan KA, Macfarlane S. Carer impressions of participation in Alzheimer’s disease clinical trials: what are their hopes? And is it worth it? Int Psychogeriatr. 2002;14(1):39-45. doi:10.1017/s1041610202008268

Mathur S, DeWitte S, Robledo I, Isaacs T, Stamford J. Rising to the Challenges of Clinical Trial Improvement in Parkinson’s Disease. Journal of Parkinson’s Disease. 2015;5(2):263-268. doi:10.3233/JPD-150541

Nuño MM, Gillen DL, Dosanjh KK, et al. Attitudes toward clinical trials across the Alzheimer’s disease spectrum. Alz Res Therapy. 2017;9(1):81. doi:10.1186/s13195-017-0311-5

Ottenhoff L, Vijverberg EGB, Visser LNC, et al. Experiences of and recommendations on clinical trial design in Alzheimer’s disease from the participant’s point of view: a mixed-methods study in two clinical trial centers in the Netherlands. Alzheimers Res Ther. 2023;15(1):72. doi:10.1186/s13195-023-01190-0

Reijula E, Halkoaho A, Pietilä AM, et al. Comparable indicators of therapeutic misconception between epilepsy or Parkinson’s disease patients between those with clinical trial experience and trial non-participants. Seizure. 2018;60:61-67. doi:10.1016/j.seizure.2018.06.006

Reijula E, Pietilä AM, Halkoaho A, et al. Clinical features of Parkinson’s disease patients are associated with therapeutic misconception and willingness to participate in clinical trials. Trials. 2017;18(1):444. doi:10.1186/s13063-017-2174-2

Solomon A, Akenine U, Andreasen N, et al. Practical Lessons from Amyloid Immunotherapy Trials in Alzheimer Disease. Current Alzheimer Research. 2012;9(10):1126-1134. doi:10.2174/156720512804142958

Valadas A, Coelho M, Mestre T, et al. What motivates Parkinson’s disease patients to enter clinical trials? Parkinsonism & Related Disorders. 2011;17(9):667-671. doi:10.1016/j.parkreldis.2011.05.023

**Studies with qualitative and quantitative data collection methods:**

Kehagia AA, North TK, Grose J, et al. Enhancing Trial Delivery in Parkinson’s Disease: Qualitative Insights from PD STAT. J Parkinson’s Dis. 2022;12(5):1591-1604. doi:10.3233/JPD-212987