

Caregiver Recruitment: An ADRC Call to Action

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BACKGROUND

- NIA ADRCs
 - Create an environment that supports **innovative research** that has a **significant impact** on the field of dementia research and treatment;
 - **Enhance dementia related research**, education, and training opportunities for people with dementia, their **care partners**, students, scientists, and clinicians.
- ORE mission:
 - provide important liaison and **engagement between the ADRC** and people with dementia, their **caregivers**, and both the professional and local lay community so that information may be communicated bi-directionally, **particularly in diverse populations**
- NIH AD and ADRD Research Summit Recommendation
 - Engage patients, **caregivers** and citizens as **direct partners in research**

NACC Data

	Non-Latino White n =11,158	African American n =1,455	Latino n = 423	Asian Pacific Islander n =286	Total N=13,322
Age	72.92 (13.61)	68.80 (13.78)	61.28 (14.15)	69.09 (14.60)	71.97 (13.81)
Education	15.45 (2.77)	14.63 (2.69)	12.49 (3.97)	15.42 (2.90)	15.27 (2.86)
Length Known	42.40 (14.66)	47.51 (15.65)	43.09 (14.12)	39.22 (16.07)	42.73 (14.82)
Gender (Female)	7383 (66)	1115 (77)	324 (77)	212 (74)	9034 (68)
Relationship					
Spouse	7486 (67.1)	473 (32.5)	103 (24.3)	179 (62.6)	8241 (61.9)
Adult Child	2693 (24.1)	714 (49.1)	230 (54.4)	78 (27.3)	3715 (27.9)
Lives w/recipient	8115 (72.7)	871 (59.9)	254 (60.0)	210 (73.4)	9450 (70.9)
Frequency in Person**					
Daily	574 (5.1)	163 (11.2)	53 (12.5)	18 (6.3)	808 (6.1)
3x/week	945 (8.5)	182 (12.5)	65 (15.4)	25 (8.7)	1217 (9.1)
Weekly	836 (7.5)	142 (9.8)	31 (7.3)	23 (8.0)	1032 (7.7)
3x/month	253 (2.3)	38 (2.6)	11 (2.6)	3 (1.0)	305 (2.3)
Monthly	232 (2.1)	33 (2.3)	6 (1.4)	1 (0.3)	272 (2.0)
<1x/month	203 (1.8)	26 (1.8)	3 (0.7)	6 (2.1)	238 (1.8)
Frequency telephone**					
Daily	1249 (11.2)	333 (22.9)	94 (22.2)	31 (10.8)	1707 (12.8)
3x/week	794 (7.1)	120 (8.2)	39 (9.2)	18 (6.3)	971 (7.3)
Weekly	450 (4.0)	72 (4.9)	21 (5.0)	12 (4.2)	555 (4.2)
3x/month	66 (0.6)	14 (1.0)	5 (1.2)	2 (0.7)	87 (0.7)
Monthly	64 (0.6)	10 (0.7)	2 (0.5)	0 (0.0)	76 (0.6)
<1x/month	420 (3.8)	35 (2.4)	8 (1.9)	13 (4.5)	476 (3.67)

**If caregiver does not live with care recipient how frequent are visits/telephone calls

Take Aways

- ADRC ORE Core Leader Survey (n=11)
 - 100% of ADRCs agree that caregivers should be engaged in research
 - 91% of ADRCs interested in caregiver intervention studies
 - 55% of ADRCs interested in observational caregiver mental health studies
 - 45% of ADRCs interested in observational caregiver cognitive health studies

If you have not yet participated: <https://www.surveymonkey.com/r/care-survey>

- Opportunity exists for ADRCs/NACC
 - <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-18-057.html>

Top 3 Strategies for Caregiver Recruitment

- Meet caregivers where they are
 - Challenge limiting beliefs (i.e. difficult to recruit)
 - Generational and geographical shift
- Community Engagement
 - Establish and strengthen meaningful relationships/trust
 - Think beyond churches
 - Be visible
 - Collaborative partnerships
 - Invest (time and money)
- Leverage existing resources

